Understanding sleep among children with Cerebral Palsy, their siblings and parents: A qualitative multi-perspectives study of the social context of family sleep

by

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Submitted for the Degree of Doctor of Philosophy

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August 2017

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Declaration of originality

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Word Count: 98,967 (Chapters 1-12, exclusive of appendices, references and bibliography).
Abstract

Children with Cerebral Palsy (CP) account for the largest group of children with a physical disability in the UK. Despite evidence that sleeplessness occurs commonly in children with CP, there is little in-depth research on their sleep. Previous research has relied on the viewpoints of parents, mainly mothers. No research has explored sleep from multiple family members’ perspectives within the same family. This study explores the meanings, organisation and practice of sleep for children with CP, their siblings and their parents.

This qualitative study of 10 families involves 10 children with CP (aged 6-13 years), 7 siblings (from 5 families) and 17 parents. Influenced by existing literature on involving disabled children in research, qualitative semi-structured interviews are supplemented by data from children’s self-directed photography and sleep questionnaires, 2 week sleep diaries and actigraphy for all participants.

Findings emphasise the importance of the social and family context of sleep. For children, the bedtime routine was significant with reference to their practice of sleep and differences were highlighted dependent on age and severity of CP. Night-time interactions with parents were important for children with severe CP experiencing sleeplessness. For some children, the use and location of their bedrooms enabled the attainment of privacy and autonomy. However, differences, regarding these factors, were found between children with severe CP and those without. Night-time parental monitoring of children with severe CP was common but methods differed depending on a number of intersecting factors including severity of the child’s CP, location of bedrooms and co-existing health issues. Different methods of monitoring had varying degrees of impact on parents’ sleep and on privacy for the child with CP. Co-sleeping was engaged in by a small number of parents with their disabled child at specific times and used as a strategy to protect the sleep of family members.
Acknowledgements

First, and absolutely foremost, my thanks go to the ten children and their amazing families. They invited me into their homes, and their lives, with such kindness and patience and it was a privilege to get to know them and spend time with them all.

Talking of patience, huge thanks to my supervisors: Sara Arber and Rob Meadows. I am so sorry it has taken this long. Your support and advice has been invaluable and thank you for guiding me, with firmness and kindness, through the highs and the lows. Thank you to Jo Moran-Ellis, whose supervision at the beginning was much appreciated.

To my mum and dad, thank you for your unwavering support. You have given me space, time, love and sustenance to see me through and I am so grateful. Thanks also to Tam, Luke and the rest of my family for their encouragement and who regularly asked me how it was going but knew when to retreat quickly when I glared at them!

Thank you to my lovely colleagues: Diane, Liz, Sam and Helen and my good friend KP. Thank you for cheering and cajoling me through the years and for understanding.

At times, writing this thesis became so difficult that I truly felt that I would never finish it, but then I thought of Terry: my friend, my colleague, and my inspiration. Terry was the first to believe that I could do this and now I can tell her that I have. Thank you, Terry.

Finally, this is for Joe, Flo and Audrey. I love you. Thank you for your support and for making me smile and laugh. I know I have made you proud, just as you make me proud every day.
Table of Contents

Declaration of originality ........................................................................................................2

Abstract ..................................................................................................................................3

Acknowledgements ..................................................................................................................4

Table of Contents ....................................................................................................................5

List of Tables ...........................................................................................................................11

List of Figures .........................................................................................................................12

List of Appendices ..................................................................................................................13

Chapter 1 - Introduction ........................................................................................................15
  1.1 Overview .........................................................................................................................15
  1.2 Background and personal motivations ..........................................................................15
  1.3 Cerebral Palsy ................................................................................................................17
  1.4 Research Aims ................................................................................................................21
  1.5 Structure of the thesis .....................................................................................................22

Chapter 2 - Sleep, sociology and disabled children .................................................................25
  2.1 Introduction .....................................................................................................................25
  2.2 Sleep - a sociological issue .............................................................................................25
  2.3 Sleep, disabled children and their families ....................................................................30
    2.3.1 The impact of sleeplessness on disabled children ..................................................34
    2.3.2 Sleeplessness in disabled children and the impact on caregivers .......................35
  2.4 Coping Strategies ..........................................................................................................39
  2.5 Conclusion .......................................................................................................................42

Chapter 3 - Childhood, disability and ‘doing’ family ..............................................................44
  3.1 Introduction .....................................................................................................................44
5.3 Research Design and Review ................................................................. 96
5.4 Development work and pilot study ....................................................... 97
5.5 Sampling Framework .............................................................................. 99
  5.5.1 Inclusion Criteria ............................................................................. 99
  5.5.2 Exclusion Criteria .......................................................................... 100
5.6 Recruitment and Access ....................................................................... 101
5.7 Initial visits and obtaining informed consent ........................................ 103
  5.7.1 First Visit ..................................................................................... 103
  5.7.2 Second Visit – Consent ................................................................... 103
5.8 Study procedure - Two Week Information Collection Period ............... 104
  5.8.1 Instructions ................................................................................... 104
  5.8.2 Sleep Diaries ................................................................................. 104
  5.8.3 Photographs .................................................................................. 108
  5.8.4 Actigraphy ...................................................................................... 109
  5.8.5 Sleep Quality Questionnaires ......................................................... 110
5.9 Qualitative Interviews with children and parents .................................. 111
  5.9.1 The need for preparation and time when interviewing disabled children.. 114
5.10 Data Analysis ....................................................................................... 116
5.11 Analysis of data collected from children who communicated in non-verbal ways 119
5.12 Conclusion ......................................................................................... 121

Chapter 6 - Introducing the participants, the families and their sleep ..... 122
6.1 Introduction ........................................................................................... 122
6.2 Demographic characteristics................................................................... 122
6.3 Family participants and data collection details .................................... 125
  6.3.1 Baker Family ............................................................................... 125
  6.3.2 Hughes Family ............................................................................ 126
  6.3.3 Jackson/Jones family ..................................................................... 129
  6.3.4 Edwards Family ............................................................................ 130
  6.3.5 Davis Family ............................................................................... 134
  6.3.6 Appleby Family ............................................................................ 136
  6.3.7 Fletcher Family ............................................................................. 138
  6.3.8 Cooper Family ............................................................................. 141
  6.3.9 King family ................................................................................... 145
  6.3.10 Gibson Family ............................................................................ 148
6.4 Conclusion and overview of data analysis chapters ............................... 151
Chapter 7 - The meanings and management of sleep for children with cerebral palsy and their siblings and the impact of sleeplessness........157

7.1 Introduction .............................................................................................................................................. 157

7.2 The meaning and ‘non’ meaning of sleep for children................................................................. 158

7.3 Actions and interactions leading up to and following night-time sleep................................. 160

7.3.1 The Lie-in ............................................................................................................................................... 161

7.3.2 The bedtime routine ......................................................................................................................... 165

7.4 Delaying sleep, asserting autonomy and covert activity ............................................................. 168

7.5 Paid carers and bedtime for children with severe CP ................................................................. 171

7.6 The impact of sleeplessness................................................................................................................ 177

7.6.1 The impact of sleeplessness on self................................................................................................. 178

7.6.2 The impact of sleeplessness on others ......................................................................................... 181

7.7 Conclusion............................................................................................................................................ 185

Chapter 8 - Actors, activities and artefacts (that help or hinder sleep)....187

8.1 Introduction.............................................................................................................................................. 187

8.2 Reasons for sleeplessness.................................................................................................................... 188

8.2.1 Bodily and physical needs ................................................................................................................. 188

8.2.2 Imaginary worlds .............................................................................................................................. 190

8.2.3 Stress, worry and anxiety ................................................................................................................. 195

8.2.4 Being disturbed by others .............................................................................................................. 198

8.3 Actors and artefacts that aid sleep.................................................................................................... 203

8.3.1 Mum and Dad ..................................................................................................................................... 203

8.3.2 Ways to alert parents ......................................................................................................................... 204

8.3.3 Cuddly toys and Pet Cats ............................................................................................................... 207

8.3.4 Nightlights and the preference for light or darkness during the night................................... 212

8.4 Independent techniques to promote sleep ...................................................................................... 215

8.5 Conclusion............................................................................................................................................ 217

Chapter 9 - The bedroom: location, use, and significance of the sleep space.................................220

9.1 Introduction.............................................................................................................................................. 220

9.2 Bedroom use and location for siblings and children with mild CP....... 221
9.3 Location of the bedroom for children with severe CP. The downstairs bedroom: a disability norm? .......................................................... 224
  9.3.1 The downstairs bedroom: the parent perspective............................... 226
  9.3.2 The downstairs bedroom: the perspective of children with severe CP .... 231
  9.3.3 The downstairs bedroom: the sibling perspective............................... 235
  9.3.4 Section summary .............................................................................. 237

9.4 The use of the bedroom by children with severe CP .............................. 238

9.5 The downstairs bedroom: an extension of the public space ................. 239

9.6 Contents of the bedrooms of children with severe CP: a clinical space . 241
  9.6.1 The ‘hospital’ or ‘adapted’ bed .......................................................... 242
  9.6.2 The hoist ............................................................................................ 244

9.7 The bedroom: a shared space ............................................................... 248

9.8 Conclusion.............................................................................................. 251

Chapter 10 - Parental night-time monitoring of children with CP ..........253

10.1 Introduction ............................................................................................ 253

10.2 Four levels of parental night-time monitoring ..................................... 254

10.3 Low level monitoring ............................................................................. 256

10.4 Informal monitoring ............................................................................. 258

10.5 Co-sleeping ............................................................................................ 263

10.6 Technological monitoring: The ‘Baby’ monitor ................................. 270

10.7 Combination monitoring ....................................................................... 277

10.8 Conclusion.............................................................................................. 282

Chapter 11 - Discussion ............................................................................ 286

11.1 Introduction ............................................................................................ 286

11.2 The social context of (disabled) children’s sleep .............................. 287

11.3 Overview of findings ............................................................................. 288

11.4 The bedtime routine ............................................................................ 290
  11.4.1 The bedtime routine: a family practice ............................................. 291
  11.4.2 Paid carers and the bedtime routine as a family practice ................. 292
  11.4.3 The bedtime routine and developing autonomy .............................. 293
## 11.5 The bedroom

11.5.1 The bedroom: a place for developing identity and enjoying privacy for ‘some’ children

11.5.2 The downstairs bedroom: ‘barriers to doing’ and ‘barriers to being’

## 11.6 Parental night-time monitoring of their disabled child

11.6.1 Night-time monitoring and the downstairs bedroom: impact on parent sleep and child privacy

## 11.7 Co-sleeping

## 11.8 Conclusion

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### Chapter 12 - Conclusion

12.1 Introduction

12.2 Summary and contribution of the research

12.3 Research reflections: Strengths and limitations

12.4 Implications for policy and practice and recommendations for future research

12.5 Concluding reflections

### Appendices (Listed on page 13)

### Bibliography
List of Tables

Table 5.1 Excerpt from Grace Baker's sleep diary, child with mild CP, aged 13 years ................................................................. 106

Table 6.1 Demographic characteristics of participating families with a focus on the child with CP .............................................................................................................. 124

Table 9.1 Bedroom location of the children with CP and their family members........ 225

Table 10.1 Method of parental night time monitoring ............................................. 255
List of Figures

Figure 6.1 Categories page of Libby Cooper’s symbol communication system......143
Figure 6.2 Themes and sub-themes of chapter 7.........................................................153
Figure 6.3 Themes and sub-themes of chapter 8..........................................................153
Figure 6.4 Themes and sub-themes of chapter 9..........................................................154
Figure 6.5 Themes and sub-themes of chapter 10.......................................................154
Figure 9.1 Bed belonging to Jacob Gibson......................................................................243
Figure 9.2 Bed belonging to Stanley Edwards and bed belonging to Alex Edwards.............................................................................243
Figure 9.3 Mobile hoist in bedroom of Charlotte Appleby........................................245
Figure 9.4 Fixed ceiling hoist in bedroom of Libby Cooper........................................245
List of Appendices

Appendix 1.1 Recruitment poster with tear off tags ........................................ 328
Appendix 1.2 Recruitment poster ..................................................................... 329
Appendix 1.3 Recruitment leaflet ..................................................................... 330
Appendix 2.1: Information sheet for child with CP – written format .............. 331
Appendix 2.2: Information sheet – Child with CP, symbol format ................. 335
Appendix 2.3: Information sheet – Child with CP, audio script as recorded on a CD .................................................................................................................. 342
Appendix 2.4: Information sheet – Older siblings ........................................... 346
Appendix 2.5: Information sheet – Younger siblings ...................................... 350
Appendix 2.6: Information sheet – Parents ..................................................... 354
Appendix 3: NHS Research Ethics Approval Letter ......................................... 358
Appendix 4: University of Surrey Ethics committee approval letter .............. 361
Appendix 5: NHS Research Governance approval letter ............................. 362
Appendix 6.1: Interview Topic Guide – Children with CP ......................... 364
Appendix 6.2: Interview Topic Guide – Siblings ............................................ 366
Appendix 6.3: Interview Topic Guide – Parents ............................................. 368
Appendix 7: Information pack covering letter ................................................ 370
Appendix 8: Background Information Form .................................................. 372
Appendix 9.1: Consent form for child with CP and siblings, written format .......................................................................................................................... 374
Appendix 9.2: Consent form for child with CP, symbol format ..................... 376
Appendix 9.3: Consent form for child with CP, audio/video recording ....380
Appendix 9.4: Consent form, adult for own participation .......................384
Appendix 9.5: Consent form, parental for child’s participation .................386
Appendix 10.1: Sleep diary instruction sheet ........................................388
Appendix 10.2: Photography instruction sheet for children .........................389
Appendix 10.3: Actiwatch instruction sheet ...........................................390
Appendix 11.1: Sleep Questionnaire – PSQI, for parents and siblings >16years ............................................................................................391
Appendix 11.2: Sleep Questionnaire – Children’s Sleep Habits Questionnaire (CSHQ), for siblings .................................................................396
Appendix 11.3: Sleep Questionnaire – Chailey Sleep Questionnaire for children with CP ..............................................................................401
Appendix 12.1: Example of Actogram of child with severe CP .................416
Appendix 12.2: Example of Actogram of parent (father) .........................417
Appendix 12.3: Example of Actogram of parent (mother) .......................418
Appendix 13: Extract of interview with Libby Cooper (child with severe CP, 12 years old) ......................................................................................419
Appendix 14: Gross Motor Function Classification System (GMFCS) descriptors .........................................................................................422
Appendix 15: Communication Function Classification System ...............424
Appendix 16: Classification of CP sub types ............................................428
Chapter 1 - Introduction

1.1 Overview

In order to contextualise the doctoral research for the reader this chapter will provide more information about the background against which the research developed and will explain more fully what the term ‘cerebral palsy’ means. Further to this the aims of the research will be outlined. Finally, an overview of the structure of the thesis will be presented.

1.2 Background and personal motivations

The initial ideas regarding this doctoral research first developed when I was employed as a research assistant to work at a specialist NHS assessment centre for children with complex disabilities to work on projects concerning sleep problems in children and young people with cerebral palsy (CP). My first project was to co-develop a ‘sleep questionnaire’ specifically aimed at assessing sleep problems in children with CP. As part of this project I visited parents of children with CP to administer the questionnaire, firstly in order to pilot and validate the questionnaire but also to obtain information pertaining to the numbers of children with CP with sleep problems and the types of problems being experienced. It quickly became apparent to me in visiting and talking to parents that many parents had, and were keen to tell, detailed stories about their child’s and their own experiences of sleep and that many had never had the opportunity to do so. Many parents commented that they were rarely asked about their child’s sleep at routine clinical assessments or annual multi-disciplinary reviews despite the fact that the child in question had, in the parents view, poor and disturbed sleep. Parents talked about how their child’s disturbed sleep patterns affected the lives of the child and the lives of them, the parents, and the family as a whole. Many parents commented on how exhausted they and their children were and that it was difficult to foresee when and how the sleepless nights would end.

This detailed and rich information was of great interest and concern but I was unable to use or reflect on this in-depth information as it fell outside the

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1 From this point on I will refer to children or young people interchangeably.
remit of the questionnaire study that I was conducting at the time. Furthermore, because of the nature of the study I rarely audio recorded the meetings with the parents. Therefore, I felt that their stories were being heard, perhaps for the first time, but then being lost again. I was also acutely aware that the information being offered to me was strictly from the parent’s viewpoint and that the children with CP within the family were not consulted about their own sleep. Therefore, I was not hearing the story of their sleep from their perspective. When administering the questionnaire in the family home I would often ask, if the child was present, if they would like to participate. On a few occasions this was welcomed by the parents and the child helped answer the questions. However, on more than one occasion I was told that the child would not be able to help as they would not understand and/or because they were unable to communicate in a verbal way and on one occasion I was told that it would be too upsetting for the child.

After two years in my research assistant post my funding was extended and as part of this I was offered the opportunity to carry out a part-time PhD in sleep and children with CP. Building on my experiences from conducting the questionnaire study I was able to develop my ideas for doctoral research and through discussion and reflection I knew my interest lay in exploring and understanding the sleep of children with CP at an in-depth level and from the multiple perspectives of family members including the children with CP themselves. In the development of my ideas for my doctoral research and for my project work as a research assistant I read much around the area of sleep research. In particular, my ideas developed against the backdrop of the emergent (at that time) field of the sociology of sleep as well as the existing (biomedical) research on sleep and disabled children. Additionally was my interest in exploring the ways and methods of meaningfully involving children with CP in the research process. At the time of developing my study ideas, research projects exploring the daily lives and experiences of disabled children that directly involved the children themselves, especially those that use non-verbal ways to communicate were scarce. However, as time went on and my research protocol began to take shape a small number of studies emerged that I was able to draw upon in order to gain ideas and inspiration for involving
disabled children directly in my research. Of particular interest was how these studies managed the potentially contentious ‘intersection’ between the sociology of childhood and social model of disability research. When I began formulating my research ideas the focus of my attention was on the children with CP and although this remained an important and central element it quickly became clear that sleep provided a window through which to view family life and the meanings and practices that family encompasses. Therefore, it was important to consider literature and research from the sociology of family field.

As discussed below, the principal impairment in CP is movement and posture. But for many children and young people with CP, additional impairments co-exist affecting cognition and understanding, sensation, and communication as well as co-morbid conditions such as epilepsy. Taking communication as an example, I was already aware that the majority of children who attend the specialist centre at which I work do not communicate verbally. Instead they use alternative and augmentative communication systems such as sign, picture symbols and systems based on assistive technology. For some children these systems are not suitable and they rely mainly on body language and eye contact for communication purposes. It was important for me to reflect on this and how communication differences as well as aspects related to cognition, understanding and perception would affect the research process and dynamics of the research relationship. This informed and influenced the design of the research and ethical considerations and raised questions when it came to analysing the qualitative interview data of children with severe CP who communicated in non-verbal ways.

1.3 Cerebral Palsy

Over the years there have been a number of attempts to provide a conclusive definition of CP. In the 1960’s Bax (1964, cited in Bax et al., 2005) defined CP as ‘a disorder of movement and posture due to a defect or lesion of the immature brain’ (p571). This definition remained in favour until the 1990’s when Mutch et al. (1992) put forward a new definition emphasising the idea that CP should be conceptualised as a ‘collection’ of clinical pictures. Mutch et al. (1992) defined CP as ‘an umbrella term covering a group of non-progressive,
but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development’ (p549). The majority of children with CP are diagnosed with the condition between the ages of 6 months and 2 years. However, as the Mutch et al. (1992) definition highlights the exact clinical picture of CP for an individual child evolves dependent on time, development, learning, training, therapies and other factors (Bax et al., 2005).

Most recently a new definition of CP has been proposed by a group of world experts following a number of meetings and discussion and this describes CP 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: 9)

This definition still emphasises the primary concept of a motor disorder but this is no longer the exclusive focus with mention of additional impairments of a wide range of functions including cognition and communication. It is important to note that CP is a descriptive term. How movement and posture are affected and the severity of this and possible additional impairments will vary greatly on an individual basis. As Rosenbaum (2003) states ‘…no two people with cerebral palsy are affected in exactly the same way’ (p970).

Cerebral palsy is the most common physical disability in childhood with approximately 2-2.5 in 1000 babies being born with the condition in the western world (Rosenbaum, 2003). The incidence rate has not changed greatly over the last 50 years. The possible reasons for this are twofold. Firstly, improvements in the health and care of mothers have decreased some causes of CP. However, in contrast to this more babies who are born prematurely, are surviving and a number of these (as a consequence of pre-term birth) will have
CP. As well as prematurity at birth other factors may increase the risk of CP occurring including infections of the pregnant mother (i.e. rubella, chicken pox, and toxoplasmosis), babies that are twins, triplets or more, severe jaundice in new-born babies and mothers who smoke, drink alcohol or take drugs have an increased risk of having a child with CP. However, in the majority of cases the cause of the damage to the brain that leads to the development of CP remains unknown.

Despite children with CP making up the largest group of children with a physical disability in the UK there is very little research focusing on the sleep of children with CP. The only research specific to the sleep of children with CP has been concerned with the presence of sleep problems and the diagnosis of sleep disorders with problems pertaining to sleeplessness (i.e. problems initiating sleep, night-time waking and early morning waking) being commonly found in this group (Newman et al., 2006).

The research by Newman et al. (2006) and more recent review work (Simard-Tremblay et al., 2011; Lélis et al., 2016; Gringras, 2017) has postulated that there are a number of possible, often interrelated, factors that lead to the increase in sleep difficulties experienced by children with CP. Lélis et al. (2016) divide these factors into intrinsic factors associated with CP and extrinsic factors.

Intrinsic factors describe co-morbidities often found in children with CP which are linked with an increased risk of sleep disturbances. As will be outlined in further depth throughout the thesis, these include epilepsy and specifically the occurrence of nocturnal seizures, intellectual disability, and the frequently associated presence of attention deficit disorder and autism (Gringras, 2017). Furthermore, a higher incidence in children with CP of visual impairment, upper airway obstruction and gastro-oesophageal reflux may all be linked to sleep difficulties for this group of children (Simard-Tremblay et al., 2011; Lélis et al., 2016; Gringras, 2017). Simard-Tremblay et al. (2011) also highlight how the severity and type of motor disability, central to the diagnosis of CP, may have an effect on sleep. Children with more severe CP affecting their whole body (spastic quadriplegia) and those with dyskinetic CP are more likely
to have sleep disorders (Newman et al., 2006). This may be linked to these children having a higher incidence of pain and being unable to change their own position at night (Gringras, 2017).

The inability to change one’s body position at night interrelates with one of the extrinsic factors outlined by Lélis et al. (2016) as it leads to a need for parents/carers to turn or move their child at night which leads to sleep disturbance for the child and, consequently, for the parent/carer.

Other extrinsic or environmental factors linked to a higher incidence of sleep problems for children with CP include the use of postural management equipment and technological devices during the night to aid feeding, ventilation and clearing of airways. The technological devices may alarm, make a general on-going noise or malfunction during the night causing a disturbance for the child and their parents/carers (Heaton et al., 2006; Kirk, 2010; Lélis et al., 2016).

Despite existing work, as outlined above, there is still uncertainty about why exactly children with severe CP have a higher incidence of sleep problems compared to children without CP. Further to this, there remains a huge gap in our understanding of the meanings, management and experience of sleep, and sleep disturbance, for children with CP and their families and also for disabled children in general. As indicated to me by the parents of children with CP in my original sleep questionnaire study, no one regularly enquires about the sleep of their child or how their child’s experiences of sleep affect them at an individual and family level. During the questionnaire study one parent commented that because sleep was never enquired about and because no ‘professional’ advice was forthcoming she assumed that her child’s poor sleep was simply ‘part and parcel’ of her child having CP. Considering that the ‘night-time’ takes up nearly half of our lives and that for many children with CP and their families, where sleep disturbances are present, the night-time becomes a time of activity and for some simply an extension of the ‘day time’ this gap in knowledge and enquiry is concerning.
In line with work from the sociology of sleep it is time to study the concept of ‘doing’ sleep (Taylor, 1993) rather than merely accepting ‘being’ asleep as a passive action. Since starting my research I have become a parent to two daughters. My views on sleep are very different now to what they were when I began on my PhD journey. The understanding of sleep must be embedded in the social contexts of people’s lives. In order to truly explore and understand sleep and the social context in which it is embedded for children with CP it is of paramount importance to gain insight from the children themselves. Furthermore, by exploring multiple family members’ perspectives of sleep an understanding of sleep at an individual level and at a family level can be achieved, leading to understanding of the relationships, roles, organisation and practices within the home that ‘family’ encompasses.

