POSTURE AND SLEEP IN CHILDREN WITH CEREBRAL PALSY

A REPORT FOR THE POSTURE AND MOBILITY GROUP

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Rationale for the study

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 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.

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). 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. 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.

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. 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.

This study aims to explore these gaps in current knowledge.

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.

Methodology: Case study

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."

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. While individual interviews were the main method of data collection, data was also gathered from physiotherapy service managers by means of an informal group discussion which was followed up with further telephone conversations.

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

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.

Sleep diaries

Parents were asked to keep sleep diaries 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 for a further 10 days.

Chailey Sleep Questionnaire

Therapists were asked to administer the Chailey Sleep Questionnaire (Khan and Underhill 2009) with parents prior to prescription of the sleep system.

Approach to data analysis

Framework analysis

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.

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.

Stage 1: Familiarisation with the data

Familiarisation with the data started immediately after the first interview. Notes were made in the margins of the transcripts of the main points that arose. Notes of initial thoughts following an interview were recorded on a contact summary form. This enabled an immediate view of the main points that arose and suggested avenues to explore in following interviews.

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.

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.

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.

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.

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).

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. 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 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.

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.

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 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 in which children were encouraged to answer questions about sleeping as each layer of wrapping was removed. 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'.

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.

Pilot study 4

Pilot study 4 was to practise using the Talking Mat technique. 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?"

"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).

- 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.

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. 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. The research team checked with the child throughout the interview process that they were willing to continue, by taking notice of facial expression, vocalisation, eye-pointing and body movement.

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 and the University of Brighton agreed to be the sponsor. The study was submitted to the Devon and Torbay Research Ethics Committee and 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 nine Trusts in the South-West region.

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. The Posture and Mobility Group was approached and the application was successful.

Launch of the study

Recruitment for the study was dependent on support from local paediatric 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.

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 et al 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 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.

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.

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.

Participants

The details of the children in the study are presented below in Table 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.

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

Table 1: Details of the children participating in the study

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 the Appendix.

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. The findings have been incorporated into the section on sleep difficulties.

Key dimensions

Details of the analysis are not provided in this report but can be seen on request to the author. The process of thematic analysis, indexing and charting led to five key dimensions which are discussed below.

Child's ability to adapt and parents' readiness to persevere

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.

Sleep difficulties

Six out of the seven children in this study had sleep difficulties. 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 3 below.

Cause of waking	Number of children
Cramp, pain, discomfort	4
Needing to be turned	1
Fits	1
Behavioural	2
Night terrors	1

Having had a nap during the day	2

Table 3: 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.

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 the child 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, were seen to be adopting extreme positions; one a foetal position and the other a 'windswept' position. Both these children experienced better quality sleep 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.

Knowledge and experience of therapist

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.

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:

Type of Sleep system	Number of therapists
Chailey Lying Support	3
Leckey Sleepform	2
Symmetrisleep	1
Jenx Dreama	1

Table 4: Types of sleep systems prescribed

The reasoning behind the choice of sleep systems is presented in the chart "Why this sleep system" in the Appendix . 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.

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 …."* (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.

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.

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.

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.

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.

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)

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)

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.

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 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.

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 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 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 factors can also be placed within the ICF framework model (Figure 1) to guide clinical reasoning.