1.4 Research Aims

At the start of my research my broad research aims were to understand the social context of sleep and the night-time for children with CP, their siblings and parents and thus support the sociological notion of ‘doing’ sleep (Taylor, 1993). I felt it was important to embed sleep within a family and relational context and use sleep as a lens through which to view family practices and ‘doing family’ in relation to the meanings, motives and management of sleep in families with disabled children. To achieve this, the aim was to obtain multiple family members’ perspectives to allow for similarities and differences based on generation, age and disability standpoints within and across families to be understood. My specific research aims are outlined in Chapter 4.

To meet the objectives I recruited 10 families which included 10 children with CP (6-13 years old), seven siblings (6-13 years old from 5 families) and 17 parents. In line with existing literature on ways to involve children, including disabled children, in research, qualitative semi-structured interviews were conducted. Information was also obtained through the use of self-directed photography with the children and sleep questionnaires, 2 week sleep diaries and actigraphy for all participants and used to prompt and facilitate discussion in the interviews.
1.5 Structure of the thesis

Chapters 2, 3 and 4 outline and discuss relevant literature. Chapter 2 presents an overview of the literature concerning the sociology of sleep. Research concerning the sleep of disabled children is outlined and it is highlighted that this is dominated by the medical realm with the majority of research describing the high prevalence rates of sleep problems among disabled children. This literature focuses on the impact of sleeplessness on the child and on their caregivers, but there is little consideration of how this may vary and depend on individual, familial and cultural factors.

Chapter 3 further contextualises the research by outlining the development of three important fields within sociology: childhood, disability and family life. Aspects of each of these fields have influenced the theoretical and methodological underpinnings of my research whilst an understanding of sleep remains the central tenant.

Chapter 4 begins by presenting the research aims and a brief overview of the study design. A discussion follows of the methodological and ethical issues relevant to my study with reference to relevant literature, specifically in relation to researching children (disabled and non-disabled). These issues informed the choice of research methods used for the study.

Chapter 5 outlines the methodological approach chosen and discusses how obtaining multiple family member’s perspectives enabled the aims of the research to be achieved. Details regarding the development and pilot work, together with a full description of the sampling framework and participant recruitment process are presented. The study procedure is detailed and the various methods of data collection are each described. The chapter ends with a description of the thematic analysis of the interview data and a reflection on the difficulties encountered when analysing and presenting the interview data of children with CP who communicated in non-verbal ways.

Chapter 6 provides an introduction to the families and the family members that took part in the study, beginning with the socio-demographic details of each of the families and the participating family members with a focus
on the child with CP. In-depth information regarding the participating family members and their sleep is outlined and presented family by family. Chapter 6 also briefly introduces the key themes and sub-themes discussed in the four qualitative data analysis chapters.

Chapter 7 focuses (in the main) on the interview data of the children with CP and their siblings in order to explore their meanings of sleep. The data emphasises the social context of sleep whereby rather than talk ‘about’ their sleep many of the children talked ‘around’ their sleep with specific reference to the activities, routines and practices leading up to, and following, night-time sleep. The presence of paid carers at bedtime for the child with severe CP is also discussed with reference to the parent data. The impact of sleeplessness on self and on other family members was also explored by the children. Differences in relation to these aspects were apparent depending on the age of the child and the severity of CP.

Chapter 8 continues to focus on the children’s data and an exploration of the social context of sleep. This chapter examines the actors, activities and artefacts that the children and young people regarded as significant, helpful or obstructive in relation to their sleep (or not sleeping) and during the night.

Chapter 9 focuses on the location of sleep for children with CP, their siblings and parents. The chapter highlights how the location, use and meanings of bedrooms differed between those of children with and without severe CP. A number of children with severe CP had their bedrooms located downstairs (or were in the process of moving to a downstairs bedroom) when the rest of the family slept upstairs. The concept of privacy is explored with a focus on how the bedrooms of children with severe CP are often ‘public’ spaces.

Chapter 10 analyses the parents’ data in relation to the monitoring they undertake of their child with CP, in varying ways, through the night. These levels and methods will be discussed in relation to informal and formal monitoring. The impact on parent/s sleep of night-time monitoring varied depending on which method was practiced. The activity of co-sleeping is also
discussed as a strategy to help the child with CP at increased times of child sleeplessness and as a strategy to protect the sleep of other family members.

The main findings from the research are summarised and discussed in Chapter 11. This discussion chapter makes reference to the existing literature and evaluates how the research contributes to, and provides, new knowledge about the experience of sleep for children with CP and their families from multiple familial perspectives.

Chapter 12 outlines the researcher's own reflections of conducting the research and the challenges and achievements that were experienced along the way. This final chapter discusses recommendations for policy and practice within clinical settings in reference to sleep for children with CP and their families. Suggestions for future research are also discussed.
Chapter 2 - Sleep, sociology and disabled children

2.1 Introduction

The majority of research on sleep concentrates on the biological and psychological aspects of this phenomenon. However, it is now recognised within the field of sociology that sleep is worthy of exploration. There is an expanding collection of written work and research recognising sleep as embedded in the social context of people’s lives. Such research has explored sleep from the point of view of children, women, men, and couples (Williams et al., 2007; Moran-Ellis and Venn, 2007; Hislop and Arber, 2003; Meadows et al., 2008; Hislop, 2007; Zarhin, 2015). However, the experiences of sleep from the multiple perspectives of children and parents in the same family have not, as yet, been explored. Furthermore, sociological research exploring sleep has not extended to disabled children and their families. The literature on sleep and disabled children is dominated by the medical realm with the majority of research describing the high prevalence rates of sleep problems in this population. This research has also sought to describe the negative impact of ‘sleeplessness’ on the child themselves and on their primary caregivers (specifically mothers). However, it is argued in line with Wiggs (2007) that, as with sleep, the definition of sleeplessness is bound up within a social context and depends on individual, familial and cultural aspects.

2.2 Sleep - a sociological issue

Sleep is a necessary yet often overlooked element of daily life. It is taken for granted that we all sleep with little in-depth exploration of the meanings and experience of sleep for people. This is despite the fact that sleep occupies about a third of our life in total (Wiggs, 2007). It is generally accepted that good quality sleep is vital for good general health and wellbeing but the exact function of sleep is still an area of some debate (Williams, 2002). As Wiggs (2007) explains one way researchers have attempted to define the function of sleep is by describing the psychological and biological effects of sleep problems, i.e. a detrimental effect on physical health, cognitive function, mood and behaviour. By reducing the definitions of the function of sleep to these purely psychological
and biological bases the importance of the socio-cultural aspect of sleep tends to be ignored. As Williams (2002) states ‘...when, where and how we sleep are all, to a considerable degree, socio-cultural matters...This in turn is dependent on history and culture, time and place’ (p. 178). Williams (2005, 2007) discusses how a sociological exploration of sleep and society takes place at three interrelated levels. These levels include an individual and (non)experiential level that includes phenomenological issues related to concepts to do with sleeping/sleepy bodies. The second level encompasses interactional issues and the ‘doing’ of sleeping’ (Taylor, 1993:464) as opposed to the passive action of ‘being’ asleep. An understanding of sleep at this level is achieved through the language used to describe, and the cultural constraints on the ‘motives, meanings and methods’ of sleep (Taylor, 1993:464) and, as Williams (2005) adds, it’s ‘management’, all of which are related to concepts such as gender, life course, norms, roles and rituals. The third level of analysis that can be applied to sleep outlined by Williams (2005, 2007) is the societal/institutional level whereby the broader sociological issues such as social organisation, social patterning and social scheduling in relation to sleep are the focus including the organisation of sleep across the private/public divide. Analysis at this level raises issues pertaining to ‘risk, regulation, medicalisation and surveillance’ (Williams, 2005:5).

The sociological dimensions of sleep were first considered and written about by Aubert and White (1959a, 1959b, cited in Williams, 2005), Schwartz (1970) and Taylor (1993). As the dates of publication suggest there was little sociological work devoted to sleep with huge gaps in time between the articles that were written. Sociological attention became more focussed on sleep from the early part of this century and sociological research has explored the sleep of women, men, couples and children.

Hislop and Arber (2003) explored, in their study of sleep disruption in mid-life heterosexual women, whether the daytime gendered roles of women extended to the night-time and sleep. At mid life, such women are expected to fulfil multiple roles including being mothers, partners, employees and, for some, carers of aging parents and it was the fulfilment of these roles that impacted on
their night-times and disrupted women’s sleep. The study found that because women’s sleep was embedded in this social context the risk of sleep disruption was high with the physical and emotional labour involved in caring and looking after family members reducing their right to a good night’s sleep and reinforcing their gender role within the home.

Studies of the sleep of heterosexual couples exploring the narratives of both partners have also been conducted. For instance, Hislop (2007) describes how couples, in sharing a bedroom and a double bed have to negotiate the spatial, temporal and relational dimensions of the sleeping environment. Hislop (2007) found that this negotiation reflected gendered roles, identities and the power dynamics inherent in the couple’s relationship but also dictated from a societal level. Venn et al. (2008) explored the gendered nature of sleep disruption among couples who have children. They found that in general women provided the emotional and physical night-time care for children even when they, themselves had returned to paid employment and that this was an extension of their daytime role. The authors label this as the ‘fourth shift’ as they see this night-time activity as an continuation of Hochschild’s (1997, cited in Venn et al., 2008) notion of the three shifts that exist for women, namely daytime work, evening work and emotion work. The result of this is significant sleep disruption for women who have children.

Pahl (2007) also focuses on gendered power relations and the concept of ‘sharing sleep’ within couples and also between couples and their children. By outlining pertinent empirical data and questions about sleep and highlighting the socio-cultural aspects of sleep, Pahl (2007) goes on to suggest theoretical approaches to be used to understand sleep within households. Furthermore, data on sleep within households can be used to ‘test’ and aid our understanding of a range of sociological theories. Specifically, the work of Morgan (2001) and his three ‘economies’ of family life is drawn upon (Morgan's concept of ‘family practices’ will also be explored in Chapter 3 when work from within the field of family sociology is considered). Firstly, Pahl (2007) focuses on Morgan’s (2001) ‘political economy’ of family life and argues that respect for an individual’s sleeping priorities will be related to the proportion of resources that
they bring to the household with economic resources given precedence. The example of the household ‘breadwinner’ not having to get up to a crying child in the night is given. Pahl (2007) highlights the persistent nature of the economic inequalities between men and women resulting in gendered structural power relations effecting patterns of ‘sharing’ sleep within couples. From this theoretical perspective Pahl (2007) notes a need to consider the design of research methods in order to identify different power positions and to allow individuals to freely express ideas which may differ from those of their partner, for instance, conducting separate and private interviews.

The second of Morgan’s (2001) economies that Pahl (2007) applies to sleep is a ‘moral economy’. Pahl (2007) notes that moral economy can be applied to exploring ‘the norms which surround broader ideologies within households’ (para. 4.1). Related to sleep, Pahl (2007) comments that ideologies supporting the gendered nature of roles within households whereby women have responsibility for children and childcare has a large impact on their sleep, as outlined above with the work of Hislop and Arber (2003), Hislop (2007) and Venn et al. (2008). Pahl (2007) also points to ideologies about masculinity as important to consider in relation to sleep. For example, a man is expected to be responsible for keeping his home and family safe so it will be he who gets up at night to investigate an unexpected noise but as the main household breadwinner he can also expect his sleep to be protected from other night-time disturbance (i.e. attending to children).

Meadows et al. (2008) explored heterosexual men’s understandings of, and attitudes towards sleep. The study discovered a complex relationship between men and their sleep whereby, on the surface, men seemed to have little regard for sleep but, on a deeper level, demonstrated a reflexive understanding, particularly in reference to the perceived function of sleep.

The third of Morgan’s (2001) economies of family life that Pahl (2007) considers in relation to sleep is an ‘emotional economy’. Pahl (2007) comments that sleep is associated with some basic emotions and this is particularly relevant when considering the ‘emotional work’ played out by couples in bedrooms. Bedrooms are a prime site for this emotional work because they
provide privacy for couples to discuss emotionally charged issues and often couples are keen to resolve any emotional issues that have occurred throughout the day hence conforming to the adage of ‘never go to bed angry’.

Despite Pahl (2007) talking of the ‘household’ the focus of her article is very much on couples with little consideration of the sleep of children within a household apart from being recipients of night-time care by (usually) the woman/mother in the household.

However, there has been some sociological exploration of the sleep of children. For instance, both Moran-Ellis and Venn (2007) and Williams et al. (2007) have sought to describe the experience of sleep from the child or young person’s point of view. This, in itself, is novel as much research into the sleep of children relies solely on parent’s recollection and accounts. The key themes that emerged from these studies (with children aged between 5 and 15 years) include children’s attitudes towards sleep, the use of bedrooms and feelings towards privacy, family interactions during the night and the experiences of sleeping away from home. Interestingly in both studies the activities and actions that precede and lead up to the moment of sleep (i.e. bedtime) emerged as important themes and included parent-child negotiations involved in going to bed.

Furthermore, from the sociological research on children’s sleep (Williams et al., 2007) it emerged that children’s experiences of the night-time and sleep are qualitatively different to those of adults and yet firmly embedded within the context of the family. Williams et al. (2007:para 3.6 ) argue that an examination of children’s sleep provides a window onto ‘...the changing character and context of everyday family life’. However, it could also be argued that for this to be truly achieved multiple narratives from children and adults within the same family need to be heard. Sleep is embedded within family life, relationships, roles and the home and different family member’s ‘night-time narratives’ will be individual but at the same time inter-weaving connections will exist. To date no in-depth studies have been conducted which take into account these multiple perspectives within the family.
Further to this, and as discussed in chapter 3, there is also a body of work coming from within the sociology of childhood relating to the lived experiences of disabled children (for example, Watson et al., 1999 and Connors and Stalker, 2003). However, this work has not extended to the lived experience of sleep for disabled children.

2.3 Sleep, disabled children and their families

The dominance of the medical is striking when referring to existing research on sleep and disabled children. In particular from the medical perspective, sleep is defined, or made visible, by the presence of a ‘sleep problem’ and the diagnosis, causes, impact and treatment of the said ‘sleep problem’. Such studies report that disabled children have a higher incidence of sleep problems compared to children without disabilities (Jan et al. 1994; Jan and Freeman, 2004). Dodge et al. (2001) state that the prevalence of sleep disorders in children with neurodevelopmental disabilities may be as high as 80%. The problem of sleeplessness (e.g. difficulty settling and falling asleep, waking up during the night and/or early morning waking) appears to be the most prominent sleep problem that children with and without disabilities present with (Wiggs, 2007). Or more commonly, the problem that parents of disabled children report. Frequently the complainant and the sufferer, in the case of child sleeplessness, are not the same person (Wiggs, 2007). This is an important element to note as it differentiates the research on child sleeplessness from that of adult sleep problems. It highlights further the family context of sleep as it intimates the impact that children’s sleeplessness has on parents’ lives.

Studies have found sleeplessness to occur at high rates in children with a number of different developmental disorders and syndromic diagnoses including autism (Patzold et al., 1998; Wiggs and Stores, 2004), Attention Deficit Hyperactivity Disorder (O’Brien et al., 2003), Angelman syndrome (Bruni et al., 2004), Rett syndrome (McArthur and Budden, 1998) and Fragile X (Richdale, 2003). Furthermore, specific sleep disorders have been found to be more prevalent in certain disabled populations. For instance, in the case of obstructive sleep apnoea and Down’s syndrome (Stores, 2001). As discussed previously, cerebral palsy (CP) is the most common physical disability in
childhood with a total of 2-2.5 of every 1000 live born children in the Western world having the condition (Rosenbaum, 2003). Despite this there has been very little research on the sleep of children with CP. Clinical experience, and the limited research that exists, suggests that sleep problems occur frequently in children with CP. Newman et al. (2006) in a questionnaire based study found that 23% of children with CP had a pathological total sleep score (indicative of overall quality of sleep) in comparison to 5% of children in the general population. Khan and Underhill (2006) reported that children with CP had a significantly higher frequency of night-time disturbance and breathing difficulties at night compared to a control group of children without disabilities. Hemmingsson et al. (2009) reported an increased risk of sleep problems among those children in their study that had a diagnosis of CP with a high need for parental night-time assistance compared to other children with different diagnoses.

All of the research cited on the presence of sleep problems in children with CP, and disabled children in general, has relied on either objective methods (i.e. actigraphy) or parental responses to questionnaires, sleep diaries and, less commonly, interviews. Therefore, none of the research has sought the perspective of the child themselves nor has there been an in-depth exploration of sleep from the child or from other family members (i.e. parents and siblings).

Many reasons, often interrelated, have been postulated as to why sleep disturbance occurs at a higher prevalence in children with CP and disabled children in general. Lélis et al. (2016) divide the factors that lead to the increase in sleep difficulties experienced by children with CP into intrinsic factors associated with CP and extrinsic factors.

Intrinsic factors that have been highlighted as linked with an increased risk of sleep disturbances in disabled children, including children with CP include delayed brain maturation, sensory dysfunction (particularly visual), and damage to, or dysfunction of, the primary sleep centres of the brain (Phillips and Appleton, 2004; Gringras, 2017). Co-morbid medical problems and disorders often found in children with CP may also disrupt sleep, for example, epilepsy.
with nocturnal seizure activity, upper airway obstruction, gastro-oesophageal reflux, pain, autism and attention deficit disorder (Simard-Tremblay et al., 2011; Lélis et al., 2016; Gringras, 2017). These co-morbidities are often found in children with other physical and developmental disabilities and have also been implicated for the high incidence of sleep problems in these groups (Dodge et al., 2001). For children with CP the type and severity of their motor disability may be linked to a higher incidence of sleep disturbance (Simard-Tremblay et al., 2011). Newman et al. (2006) found that children with spastic quadriplegia (total body involvement) and dyskinetic CP were more likely to have sleep problems. Gringras (2017) describes how sleep disorders are positively associated with level of motor functioning using the Gross Motor Classification System (GMFCS) in children with CP. Gringras (2017) explains this by highlighting how children with more severe CP (as defined by the GMFCS, see Chapter 6) are more likely to experience pain, hip dislocations and have an inability to change sleeping position during the night which will all negatively impact on their sleep.

The inability to change their own position during the night interrelates with the extrinsic factors associated with sleep disturbance in children with CP outlined by Lélis et al. (2016) as they will need to be physically repositioned by parents/carers resulting in disturbed sleep for the child and the parent/carer (Wright et al., 2006; Hemmingsson et al., 2009; Lélis et al., 2016). Children with CP, and those with other complex disabilities, may also be technology dependent for such things as feeding, ventilation and the clearing of their airways (suction). Often these devices are used during the night and may cause disturbance. For instance, feeding pumps will alarm when a feed has finished or if an error has occurred, such as a blockage. Furthermore, just the general noise of machines being on could be enough to disturb a child’s sleep and that of their caregivers (Heaton et al., 2006; Kirk, 2010).

Some children with CP use postural management equipment to lie, and sleep, in during the night. Simard-Trembay et al. (2011) discuss how this might, for some, contribute to sleep disturbance. However, Newman et al. (2006) did not find this association to be significant. Additionally, Gringras (2017)
highlights how children with CP are often prescribed a number of different medications including anti-convulsants and drugs to reduce muscle tone. These medications, in combination or on their own, can lead to sleep maintenance difficulties and can increase the risk of sleep-related breathing difficulties and reduce daytime alertness.

Other extrinsic psychological and social issues that have been linked to sleep disturbances in disabled children include difficulties with limit and routine setting and ‘teaching’ the child to develop good sleep hygiene (Dodge et al., 2001). Children with neurodisabilities (including children with CP) may find it more difficult to interpret environmental ‘zeitgebers’ or environmental cues (for example, sunlight, noise, mealtimes, social interactions etc.) which make it difficult for these children to synchronise their sleep-wake cycle generating system leading to sleep problems (Jan and Freeman, 2004).

Sleep problems in disabled children appear to be persistent over time, with similar high prevalence rates being found in children aged 12-16 years as found in children aged less than 6 years (Wiggs, 2007). Quine (1991), in her study of disabled children, found at follow up 3 years later half of those with settling problems and over two-thirds of those waking during the night still had these problems. Wright et al. (2006) also discuss the pervasive and long lasting nature of sleeplessness in disabled children and, to illustrate this, they quote a mother of 17 year old boy with CP who said ‘The sleep pattern for 17 years is to be awakened every two hours, all night long’ (p67). However, the effect on other family members in light of persistent broken sleep has not been specifically explored.

When considering what constitutes sleeplessness or a sleep problem one must first refer to what constitutes ‘good’ sleep and ‘poor’ sleep. In its very definition ‘poor sleep’ must deviate from an already held ideal of ‘good sleep’. Wiggs (2007) discusses that the definition of ‘good sleep’ will vary depending on who the informant is (e.g. child themselves, parent or clinician). Furthermore, definitions will vary over time and with the child’s age. Additionally, definitions will depend on what or who people are benchmarking, or comparing, their definitions against. This reminds us, once more, of how sleep is firmly placed
within a social context and as a consequence so is one’s definition of ‘good’ or ‘poor’ sleep.

One way that some researchers have attempted to define sleeplessness in children is by looking at their daytime functioning and behaviour with the assumption that if a child is functioning optimally during the day then they are probably getting ‘adequate’ or ‘good’ sleep. However, as Wiggs (2007) cautions ‘optimal functioning’ is in itself difficult to define. Furthermore, in disabled children daytime functioning may already be compromised due to aspects related to their disability making it difficult to assess whether adequate sleep is being achieved and what effect sleeplessness is having. Despite these cautions there has been a great deal of research that attempts to link children’s sleeplessness with an impact on their daytime functioning. Further to this, research has focussed on the impact of children’s sleeplessness on the lives of their caregivers. The following two sections will outline the literature further, starting with a discussion of the work on the impact of sleeplessness on disabled children.

2.3.1 The impact of sleeplessness on disabled children

The impact of sleep problems on disabled children has been explored in a number of studies. Wright et al. (2006) report a negative impact on the child’s participation in social and academic activities. Wiggs and Stores (1996) in their study of the sleep patterns of children with severe learning disabilities found that those with sleep problems were more likely to exhibit daytime irritability, lethargy and hyperactivity. Additionally, they investigated the link between sleep problems and specific forms of ‘challenging behaviour’ including self injury, aggression and non-compliance. They found that those children with sleep problems were more likely to exhibit the forms of challenging behaviour investigated and at a more severe level. Similarly, Didden et al. (2002) found a relationship between severe sleep problems in children with learning disabilities and severe levels of aggression, non-compliance and hyperactivity. Quine (1991) in her study of sleep problems among children with learning disabilities found that night-settling problems were related to a large number of daytime behaviour problems including hyperactivity, reduced concentration, being
destructive, and being disruptive at school. Night waking problems were also associated with daytime behaviour problems including temper tantrums, moods, hyperactivity, attention seeking, running away and problems with social interaction. An association between sleeplessness problems and poor communication, poor academic skills and poor self-help skills was also found.

2.3.2 Sleeplessness in disabled children and the impact on caregivers

Research suggests that carers, most commonly mothers, of disabled children experience higher levels of stress, depression and physical health problems compared to carers of children without disabilities (e.g. Florian and Findler, 2001; Manuel et al., 2003). There is a vast and wide ranging literature on why caregivers of disabled children experience higher levels of stress and the impact this has on them. Many authors have attempted to conceptualise the burden of caregiving by applying existing models of stress or developing specific caregiving models. One model of stress that has been applied is Lazarus and Folkman’s classic process model of stress and coping (1984, cited in Beresford, 1994). This model places emphasis on the meaning that an event has for the individual and not just on the physiological responses and conceptualises stress as a process influenced by both external and internal factors. Raina et al. (2004) have developed a model more specific to the process of caregiving. This model incorporates 5 constructs which categorise separate factors influencing caregiver health. These constructs are background and context; child characteristics; caregiver strain; intrapsychic factors; and coping/supportive factors. These models are only useful to a certain extent as they fail to provide the details or to illustrate the complexity of caring for a child with a disability. Importantly what they fail to provide is a whole family perspective on experiences of stress as studies mainly focus only on the parents/carers and specifically on mothers. Fathers and siblings feature in very few studies (e.g. Herbert and Carpenter, 1999; Shulman, 1988; Dyson, 1996) and the perspective of the disabled child themselves, despite being the perceived cause of stress, is rarely considered.

How child sleeplessness potentially adds or contributes to the burden of care for parents of disabled children has been explored. Quine (1991) found
that sleep problems among disabled children were strongly associated with maternal stress. However, as Quine (1991) discusses the causal direction of this association is difficult to determine. Similarly, Richdale et al. (2000) found that the presence of a sleep problem was significantly associated both with behaviour problems in children and hassle (a measure of stress) frequency and intensity in their parents. Again, however, it is difficult to determine the direction of causality between child sleep problems, behaviour problems and parental stress.

The impact on caregivers (predominantly mothers) own sleep has also been explored. In a systematic review examining research specifically on parental sleep deprivation, and contributing factors, for parents caring for children with complex needs at home, 32 studies were identified that met the reviews eligibility criteria (McCann et al., 2015). Fifteen of these studies reported parental sleep timings including average night-time sleep length. A majority of these studies report comparatively low average sleep lengths (noted in the review as less than 7 hours per night; however it is not noted how this parameter was decided upon). There was an extensive variability in average sleep time observed within and between studies.

Meltzer et al. (2006) found that sleep disruption was common in mothers of children with chronic illness and that the mothers reported this as due to the stress related to their child’s ill-health. The study reported that caregiver sleep quality was found to mediate the relationship between child health and caregiver depression and fatigue. McCann et al. (2015) note that in a number of studies parents reported that their own (already disrupted) sleep patterns deteriorated when their child had periods of acute illness, therefore there were times of ‘acute lack of sleep [set] against a backdrop of chronic [and persistent] sleep deprivation’ (McCann et al., 2015: 105).

In a qualitative study on the impact of caring for a child with cerebral palsy on the quality of life of their parents Davis et al. (2009) found that many parents experienced interrupted sleep generally because of their child’s dependence and need for physical care throughout the night and the resulting disrupted sleep impacted negatively on parents physical and emotional well
being (Davis et al., 2009). Furthermore, in a qualitative study conducted by Heaton et al. (2006) exploring the everyday routines associated with the care of technology-dependent children living at home, parental sleep disruption was experienced and mentioned by over half of the parents. Interestingly, in this study the majority of the children, when asked, did not appear to be as sleep disrupted as their parents. However, it is difficult to draw firm conclusions on this matter as sleep was not the primary focus of the study and, therefore, how much opportunity the children were given to explore their sleep experiences is unknown. For the parents in the Heaton et al. (2006) study the effects of sleep disruption were varied. A few parents reported no ill effects and felt that they had 'normalised' getting up during the night. However, other parents reported extreme tiredness and exhaustion and for a small number this affected their ability to take on paid employment and impacted on their social lives.

The need to be vigilant of their children with complex needs throughout the night was highlighted, along with night-time care, as the main contributing factor for parental sleep disturbance by a number of studies identified in the systematic review by McCann et al. (2015). Vigilance or parental surveillance at night was either due to a need to monitor their child’s health condition or their behaviour, or due to fear for their child’s safety, and was a commonly reported contributor to sleep disturbance in the included qualitative studies. Heaton et al. (2006) discuss how one parent of a child dependent on technology stayed awake five nights per week to monitor her son in case his airway needed suctioning. Wright et al. (2006) mention the mother of a 17 year old boy with cerebral palsy who regularly monitored her son all night, because she had an overwhelming fear that he may vomit, choke and die.

Parallels between the research on sleep disruption and the contributing factors for parents caring at home for children with complex needs can be drawn with research on the effects on sleep of caring for older people (e.g. partners, spouses or parents) with dementia or life threatening illnesses at home. For instance, Arber and Venn (2011) identify six different aspects of night-time care that impact negatively on the sleep of carers looking after their partners or older relatives with dementia or illnesses at home. These factors
include attending to the night-time physical needs of the person being cared for (e.g. personal care needs including toileting and cleaning after incidences of incontinence, medication administration, turning and repositioning in bed). If those being cared for are awake at night being disruptive, noisy or wandering out of bed (as can be the case for someone with dementia) then this would directly affect a carer’s sleep, as well as if the recipient of care experiences pain and requires comfort at night. Vigilance and monitoring during the night by the carer was also identified as a factor especially if the person being cared for was considered vulnerable, ‘at risk’ or in danger to themselves. Carers also experienced feelings of anticipation of their care being required so would often stay up later in readiness or reported having ‘alert, light sleep’ (p6). Arber and Venn (2011) also identify the ‘emotional support’ that carers provide at night whereby their sleep is disrupted by worries related to their caregiving. A final reason identified is labelled as the ‘legacy of caregiving’ whereby a carer’s sleep continues to be disrupted even after caring ceases because of distressing images and memories of their loved one’s illness and suffering. All of these factors, apart from the last one, have been raised as contributing factors related to the sleep disruption of parents caring for children with complex needs at home (McCann et al., 2015). An added issue for parents of children with complex needs is the persistent and long lasting nature of their care work. Children with complex disabilities and needs may remain in the family home right up to and throughout adulthood. As mentioned above the sleep disturbance and factors that cause sleep issues in children with complex needs are persistent, therefore it is easy to assume that the resulting sleep disruption for parents is also long-lasting.

Caution is still needed in assuming that child sleep problems automatically equate to parental stress or increased burden of care. Caution is also needed in considering how a parents’ own sleep disruption, as a consequence of caring, is perceived and experienced. Where associations and contributing factors, as identified above, are present consideration is required of the complexity and likelihood that associations are mediated by a large number of different variables which may be individual to the multiple family members and to the family as a unit. As Wiggs (2007) makes clear there is no
consideration in many studies focussing on the association between child sleeplessness and parental burden of care ‘...of the interaction between a child’s sleep pattern and the parents’ beliefs, expectations, values and resources’ (para. 2.6). Similarities and differences between family member’s definitions of ‘good sleep’ and definitions of ‘poor sleep’ will exist just as they will exist between families. It is these narratives and the socio-cultural context they are embedded in that have not, to date, been explored. An exploration of the meanings behind such definitions may provide answers as to why some families are more severely impacted on by perceived sleeplessness compared to others. With specific reference to the resources utilised by families (as mentioned by Wiggs, 2007), Beresford (1994) comments that it is important to move away from describing all the particular stressors (of which sleep disruption may be one) and their adverse effects. Instead an exploration of the ways in which families cope with varying degrees of success should take place as this would have ‘...far greater implications for the understanding and improving the ways that these families can be helped’ (Beresford, 1994: 171).

2.4 Coping Strategies

The concept of coping forms an important element central to the models of stress and caregiving described above. Beresford (1994) describes parental coping resources which inform the coping strategies employed by caregivers. These resources are divided into personal coping resources and socio-ecological coping resources. Personal coping resources include physical health, morale, ideological beliefs, previous coping experiences, parenting skills, intelligence and personality characteristics. Socio-ecological coping resources include the marital relationship, social networks, practical or functional resources and economic circumstances. Coping strategies are the actual actions, behaviours and thoughts used to deal with the stressor and are generally divided into two classes: Emotion-focused coping and problem-focused coping. Emotion-focused coping strategies, (for example, having an alcoholic drink, going to the gym, wishful thinking or watching a funny film) are employed in order to reduce the unpleasant physical sensations of being stressed. Whereas problem-focused coping strategies, (for example, asking for practical help, training, or cognitive restructuring of the stressor) are used to
directly try to reduce, modify or eliminate the source of stress (Hatton, 1995). In general, problem-focused coping strategies are considered as more adaptive and successful in leading to better outcomes, however, that does not mean that the use of emotion-focused strategies is redundant and, in the short term, they can be vital for the well being of caregivers (Beresford, 1994).

With reference to sleep disturbance in disabled children and coping strategies it is important to consider treatments that may be implemented by parents for child sleeplessness. As Wiggs (2007) comments, if the sleeplessness problem can be halted the perceived and actual negative impact of that sleeplessness will be reduced. Behavioural therapy programmes, whereby children are helped to learn new sets of sleep behaviour and, therefore, un-learn undesirable sleep behaviours are often recommended. Wiggs (2007) comments that successful behavioural programmes have been found to reduce child problem behaviour and to improve parental well-being and parental sleep patterns. However, as Wiggs (2007) discusses there are a few studies that have failed to find positive associated changes and this, therefore, highlights once more the complex relationship between child sleep disturbance and the impact on caregivers. Of interest is a study described by Wiggs (2007) which suggests that the effects of resolving a child’s sleeplessness problem may be gendered. A study conducted by Wiggs and Stores (2001, cited in Wiggs, 2007) found that following a successful intervention for their child’s sleeplessness problem, mothers had reduced levels of stress, increased perceived control and were more satisfied with their sleep, their child’s sleep and their ability to cope. In contrast, fathers experienced a significant reduction in their feelings of perceived control. The authors hypothesised that this was due to mothers taking a more active role in the intervention process and that as they gained new skills, fathers felt de-skilled. This highlights the importance of exploring the complex interactions between family members in reference to sleep, sleeplessness and coping strategies and the possibility that these are gendered.

When interventions such as behavioural therapy or medication are not successful or applicable other coping strategies may be employed by families to
deal with child sleeplessness and to lessen its impact. Heaton et al. (2006) found in their study that some families made practical changes to their sleeping arrangements, for instance parents slept in the child’s room or bed so they could respond in a quick and more efficient manner. Williams et al. (2000) in their study of sleeping arrangements of parents of children with epilepsy found that 22% chose to co-sleep either in the same bed or same room because of concern about the danger of night-time seizures. McCann et al. (2015) in their systematic review of articles on the sleep disturbance of parents of children with complex needs found that co-sleeping was often both a contributing cause of parental sleep disturbance and a way to help limit such disruption (as in the Heaton et al. 2006 study). Despite some parents using co-sleeping as a way to reduce sleep disturbance it was a practice identified by one study in the systematic review as having a negative effect on the relationship between husband and wife. Families also made major changes in their daily lives in order to cope and manage their child’s sleep disturbance at night. Heaton et al. (2006) report that one father in their study gave up his job so that he could look after his child in the daytime and his partner could stay awake during the night to attend to the child.

With reference to other coping strategies employed by parents caring at home for children with complex disabilities and who are technology dependent, Heaton et al. (2006) identified the value of the provision of overnight carers and respite care. However, it should be noted that the provision of overnight carers in the family home also brought about additional stress with a perceived intrusion on privacy and family life. This was also corroborated by Kirk et al. (2005), who found that for some parents caring for technology dependent children, the meaning of ‘home’ became negatively transformed by the presence of equipment and the continual presence of home carers. This emphasises further the complexity in meaning that the night-time and sleep holds for families and that for many this time is seen as primarily private family time.

In the Heaton et al. (2006) study the use of respite care away from the home was more highly valued and could be construed as a successful coping
strategy for families dealing with child sleeplessness. MacDonald and Callery (2004) found that overnight respite care was highly appreciated by parents and used as a time for them to rest, replenish their energy stores, attend to their other children and to their relationship with their partner whilst having the reassurance that their children were safe and been well cared for. Without respite provision the majority of families in the study felt they would not be able to maintain the family unit and that ultimately their child with disabilities would have to be given up to full time care. The amount of overnight respite care received away from the family home varies greatly from family to family and is dependent on location. Heaton et al. (2006) found that 20 of the 36 families caring for technology dependent children at home included in their study received no overnight respite care at all (either within or outside of the family home). Thirteen of the families had received overnight respite care over the preceding year, but the amount received ranged from one weekend a year through to two weeks a year plus one weekend. One family received respite care that did not include technical care, so could only be used when the child was not on dialysis.

Although, it is beyond the scope of this chapter, it is important to note that the provision of respite care is not without controversy. Some writers believe that respite care is provided solely for the benefit and according to the agenda of parents and professionals and that the views and feelings of the child themselves is not considered. This may then lead to a situation whereby children find themselves attending respite care with little understanding as to why they are there (see Cocks, 2000 for a full discussion of these particular issues).

2.5 Conclusion

This chapter has discussed how sleep is now regarded as worthy of exploration within the field of sociology. A number of studies that describe how sleep is embedded in a social context have been outlined. However, it has been argued that the experiences of sleep from the multiple perspectives of members of the same family have not yet been explored. Furthermore, despite there being sociological research on the experiences of sleep for children and, separately,
on the everyday lives of disabled children (as discussed in Chapter 3) there is, to date, no in-depth research exploring the experiences of sleep for disabled children.

Existing research on sleep and disabled children is firmly placed within the medical field and dominated by the perspectives of parents and their definitions regarding 'good' and 'poor' sleep. How these socially constructed definitions vary and depend on individual, familial and cultural aspects, including access to coping resources and strategies has been discussed but some important aspects are neglected. Therefore, this chapter has highlighted other areas where further research is needed and, therefore, drawn attention to the issues that this doctoral research aims to explore.
Chapter 3 - Childhood, disability and ‘doing’ family

3.1 Introduction

The previous chapter outlined the literature that has emerged in recent years regarding sociological exploration of sleep. This research diverges from the majority of sleep research, where the focus has been on the bio-psychological aspects of sleep and sleep problems. Sociological sleep research, in contrast, has highlighted the importance of the socio-cultural aspects of sleep. A sociological enquiry and understanding of sleep is the central tenet of my research; however, it is also important to contextualise the research further by detailing the development of three important fields of sociology, aspects of which have influenced the theoretical and methodological underpinnings of my research: childhood, disability and family life.

This chapter begins by detailing the history and development of the sociology of childhood, highlighting that children are social actors in their own right and that research should explore children’s everyday lives and their active participation within it. An outline of the social model of disability will then follow. The emergence of this model shifted the focus on disability from the medically led definitions of ‘impairment’ to the study of disabling barriers as situated in social constructions (Priestly, 1998). Recent criticisms of the social model of disability have led to new work, including the social relational model of disability, whereby impairments are recognised as having an impact on the daily lives of disabled people. Furthermore, oppression of disabled people is not just experienced through socio-structural barriers but also at a more personal and psycho-emotional level. Research that has aimed to synthesise elements of the ‘new’ perspectives of childhood and disability will also be discussed. This research seeks the views of disabled children themselves and recognises that disabled children are agentic social actors who can affect the structures of their daily lives. It also seeks to recognise and identify the barriers that exist for disabled children which oppress and retain them in a passive and dependent role. Lastly, relevant aspects from the sociology of family will be discussed. The concept of ‘family practices’ (Morgan, 1996) will be explored as a way to understand the meanings of family and to highlight the notion that family is
something that is actively created by its members. A further development to this work, known as ‘displaying’ families (Finch, 2007) will be discussed which extends the social element of family practices and emphasises that family ‘must not only be “done” it must be “seen to be done”’ (Finch, 2007: 79).

3.2 The ‘New’ Sociology of Childhood

Sociological understandings of, and research on, childhood changed, developed and emerged throughout the last part of the twentieth century in reaction to the established views of children dominated by a psychological, physical and social development focus. From a traditional standpoint, children were assigned a passive role and seen through adult eyes. Classic sociology, in particular socialisation theory, regarded children as ‘emergent’ members of society with childhood reduced to a transitional period moving towards the end goal of adulthood. As Connors and Stalker (2007) remark the perception of children was as ‘adults in training’ (p20). Socialisation theory placed children as passive receptors reliant on socialising agents (adults) to teach, model and conform them into becoming successfully socialised adults, thus maintaining social order.

During the late 1980’s and throughout the 1990’s a redefinition of childhood emerged as a socially constructed stage of life separate from adulthood. In the UK James and Prout (1990), with their book ‘Constructing and Reconstructing Childhood’, were pioneers in raising the profile of childhood studies and paved the way for a ‘new’ sociology of childhood. Along with work from the Nordic countries, particularly the work of Qvortrup et al. (1994)

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2 It seems pertinent to mention here the use of the term ‘new’ and highlight recognition that it is now somewhat a misnomer when discussing a body of work that emerged over 30 years ago. The use of ‘new’ as a prefix to sociology of childhood is still evident in recent writing and journal articles with some authors framing the word ‘new’ within inverted commas (as I have chosen to do) or even within brackets (for example, Bartholomaeus and Souza Senkevics, 2015). The continued use and inclusion of ‘new’ in relation to this body of work does not, in my view, pertain to novelty but instead becomes a way to encapsulate the work and distance it from former theories and research practices.
stemming from the international project ‘Childhood as a Social Phenomenon’, new agenda’s were established detailing how sociology could engage with childhood.

Two main overarching principles emerged from this social constructionist body of seminal work. Firstly, childhood is positioned as a structural form, therefore a category or a part of society akin to, and interrelated with, social class and gender and the experience of childhood is structured by wider policies and practices (Qvortrup et al., 1994). As Cosaro (2014) states, children themselves perceive childhood as a temporary period, however, for society it is ‘a permanent structural form’ (p3). As such the category of childhood does not disappear despite its continuous changing membership and changing nature dependent on historical and cultural variables and emphasis on the plurality of childhoods emerges. The plurality of childhoods is not only evident across societies but also within the same society and across the settings in which children conduct their everyday lives (Matthews, 2007). Secondly, children are recognised as social actors demonstrating ‘agency’ and competently constructing their own cultures and actively shaping their own lives. Children are dynamic in assessing, responding, changing and contributing to the circumstances in which they find themselves. Children are perceived as members of society in the here and now rather than in terms of what they will become when adults. Therefore, the focus moves from perceiving children as ‘becomings’ to recognising them as ‘beings’ in their own right:

[T]he child is conceived of as a person, a status, a course of action, a set of needs, rights or differences – in sum as a social actor… this new phenomenon, the ‘being’ child, can be understood in its own right. It does not have to be approached from an assumed shortfall of competence, reason or significance. (James et al., 1998: 207)

Therefore, there is a delineation between the terms ‘childhood’ and ‘children’ whereby the sociology of childhood attempts to encompass both a macro and micro perspective. As Qvortrup (1998) explains there is both the question of childhood as a social form and the question of children as agents and participants in society. Prout (2011) argues that this delineation remains a
dichotomous paradox for the ‘new’ sociology of childhood. Similarly, Moran-Ellis (2010) comments that questions still need to be answered about the relationship between structure and agency in relation to children. Morrow (2011) also highlights a need for social research to ‘illuminate the interconnectedness of the ‘micro-social’ with the broader socio-political contexts in which the everyday lives of children are played out’ (p24).

Moran-Ellis (2010) notes how the rise of feminism and feminist sociology during the 1980’s played an important role in the re-definition of childhood and in making children sociologically visible. Specifically, feminist sociology provided theoretical understanding of women as a marginalized group. Attention was then given to, and comparisons made with, other subordinate groups such as children who share key characteristics rooted in the experience of marginalisation. The interrelationships with others is a key component of the ‘new’ sociology of childhood as it moved away from the individualistic nature of classic developmental psychology and socialisation theories. Children are active agents in the creation of their everyday lives that are experienced through social relationships with other children and with adults who are present within the structures of their lives. As Cosaro (2014: 45) states ‘even though children are active agents, the nature of their activities, power, and rights must be considered in relation to their role as a generational group in society and their place in the generational order’. It is argued that such relationships with adults will always be based on inequality of power. According to Mayall, (1994: 118):

The crucial distinction that makes children children is that they are not adults; as individuals and as a social group, they lack adulthood. This lack can be defined variously as deficiency, disadvantage, and/or oppression. The components may vary according to individual and societal standpoint. What is common to the intergenerational relationships of children to adults, is that children are inferior to adults.

Socialisation theories characterise children as ‘deficient’ as compared to adults whereas recent theories of childhood emphasise the disadvantage and
oppression experienced by children in relation to adults and in turn highlight the dependent nature that exists (Matthews, 2007).

3.2.1 Influence on research methods

Theoretical work concerning the ‘new’ sociology of childhood has had a huge influence on the empirical work carried out in the field of childhood studies. Proponents of this approach call for research to pay attention to children’s own accounts and interpretations of their everyday experiences within the structures of their lives. All too often child-focussed research has relied on the accounts of adults instead of, and thus silencing, children. As outlined in Chapter 2, this is evident in the majority of research on the sleep of children (disabled and non-disabled) which has relied primarily on the accounts of adults, particularly parents. Researchers working from the ‘new’ perspective of childhood advocate interacting directly with children, and there has been a considerable amount of work and exploration of the most appropriate methods by which to obtain points of view, actions, behaviours, and beliefs of children themselves without reliance on adults. The emphasis has moved from doing research on children to doing research with children. This work is set against a backdrop of exploration and a child-focussed shift concerning issues pertaining to the ethics of researching children with a focus on addressing issues such as power relations, access, privacy and confidentiality, all of which are pertinent in a research process that includes children (Morrow and Richards, 1996; Alderson and Morrow, 2004; Christensen, 2004). This body of work will be explored in more detail in Chapter 4.

3.2.2 Changes in policy and legislation – children’s rights

As the ‘new’ sociology of childhood emerged and children became visible within sociology a shift in public policy and legislation (in the UK and internationally) was also taking place. Children’s voices were recognised as needing to be heard as was the seeking of their opinions about matters that affected their lives (Morrow and Richards, 1996). Most notably in the UK was the passing of the Children Act 1989 and internationally, the UN Convention on the Rights of the Child in 1989, ratified by the UK government in 1991.
Within the UN Convention on the Rights of the Child (UNCRC, 1989) substantive rights are grouped under the so called ‘Three Ps’ which include Provision rights (to necessary goods, services and resources); Protection rights (from neglect, abuse, exploitation and discrimination); and Participation rights (whereby children are respected as active members of their family, community and society) (Alderson, 2000). Whilst all three of the UNCRC ‘P’s are important, the one that has had a significant influence on conceptions of children’s role in social and political life, relates to participation and the acknowledgment of the right of the child to be consulted and heard on decisions affecting them (as outlined most pertinently in article 12 of the UN Convention of the Rights of the Child, 1989)

Moran-Ellis (2010) outlines how the Children Act 1989 introduced legislation related to three areas associated with seeing the child as an individual agent. Firstly, a child has a right to be legally represented (separately from parents or the state) in proceedings affecting them. Secondly, a right to be consulted about decisions that directly affect them. Lastly, children must have access and information pertaining to a complaints procedure with respect to any state care they receive.

Despite significant and positive developments being made in terms of children’s rights through the principles outlined in the UNCRC, 1989 and the legislation of the Children Act 1989, interpretation and application of this is open to variation. Franklin (2002) notes that in the UK the ambitions of the UNCRC, 1989 have not been fully realised whereby the goal of securing social, welfare and participation rights for children ‘has tended to be faltering and uneven rather than strident’ (p2). Furthermore, Alderson (2000) raises the point that children’s rights cannot be realised when those (i.e. teachers, social workers, healthcare professionals) who are in a position to promote and implement the principles are themselves ignorant of the UNCRC, 1989. This is further compounded and maintained by the fact that most children are unaware of their rights as outlined in the UNCRC, 1989.

With reference to the Children Act 1989, Franklin (2002) highlights how it attempts to straddle the divide between protectionist (paternalist) and
participatory rights. The guiding principle of the legislation is that ‘the child’s welfare is paramount’ whilst also supporting rights for the child to be consulted about decisions which directly affect them. However, as Franklin (2002) argues the legal system’s interpretation of this right tends to be conservative and tentative and, therefore, often reverts back to ‘paternalistic assumptions of children’s incompetence’ (p4).