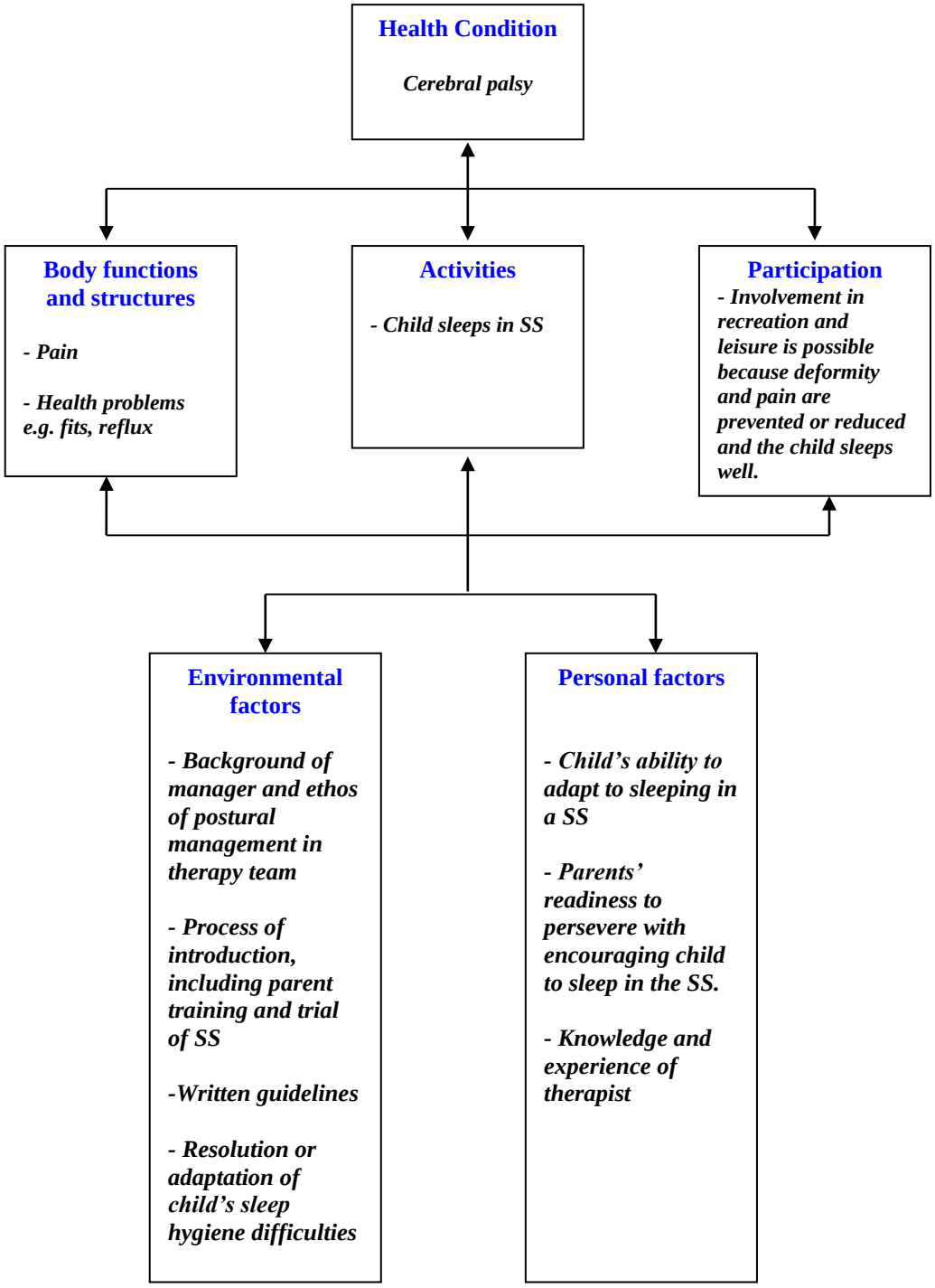

Figure 1: ICF framework model redrawn with factors for consideration prior to prescription of a sleep system

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 ICF framework model 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 children as young as three reported pain. 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.

This study was unusual in its in-depth exploration of parents' concerns about sleep. 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.

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APPENDIX

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

Chailey Sleep Questionnaire scores

Child number	**Problem Category**		
	Bedtime Routine	**Night-time Behaviour**	**Breathing Quality at Night**
1	Low	Low	Low
2	High	High	Low
3	High	High	High
4	N/A	N/A	N/A
5	Low	Medium	Low
6	Low	Medium	Low
7	Low	Medium	Low
8	Medium	Medium	High

N/A = not available

APPENDIX

Chart of Therapists' clinical reasoning – why this sleep system?

Case number	Therapist	Type of sleep system chosen	Reasons	Quote
1	PT	Chailey Lying Support	Good position. Can lie in supine and prone. Good for playing in prone.	*"I like to use the Chailey first… because you can move it easily, the children can play in it on their fronts and on their backs and I think it keeps them in a lovely position …"*
2	PT	Leckey Sleepform	Good for young children.	*"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."*
3	PT	Leckey Sleepform	Not bulky or too obvious. Appealing to parents.	*"I didn't want anything too bulky and obvious and so that's why I thought something that's quite simple and when I showed it to mum, she said, Oh, that's not too bad is it?"*
4	OT	Symmetrikit Symmetrisleep	Only Symmetrisleep available for loan so tend to start with Symmetrisleep.	*"… it's only the Symmetrikit sleep systems that we've got access to so if you want the Jenx or the Chailey, we then have to organise that separately, so that makes life that little bit harder."*
5	PT	Jenx Dreama	More freedom than in Symmetrikit. Mattress is really comfortable and children do not get hot in it.	*"I think different Sleep Systems suit different ages actually. I think the Leckey ones are really good for the tiny ones, babies, sort of up to two. And then after that, I prefer the Dreamer."*
6	PT	Chailey Lying Support	For the postural support and the abduction at the hips.	*" …because of the degree of postural support that it gave … quite a lot of trunk and pelvis support and allowed her legs to be…maintained in an abducted position*
7	PT	Chailey Lying Support	Good definite position in supine. Symmetrisleep moves if child is active.	*"It holds her quite definitely but gently in a nice aligned supine position."*

PT = physiotherapist OT = occupational therapist