Moran-Ellis (2010) comments on a ‘paradox’ that is evident in the UK between the development of a rights agenda for children with an apparent ‘national anxiety’ about children. There is a:

...simultaneous positioning of children as ‘in danger’ and ‘dangerous’... leading to particular approaches to children’s rights, on the one hand, and to controlling children, on the other. (p197)


3.2.3 Critiques and further developments of the ‘new’ sociology of childhood

The sociology of childhood continues to develop as questions concerning certain aspects remain unanswered and troubling for theorists. In recent years the dichotomy between ‘becomings’ and ‘beings’ has been questioned (Prout, 2011). Uprichard (2008) argues for children to be recognised as both ‘becomings’ and ‘beings’ stating that the focus of the new sociology of childhood on children as ‘beings’ has led to the loss of temporality of the ‘becoming’ child. Uprichard (2008: 306) states:

‘Looking forward’ to what a child ‘becomes’ is arguably an important part of ‘being’ a child. By ignoring the future, we are prevented from exploring the ways in which this may itself shape experiences of being children.
This has not been entirely ignored by the proponents of the ‘new’ sociology of childhood as Qvortrup (2004: 269) reiterates that anticipating adulthood is part of what it means to be a child. Furthermore, in some of the early writings of James et al. (1998) there is recognition of the temporality of the ‘being’ child, therefore: ‘...there is no necessity to abandon ideas of past and future just because we have shifted from a conceptual framework that is predicated on becoming’ (p207). Uprichard (2008) concludes that a balance between the temporal constructs of ‘being’ and ‘becoming’ is desirable and possible ‘without diminishing the humanity or the personhood of every human being, child or adult’ (p309).

This links with questions that have been raised in regard to the ‘new’ sociology of childhood failing to recognise the existence of dependencies and immaturity by proposing that children are active agents. Lee (1998) argues that the ‘new’ sociology of childhood implies some sort of pre-existence of agency, competency and maturity in each individual:

To enter the world of sociology, unaccompanied by an adult, the image of children must be ‘matured’. This tells us that sociological theory presents us with a model of the social world that is peculiarly 'mature'. The young cannot figure in their own right in sociological theory unless they are understood as 'mature' in their possession of agency. (Lee, 1998: 460)

Lee (1998) argues that both the socialisation theory positioning of children as ‘becomings’ and the ‘new’ sociology of childhood redefinition of children as ‘beings’ privileges the concept of completeness and the ‘finished’ over those concepts of the incomplete and immature. By emphasizing children as beings ‘in their own right’ there is a risk of ignoring ‘the complex web of interdependencies’ that exist between children and adults (Prout, 2011). Therefore, both children and adults should be seen through a multiplicity of becomings in which all are incomplete and dependent. Lee (1998) calls for an acceptance of an ‘immature sociology’ whereby adults and children alike can move between and across the dimensions of ‘being’ and ‘becoming’. As
discussed by Leonard (2015) there is then a recognition that children and adults ‘move in and out of states of competency, maturity and rationality’ (p 30).

With specific reference to disabled children, Cocks (2006) argues that an outcome of adopting the essentialist view of agency purported by the ‘new’ sociology of childhood and rejected by Lee (1998) is that children who are not considered as ‘mainstream’, i.e. disabled children, have sometimes been excluded from studies in childhood because they have dependencies outside of this mainstream childhood realm and thus any demonstration of agency is not recognised or recognisable. In line with Lee (1998) and an acceptance of an ‘immature sociology’, Cocks (2006) confirms the need to incorporate incompetence, dependence and immaturity in such a way that (especially with reference to research with disabled children) ‘they are not portrayed negatively or misunderstood and thus left open to misuse’ (p255). Furthermore by accepting that agency is not an essential possession can lead to questions about when and how it occurs, what facilitates this occurrence and if macro-level factors influence it. Cocks (2006) goes on to make the connection between this and the work of Hutchby and Moran-Ellis (1998) who position agency and competence in relation to context. Cocks (2006) uses this discussion to raise questions regarding the obtaining of consent from disabled children as part of the research process:

...if agency is not always a static characteristic or ‘possession’ of the child then is it possible to judge or measure a child’s ‘competence’ in consenting to research as there are so many contextual factors. (p256)

Building on the work of Cocks (2006) and her discussion with reference to disabled children this chapter will now focus on theories and models of disability and the bringing together of these disability models with the ‘new’ sociology of childhood to better understand disabled childhoods.

3.3 The social model of disability

Over the last 40 years there has been a significant shift in the understanding of disability leading to a strengthening of disability movements and activism both within the UK and internationally and the development of disability studies. At
the core of this movement was the conceptualisation of the ‘social model of
disability’, which was developed in the 1970s by activists in the Union of the
Physically Impaired Against Segregation (UPIAS). The model was then given
academic credibility by disabled writers such as Oliver (1990, 1996). At the
heart of the social model of disability was the distinction between the terms
‘disability’ and ‘impairment’:

[W]e define impairment as lacking all or part of a limb, or having a
defective limb, organism or mechanism of the body and disability as the
disadvantage or restriction of activity caused by a contemporary social
organisation which takes little or no account of people who have physical
impairments and thus excludes them from participation in the
mainstream of social activities. (Oliver, 1996: 22)

Oliver (1996) argues that disabled people are an oppressed group in
society whereby through structural physical barriers they are isolated and
excluded. The social model of disability was developed in defiance and
opposition to the traditional medical and individualistic model of disability. The
traditional model places the impairment as the primary cause of the problems
faced by disabled people. As a result services and research are then also
aimed at the individual level whereby the aim is to alter the individual rather
than changing social or environmental elements. As outlined by Shakespeare
and Watson (1998) the aim is to restore or generate ‘normality’ and therefore
disabled people are presented as a ‘tragedy’ because they cannot conform to
this ‘normality’. This approach is very apparent, as outlined in Chapter 2, in the
research on sleep and disabled children. Sleep is seen as problematic for
disabled children because of their impairments. Interventions (both medical and
behavioural) are held in high regard if they successfully ‘fix’ the sleep problem
and thus align disabled children and their sleep to that of their ‘normal’ non-
disabled counterparts.

Shakespeare and Watson (2002) explain that the social model of
disability has been important to the disability movement in the UK for two main
reasons. Firstly, it identified a solution to the oppression and discrimination of
disabled people, namely barrier removal. If people with impairments are
disabled by society, then a strategy of removing such barriers has to be the priority:

Rather than pursuing a strategy of medical cure, or rehabilitation, it is better to pursue a strategy of social change, perhaps even the total transformation of society. (Shakespeare and Watson, 2002: 12)

To this end the social model of disability has been a powerful tool in influencing policies and legislation. Watson (2012) outlines the influence it has had on UK policy, for example the Prime Minister’s Strategy Unit (2005) and on European Union policy, for example, the European Commission of the European Communities (2003), as well as informing The UN Convention on the Rights of Persons with Disabilities (2006) and forming the basis of the case for anti-discrimination legislation. Secondly, the social model of disability enables the liberation of disabled people since the fault does not lie with them but with society. They do not and should not have to change. Change has to happen at a societal level. In theory the social model of disability empowers people with impairments to join a movement and to demand, and fight for, equal civil rights.

3.3.1 Criticisms of the social model of disability

Undoubtedly, the social model of disability has led to enormous positive change at a structural and political level. However, critics of the model (some of whom were the early proponents of the model, for example recent writing by Tom Shakespeare and Nick Watson) argue that it is too simplistic and is useful only in the political arena and as rhetoric for activists rather than having academic and empirical relevance (Watson, 2012). Shakespeare and Watson (2002) argue that the need to uphold a ‘strong’ version of the social model of disability in order to demand and achieve social change has led to a rigid dichotomy between disability and impairment. In reality this dichotomy need not exist and impairment, and therefore difference, needs to be recognised as real and impacting on the lived experiences of disabled people. Through the social model of disability the multiple voices and experiences of individuals with impairments has been lost. Writers and theorists, particularly those writing from
a disabled feminist viewpoint, have argued that this has been hugely detrimental and needs to be rectified. As Morris (1991:12) explains:

[T]here is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying.

Furthermore, Shakespeare and Watson (2002) argue that to deny impairment and ignore difference runs the risk of leading to a reluctance to identify with the disability movement on the part of disabled people and to commentators dismissing the movement as ‘idealistic’.

The dichotomy between impairment and disability as socially constructed is further weakened if consideration is made, as highlighted by Shakespeare and Watson (2002), of variable effects of different impairments. This not only has implications at an individual level, in terms of health and capacity, but also at a wider social level as different impairments will lead to different responses ‘from the broader cultural and social milieu’ (p19).

### 3.3.2 The social relational model of disability

In response to criticisms of the social model of disability there have been theoretical developments in the understanding of disability. One such development comes from the work of Thomas (1999, 2004) and the social relational model of disability, which originated from the accounts of disabled women. This has particular resonance for my own research as it has been adopted and applied to research with disabled children by Connors and Stalker (2003; 2007) whose research is discussed in more detail in Section 3.4.2.

The social relational model retains the materialist basis of the social model of disability and continues to emphasise that structural barriers are the cause of many issues faced by disabled people. As such disability is rooted in
unequal social relationships leading to the oppression of disabled people by those without impairments. Thomas (1999) labels this as ‘disablism’ (rather than disability as conceived by the social model of disability) in a deliberate way to draw comparisons with racism, sexism and other identity-based discriminations. However, in an extension to the original social model of disability, Thomas (1999) perceives disablism as a form of social oppression that operates at both the public and personal levels, ‘affecting what people can do as well as who they can be’ (Reeve, 2004). Disablism is the result of two processes that can occur separately or together. ‘Barriers to doing’ are akin to the structural, physical and environmental barriers as highlighted by the social model of disability. ‘Barriers to being’ refers to behaviour that is directed towards a disabled person (wittingly and/or unwittingly) that is hurtful, hostile or inappropriate and leads to a negative impact on the disabled person’s self confidence, self esteem, self worth and value. Thomas (1999) terms the disablism occurring through ‘barriers to being’ as ‘psycho-emotional disablism’.

As outlined by Reeve (2004) psycho-emotional disablism emerges from the relationship that a disabled person has with other people, often family members, friends, professionals or strangers, but also with themselves in the form of internalised oppression. Reeve (2004) discusses how disabled children may experience more acute internalised oppression because of their less powerful position (as both children and as disabled) resulting in higher levels of vulnerability to the views of the wider society. Reeve (2004) goes on to say that their parents may be ‘unwitting oppressors’ in the process of psycho-emotional oppression because ‘their beliefs and expectations will be shaped by the professionals they defer to’ (p91). Indirect psycho-emotional disablism can arise from the experience of structural disablism especially through such barriers as exclusionary institutional policies and practices as well as the emotional impact of being faced with, for example, an inaccessible building.

In addition, and in response to criticism of the social model of disability, the social relational model recognises the existence of impairments and that some restrictions of activity faced by disabled people are the direct consequence of living with impairment. Thomas (1999) terms these restrictions
as 'impairment effects' and they could include fatigue or pain associated with certain impairments or the inability to do certain things (Connors and Stalker, 2007). Thomas (1999) argues that impairments are not irrelevant and their effects can combine with disablism.

Difference is, therefore, also acknowledged and not denied so that disabled people are seen as 'essentially' different from non-disabled people (it is important to note that the dichotomy of 'disabled' and 'non-disabled' has also been criticised – Shakespeare and Watson, 2002). As Morris (1991) argues the social model of disability deliberately denies difference in order to push forward a progressive and liberating agenda because these differences have such negative meanings for non-disabled people, for example, damaged, tragic, weak, and abnormal. But as a disabled person, Morris (1991) acknowledges that she is different. Therefore, it is possible to reject the meanings that are attached to disability by non-disabled society while at the same time accepting that the differences form an important part of a disabled person's identity.

The social relational model of disability highlights how impairments, impairment effects, and disablism are intertwined with 'the social conditions that bring them into being and give them meaning' (Thomas 2007, p137) and, therefore, the boundaries between them are in a 'dynamic relationship'.

3.4 Research with disabled children: Bringing together the ‘new’ sociology of childhood and models of disability

A body of research has emerged that acknowledges the potential in bringing together aspects of the ‘new’ perspectives on childhood and on disability in order to understand disabled childhoods. Some commonalities exist between the sociology of childhood and disability studies. Both explore the construction of social inequality and exclusion, and advocate use of participatory research methods. However, during the time that the new perspectives were being developed there was little research on the 'intersection' between childhood and disability (Priestley, 1998). Research on childhood excluded or marginalised the experience of disability, whilst the social model of disability marginalised the
experience of childhood. Research on disabled childhood had ignored the view of disabled children themselves and relied instead on the views of parents and professionals (this is evident from the existing research on sleep and disabled children).

Building on criticism of the social model of disability and the tendency to ignore children and childhood, Davis et al. (2000) comment that disabled children need to be perceived as being able to affect and even influence the structures surrounding their lives. The ways in which the social model of disability promotes a universal concept of disability and homogenises disabled people is problematic when considering children. It does not account for disabled children as it does not account for the major differences between disabled adults and children. Homogenising the ‘disabled child’ leads to generalisation of disabled children’s lives and little recognition that children (disabled or not) are ‘social actors’. There is little exploration of the differences within and between groups when they are homogenised in this way.

3.4.1 The ‘Life as a disabled child’ project

During the late 1990’s and 2000’s, work exploring the everyday lives of disabled children emerged as well as research on methods and strategies to involve disabled children in the research process. A highly significant piece of work was the ‘Life as a Disabled Child’ Project (Watson et al., 1999). This project was the first time in the UK that disabled children had been included in research based within the ‘new’ sociology of childhood paradigm. The project aimed to present disabled children as active and agentic in their everyday lives and able to contribute fully to the research process rather than as passive, dependent victims as epitomised by ‘traditional’ research that has been focussed on ‘impairment, vulnerability and service use’ informed only by the views of parents and professionals. The project highlighted how the views and experiences of disabled children varied, both between children with different impairments but also amongst children with the same impairments, and thus emphasised the heterogeneity of disabled children. Using a variety of qualitative methods including participant observation, interviews and focus groups in diverse settings (schools, family homes, residential homes, social and leisure clubs)
over 300 young disabled people were included in the project. Four key themes emerged from the data: adult surveillance, the creation of the disability category, peer relationships, and identity.

Adult surveillance was observed and described as occurring by many of the young people in environments that were highly structured. Watson et al. (1999) also noted how it influenced the research process itself. Young people highlighted how the high levels of adult surveillance negatively impacted on their need for privacy and also influenced and limited peer relationships and social interaction. However, many of the examples of the high levels of surveillance observed were confined to the school settings with little written about how this might manifest itself in a family home setting. The research did highlight some resistance to such surveillance asserted by some young people emphasising again the agentic capabilities of the young disabled people.

It was observed that children were primarily categorised as disabled by adults and this ‘bounded children’s experiences’ (Watson et al., 1999:3). ‘Disabled’ was the dominant label applied to the young people and everything related to them was explained by their impairment rather than other differences or similarities, for example, gender, age, race. The young people themselves were more ambivalent about the use of the ‘disabled’ category.

Peer relationships were often limited for disabled young people. Physical, attitudinal and communication barriers were ‘barriers to doing’ and ‘barriers to being’ (Thomas, 1999) and restricted and prevented peer relationships from developing. A common occurrence of bullying was highlighted by young people and the effect this had on them in terms of their confidence and self esteem. Again, however, there were a number of disabled young people who had been able to resist the process of bullying and ‘stand up for themselves’.

The young people in the project had a fluid and ever changing view of their identity as ‘disabled’. Their definitions of disability varied and were often contextually based. For instance, some described how they were not always disabled.

Connors and Stalker (2003, 2007) also sought to combine ideas from childhood sociology and disability studies and their study aimed to explore disabled children’s understandings of disability and the ways in which they negotiated the experience of disability in their daily lives. Threaded throughout their analysis was a particular emphasis on the social relational model of disability. They argue that the social model of disability is not applicable to children as its focus on systems and social factors fails to incorporate children’s real and heterogeneous experiences of disability. Some of the main concerns of the social model of disability are focussed on such material factors as employment and economics which have very little relevance to disabled children (Cocks, 2011).

Connors and Stalker (2003) conducted a two-year study exploring the lived experiences of 26 disabled children aged 7 to 15 years. Through interviews with the children (which often took place in the children’s family homes) they found that the disabled children in their study experienced disability in four main ways: impairment, difference, other people’s behaviour towards them and material barriers.

Many of the children talked about their disability in terms of ‘impairment’ and the effects of the impairment on their daily lives despite there often being little discussion within families about impairment. The majority of disabled children framed impairment medically but it was rarely framed as a tragedy. Connors and Stalker (2007) highlight this as interesting given the usual association between the medical model of disability and the viewing of disability as a tragedy. For many of the disabled children, impairment was seen as ‘no big deal’ and ‘just one of those things’ and there was a common attitude of ‘having to get on with it’. However, in line with the social relational model of disability a number of disabled children did refer to and identify ‘impairment effects’ (Thomas, 1999) as leading to restrictions in activity. Examples of these impairment effects included repeated chest infections, having pain, tiring easily and finding it difficult to carry out school work.
Very few disabled children in the Connors and Stalker (2003, 2007) study discussed the concept of ‘difference’. The majority of children focussed on similarities between themselves and their non-disabled peers. This was in direct contrast to parents who focussed much more on the differences between their disabled children and others. When disabled children did acknowledge and discuss difference and feeling different it was often as a direct result of poor management on the part of professionals and settings that the children had most contact with, e.g. school. Connors and Stalker (2007) discuss how schools with stringent ‘inclusive’ policies, whereby difference is not acknowledged, can actually have a detrimental effect and magnify feelings of difference for disabled children because ‘rules and procedures designed for the majority do not always fit the minority’ (p27). In other schools, specifically special needs schools, difference is focused on but again this can be poorly managed and have a detrimental effect on disabled children and their sense of identity. One example of this was a teacher at a school who referred to pupils as either ‘wheelchairs’ or ‘walkers’.

A number of disabled children did make reference to ‘barriers to being’ (Thomas, 1999) whereby the hostile and unthinking words of others led to them feeling inferior, which did highlight their feelings of difference. Examples of these actions included people staring at them, talking down to them, inappropriate behaviour, inappropriate comments and overt sympathy. Bullying by other children also seemed to be a common experience for disabled children. In line with the work of Reeve (2004) the effects of ‘barriers to being’ and the resulting psycho-social disablism can be particularly significant and detrimental to disabled children (as opposed to disabled adults). Disabled children are vulnerable because of their less powerful position but also because childhood represents a time when identity formation begins and negative experiences as a result of ‘barriers to being’ can have long lasting detrimental effects on self confidence and self worth.

‘Barriers to doing’ (Thomas, 1999) were also identified and discussed by disabled children in the Connors and Stalker (2003, 2007) study with reference to restrictions of activity placed upon them by social or physical factors such as
lack of access to leisure facilities, transport difficulties, lack of after school activities, and limited help with communication. These physical barriers were particularly pertinent for children with physical and sensory impairments compared to those with learning disabilities, once again highlighting how disabled children are not a homogenous group.

Connors and Stalker (2007) conclude that the overarching theme that emerged from their research was that most of the disabled children presented themselves as much the same as others. This insistence on sameness may have occurred for a number of reasons. Firstly, it may be due to societal (both at a macro and micro level) pressures to conform and to not stand out in any way. Secondly, as self-directing agents, the children may have actively chosen to ‘manage their day-to-day lives and experiences of disability in a matter of fact way’ (p30). Despite recognition of impairment effects and barriers to ‘being’ and ‘doing’, the children actively resisted being defined as ‘disabled’. However, Connors and Stalker (2007) dismiss both these reasons and argue that the theme of sameness was so prevalent in the disabled children’s accounts because disabled children simply do not have a language with which to discuss difference and thus:

Perhaps the children were neither ‘in denial’ nor fully in command of resisting the various barriers they face. (Connors and Stalker, 2007: 30)

They argue that this is because many disabled children have little or no contact with disabled adults so do not have positive disabled role models and they rarely have opportunities to share their experiences with other disabled children. Because of this disabled children have little choice but to strive to be the same as non-disabled children. In criticism of the social model of disability, Connors and Stalker (2007) argue that disabled children’s focus on sameness further evidences the model’s exclusion of disabled children’s experiences and narratives and failure to empower disabled children as it has disabled adults. Furthermore, they argue that the social model of disability cannot be considered a true ‘counter-narrative’ when children’s narratives have played little part in its construction and they conclude that:
There is a need for a two-way process in which disabled children have access to ideas and information about social models of disability, and social models of disability take account of their experiences and understandings. (p31)

Connors and Stalker (2007) also conclude that for their study the social relational model of disability (Thomas, 1999) is a useful framework to apply and can go some way to inform our understandings of disabled children’s experiences as reflected by the disabled children’s discussion of ‘impairment effects’, ‘barriers to being’ and ‘barriers to doing’.

### 3.5 Siblings of disabled children

The work of Connors and Stalker (2003, 2007) is particularly relevant to my own work not just because it incorporated methods to listen directly to the experiences of disability from the disabled children themselves but because it also sought the views of their siblings (age 6 to 13 years). Interestingly, the siblings interviewed in the Connors and Stalker (2003) study had similar views concerning impairment, disability, and difference as the disabled children. In a paper written specifically to present the findings from interviews with the siblings, Stalker and Connors (2004) use the social relational model of disability to make sense of the siblings’ experiences. Many of the siblings were aware of their disabled brother or sister’s impairment. In a similar vein to findings from the disabled children, impairment was often talked about using the language of the medical model of disability. Therefore, often siblings used the name of their brother/sister’s impairment e.g. cerebral palsy, autism etc. A number of the siblings identified associated conditions of the impairment, such as epilepsy, and also discussed what they believed to be the cause of the impairment. Despite using language most associated with the medical model, very few siblings viewed their brother/sister’s impairment as a tragedy (this also mirrors the findings from the disabled children). Furthermore, even though many of the siblings were able to identify their sibling’s impairment, the majority did not see it as making their sibling different. Where difference was identified and discussed it was often with reference to siblings’ perceptions of the ‘barriers to being’ that their disabled brother/sister was subject to. Siblings were aware of
occasions and situations where their disabled sibling had encountered negative reactions from other people, both adults and children, in a range of settings and gave examples such as name-calling, staring, patronising remarks and misplaced sympathy. A number of non-disabled siblings also disclosed that they themselves had been subjected to bullying behaviour because they had a disabled brother or sister. The siblings made few references to ‘barriers to doing’ (i.e. physical, material and economic barriers) that their disabled brother/sister encountered. Stalker and Connors (2004) purport that this may be because often ‘parents strove to avoid the lives of their non-disabled children being unduly restricted’ (p224).

As mentioned above, despite identifying their brother or sister’s impairment, many siblings did not appear to see their disabled brother or sister as different from them in any significant way and similarities were often discussed instead. A number of older siblings described their disabled brother/sister as ‘normal’ and emphasised the ‘ordinariness’ of their sibling relationship, which included a balance of love and affection with the expected irritation, rivalry and bickering found in most non-disabled sibling relationships. Where differences were identified they were often not attributed to the impairment or disability but to everyone being an individual with unique attributes, behaviours and traits. If difference due to impairment was identified by the siblings it was not necessarily seen in a negative light but more as just ‘one of a number of attributes which together made the [disabled] child who he was’ (p228). An exception to this was when a number of siblings identified difference due to impairment leading to restrictions in activity in terms of ‘barriers to doing’ and, more significantly, when difference led to ‘barriers to being’ in the form of hostile and discriminatory attitudes and behaviour of others.

Overall, however, the majority of siblings highlighted similarities rather than differences between themselves and their disabled brother/sister which mirrors the findings from disabled children themselves. Stalker and Connor (2004) allude that the reasons for this are the same for the two groups, namely that children (both disabled and non-disabled) lack the language to discuss
difference based on disability. Further to this Stalker and Connors (2004) also conclude that siblings do not define their disabled brother/sister by their impairment but instead ‘hold a range of views about their brothers’ and sisters’ identities’ (p228). For siblings a sense of sameness is much more pertinent than difference and this is shaped by the shared ‘identities and biographies’ siblings have by being members of the same family.

The notion of members of the same family sharing identities and biographies is notable and to understand this further it is important to think and explore the notion of family in more detail. The sociology of family has also undergone developments and changes in terms of focus, theory and approaches to research comparable to the fields of childhood and of disability. The next section is concerned with these developments within the sociology of family with a specific focus on the move away from traditional views of the ‘family’ towards an approach more concerned with ‘doing’ family and, in particular, the concept of ‘family practices’ (Morgan, 1996, 2011).

3.6 The sociology of family

While major developments were taking place within the fields of childhood and disability, changes were also occurring within the sociology of family. One reason for these changes was directly linked to the approaches to research being proposed by proponents of the ‘new’ sociology of childhood who were critical of how the views of children were neglected in studies of family life. Morrow and Richards (1996) discuss how traditionally the sociology of family had not been about children and little was known about children’s experiences of family life. Furthermore, within this discipline parents were often used as the informants about children so even if the central tenet of the enquiry was about children they tended not to be directly involved. Qvortrup (1985) also noted that family sociology tended to be about parents and not about children as a separate social group. There tended to be ‘sociologically relevant discussions of children’s problems and problem children’ (Qvortrup, 1987: 3), but very few of these studies were grounded in children’s experiences of their daily lives. Since the 1990’s, research from within the field of family sociology has sought to rectify this and there has been a move to incorporate the multiple perspectives
of family members into research including those of children (Ribbens-McCarthy et al., 2003).

Approaches within the sociology of family, or family studies, also changed during the late 1980’s and early 1990’s in reaction against ‘structural-functionalist approaches’ whereby ‘the family’ was considered a single social unit (Cheal, 2002). Instead the emphasis changed to one of diversity and recognition that families were much more about sets of relationships than units and structures.

In this context of fluid and changing definitions of families, a basic core remains which refers to the sharing of resources, caring, responsibilities and obligations. What a family is appears intrinsically related to what it does. (Silva and Smart, 1999: 7)

Studies, therefore, began to focus on how family life was ‘done, practised and negotiated interactively’ (Mason and Tipper, 2014:154). Definitions of family moved from a noun usage of ‘the family’ to that of an adjective or even a verb. As Morgan (1996) argues there is no such thing as ‘the family’. To use ‘the family’ as a noun gives it ‘thing-like quality’ (Morgan, 2011) that is a single, fixed, and concrete object or structure. In using the noun ‘the family’, the ever changing and diverse nature of family is ignored and there is no distinction between ‘ideas about and understandings of the family on the one hand and actual day-to-day living on the other’ (p3). Using the noun ‘the family’ also has political and moral implications as ‘the family’ becomes associated with a normative status or standard model which has the potential to disadvantage and exclude certain societal groups. The standard model of ‘the family’ has traditionally been viewed as including a father, a mother and two or three children – the nuclear family or as Morgan (2011) terms it the ‘cornflakes packet’ image of the family that invokes ‘heteronormativity’. For Morgan (2011) the term ‘the family’ not only oversimplifies a complex range of ‘practices, statuses and experiences’ but it also invokes political and ideological issues that run the risk of disadvantaging certain groups in society who do not fit the standard model, for example, gay and lesbian couples and single parents. Interestingly research exploring children’s own views about family has found
that children do not tend to have a fixed idea of a ‘family’ (Madge and Wilmott, 2007). Brannen et al. (2000) consulted with over 1000 older children about family life and found that few children agreed with the notion of a ‘proper family’ or the nuclear stereotype of two parents and their children. O’Brien et al. (1996) found that younger children also acknowledged that families differ from one another. It is important to mention here too that family does not necessarily equate to children, just as children do not always necessarily have a family (Mason and Tipper, 2014), therefore the standard model of ‘the family’ also excludes couples without children and people living on their own.

Therefore, there has been a move away from using the term ‘the family’ with some writers using the plural term ‘families’ instead (Ribbens-McCarthy et al., 2012). However, Morgan (2011) argues that the plural usage does not solve the ‘fuzziness’ of the borders that exist between families and non-families, nor does it solve the possible ‘heteronormativity’ that the term ‘families’ can still invoke. Another option is to use ‘family’ as an adjective, such as ‘family life’, ‘family values’, ‘family events’, or ‘family practices’ (see section 3.5.1). By using ‘family’ in this way it can be used as a ‘lens through which to describe and to explore a set of social activities’ (Morgan, 2011: 5). Using family in this descriptive way to refer to a particular feature or character present in other areas of social life and activities emphasises the emotional significance people (and society) still attaches to ‘family’ and it also highlights connectedness to other concepts such as gender, class, and employment:

[F]amily is like a primary colour which is most useful when blended with other primary colours to produce something distinct from the constituent parts, ‘family and class’ or ‘family and gender’ for example. (Morgan, 2011: 5)

Another usage for the word ‘family’ is as a verb, and this leads to the idea of ‘doing family’. This emphasises the notion of family as involving action, process and interchanges. As Morgan (2011) highlights ‘doing family’ refers to the active presentation of family to others in everyday life. It is important to note the parallel between the use of ‘doing family’ and ‘doing sleep’ as discussed in
Chapter 2 whereby the focus was also on action and the performing of social practices involved in sleep as a presentation to others.

The concept of ‘family practices’ (Morgan, 1996, 2011) strongly emphasises the ‘doing’ of family as an interactional activity (or a collection of activities). These everyday activities or ‘practices’ are performed and undertaken within a complex and fluid society and lead to ‘family’ being continually created and recreated by its members. The sense of the everyday, and perhaps the every night, resonates when considering sleep and the doing of sleep within a family context, therefore, the concept of family practices will be discussed in more detail.

3.6.1 Family practices

David Morgan introduced his concept of ‘family practices’ in his 1996 work ‘Family Connections: An introduction to family studies’. According to Morgan, family practices are wide ranging as they cover everything to do with ‘those relationships and activities that are constructed as being to do with family matters’ (p192). Family practices can include interactions, activities, feelings, understandings and draw on ‘ideas of parenthood, kinship and marriage and the expectations and obligations which are expected with these practices’ (p11).

The key features of the concept of family practices, as outlined in his 1996 book and further developed in his 2011 work ‘Rethinking Family Practices’, are:

- A link between the perspectives of the observers and the social actors;
- An emphasis on the active or ‘doing’;
- A sense of the everyday;
- A sense of the regular;
- A sense of fluidity;
- A linking of history and biography.

In describing the first key feature, Morgan (1996) aims to convey a sense of difference with the use of the word ‘practices’ and a sense of movement or
‘flow’ between the differing (although possibly overlapping) viewpoints of the observer (e.g. researcher) and the observed (e.g. family member). The second key feature emphasises the notion of ‘doing family’ and invokes the idea that family life is based on a set of activities which are given meaning and significance by being grouped under the umbrella term ‘family’. By focusing on ‘doing’ there is a move away from the conception of the family as ‘static structures or sets of positions or statuses’ (Morgan, 2011: 6). In a specific (and rare) reference to sleep, Morgan (1999) discusses how even a supposedly ‘passive’ activity such as sleeping can be reframed and considered as ‘doing’ family:

…the sleeping arrangements, shared or separate beds or bedrooms, both constitute and derive from notions of family and proper conduct between family members (p17).

The third feature of family practices is that they invoke a sense of the everyday. They are activities that may seem unremarkable, trivial or meaningless, for example, the school run, leisure activities, Sunday dinner or reading children a bedtime story. Their significance relates to the link they have into wider systems of meaning. To demonstrate this Morgan (1996) uses the example of practices related to feeding children and argues that the significance of these practices emanates from their location ‘within systems of parenting, of consumption and possible others such as gender or stratification’ (p190). According to Morgan, the fourth key feature of family practices is a sense of the regular. The term ‘practices’ is not usually used in reference to a ‘one-off event’, but rather invokes a sense of regularity and repetition. Furthermore, the term ‘practice’ is often used to describe the repeating of an activity to improve the related skill such as violin practice. However, Morgan (1999) stresses that unlike the deliberate improvement of a skill through regular practice, e.g. violin practice, family practices ‘constitute part of the everyday taken for granted worlds of the social actors concerned’ (p17). A sense of fluidity is the fifth key feature of family practices because although they are every day and regular they are also open-ended.
As discussed above with reference to the practices related to feeding children the practices identified have the potential to be described in similar or different ways and can flow into other practices of the same kind or overlap with those that might be described differently and rooted in wider systems e.g. gender practices, consumption practices, ethnic practices etc. This point also links back to the first key feature whereby the actor and observer can have shared or different perspectives in relation to practices. The sixth and final key feature of family practices proposed by Morgan (1996) is the link they convey between history and biography. Family practices are not just about the here and now and solely influenced by an individual’s life history and experiences. They are also strongly rooted in a social and historical context. Using the example again of feeding children, Morgan (1996) argues that such practices are constituted from ‘elements of individual biographies’ and are also shaped by a number of other historical and social factors, for example, expert notions of nutrition, commercial and advertising influences, as well as gendered, class or ethnic expectations.

An emphasis on the social context has been something that Morgan has further developed and focussed on in his later work on family practices (2011a, 2011b). Some of this development resulted from criticism that the concept of family practices, despite the social and historical context being included as the sixth key feature, underplays the influence of broader social and cultural factors. The concept of ‘displaying families’ (Finch, 2007) is seen as an extension of ‘family practices’ highlighting in more detail the social nature of practices in conveying family life to others.

3.6.2 Displaying families

The concept of ‘displaying families’ (Finch, 2007) builds on and strengthens the notion of ‘family practices’ as being fundamentally social in nature, further emphasising the importance of the interaction between actor and observer and the links into wider systems of meaning. Finch (2007) argues that if activities are to be effective as family practices they not only have to be done as an everyday regular activity, but there also has to be a sense of display to others.
whereby the meaning, i.e. that it is about ‘family’, is conveyed to and understood by others:

Display is the process by which individuals, and groups of individuals, convey to each other and to relevant audiences that certain of their actions do constitute ‘doing family things’ and thereby confirm that these relationships are ‘family’ relationships. (Finch, 2007:67)

Finch (2007) describes the concept of displaying families in more detail by addressing three elements. Firstly, why is display important in contemporary families, secondly, how displaying is done and thirdly, to whom family relationships need to be displayed.

In a similar vein to Morgan (1996), Finch (2007) highlights the fluid and diverse nature of contemporary family relationships and purports this as a reason why ‘displaying family’ is important. Family displays take place in direct social interaction between family members through the use of ‘tools’ to display or demonstrate ‘family’ and involve a process of identification, recognition and feedback. Tools can include such items as family photographs, heirlooms, or mementos as well as shared family stories, jokes and narratives. Finch (2007) highlights the importance of considering the interaction and feedback elements of family display. Through direct social interactions and feedback among family members affirmation as to what is ‘family-like’ about their relationships is received. Feedback can also be obtained outside of the family as often activities to ‘display family’ take place outside of the private sphere of the family.

James and Curtis (2010) reflect that others may observe ‘a family’ or ask about ‘the family’, as they did in their role as researchers, and feedback from others outside of the family may be less affirming, i.e. more critical, and may reflect wider social and cultural values. The need to display family may be particularly strong for certain families, such as those that deviate from cultural norms or notions of what normal ‘family’ is, and also at particular times in family life, such as transitional periods. James and Curtis (2010) suggest that displays of family will be more acute when they directly involve children. They purport that the cultural stereotypes of ‘the child’ as, for example, vulnerable and
dependent and the current concerns around parental responsibility, risk, safeguarding, protection and surveillance have led to child-rearing practices and the associated displays of ‘family’ being ‘less negotiable in relation to wider cultural values and norms than perhaps they once might have been’ (p1166). This would seem to be even more important to consider when reflecting on displays of family that involve disabled children. It also seems pertinent to the subject of sleep and how certain sleep practices can be viewed through the lens of family practices and as displays of family, and the importance of reflection on how these link in with wider cultural views.

3.7 Conclusion

This chapter has outlined the theoretical developments that have taken place over the last 30 years in the fields of childhood, disability and sociology of family. The importance of outlining these developments lies in the principal need to explore sleep but at the same time acknowledge and place it within a theoretical context. By aiming to explore the sleep experience of children with cerebral palsy and that of their siblings and parents the contexts of childhood, disability and family are pertinent. Not only are the theoretical concepts relevant to consider but the impact that these have had on the research process and the methods used is of paramount importance. This will be reflected on in more detail in the next chapter (Chapter 4) with a focus on child-focused research as an approach to conducting research about sleep with disabled children which puts the thoughts, beliefs and opinions of disabled children at the centre of the research project. The core ethical issues involved in research with children, disabled and non-disabled, are particularly important to consider and consequently specific attention is paid in the next chapter to the issues related to confidentiality, privacy, gaining access, informed consent and power. Issues related to gathering the views of different members of the same family will also be explored with a focus on the complexity of analysing multiple realities from within a family context.
Chapter 4 - Child-focussed methodology and ethical issues when researching (disabled) children

4.1 Introduction

The previous chapters have examined the literature regarding sleep, childhood, disability and ‘doing’ family. The purpose of this chapter is to examine the methodological and ethical issues pertinent to this research project, specifically in relation to researching children (disabled and non-disabled). These issues informed the choice of research methods used for the study.

As discussed in Chapter 3 the ‘new’ sociology of childhood advocates that researchers move towards methodologies that recognise children’s competency in being able to take part in the research process. This move brought about a development of research methods to facilitate children’s participation in research. Ethical issues related to involving children in research were highlighted as important and as Morrow and Richards (1996) make clear ethical considerations need to be of ongoing concern throughout the research process.

This chapter will examine child-focused research as an approach to conducting research with children. The core ethical issues involved in research with children, are particularly important, and consequently specific attention is paid to factors related to power relations and issues concerning adult gatekeepers in child research. These issues will be discussed with specific reference to gaining access, obtaining informed consent and issues of confidentiality when researching children, disabled and non-disabled. These areas of discussion will be reflexively considered and addressed with reference to my research project. For this purpose it is, therefore, useful to provide an outline of my research aims followed by a brief overview of my study design and methods (which will be discussed in more detail in Chapter 5).
4.1.1 Research aims and overview of study design

The objective of the study was to explore the lived experience of sleep for children with cerebral palsy (CP), their siblings and their parents. The specific conceptual aims of my research are to:

1. Explore the everyday organisation and practice of sleep among children with CP, their siblings and their parents.

2. Analyse how severity of CP and child age influence the meanings and management of sleep.

3. Explore how sleep is embedded within family life.

My research also involves the following methodological aims:

4. To directly involve children with CP in the research process in order to gain their perspectives about their own sleep.

5. To explore sleep from the multi-perspectives of family members, including siblings.

In order to achieve these research aims ten families were recruited, representing 34 participants, comprising 10 children with CP, who were aged 6 to 13 years, 7 siblings who were aged 6 to 13 years, and 17 parents. For a family group to be included in the study there had to be at least one child with CP and one parent, fulfilling the relevant inclusion criteria (see Chapter 5), who agreed to participate in the study. Once informed consent was obtained from all participants a two week data collection period began, during which all participants completed daily sleep diaries (either written or audio recorded), wore Actiwatches and completed a sleep questionnaire. Additionally, children with CP and participating siblings were asked to take photographs related to their experiences of sleep, including photographs of their bedrooms. The information gathered through these methods were then processed, collated and used to prompt and facilitate discussion in qualitative interviews that took place with each participant approximately 1-2 weeks after the 2 week data collection period.
4.2 Approaches to researching with (disabled) children

In line with the new sociology of childhood viewpoint, outlined in Chapter 3, children should not be seen as objects but rather subjects of research whereby research with children is emphasised rather than research on children (Hood et al., 1996). Christensen (2004) advocates an approach that explores the social constructions of the terms ‘adult’ and ‘child’ in order to understand that power does not simply reside in people and social positions but in the process of doing research. For Christensen (2004), power is neither fixed to the role of researcher or that of the child being researched but shifts and is shared throughout the research process. The issue of power and how one seeks to redress it in research has strong implications in terms of the methodology and practical approaches adopted. For instance, practical suggestions associated with assuming differing researcher roles (Davis, 1998), employing multiple participatory methods (Morrow and Richards, 1996) and the ways in which data are interpreted (Thomas and O’Kane, 1998) can all go some way towards rebalancing power relations.

A reflexive approach is vital as researchers need to recognise how they view ‘children’, what has informed their views and how their views may facilitate power imbalances and impact on the ways in which research is carried out, including the methods chosen and how data is interpreted (Harden et al., 2000). James (1995; cited in Morrow, 2008) outlines four ways of viewing and understanding children and links these to the different ways that children are conceptualised in research, which in turn influences the research methods selected, ethical issues and the power balance between researcher and participant. Each of these four views will be briefly discussed.

Firstly, the ‘developing child’ view encapsulates the child as incompetent and unreliable. This is the traditional view that the ‘new’ sociology of childhood strived to move away from and the methods that it implicated, for instance, experimentation within which the power lies entirely with the researcher.

Secondly, the ‘tribal child’ perspective places the child as a competent actor who is entirely autonomous from adults inhabiting a conceptually separate
world. The method of choice for those holding this view is participant observation. However, Morrow and Richards (1996) highlight an ethical implication of this view as adult researchers, in trying to inhabit the conceptually separate world of the ‘tribal child’, are being misleading trying ‘to engage with this other world by attempting to suspend their adult status, because they cannot become children again’ (p99). They argue that to try and do so is ‘confusing’ to children and on a par with the deception experienced by children in experiments.

Thirdly, those who adopt an ‘adult child’ view consider children as competent actors but in an adult-centred world. Here the perspectives of the child are sought but these are focussed on their thoughts and understandings of an adult world in which they participate. Therefore, the methods employed when taking this viewpoint are also adult-centric and based on the assumption that children do not differ from adults, for instance, by use of interviews and survey questionnaires. However, the assumption that there are no differences between children and adults raises ethical issues as the difference in terms of social status is never adequately addressed (Morrow and Richards, 1996; Punch, 2002). From this viewpoint, children will inevitably be asked about (adult) things that they are simply not experienced in, which can perpetuate a view that children are incompetent and unable to understand (Morrow, 2008).

The fourth view as outlined by James (1995; cited in Morrow, 2008) is of the ‘social child’ which accepts that children are comparable to adults in terms of being research participants, as they are competent social actors in their own right, but that they have differing competencies compared to adults. These differing competencies may need to be tapped by using a range of different research methods to enable children to participate fully in the research process. Proponents of this view have developed child focussed ‘task-based’ methods based on children’s skills such as drawing exercises, storytelling tasks and sentence completion games in order to engage with the ‘diversity of childhood’ (Morrow and Richards, 1996:100) and proponents of such methods believe that, through these methods, power imbalances that exist in adult-child research can be redressed.
4.2.1 ‘Child-friendly’ or ‘person-friendly’ research methods?

There is some discordance within the ‘new’ sociology of childhood with reference to the use of different types of ‘child-friendly’ methods to engage children in research. For instance, Punch (2002) notes that it is a paradox to suggest that ‘special child-friendly methods’ are needed if one is, at the same time, arguing that children are competent social actors. However, researchers can take the view that children are competent social actors whilst also accepting that these competencies can be different to those of adults. Furthermore, children are not familiar with expressing their views freely, as often they are controlled and limited by adults and ascribed a position from which they are viewed as incapable and not to be taken seriously (Alderson and Goodey, 1996; Punch, 2002). The challenge, therefore, is how research methods can be adapted and developed to ‘enable children to express their views to an adult researcher’ (Punch, 2002:325) at the point of data-gathering, facilitating their willingness and enjoyment in participating and, hopefully, leading to a richness in the data obtained. The focus should not necessarily be on ‘child-friendly’ methods to achieve this, but rather on ‘participant-centred’ or ‘person-friendly’ methods (Punch, 2002) that have been chosen as appropriate for the group being studied and are relevant to the field of study. It is important to note that just as children have differing competencies to those of adults, children will also differ in their abilities and competencies when compared to one another. As Harden et al. (2000) point out, an adult researcher may regard a drawing research task as ‘fun’ and ‘child-friendly’ but for a child who does not enjoy drawing and does not feel confident in their drawing ability it will be neither and their participation may then be at risk. Researchers need to be flexible, reflexive and sensitive in terms of how best to involve and include all their individual participants (Davis, 1998).

My own approach when designing the methods of data collection for my doctoral research moved between viewing and conceptualising children as the ‘adult child’ and the ‘social child’. I was keen to explore alternative and participatory research methods and ‘task-based’ activities influenced by Participatory Rural Appraisal techniques (Thomas-Slater, 1995). However, it
was also important to me to utilise these methods together with the more ‘traditional’ interview based research method. As Punch (2002:330) notes:

...by using traditional ‘adult’ research methods, such as...interviews, children can be treated in the same way as adults and display their competencies. Thus, they are not being patronized by using only special ‘child-friendly’ techniques.

For my study, interviews were chosen as the primary data collection method, because I felt they were the most appropriate method to elicit views about the subject of sleep from the multiple viewpoints of disabled children, siblings and parents. Specifically, this qualitative approach would explore in-depth the concept of ‘doing’ sleep and the factors that ‘surround, inform, induce and influence’ sleep (Williams et al., 2007:4.5) for children with CP and their family members. However, by also using supplementary task-based activities, I felt the children, and to some degree the adults, in the study would be better supported and encouraged to express their views in differing ways, which is important especially as such methods can provide opportunities for rapport to build between the adult researcher and child participant (Harden et al., 2000; Punch, 2002). Punch (2002) comments that task-based research techniques can be beneficial to use with adults as well as children, therefore, confirming that such methods should be classed as ‘participant-friendly’ or ‘person-friendly’ rather than ‘child-friendly’.

In line with Harden et al. (2000) and Punch (2002), my view was that a balance between task-based activities and ‘straight forward conversation’, that is interviews, is possible and useful and this, once again, relies on flexibility of the researcher. Specifically, the task-based methods that I used were photographs taken by children, as well as sleep diaries, actigraphy and sleep questionnaires with all participating family members. These task-based methods took place in a two week period prior to undertaking the qualitative interviews and were valuable as they focussed the participant’s thoughts on the subject of their sleep, allowing them to think about and explore aspects of sleep prior to their interview. The photographs, sleep diaries, actigraphs, and sleep questionnaires were used as prompts in the individual interviews which proved
very successful as a ‘stimulus for talk rather than as evidence in their own right’ (Harden et al., 2000: para. 2.10). Details about the interviews and the task-based activities will be discussed in Chapter 5.

4.3 Ethical considerations in research with (disabled) children

Ethical considerations should be explored and at the forefront of the researcher’s mind whether the research subjects are adults, children or disabled children or, in the case of this research, all three groups. Morrow (2008) defines ethics as a ‘set of moral principles and rules of conduct’ (p51). When applied to research, ethical conduct is related to upholding this set of moral principles in order to prevent harm to others and to be respectful and fair. When completing the application form for NHS ethics approval I was very aware of how the inclusion of children in research equates to the inclusion of a vulnerable group and as a consequence ethical considerations were of great importance. The British Sociological Association’s (BSA) ‘Statement of ethical practice’ (2002) instructs researchers to take ‘special care’ when participants are deemed vulnerable, because of factors such as age, social status and powerlessness. As Morrow and Richards (1996) point out children are disadvantaged by all three factors and for disabled children the disadvantage is further exacerbated. In general the literature on ethics and research with children (disabled and non-disabled) agrees that ethical considerations should be the same when researching children as with adults, however, research with children raises additional considerations because of a number of reasons linked to the ways in which childhood ‘is constructed and understood within specific cultural contexts’ (Morrow, 2008: 51).

Morrow (2008) outlines four reasons why additional ethical considerations are raised when carrying out research with children as opposed to adults:

- Children’s competencies, perceptions and viewpoints differ because they have ‘a range of social differences, including culture, age, gender, ethnic background, personal characteristics’
Therefore, acknowledging that a plurality of childhoods exists (Qvortrup, 1994).

- Children are potentially vulnerable to exploitation by adults and adults have specific responsibilities towards children.

- The differential power relationships between adult researcher and child participant may become problematic throughout the research process including at the point of interpretation and presentation of research findings.

- Research with children requires that access to children has to be mediated via adult gatekeepers, and this has ethical implications in relation to involving children in research, gaining their informed consent and issues relating to privacy and confidentiality.

This last point is one that will now be discussed in more detail; however, it is important to note that all four points highlighted by Morrow (2008) are interlinked so the other points will also be touched on.

The presence of adult gatekeepers (for example, parents, teachers, and care staff) is an issue that many researchers contend with when carrying out research with children. In my research it had implications in relation to three main areas: gaining access, obtaining informed consent, and factors related to interviewing children on their own (including confidentiality issues). It could also be argued that the difficulties raised by the presence of adult gatekeepers is all the more pertinent when carrying out research with disabled children because, as outlined in Chapter 3, they experience high levels of adult surveillance throughout all areas of their life (Watson et al., 1999).

4.4 The presence of gatekeepers and gaining access to (disabled) children

For my research an opt-in strategy for recruitment was decided upon as it is generally agreed that this is more respectful of people’s privacy and least coercive. However, often this strategy results in lower response rates compared to opt-out approaches (Hewison and Haines, 2006). Furthermore,
there are often barriers in place that make it hard to reach or make contact with certain groups (Alderson and Morrow, 2004), which is particularly pertinent when trying to gain access to disabled children and their families. To recruit children it is often necessary to access them through, or via, adult gatekeepers, for example their parents or their teachers.

The recruitment material (Appendices 1.1, 1.2 and 1.3) used in my research was aimed principally at children, in terms of the wording. However it relied on a presumption that either the target child could read or that parents or other ‘gatekeepers’ would relay the information to the child. When trying to access children with disabilities the latter is more likely. Therefore, with such opt-in methods there is the potential risk of not knowing whether children have been informed about the research. Any non-response or refusal has to be respected but there remains an uncertainty about whether this is truly the choice or perhaps the ‘voice’ of the child or that of the adult ‘gatekeeper’ who has not, for whatever reason, passed the information about the research on to the child. Despite this, opt-in methods are still preferred and tend to be favoured by NHS ethics committees (Hewison and Haines, 2006).

It should also be noted that on many occasions ‘gatekeepers’ are a vital source of help and facilitation (Scott et al., 2006) especially when accessing research settings. Alderson and Goodey (1996) describe their varied experience of ‘gatekeepers’ when accessing schools for classroom observation. For example, some teachers were welcoming and helpful whilst others seemed almost angry that the head-teacher’s permission had imposed the researcher on them. Some teachers introduced the researcher or asked her to introduce herself to the class, whilst other teachers did not and simply started the lesson leading to a feeling of awkwardness for the researcher.

Using the opt-in method for my research resulted in a slow and, at times, frustrating recruitment process. After an initial small flurry of interest, when my recruitment posters and leaflets were first displayed, my recruitment slowed considerably. I had to find ways to be more proactive in advertising my study, including contacting local parent support groups, having posters and leaflets displayed at parent evenings at special needs schools and asking three
disability charities to advertise the study via parent newsletters. However, all of these ways led me only to parents and not directly to children, so even with these additional methods of recruitment, I was still reliant on adult gatekeepers to relay information about the study to potential target children.

4.5 Information and Informed Consent for (disabled) children

Inextricably linked to the discussion of adult gatekeepers in child-focused research is the ethical issue of informed consent. Harden et al. (2000: para 2.24) comment that:

...‘informed consent’ [in research with children] is problematic not primarily because of children’s lack of understanding of research, but because their participation in any research project is dependent on adult gatekeepers.

Historically, research ‘about’ children has relied on gaining the consent of parents or other adult gatekeepers and has not attempted to obtain informed consent from children themselves. This was often based on socially constructed preconceptions that children (disabled and non-disabled) are unable or incompetent to make informed decisions, in line with a ‘developing child’ view as outlined by James (1995, cited in Morrow, 2008, see Section 4.2).

Davis et al. (2000) describe when, at the beginning of their observations of disabled children in school, they attempted to discuss issues of informed consent, confidentiality and so forth with staff and children. The school staff felt and argued that the children would not understand so there was no point trying to explain the research to them and, therefore, no way to obtain informed consent from them. Davis et al. (2000) felt strongly that staff were trying to ‘resocialise’ the researchers into believing that the children were incapable of thinking for themselves and they felt a pressure to conform to staff views or risk limiting the access they had gained to observe the children.

Much of the discussion around obtaining informed consent from children centres on the concept of competency. In the UK, the competency of children to consent to medical research and medical treatment is assessed with reference
to the Gillick 1985 ruling whereby competence is not assessed purely in terms of the child’s chronological age. Instead children are deemed as competent if they have ‘a sufficient understanding and intelligence to understand what is proposed’ and if they have ‘sufficient discretion to enable [him or her] to make a wise choice in his or her own interests’ (Alderson and Morrow, 2004: 99). Morrow and Richards (1996) question how far it is possible to draw a comparison between consent to medical treatment with consent to participating in social research, but they highlight that the premise that competency is not based simply on chronological age is an important one. Other factors are important to consider when assessing a child’s competency to consent to participate in research such as context, what exactly the child is consenting to doing, the level of risk and harm and the potential benefits of taking part. Competency to consent also depends on the researcher’s ability to relay information about the study in ways that can facilitate and enable understanding of what taking part entails. With specific reference to disabled children giving consent to participate in research, Morris (1998) comments that it depends on the information about the research being received and understood as well as on potential participants being able to respond. The values of respect, trust, clear information and good communication are considered key in obtaining informed consent from all potential participants. As Alderson and Morrow (2004) make clear, respect for consent or refusal helps to prevent harm and abuse.

For my research, I felt strongly that informed consent should and could be obtained from children as opposed to assent. Obtaining assent from children is often considered good enough with consent being obtained solely from parents or other adult gatekeepers. Alderson and Morrow (2004) argue that assent refers to agreement by children who understand some, but not all of the main issues required for consent. Like Alderson and Morrow (2004), I question whether this is good enough and whether ‘a partly informed decision can count as a decision at all…’ (p97). As mentioned above competency to consent depends, in part, on the quality and standard of the information given. For my research, I felt it was essential that the information that was given was truly accessible for all the children. Because of my uncertainties linked to the opt-in recruitment methods (discussed in Section 4.4) it was important for me to know
that informed consent came truly from the children. I, therefore, wanted to ensure that children acted as their own final gatekeepers in deciding whether they took part in the research or not. To do this I developed information sheets in a variety of formats. For children with CP this included a written version, a symbol version and an audio recorded version on CD (Appendices 2.1, 2.2, 2.3). For sibling (child) participants separate written versions were provided for older children and for younger children (Appendices 2.4 and 2.5) and a written version for parents (Appendix 2.6).

Unlike some research (e.g. Thomas and O’Kane, 1998) I did not need to contemplate a situation whereby children consent to participating but their parents (or other ‘gatekeeper’) do not. To take part in my research the index child with CP and at least one parent per family unit had to participate, as the purpose of the research was to gain multiple family members’ perspectives with regard to sleep. My approach, therefore, centred on gaining the consent of the child with CP first, consent from the parent second (with regard to their own participation), and then further consent from the parent in terms of their disabled child’s participation. Therefore, if a child made an informed decision not to participate I would not have approached the parent for either of their consents. I ensured that there were opportunities for the information regarding the study to be discussed and for participants to ask questions throughout the research process. Time was given for participants to consider their participation and consent and they were encouraged to discuss the research with friends or family members before making a decision.

Further to this it was regularly explained to participants that they may withdraw from the study at any time without giving a reason and without prejudice, and that if they did so, any information they had given would not be used without their permission. The giving of consent was considered a continual process, therefore, each time I met with participants I checked that they were happy to continue in the research.

The use of lay advisors has been advocated, when planning and designing research involving children, both disabled and non-disabled, as an useful way to think through ethical issues and research methods from the point
of view of children themselves. Four lay advisors were consulted prior to my research starting; their role is discussed in the next section.

4.6 Lay Advisors

Advice was sought, regarding my research, through detailed discussions with two young people with CP (one female and one male aged 11 years and 15 years respectively), the sister (aged 13 years) of a child with CP and a mother of a child with CP. The advisors were recruited through a research advisory group that I had set up at the NHS specialist centre for children with complex disabilities where I work. This research advisory group is made up of volunteer parents and children/young people who attend the centre for assessment and/or treatment or have attended in the past. The purpose of the group is to advise on aspects related to research taking place at the centre. The advisors for my study were each visited at home or, in the case of one of the young people with CP, at school at the end of the day.

The idea to set up a group of lay advisors and to consult with them for this project was inspired by the work of Morris (1998) who explored the experiences of young people with disabilities living away from home. At the beginning of the project, Morris brought together a reference group of disabled young people to advise on certain aspects of the project including what information potential participants would want, issues related to ethical aspects such as confidentiality, and how to best disseminate the research findings. For the purposes of my own research, information was gathered individually from the lay advisors in relation to:

- their understanding of what research means and entails and how to make this accessible to young people and parents;
- possible aspects of sleep to discuss in interviews;
- how it feels to discuss issues related to sleep and the best ways to do this;
- the format and design of information regarding the study;
• issues relating to confidentiality;
• ways to recruit participants;
• attitudes toward the use of actigraphy;
• the format of sleep diaries (e.g. written or audio);
• how to disseminate findings in an accessible way.

The information gathered from the lay advisors directly informed the interview topic guides and the research design and methods. For instance, e-mail contact with one of the young people with CP was continued as she had asked to carry on being involved as an advisor. The first versions of information sheets and consent forms were sent to this young person for her comments and amendments were made accordingly.

Issues concerning children being interviewed on their own were raised by two of the lay advisors which will be discussed in the next section. In terms of the impact on the design of the research these comments emphasised the need to ensure that the purpose of the research was understood fully by all involved. This meant ensuring that the information given was clear, appropriate and that there were opportunities for questions to be asked. Although at the start of my project I really wanted children to be interviewed alone I needed to accept that this might not be a comfortable situation for some children and, therefore, the choice was given to children about whether they wanted someone else present during the interview and, if so, who this should be. These issues will now be discussed in more detail.

4.7 Interviewing children on their own and confidentiality issues

I approached my research design with the view that I would maintain confidentiality for all my participants throughout the research process. However, in line with British Sociological Association (2002) guidelines, my own organisation’s child concern protocol and writings on ethics and research with children (Alderson and Morrow, 2004); I recognised that confidentiality for both
children and adults may have to be breached in extreme circumstances. For example, if participants disclosed something which indicated that they or others were at risk of significant harm. This was stated clearly in the information sheets (Appendices 2.1-2.6) given to all participants and explained during the initial meeting. This issue is linked inherently with discussions around power imbalances in research with children and is one potential issue that marks research with children from that with adults. It was necessary to think carefully about how to approach this. Like Thomas and O’Kane (1998) I strongly felt that children have their own views and priorities and ‘their own strategies for dealing with difficulties based on their own knowledge and experience’ (p340).

However, unlike Thomas and O’Kane (1998) I was bound by, and committed to, my organisation’s child protection procedures for safeguarding children and therefore, I was unwilling to guarantee complete confidentiality to my participants. Therefore, if such disclosures were made, guidance would have been sought from supervisors and, if appropriate, referrals made to the Child Concern Pathway linked to my organisation’s Good Practice Guidelines.

It is clear that mine is a view based on and influenced by my past work-based experiences and training, perhaps coming from what Hood et al. (1996) term ‘a social work agenda of child protection’. I accept that this standpoint can be seen to contradict my attempts to redress the possible power imbalance between adults and children within the research process. It may have been that in some circumstances I would have needed to ‘exert my power’ as a responsible adult by reporting and taking forward any such disclosures. But I also argue that the strong moral obligation I feel would be the same if a scenario arose whereby a disclosure was made by a vulnerable adult (Morrow and Richards, 1996). I was and I am, therefore, comfortable with my standpoint and accept that this position may have reduced my credibility in the eyes of the participants (Thomas and O’Kane, 1998) and could have affected the research relationship built between researcher and participant. However, I also question, in line with Morrow and Richards (1996), that this is unavoidable as children expect adults to behave in certain ways and, therefore, by not intervening in certain situations, adult researchers may, just as easily, lose credibility. My viewpoint influenced the type of researcher role that I felt able to adopt. I felt
unable to assume a ‘least adult’ role as advocated by Mandell (1988) whereby the researcher distances themselves from the position of adult in all ways other than that of physical size. As Mandell (1988:438) explains whilst taking the ‘least-adult’ role in her own research:

While my size dictated that I could never physically pass for a child, I endeavored [sic] to put aside ordinary forms of adult status and interaction - authority, verbal competency, cognitive, and social mastery – in order to follow their ways closely.

My stance, in terms of confidentiality and possible disclosures, further emphasised that I was unable to adopt this role so instead I attempted to adopt Christensen’s (2004) position of ‘a different sort of adult’. Therefore, I tried to retain a balance between acting as a responsible adult whilst maintaining a positive and respectful relationship with the children.

‘Public confidentiality’ (Hill, 2005) refers to ensuring anonymity to research participants whereby they are not identified in the dissemination of the project findings, for example, in research reports, presentations, journal articles and so forth. In my research, public confidentiality was upheld by changing participant’s names, the names of family members and of any friends, teachers or relatives that were mentioned and the names of any school, town or city. Each child participant was given the option of choosing their own pseudonym to be used, rather than their real names, in analysis and subsequent publication of findings. Although confidentiality is high up the ethical agenda for most researchers it may be perceived in a different way by children. Morris (1998) comments on how some of the young people in her research were disappointed when they learnt that their names would not be used in publication. This also occurred in my own research. Two of the older girls, Grace Baker (13 years old, mild CP) and Ellen King (12 years old, younger sibling), were both noticeably disappointed that their own names would not be used with Ellen stating that she wanted her own name used because ‘I want to be famous’. In the end, after discussion with my supervisors, it was decided that Ellen could use her own first name as I was allocating a pseudonym for all the family surnames, hence
upholding public confidentiality but potentially denying Ellen her ‘chance of fame’.

Social network confidentiality refers to not passing on information to family members, friends or others known to the child (Hill, 2005). Network confidentiality is an important consideration in research with children and parents, as members of a family may wish to know what the others have said when they have been interviewed separately (Harden et al., 2010). It was a specific concern for me when I designed the research that I did not communicate information obtained through the data collection between members of the same family, as I anticipated that individuals would be curious as to what others in their family said. Specifically, parents may have wanted to know what their children had said.

When designing the research I consulted a number of lay advisors (see Section 4.6). During discussion with the lay advisor who was mother of a child with CP, I explained that, if possible, children would be interviewed on their own. When asked what she thought about this she commented that it depended on the age of the child and that younger children should be ‘chaperoned’. She also went on to say that:

…as a parent I think I would feel happier if I was in… to listen to what’s been said [laughs]… not that I’ve got anything to hide but just to make sure it’s all…

Hood et al. (1996) interviewed children and parents separately for their study exploring the ways in which risks to children are understood and managed by children and parents. They found that in their efforts to give children an equal voice with their parents, by talking to children separately, parent-child power relations were threatened. During their fieldwork a mother directly asked for feedback about what her child had said. As Hood et al. (1996) comment this may have been exacerbated by the research area of interest (i.e. risk) and a fear that the researcher was somehow checking up on the parents and their ability to protect their children. Interestingly, children themselves may also feel threatened and unsure of the researcher’s purpose. When asked her views on
interviewing children separately from parents my sibling lay advisor (11 years old) said:

I think I would feel more comfortable with my mum or dad [present]. It would probably be a bit easier as some things are a bit difficult to explain... it might... and I think mum would probably feel better if... I think everybody would feel better if they had someone with them, so that they can share.

This view intimates that young people may lack confidence or be unsure of their ability to participate meaningfully. Potential power imbalances and preconceived social constructions of the roles within the research process (i.e. researcher, participant, adult, child) may lead to the researcher being placed within an ‘expert’ role. Children may, therefore, feel that they are not the experts and are unable to give the ‘correct’ answers or that the responses they do give are not good enough or will not be taken seriously. This links to Alderson and Goodey’s (1996) informal barriers to research which need to be negotiated throughout the research process. As well as children’s caution, mistrust and fear of giving the wrong answers Alderson and Goodey (1996) discuss the need to find the appropriate words for each respondent and to explore the meanings in the words children use. Therefore, it is of utmost importance that children are told that there are no right or wrong answers and to ensure that plenty of time and space is given for children to explore issues in ways that suit them. Multiple methods for data collection may be useful to tap into children’s own experiences and realities because this provides more opportunities for children to relay their experiences in various ways that can complement children’s differing competencies.

It is possible that parents and children in my study felt concerned about the purpose of the research, the subject area of sleep and the researcher’s ‘true’ motives. As Hood et al. (1996) comment conducting research in the home environment is difficult, entrenched with ideologies and emotions. In my mind this was further exacerbated by exploring sleep and the night-time as this is a fundamentally private and potentially sensitive time for families. Hood et al. (1996) discuss how researchers can be perceived as invading the traditional
boundaries between the public and the private when entering the home to ask questions. In order to try and overcome some of these issues participants in my research (children and parents) were given the choice of whether they wanted to be interviewed alone and, if not, who they wanted to be present.

Prior to the individual interviews, I explained to children that there were no right or wrong answers to the questions, that they did not have to answer questions if they did not want to and that they were able to stop the interview at any time. In line with advice from Morris (1998) and Marchant et al. (1999), a way for children to indicate that they wanted a break or to stop the interview was rehearsed and this action was role played at the beginning of the children’s interviews.

Despite my preference to interview children on their own this was not dictated by me as this would be, as Alderson and Goodey (1996) explain, counter-productive and inhibiting. Marchant et al. (1999) suggest there are practical strategies that can be used and negotiated with parents when they were present at their child’s interviews. For instance, I ensured that all questions were asked directly to the young person, if parents attempted to answer I redirected this back to the young person (e.g. “your mum says that...”). Marchant et al. (1999) also suggest asking parents to physically distance themselves during the child’s interview so, for instance, to sit further back if possible. However, I did not feel confident or comfortable in doing this. Interestingly, a number of parents did automatically distance themselves physically during their child’s interview. For example, when I visited and interviewed Charlotte Appleby (child with severe CP) for the first time, her mother Sue stayed in the same room and sat next to Charlotte. When I visited to interview for the second and third (final) time, Sue ‘busied herself’ tidying up and popping in and out of the sitting room where the interview was held. However, it was clear that Sue was still listening to the interview as there were occasions when she would interject with her own answers or prompt Charlotte to respond. Other parents did not attempt to distance themselves during their child’s interviews. For example, Aileen Edwards (mother) sat in on all three of her children’s interviews (child with CP and two siblings). This was decided on
through discussion with each of the children, however, I felt some uncertainty about the amount of real choice the three children felt they had. This was further reflected in my own research diary entries that noted that Aileen was quite dominant during the children’s interviews and that I had difficulty retaining the focus on the children’s own answers and responses. This is the reality of research with children and their families and despite planning and designing research that, it is hoped, facilitates the participation of children and upholds ethical standards it can turn out to be quite different in practice.

4.8 Conclusion

This chapter has examined child-focused research, as advocated by the ‘new’ sociology of childhood, as an approach to conducting research with children. The way in which the researcher views children and childhood has been discussed as influential in terms of the research methods chosen and the ways that power and ethical issues are addressed. Despite a move towards adopting specific ‘child-friendly’ methods within the ‘new’ sociology of childhood some questions remain regarding their use. Instead methods should be chosen and used on the basis of them being ‘participant-friendly’ and also ‘fit for purpose’, in terms of the topic or subject area being researched (Punch, 2002).

Ethical issues should not be considered as pertinent only in research with children but in all social research and should be at the forefront of the researcher’s mind throughout the entire research process. However, as discussed there are factors relating to research with children that require specific ethical considerations because of the ways in which children and childhood are perceived at societal and cultural level. These issues are further highlighted and exacerbated when research includes disabled children. The ethical issues of power, the presence of adult gatekeepers and gaining access to children, informed consent, interviewing children alone and confidentiality were explored in this chapter with examples taken from this research project. The value of consultation with lay advisors about what information to give to potential participants, ways to recruit, study methods and ethical issues such as confidentiality was also discussed.
Chapter 5 - Research Methods

5.1 Research background

As discussed in Chapter 2, sleep as a sociological topic is now recognised as worthy of exploration (Williams, 2002, 2005; Hislop and Arber, 2003; Meadows, 2005; Meadows et al. 2008; Venn et al. 2008; Williams et al. 2010; Arber and Venn, 2011; Arber et al. 2012; Coveney, 2014; Venn et al. 2013; Zahrin, 2015). This exploration of sleep has begun to infiltrate the sociology of childhood (for example, Moran-Ellis and Venn, 2007; Williams et al. 2007; Power et al., 2017). These studies seek to analyse the experience of sleep from the child or young person’s point of view. However, this work has not extended to the experiences of sleep for children with disabilities.

The dominance of medical writing is striking within existing research on sleep and children with disabilities as discussed in Chapter 2. Such research reports that children with disabilities have a higher incidence of sleep problems compared with children without disabilities (Jan et al. 1994; Jan and Freeman, 2004). The majority of this research has relied on parental responses to sleep questionnaires and sleep diaries. Children with CP make up the largest group of children with a physical disability in the UK (Rosenbaum, 2003), yet there is very little research focusing on their sleep or the possible impacts of their sleep on other family members. Furthermore, no in-depth research has been conducted to examine the experiences of sleep from the viewpoint of children and young people with CP themselves. Additionally, there has been no research exploring the conceptualisation of sleep from multiple family members’ perspectives from within the same family, including both parents and children. This is despite the assertion that sleep is embedded within family life and that potentially an exploration of sleep could provide novel information pertaining to family life (Williams et al., 2007).

5.2 Obtaining multiple perspectives and methods overview

Given the lack of previous in-depth research, the primary focus of this study was to explore the meanings of sleep for children and young people with CP, their siblings and their parents. Starting from a broadly interpretive sociological
standpoint my research aimed to meaningfully involve all family members in the research and to allow participants to explore and describe their lived experiences and views on sleep from their own perspectives.

Harden et al. (2010) advise that researcher’s who explore the views of more than one participant within families in qualitative research should examine their motivations for doing so. For my research the seeking of multiple family member perspectives, in relation to sleep, was related to my overall research objectives. Firstly, I wanted to hear directly from children with CP about their sleep and as Harden et al. (2010) comment ‘multiple perspectives’ research with families is one way to ‘ensure that the voices of a particular group are heard alongside others’ (p441). I also wanted to build an understanding of sleep within the family context and analyse the family practices that surround and encompass sleep. I hoped that multiple perspectives would provide a more ‘rounded’ picture of individual family member’s sleep and the sleep of the family as a whole. An individuals’ own sleep is inevitably difficult to self-report on so multiple perspectives can be useful. Furthermore, I wanted to compare and contrast the views of different family members with regard to their own and other family member’s sleep.

Harden et al. (2010) discuss that broadly identifying a researcher’s motivations behind choosing to seek multiple family member perspectives will inevitably lead them to ask ‘what meaning do we attribute to the term ‘multiple perspectives’ in family research?’ (p441). This is not necessarily straightforward as there are several different, and not entirely separate, dimensions related to multiple perspectives which can inform a researcher’s analytic focus. Ribbens McCarthy et al. (2003) describe several different dimensions of multiple perspectives including between individuals within ‘families’ and between ‘families’, as well as between standpoints across different families such as according to gender and generation. As Harden et al. (2010) comment researchers may choose to focus on one particular dimension or may explore several perspective dimensions, both within and between families. As discussed in more detail in the data analysis section of this chapter (Section 5.10), I explored several perspective dimensions as my initial analytic
focus was on the family group and the views and perspectives of family members, starting with the child with CP. However, because of my interest in children’s perspectives and wanting to, specifically, hear the voices of children with CP with regard to their experiences of sleep my analytic focus shifted to comparing the standpoints across families based on generation, e.g. children compared to parents, and age, so younger children compared to older children. I also compared standpoints within and between families based on disability and severity of CP, for example, children with CP compared to those without CP (i.e. siblings) or children with severe CP compared to those with mild CP.

A qualitative approach was adopted using semi-structured interviews with children with CP, their siblings and their parents. Supplementing this approach, and in line with child-focused methodology and research involving disabled children (as discussed in Chapter 4), was the use of task-based methods. All the children in the study (children with CP and their siblings) were asked to take photographs of aspects related to sleep using a provided disposable camera. Additionally, all participants (children with CP, siblings and parents) were asked to complete daily sleep diaries for two weeks and could choose to do this by audio recording with a Dictaphone, hand writing or word processing their diary entries. During this two week period, participants were also asked to wear an Actiwatch and to complete a one-off sleep questionnaire. The information collected via these activities was used to facilitate, and prompt, discussion in the semi-structured qualitative interviews.

The primary qualitative approach was decided upon to explore in-depth the concept of ‘doing’ sleep and to examine the factors that ‘surround, inform, induce and influence’ sleep (Williams et al. 2007:4.5) for children with CP and their families. This is in recognition of the importance of the socio-cultural aspects of sleep and that sleep is a sociological concern, as well as a biological and psychological one (Williams, 2002). This approach also mirrors that used in the work of Moran-Ellis and Venn (2007) and Williams et al. (2007) in their explorations of the experience of sleep from children’s own perspectives. The qualitative interview is also a method commonly used in family research as Mason and Tipper (2014: 55) explain:
Interviews can enable research participants to ‘report on’ aspects of family life that take place outside the interview setting, as well as enabling interviewer and interviewee to ‘co-construct’ or evoke the contexts and practice of family life through an interactive exchange.

Mason and Tipper (2014) advocate the use of interviews to explore aspects of family life as opposed to participant observation because, they argue, family practices and connections are not always conducted ‘face to face in physical spaces at particular moments in time’ (p155) which makes it difficult for researcher observations to take place. This is further emphasised when considering sleep within the context of the family. As Williams et al. (2007) state:

*Participant observation, for example, is a non-starter if it is sleeping we are interested in…*(para. 4.4)

Because the night-time and sleep is considered a fundamentally private time for families it is not easily or ethically accessible for observation by a researcher.

### 5.3 Research Design and Review

The study was designed by the researcher, with advice regarding the study obtained from her supervisors and lay advisors (discussed in Chapter 4). The research consisted of an initial visit to the family home, followed by a second visit to obtain informed consent. The 2 week information collection period then began with a third visit to the family home. One to two weeks after this 2 week period, semi-structured qualitative interviews with all participants were conducted. Families received a £50 ‘High Street Gift Voucher’ (this is a gift voucher that is valid for use in a large number of different high street shops) and a thank you letter at the end of the individual interviews for their time and effort in participating in the research project.

A study protocol was written with full details of the methods and included a full document set. The study protocol was submitted to my local NHS Research Ethics Committee and a favourable ethical opinion was received after a few minor amendments were made (July 2008, see Appendix 3). Additionally,
a favourable ethical opinion was received from the University of Surrey Ethics committee (August 2008, Appendix 4). NHS research governance approval was also obtained for each of the four NHS Trusts through which children and families were to be recruited (August 2008, Appendix 5).

5.4 Development work and pilot study

Once all approvals were in place I completed a short period of development work whereby I kept an audio sleep diary and wore an Actiwatch for 2 weeks. I found that wearing the Actiwatch was non-intrusive to my daily life and after the first couple of days it was easy to remember to put the Actiwatch back on after bathing and showering. I did forget to record an audio sleep diary entry on 2 consecutive mornings during the 2 week period. On both these mornings I was in a rush and it happened halfway during the 2 week period. Therefore, I decided to emphasise to participants that, if in a rush, they should aim to record the basic information (i.e. day and date, time to bed, time of waking and whether it was a ‘good’ or ‘bad’ night) and return to add more to the diary entry when they had more time during the day. Additionally, I decided that I would phone or e-mail the participating parent halfway through the 2 week information collection period to check how things were going. It was hoped that this would serve the purpose of being a gentle reminder to continue completing the sleep diary.

Three families were recruited as part of a pilot study. Those who participated from these 3 families included 3 children with CP (2 with severe CP and one with mild CP), 2 siblings (from one of the families) and 5 parents. The participating family members took part in all aspects of the study with the view that their data would be incorporated into the main study findings if the pilot study proceeded without major amendments being needed to the research design of the main study.

The pilot stage of the research proceeded successfully and for me it was a rewarding and positive experience. Prior to conducting the pilot study and in conjunction with the review of the literature and consultation with my lay advisors, specific topic areas were identified as important to include in
interviews. Questions related to the topic areas were formulated, however, during interviews the exact questions were not always asked as long as the topic areas were covered (Appendices 6.1-6.3). The pilot study confirmed the topic areas as useful and relevant and that the questions would produce valid data with the language and content being appropriate for most of the participants. For the two children with severe CP, Charlotte Appleby and Libby Cooper, and also for Joseph Cooper (8 year old brother) I did have to simplify some of my language and there was more repetition and/or clarification of questions too.

The pilot study also highlighted differences in relation to the quantity and quality of information recorded using the different ways the sleep diary could be completed (i.e. audio diary using a Dictaphone, written diary, or word processed). For instance, Catherine and James Cooper (parents) were the only ones who chose to do audio sleep diaries and this proved very successful as the information obtained was detailed and both Catherine and James commented that they found it a very easy process. This was in direct contrast to the information collected via written sleep diaries completed by Daniel and Joseph Cooper (siblings of Libby who has CP). When asked for feedback about how the study could be improved Catherine Cooper (mother) commented that she felt that it would have been much better for Daniel and Joseph to have carried out audio diaries as they got bored with the written diaries and saw them as a bit of a chore to complete; almost like homework. With hindsight I perhaps should have anticipated this as prior to the data collection period Joseph Cooper asked me if his handwriting had to be neat for the sleep diary and he was worried as he felt it could be quite messy. He seemed to think that I would somehow be judging this aspect of the sleep diary and I had to reassure him that this was not the case. This highlights the findings of Hislop et al., (2005) who comment that audio sleep diaries used in their research provided much more detail compared to written paper diaries. Following the pilot study I did consider whether I should only offer audio diaries as an option. However, I felt that this would take away the aspect of choice; an aspect that I felt was integral to the research. Instead I decided it would be useful to take more time to explain the choices for the sleep diary and to take a Dictaphone with me to
show participants the meaning of an audio diary before the data collection period began.

Overall, there were very few changes that needed to be made to the design of the research as a result of the pilot study; therefore, it was felt that the pilot data collected could be incorporated into the main study. Details regarding the procedure of the main study will now be outlined.

5.5 Sampling Framework

The study aimed to explore the meanings of sleep for children and young people with CP and their families, therefore, children and young people with CP were recruited together with their parents and siblings. For a family group to be included in the study there had to be at least one young person with CP and one parent who fulfilled the relevant inclusion criteria and agreed to participate in the study. Given the depth and variety of data collected from multiple family members, ten families were considered an appropriate sample size for this qualitative research.

5.5.1 Inclusion Criteria

Inclusion criteria for the young person with cerebral palsy were:

- aged between 6-15 years (therefore school aged),
- has a reliable method of communication (verbal or non-verbal) and is able to understand questions,
- able to give informed consent,
- has at least one parent who wishes to participate in the study.

Inclusion criteria for parent(s) were:

- has a child aged between 6-15 years with a diagnosis of CP,
• their child with CP wishes to participate in the study,
• their child with CP lives with them for the majority of the week,
• able to give informed consent,

Inclusion criteria for sibling(s) were:

• aged 6 years or above,
• has a sibling aged between 6-15 years with a diagnosis of CP,
• their sibling with CP and at least one parent wishes to participate in the study,
• lives at the family home for the majority of the week,
• able to give informed consent.

5.5.2 Exclusion Criteria

Exclusion criteria for child with cerebral palsy (index child):

• Where there is diagnostic uncertainty and where it is likely that the young person’s disability is not caused by a fixed lesion in the developing brain (i.e. not cerebral palsy) as determined through discussion with parents.

The age range of 6 to 15 years was decided on in order to access school-aged children and young people with CP. This age range allowed recruitment of potential participants through local schools.

Children and young people with CP with a reliable method of communication (verbal or non-verbal) and able to understand questions were recruited for the research. This criterion was included due to the purpose and methods chosen for the research. One of the main purposes of this research was to elicit the lived experiences with regard to sleep from the children themselves, and to achieve this the primary method for this research was in-depth interviews. In order to conduct these with children with CP, they needed
to have a method of communication, for instance verbal communication, sign language, picture symbol communication books, use of computer based or augmentative communication systems or a combination of these methods. This does not mean that children who did not use such methods of communication or who may be considered to not use a form of recognised communication method could not be included in research in general. There have been a number of studies that have successfully included children who do not use formally recognised communication methods (Marchant et al 1999; Morris, 1998; Cocks 2008). The methods advocated by these researchers tend to be based around participant observation methods. When non-verbal communication methods were used adaptations were made to my research process such as scheduling more than one visit in order to complete the interview or the use of a facilitator as chosen by the child with CP, which are discussed in more detail in Section 5.9.1. However, the use of non-verbal communication methods did affect the qualitative analysis of this data and this will be discussed in Section 5.11.

5.6 Recruitment and Access

Families were recruited via local special needs schools, local respite units, the specialist NHS centre where I worked, local NHS child development services and through local parent/family support groups and three disability charities.

Posters advertising the project were displayed at the specialist NHS service where I worked, which included tear off tags that young people with CP and/or interested families could complete with their contact details (Appendix 1.1) and post in a box stationed in the reception area which I checked daily. Posters displayed at the other specified locations included the contact details of the researcher and requested that interested families get in touch with me (Appendix 1.2). Leaflets were distributed within the local schools, family/support groups and the NHS services (Appendix 1.3). The leaflets included a contact slip that could be returned to me, in a provided freepost envelope, to indicate a family’s interest in taking part. Three relevant disability charities also agreed to include details of my project in their newsletter available to families of disabled children.
Once families indicated their potential interest in taking part in the study I contacted them and posted further information to them regarding the study (Appendix 7). Separate information sheets were sent for each family member who was interested in participating (Appendices 2.1-2.6). As discussed in Section 4.5, for young people with CP the format of the information sheet could be written, symbol based or an audio version on CD. The most appropriate information sheet format was decided on when I contacted parents prior to sending the information out. For siblings and parents the appropriate written information sheets were sent.

The pack of material sent out also included a background information form (Appendix 8) for interested families to fill out and send back (via freepost). The form asked for demographic information about each family member interested in taking part and also contact details. Once the background information forms were sent back and I verified that the inclusion criteria were met, I contacted the families to arrange the first visit. Three families that had originally expressed interest in the study chose not to send the background information sheets back. I contacted these families two further times but they did not phone me back. I decided that two follow up phone calls was enough and that their non-response was confirmation that they no longer wished to participate.

A description and discussion of each of the participants recruited will be presented in Chapter 6. Ten families took part in the study (including the 3 pilot families) which represented 34 participants - ten children with CP, seven siblings (from 5 families) and 17 parents. The 3 pilot families took part in the research in late 2008 and early 2009. I then went on maternity leave for one year. When I returned in summer 2010, I began recruiting again and the remaining 7 families were recruited during late 2010 and the first half of 2011. The next section will outline the study procedure.
5.7 Initial visits and obtaining informed consent

5.7.1 First Visit

I initially visited each family at their home (when all potential participants were present). The information sheets (Appendices 2.1-2.6) were discussed and I encouraged family members to ask any questions regarding the research. I discussed with the child and their parent/s the preferred method of communication for the child with CP, and if they would like someone present at their individual interview. Issues concerning the need and process of obtaining consent were also explored and consent forms given out (Appendices 9.1- 9.5). After approximately two weeks, I telephoned the families to enquire if they wanted to participate in the research. All the families that reached this stage of the study agreed to participate.

5.7.2 Second Visit – Consent

During the second visit informed consent was obtained. All young people (including siblings) were asked to sign their own consent forms. For siblings and children with CP who could read and write this was in written format (Appendix 9.1) or symbol/written format (Appendix 9.2). For children with CP who were unable to write or sign their names but who communicated verbally, used sign language (i.e. British sign language, Makaton or Signalong) or used a symbol communication system; I audio and/or video recorded the child's verbal, hand signed or symbol based consent (Appendix 9.3). I recorded in writing that this had happened and I signed the consent form in the presence of the child. Parents were asked to sign consent forms consenting to their own participation in the study (Appendix 9.4) and asked to sign a separate form consenting to the participation of each of their children (including siblings) who agreed to participate (Appendix 9.5).

Once informed consent was obtained, I arranged with the family a convenient date for the 2 week information collection period to begin.
5.8 Study procedure - Two Week Information Collection Period

5.8.1 Instructions

I visited the families at the start of the proposed 2 week information collection period. During this visit I gave instructions and information regarding the different ways that participants could complete the 14 day sleep diary which were by audio-recording (I showed participants a Dictaphone), hand writing or by word processing. Participants chose their preferred method and the appropriate equipment and instructions on use were given (Appendix 10.1), see Section 5.8.2. Children with CP and participating siblings were asked to take photographs during the 2 week period to record aspects related to their sleep and an instruction sheet was given (Appendix 10.2), see Section 5.8.3. A disposable camera was given to each young person and labelled with their name. The use of the Actiwatch-L was explained to participants and a demonstration of how to wear the Actiwatch-L was shown. Written instructions were left with participants and they were asked to note down on a provided log sheet when, for how long and why they took off the Actiwatch-L (Appendix 10.3), see Section 5.8.4. At this visit participants were also asked to individually complete a sleep quality questionnaire (Appendices 11.1-11.3), see Section 5.8.5.

5.8.2 Sleep Diaries

All participating family members were asked to complete a daily sleep diary as soon as possible after waking on each day during the 2 week information collection period. Participants were asked to describe and reflect on their nighttime sleep, any disturbances, day time sleep and asked to include sleep timings (Appendix 10.1). Elliott (1997) discusses how diaries are a useful and important data collection method in sociological research because they allow participants a closeness to the experience that they are being asked to recall and describe. Elliott argues that by reducing the temporal gap between the experience and the record of experience means that diaries are less dependent on the ‘vagaries of memory, to retrospective censorship or reframing than other autobiographical accounts’ (Elliott, 1997: para. 2.4).
In my research, participants were asked to choose how they wanted to complete their sleep diary from the following methods:

- Audio diaries – verbal reflections recorded into a provided Dictaphone
- Written diaries – participants recorded their reflections using pen and paper (a small notebook was provided)
- Word processed – participants recorded their reflections on their own home computers.

For those young people with CP who were unable to use any of the above options, a discussion took place and they chose someone to facilitate the completing of their sleep diary. This occurred for eight of the young people with CP and three of the younger siblings. For 7 children with severe CP a parent was nominated by them to complete a written sleep diary and for one young person with CP it was decided that the mother would record an audio sleep diary on his behalf (the mother chose to complete a written diary for her own sleep). In this situation, where parents were completing sleep diaries on their child’s behalf, I did emphasise to both the children and parents that the child be as involved as possible in describing their nightly experiences.

Overall, written paper sleep diaries were chosen by 26 participants (including the 7 children with CP and 3 younger siblings for whom written diaries were completed by parents). Four participants (3 parents and 1 child with mild CP) chose to word process their sleep diaries which they emailed to me at the end of the 2 week information collection period. Four participants (2 parents, 1 child with CP and 1 parent on behalf of their child with CP) chose to complete an audio sleep diary using a provided Dictaphone.

There was great variability in terms of the detail and richness of information provided by the sleep diaries. The word processed sleep diaries, in particular, were less rich and tended to list facts in log form relying heavily on the structure and example questions given in the sleep diary instructions (Appendix 10.1). The Baker family (Grace Baker, aged 13 with mild CP and her
parents Robert and Lynn) all chose to complete word processed diaries and all tabulated their entries using the exact ‘example’ questions from the sleep diary instruction sheet as the table column headings. The following example is an excerpt from Grace’s word processed sleep diary.

**Table 5.1 Excerpt from Grace Baker’s sleep diary (child with mild CP, aged 13 years)**

<table>
<thead>
<tr>
<th>Day</th>
<th>Time to bed. Why?</th>
<th>Did you sleep alone? Who else was in the room?</th>
<th>Was it easy or difficult to get to sleep? Why?</th>
<th>How did you sleep?</th>
<th>Did you wake during the night? When? Why?</th>
<th>What time did you awake in the morning? Why?</th>
<th>Anything different or unusual about your sleep?</th>
<th>Anything else you can think of?</th>
</tr>
</thead>
<tbody>
<tr>
<td>29.10.08</td>
<td>9:30</td>
<td>On my own.</td>
<td>I took a quarter of an hour to get to sleep.</td>
<td>I slept very well.</td>
<td>I woke once during the night at 5.</td>
<td>I awoke at 9.30</td>
<td>No.</td>
<td>No.</td>
</tr>
</tbody>
</table>

In contrast, as discussed in section 5.4, with reference to the pilot study, the audio sleep diaries recorded by Catherine and James Cooper (parents) were full of detail and were narrative in their form. The richness of these audio sleep diaries was highlighted when directly compared to the written paper diaries completed by Daniel and Joseph Cooper (siblings) who noted down very little detail. This finding emulates that of Hislop et al. (2005) who discuss how in their ‘Sleep and Ageing Women’ project the audio sleep diaries provided rich and descriptive information allowing insight into the social context of women’s sleep compared to written paper sleep diaries that only gave listed sleep based facts. However, during my research the difference, in terms of quality of information recorded, was not so clear between audio sleep diaries and written paper sleep diaries. For instance, in the main study Greg Jackson (child with CP, aged 13 years) chose to record an audio sleep diary but did not provide much detail about his sleep and each diary entry was brief. An example of Greg’s audio diary daily recording is as follows:
Today is the 14\textsuperscript{th} November 2011. I woke up at 6:45 a.m. because I had school. I went to bed at 8:00 p.m. because that is my normal bedtime. I did not wake up at all.

\textit{(Excerpt from Greg Jackson’s audio sleep diary, child with CP, 13 years)}

Furthermore, some of the written sleep diaries included rich narrative detail that included information that highlighted the social context and interactional nature of sleep and the night. This was not necessarily dependent on generational standpoint, with an assumption being that adults would provide more detail than children, as a number of the children wrote eloquent, affective and detailed accounts of their sleep. This was particularly evident from the sleep diaries written by two siblings, Willow Edwards (10 years) and Ellen King (12 years). Conversely, a number of adults wrote short fact-based entries with no embellishment or detail in their own written sleep diaries.

The majority of parents that completed paper diaries on behalf of their child with CP tended to write it from the point of view of the child. There was some evidence in the way that they were written that the child had been consulted about what to include in the diary entry. For example:

8:00pm – Mum and me laid (\textit{sic}) down together to read a story. I didn’t fall asleep with mum as she needed to get [older sister] from work. I laid (\textit{sic}) in bed with my toy dog Duke and fell asleep very quickly I think, I don’t remember laying there awake for long.

\textit{(Excerpt from Oliver Davis’ sleep diary, child with CP, 8 years written by his mum, Nicola Davis)}

Overall, there was much variability in terms of the detail and richness of the information recorded in the sleep diaries. The four word-processed diaries, in particular, were purely fact-based listing dates, times and little additional detail about aspects surrounding the participant’s sleep. The written paper sleep diaries and the audio sleep diaries included both entries which were short and purely factual and also more detailed accounts that were full of supplementary
information written in a narrative form. The variability may be due to a number of factors, including time restrictions, especially when considering that sleep diaries were often completed in the morning, a time that is notoriously busy in households with school aged children. There may also be individual or personality related factors at play. Elliott (1997) notes that not all participants warm to the task of diary keeping and that some individuals are predisposed or more familiar with diary keeping than others which in turn may affect the quality of diary entries. This may be relevant regardless of the method of sleep diary chosen.

5.8.3 Photographs

Young people with CP and participating siblings were asked to take photographs to describe and reflect on aspects relating to their sleep. For example, the things that help them to sleep well, the things that disturb their sleep or aspects relating to their bedrooms. A disposable camera was given to each young person and labelled with their name. If a young person with CP was unable to physically use a disposable camera they were asked to nominate a family member or friend to facilitate taking of photographs as directed by them. A range of people were chosen by those children with CP unable to use a disposable camera including parents, siblings, and paid carers.

The use of photography in research is influenced by participatory techniques (O’Kane, 2000; Clark and Moss, 2001). Photography allows data to be generated ‘by’ rather than ‘of’ or ‘from’ research participants (Gabhainn and Sixsmith, 2006). In the case of research with children this is particularly advantageous as research has in the past relied on information obtained from parents or other adults.

The use of photography in research can be particularly appropriate for children with disabilities (Sloper and Beresford, 2014). Specifically photographs have been found to be useful in conjunction with an interview as they provide children who have limited speech and/or learning disabilities with a more ‘concrete stimulus to help [disabled] children to understand and relate to [interview] questions’ (Sloper and Beresford, 2014:247). Murray (2004) used
photographs in a project with disabled children about leisure. Disposable cameras were given to the children to take photos of activities they enjoyed, places they went to, and the people they liked to be with. If some children were unable to use the camera then parents photographed activities that the young person enjoyed. Murray (2004) concluded that the photographs were powerful in enabling the young people to let the researchers know about their leisure experiences and were invaluable in facilitating conversation and discussion to take place. Therefore, techniques using photography allow children and young people, both disabled and not, a way to reflect on their experiences that is not solely reliant on verbal ability or the written word and can provide an insider view of their world related to sleep.

5.8.4 Actigraphy

All participating family members were asked to wear an Actiwatch for the whole of the 2 week information collection period. An Actiwatch is a watch-like device that provides an un-intrusive method of recording movement and light exposure for a long period of time. The participants were asked to wear an Actiwatch on their wrist to provide an indication of sleep times and sleep disturbances during the night. Actigraphy has been established as a reliable method for ascertaining sleep-wake patterns in adults and children (Sadeh et al., 2000). Although polysomnography is regarded as the ‘gold standard’ for assessing sleep (Sadeh et al., 2000) actigraphy has the advantage of being comparatively cheap and enables continuous recording for prolonged periods with no interference with the participant’s natural sleep environment.

Actograms (a graph indicating hourly activity levels) were printed out (as a one-sided A4 printout) and used during individual interviews as a visual prompt for discussion about sleep. The Actograms were useful to refer to when participants were asked to describe their sleep during the two week data collection period and, if applicable, the reasons why they may not have slept well. Only the Actogram of the family member/s being interviewed were presented during the interview. Therefore, if I was interviewing a parent I would only show them their own Actogram and not those of the other participating family members. Analysis of the actigraphy data and the sleep variables
calculated for each participant, such as total sleep time, sleep latency and sleep efficiency were not presented during interviews and this analysis of the raw actigraphy data is not included within this thesis. Three illustrative Actograms are included in Appendices 12.1-12.3.

5.8.5 Sleep Quality Questionnaires

Parents and siblings aged 16 years and over completed the Pittsburgh Sleep Quality Index (PSQI), Appendix 11.1. This is a validated measure of sleep quality (Buysse et al., 1989). For parents, three additional questions were added to the PSQI, in line with the work of Meltzer and Mindell (2006), who explored the sleep of parents of children with complex health needs. The additional items asked whether parents had trouble sleeping because of:

- Attending to the child’s health needs.
- Stress related to the child’s health status.
- Stress not related to the child’s health status.

Siblings below the age of 16 years were asked to complete the Children's Sleep Habits Questionnaire (CSHQ, Appendix 11.2). This questionnaire is widely used and has been validated on a large number of 'healthy' children (Owens et al., 2000). It is designed to be answered by parents on behalf of their child (as are most existing paediatric sleep questionnaires). However, I did request that parents involve siblings in the answering of the questions if possible.

The Chailey Sleep Questionnaire (Appendix 11.3) was completed for children with CP. This questionnaire was developed to assess sleep in relation to children with cerebral palsy and record clinical information that may have an impact on their sleep quality. As with the Children's Sleep Habits Questionnaire, this questionnaire was designed to be answered by parents on behalf of their children. As above, the researcher requested that, if possible, the young person with CP was involved in the answering of the questions.
The majority of the families preferred the questionnaires to be left with them to complete at a time of their choosing. However, some families chose to complete the questionnaires during this visit and I helped a couple of the young people (one with CP and one sibling) to complete their questionnaires at this time.

Each of the 17 parents completed their own PSQI. For 9 out of the 10 children with CP the Chailey Sleep Questionnaire was completed by their parents. Grace Baker (child with CP, aged 13 years old) asked to complete her own Chailey Sleep Questionnaire with me, to which her mother agreed. For 5 out of the 7 siblings the CSHQ was completed by their parents. The exceptions to this were Daniel Cooper (older brother, 13 years old) and Ellen King (younger sister, 12 years old) who completed their own CSHQs. I sat with and helped Ellen King while she completed her questionnaire.

Questionnaire responses were drawn upon in participant interviews when I asked participants to reflect on their sleep and possible reasons for their poor sleep. The questionnaires were also used to collate information about each participant and were drawn on in the discussion of participants and families in Chapter 6.

Sleep diaries, cameras, Actiwatches and completed questionnaires were collected from participating families at the end of this two week period. The cameras were sent off and the photographs were developed. If audio sleep diaries had been chosen and completed then these were transcribed verbatim by myself. Actigraphy data was downloaded and Actograms printed. The photographs, audio sleep diary transcripts and the written sleep diaries and Actograms were looked at and read through and I identified and made notes about any interesting, unusual or ambiguous aspects to use as prompts for discussion, or for clarification, in the upcoming individual in-depth interviews.

5.9 Qualitative Interviews with children and parents

Approximately 1-3 weeks after the 2 week information collection period I visited the families to conduct a semi-structured qualitative interview with each participant. All the interviews took place at the family home. The interviews
with parent participants lasted between 1.5 to 2 hours. The children’s interviews usually lasted about 45 minutes to 1 hour.

As discussed, all the young people could choose if they wanted someone else present during their interview. Out of the ten families, parents were present for interviews with seven of the children with CP. The exceptions to this were Grace Baker and Greg Jackson who were interviewed alone and Libby Cooper, who was interviewed with one of her paid carers. Out of the five families that included sibling participants, a parent from three of the families sat in on each of the sibling interviews.

A number of husband and wife couples chose to be interviewed together (four out of the seven families where both parents took part). It is not clear why this was but there may have been a number of factors that played a part. Firstly, joint interviews may have been chosen to save time. These were busy households and it was not always easy to arrange dates and times for interviews so couples may have felt that it was more time efficient to be interviewed together. Secondly, parents may have perceived the focus of the research and the interview to be on the sleep of their child with CP. In the four households in which joint parent interviews took place, the night-time care of the child with CP was generally shared between the mother and father. Therefore, these parents may have felt a joint interview was appropriate as they would be discussing shared views and experiences of their child’s sleep and the care role that they equally partook. This was not necessarily the case across all the families, however, as Catherine and James Cooper both attended to their daughter Libby’s night-time care needs but chose separate interviews.

Another reason may be more based on individual personality factors. As discussed in Chapter 4, Aileen Edwards (mother) sat in on all 3 of her children’s interviews and although some discussion took place about this I retained some uncertainty about the amount of ‘real’ choice the children had. I also felt the same uncertainty about the amount of choice that Mark Edwards (father and husband of Aileen) had when Aileen sat in on his interview. As with the children’s interviews, Aileen was quite domineering and did the majority of the talking in Mark’s interview (even though she had already had her own individual
This may simply reflect the normal dynamics of their family life and relationships of the family members. It may also reflect my lack of confidence in speaking up and starting a discussion about whether Mark (and each of the children) would prefer to be interviewed alone, which further highlights one of the difficulties of conducting family research within the home.

Prior to conducting the pilot study and in conjunction with the review of the literature and consultation with my lay advisors, specific topic areas were identified as important to include in interviews (see Appendices 6.1-6.3 for the interview topic guides). The participants were asked to talk about and describe their sleep and reflect on the information collected during the preceding two week period. Questions concerning sleep quality and the impact of perceived poor sleep on well being, quality of life, relationships and family life were explored. The coping strategies tried and utilised by individual family members to help overcome poor sleep were asked about (if relevant) and participants were asked if they had any advice regarding sleep for other families with children with CP. During the individual interviews I asked the young people to look through their set of photographs and to describe what each photograph depicted and why they took it. Where possible the young person wrote their own annotations on the back of the photographs. If this was not possible I wrote on the back of the photographs as directed by the young person. The descriptions of the photographs given by the young people and the discussion prompted then became part of the interview and analysed as such. The participant’s sleep diary and their Actogram were presented to them during their interview to prompt discussion; in particular, they were used when the participant was asked to describe their sleep patterns generally and during the 2 week data collection period. Additionally, the sleep diary and Actogram were drawn upon by me to prompt participants to describe the reasons (if applicable) why they may have experienced poor sleep in the 2 week data collection period. The participant’s sleep questionnaire was also used in the interview to prompt discussion and recall about their sleep. I also used the sleep questionnaires to collate information and present an overview of each participating family member’s sleep (see Chapter 6).
All interviews were audio recorded (with permission) and if a young person with CP used a non-verbal communication method the interview was also video recorded with permission (6 interviews were video recorded).

5.9.1 The need for preparation and time when interviewing disabled children

Prior to the pilot study my reading on conducting research with children with disabilities who have additional communication difficulties highlighted the importance of allowing enough time in interviews. Alderson and Goodey (1996) and Davis et al. (2000) discuss how in their research with children with disabilities the research process took longer than anticipated. Beresford (1997) suggests that a number of introductory visits might be needed before embarking on interviews with children with disabilities ‘in order to develop a relationship in which the child feels comfortable enough to respond to the researchers questions’ (p30). Marchant et al. (1999) suggest that initial meetings allow the researcher to learn more about how the child communicates and about their ability to understand. Multiple visits also give the researcher a chance to check with the child that they are happy to continue in the research on a number of occasions and, therefore, informed consent can be a continual process as advocated by Alderson and Morrow (2004).

Time is also needed for children to use their augmentative communication systems and use of their existing systems may present problems. Morris (1998) explains how she did not develop visual aids specially for her research project but felt it was more appropriate to work with the communication systems that the young people already used, however, these were not always effective. For example, a young person might have a way to say ‘yes’ or ‘no’ but there is often no way for them to communicate the stages in between e.g. ‘maybe’, ‘almost’, ‘I’m not sure’. Often young people used equipment such as 'typetalkers', word processors or symbol books/boards to communicate, however, Morris (1998: 37) reports that often this equipment was broken or not available to the young person in her research and that:
This kind of experience again illustrates the importance of flexibility and persistence, and the frustrations of life for the young people concerned.

Because of my prior reading and based on findings from the pilot study, I designed the research to allow for a number of visits prior to the 2 week information collection period. This allowed me to meet the family members on at least 3 occasions (first visit, second visit to obtain consent, and third visit to drop off equipment) and proved valuable in getting to know the family members and was especially useful with those young people with CP who had communication difficulties. At these visits I became more familiar with the ways in which these young people communicate and the visits also gave me the opportunity to ask questions about communication issues to either the young person themselves or their parent/s. These meetings also allowed me to consider if a number of shorter interview visits might be more appropriate for some young people in order to complete their interview. This was pertinent for the young people using non-verbal methods of communication as communication was often time-consuming, frustrating and tiring for them. Shorter interview visits may also be useful for younger children who find it hard to remain focussed for longer periods of time. It was decided, in discussion with the young person and their parents that shorter interviews spread over a number of visits would be more appropriate for three of the young people with CP. This was also the case for one sibling (who was one of the youngest participants). For one of the children with CP, the visit to obtain consent was also scheduled over two shorter visits as her focus and attention waned after approximately 15-20 minutes.

From the initial visits to two of the families in the pilot study, where the young person with CP had communication difficulties and used picture symbols, it was highlighted that picture symbols related to sleep were rarely available. Morris (1998) asks whether it would be best to develop specific aids to communication for research ‘interviews’ or whether we should build on people’s existing communication methods and aids. Clarke et al. (2001) researched disabled young people’s views on using augmentative and alternative communication systems. To gain the children’s views they had to develop a
symbol-based tool to allow children to express complex issues through visual means as their existing communication systems did not contain the appropriate symbol vocabulary. The tool they designed was based on Murphy’s (1998) ‘Talking Mats’ concept. However, like Morris (1998) I was wary of introducing a new system specifically for the research interview as I feared it may have been stressful for children. For children using symbol systems, the learning of new symbols is an activity or exercise inextricably linked to the school setting or the home as part of ‘homework’ and I did not want to confuse the children. However, I did produce some picture symbols related to sleep including ones for ‘sleep’, ‘bed’, ‘dream’, ‘nightmare’ and ‘pyjamas’. In my initial visits during the pilot study and then throughout the main study, I discussed with the young people (with CP who used symbol based systems) if they recognised the symbols and many indicated that they did. One young person was asked if she would like the sleep picture symbols incorporated permanently into her picture symbol communication book and she agreed. Therefore, the sleep-related picture symbols were then readily available to her and became a permanent feature of her communication system before her interview took place.

5.10 Data Analysis

As discussed the information collected via sleep diaries, photography, actigraphy and sleep questionnaires were used within the qualitative interviews as ways to prompt and facilitate discussion. Therefore, this was not a multiple methods study and the information collected via these diverse means was not considered as stand-alone data to be separately analysed from the interview data as it became incorporated into the interview data. The qualitative interview data were analysed using thematic analysis, a method for identifying, interpreting and reporting patterns (i.e. themes) within data (Braun and Clarke, 2006). One of my analysis aims was to provide a rich thematic description of my data in order to present the important themes which Braun and Clarke (2006:83) discuss as an useful approach when ‘investigating an under-researched area, or [when] you are working with participants whose views on a topic are not known’ (for example, in my study the views of children with CP about their sleep). Linked to this was the primarily inductive approach I took to the thematic analysis whereby codes and themes were developed from the data.
or were ‘data-driven’ (Boyatzis, 1998: 29). I refer to a ‘primarily’ inductive approach because a pure inductive approach would mean that any themes identified would not have been influenced in any way by my own theoretical interests or knowledge of the research topic. In line with Braun and Clarke (2006), I argue that this is very difficult to achieve. For instance, my interview topic areas and resulting questions were based, in part, on existing literature. Furthermore, as discussed in Chapter 4, the approach to my research was one based on reflexivity and, therefore, being open and transparent about how my views, knowledge and experiences affected the whole research process including the data analysis.

Notes were made following each semi-structured interview and I listened to (and watched if there was a video recording) each interview once through before listening (and watching) again in order to transcribe verbatim the interview. Because the transcription process took place soon after the interview I tended to listen and transcribe interviews in family sets. This also fitted with my initial analytic focus on family groups, as discussed in Section 5.2, and I usually started by transcribing the interview of the child with CP, followed by that of the siblings (if applicable), and then the parent(s) interview(s) for each family. In this way I got a sense of each individual family member and their views about sleep, but also a sense of the interactional and interrelated meanings of sleep at the family level. Once I had finished the transcription process I read and re-read each transcript and made an initial list of ideas and aspects that I found of interest. From this list and from the transcripts I began the coding process and produced a number of initial codes. Coding is a way to break the data down into manageable pieces (Coffey and Atkinson, 1996). A code can be described as ‘a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data’ (Saldaña, 2013:3).

Coding at this stage was broad and following the advice of Braun and Clarke (2006:89) I coded ‘for as many potential themes/patterns as possible’ and coded data extracts ‘inclusively’ so I kept some of the surrounding data, thus retaining some context of the codes. This was particularly important when
coding the interviews of children with CP who used non-verbal communication methods (see Section 5.11). Coding was done by hand. I started with each family set of transcripts and used highlighter pens to indicate the different codes. I had a large office space at work to carry out my analysis stage so was able to use the walls to cut and pin highlighted transcript extracts separated into ‘Post-it’ headed code categories.

The next phase of searching for themes involved sorting the codes into potential themes, using the wall space I had and re-arranging my highlighted transcript excerpts and ‘Post-it’ notes. Braun and Clarke (2006:89) describe this phase as a time to ‘start thinking about the relationship between codes, between themes, and different levels of themes’. Using large flip chart paper I was able to map the themes and differentiate between main overarching themes and sub-themes. I then spent time reviewing and re-reviewing the themes and re-visiting the initial codes illustrating the recursive nature of thematic analysis whereby there is movement back and forth between the phases of analysis. The recursive element was also evident in relation to analysis of multiple family members’ perspectives. By reviewing and re-reviewing both the code and theme identification phases my analytic focus alternated from within family groups (and the views and perspectives of the family members reflecting particular generation or role standpoints i.e. child with CP, sibling, parent) to between families and specifically between the standpoints of generation, age and disability across families. Therefore, coding and themes were also divided and categorised as relevant to children or to parents or to both, and younger children were compared to older children. I also identified themes that drew comparisons and differences of standpoint within and between families based on disability so, for example, children with CP compared to those without CP (i.e. siblings) or children with ‘severe’ CP compared to those with ‘mild’ CP.

Further refinement and definition of the potential themes then followed which involved thinking about and ‘identifying the ‘essence’ of what each theme is about’ (Braun and Clarke, 2006: 92) and also a consideration of the themes overall and the overarching story of my data. Sub-themes were also defined
and refined at this phase and proved useful in providing structure to the larger more complex themes. Extracts from the interview data were chosen at this point to include in my thesis and were determined as the best examples of the different themes and sub-themes.

I found the analysis of my interview data immensely complex, time-consuming and, at times, lonely. It was also a process, for me, that constantly raised doubts and questions in my mind about the problems of analysing the data of children with CP who communicated in predominantly non-verbal ways or whose answers to questions were limited to ‘Yes’ and ‘No’ responses. These issues are discussed in detail in the next section.

5.11 Analysis of data collected from children who communicated in non-verbal ways

As discussed in this chapter and Chapter 4 there has been much written about the approaches and the methods to use when conducting research with disabled children who communicate in non-verbal ways. I feel strongly that my approach and design was in line with the influential writings and advice provided by Beresford (1997), Morris (1998), Marchant et al. (1999) and Ward (1997). I prepared tirelessly before beginning the project by involving disabled children at an advisory level and through detailed preparation of the recruitment and participant information. I worked hard to make sure that I was ethical and inclusive in my approach and methods choice, for example, having my participant information sheets available in a variety of formats. When I was carrying out my field work and visiting and interviewing family members I noted in my research diary how successful I was in including the children with severe CP who did not communicate verbally. I spent time with them, getting to know them and their nuanced ways of communicating and truly felt that they were able and enabled to positively contribute to the research process.

However, after the fieldwork was completed and initial analysis began, doubts started to emerge in my mind. My qualitative analysis and consequently the presentation of the qualitative data analysis from the 5 disabled children who used non-verbal communication methods triggered worries and doubts about whether their experiences and voices truly emerged and whether the
influence of my own choice of questions and my own interpretation and assumptions about their experiences was too apparent and obvious. An example extract of an interview with Libby Cooper (12 years old) who uses a symbol communication book is presented in Appendix 13.

Doubt, on the part of the qualitative researcher, about the authenticity and validity of their data is not a new phenomenon (Harden et al. 2010). However, when analysing qualitative data which consists of symbol choices and purely ‘Yes’ or ‘No’ answers (sometimes verbal but, in the case of my research participants, sometimes signalled through the slightest of physical movements) in interviews which are heavily interspersed with one sided researcher-voiced questions and then repeated, sometimes re-worded, questions, qualitative analysis becomes problematic. The data that is obtained from these children cannot be regarded as truly qualitative and, therefore, qualitative analysis is difficult. Data obtained through the use of symbols or through only ‘Yes’ and ‘No’ answers is restricted in terms of the detail, meanings and depth that qualitative data should provide. An examination of the interview excerpt provided in Appendix 13 illustrates the lack of depth and detail obtained when Libby Cooper was asked about how it felt, and therefore what it means, when she was tired. Through a long process of Libby choosing or not choosing single symbols/words the data obtained is list-like and lacks depth and quality. Furthermore, the choice of symbols for Libby is limited and pre-determined by someone else so may not entirely represent what she wants to relay.

Obtaining multiple family member’s perspectives, including siblings and parents and the inclusion of children with CP who communicated verbally, and who differed in terms of the severity of their CP went some way to minimise the issues inherent in the analysis of the data of children who communicated in non-verbal ways. As discussed in Section 5.2 obtaining multiple family member’s perspective can provide a fuller and more rounded picture of individual’s sleep as well as the sleep of the family. Furthermore, the use of self-directed photography was also useful in providing details about the sleep of all the children including those who communicated in non-verbal ways. This was especially in reference to their bedrooms and the actors, activities and
artefacts related to the meanings and practice of sleep that children identified as significant and important.

The difficulties apparent at the data analysis stage with reference to the children with CP who communicated in non-verbal ways has not been previously written about or explored in detail. As part of my own reflexive process I felt it important to highlight these issues.

5.12 Conclusion

This chapter has outlined the study background and objectives and discussed the framework and methods chosen for the research. The chapter began with discussion of the objectives with reference to obtaining multiple family member’s perspectives and outlined the methodological approach chosen. Details regarding the development and pilot work are provided, followed by a description of the inclusion/exclusion criteria and participant recruitment process. The study procedure is outlined including details about the initial visits made by the researcher to meet the families and to obtain informed consent and the two week information collection period that followed. The different methods of photography, sleep diaries, actigraphy and sleep questionnaires are described separately and the ways in which this information was used to facilitate and prompt discussion in the semi-structured qualitative interviews that followed the two week information collection period is outlined. Details of the qualitative interviews are provided and specific factors related to interviewing disabled children are considered. The chapter ends with a description of the thematic analysis of the interview data and a reflection on the difficulties encountered when the interview data of children with CP who communicated in non-verbal ways was analysed.
Chapter 6 - Introducing the participants, the families and their sleep

6.1 Introduction

This chapter will provide an introduction to the families and the family members that took part in the study. I begin by presenting the socio-demographic characteristics of each family and the participating family members with a focus on the child with CP. The severity of the child’s CP will be described with reference to the effect on the child’s gross motor function and ability, method of communication and type of CP. In the second part of this chapter further details regarding the participating family members, including information about their sleep, will be outlined and presented family by family. The family surnames and parent first names are all pseudonyms chosen by me. Each child participant was given the choice to choose a pseudonym for their first name. Nine out of the 17 participating children chose their own pseudonym and for the remaining 8 children I chose a pseudonym for them.

The sleep questionnaires and sleep diaries completed by the participants during the 2 week information collection period will be drawn upon to provide an overview of each participant’s sleep. The sleep questionnaires and sleep diaries were used to facilitate discussion in the interviews and interview data will also be used to expand information regarding the participant’s sleep, if relevant. The Chailey Sleep questionnaire completed by, or on behalf of, the children with CP includes a clinical section which has also been drawn upon to describe the child’s cerebral palsy and any additional health needs they have.

6.2 Demographic characteristics

Table 6.1 summarises the demographic characteristics of the 10 families and the participating family members. The families are presented in the order of the severity of the child’s CP (based on Gross Motor Function Classification System level), starting with those least affected by CP. The Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997) is a tool that assesses the gross motor skills (e.g. sitting and walking) of children and young people with CP and categorises them into 5 different levels (I to V). A higher level
number indicates a higher degree of severity. This system is now internationally used as a way to provide families and clinicians with a clear description of a child’s current motor function and indicates what equipment and aids a child may need. Generally the level that a child is classified at (when over 5 years of age) will not change. Throughout the rest of this thesis I refer to the children with CP, who took part in my study, as having mild or severe CP. This differentiation is based on and defined by their GMFCS level. In line with the work of Palisano et al. (1997) and more recent work using the GMFCS (Stevenson et al. 2006; Gringras, 2017), mild CP is defined by GMFCS levels I and II, moderate CP by GMFCS level III (no children with GMFCS level III took part in my study) and severe CP by GMFCS level IV and V. A copy of the descriptors for each level of the GMFCS is included in Appendix 14.

The communication method is also summarised for each child with CP and categorised using the Communication Function Classification System (CFCS, Cooley-Hidecker et al., 2011). The CFCS provides 5 levels (I to V) to describe everyday communication performance of individuals with CP. A higher level number indicates a higher degree of limitation. All methods of communication are considered in determining CFCS level. A copy of the CFCS including the descriptors for each level is included in Appendix 15.

The cerebral palsy sub-types are based on the definitions adopted by the European classification of cerebral palsy and agreed for the Surveillance of Cerebral Palsy in the Europe consensus report (SCPE, 2000). An outline of this classification system is included in Appendix 16.

Information pertaining to the children’s GMFCS and CFCS levels and their type of CP was ascertained through information collected via the Chailey Sleep Questionnaire and through more general discussions with parents.
### Table 6.1 Demographic characteristics of participating families with a focus on the child with CP

<table>
<thead>
<tr>
<th>FAMILY NAME</th>
<th>CHILD WITH CP, NAME AND AGE</th>
<th>PARTICIPATING FAMILY MEMBERS AND RELATIONSHIP TO CHILD WITH CP</th>
<th>CHILD WITH CP - CP TYPE* &amp; GMFCS¹ LEVEL (I-V) &amp; ADDITIONAL HEALTH NEEDS</th>
<th>INFORMATION RE. FAMILY STRUCTURE</th>
<th>CHILD WITH CP - CFCS* LEVEL &amp; COMMUNICATION METHODS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baker</td>
<td>Grace* - 13 yrs</td>
<td>Robert – father Lyin – mother</td>
<td>Spastic unilateral CP GMFCS level I</td>
<td>Two parent family &amp; 2 older half sisters - neither live at home so not participating.</td>
<td>CFCS level I – Speech</td>
</tr>
<tr>
<td>Hughes</td>
<td>Charlie* (male) - 6 yrs</td>
<td>Chris – father Sarah – mother Thomas* – 8yrs, brother</td>
<td>Spastic unilateral CP Epilepsy GMFCS level I</td>
<td>Two parent family &amp; 2 children (all taking part).</td>
<td>CFCS level I – Speech</td>
</tr>
<tr>
<td>Jackson/</td>
<td>Greg* Jackson - 13 yrs</td>
<td>Toby Jones – stepfather Alice Jones – mother</td>
<td>Spastic bilateral CP GMFCS level II</td>
<td>Mother and step father, no other children.</td>
<td>CFCS level I - Speech</td>
</tr>
<tr>
<td>Edwards</td>
<td>Stanley* - 7 yrs</td>
<td>Mark – father Aileen – mother Willow* - 10yrs, sister Alex* - 6yrs, brother</td>
<td>Dyskinetic: Choreo-Athetotic CP GMFCS level IV Epilepsy Thrombophilia</td>
<td>Two parent family &amp; 3 children (all taking part)</td>
<td>CFCS level IV - Limited speech, use of sounds, eye gaze, facial expressions, gesturing, pointing, symbol cards</td>
</tr>
<tr>
<td>Davis</td>
<td>Oliver - 8 yrs</td>
<td>Nicola – mother</td>
<td>Dyskinetic: Dystonic CP GMFCS level IV</td>
<td>Two parent family &amp; 1 older half sister. Half sister and father not participating.</td>
<td>CFCS level III – Speech</td>
</tr>
<tr>
<td>Appleby</td>
<td>Charlotte - 8 yrs</td>
<td>Sue - mother</td>
<td>Dyskinetic: Dystonic CP GMFCS level IV.</td>
<td>Two parent family. No other children. Father not participating.</td>
<td>CFCS level IV - Limited speech, use of sounds, facial expressions, gesturing, pointing, symbol cards</td>
</tr>
<tr>
<td>Fletcher</td>
<td>Sam (male) - 7yrs</td>
<td>Kate – mother Alfie – 7yrs, twin brother</td>
<td>Dyskinetic: Dystonic CP GMFCS level V</td>
<td>Two parent family &amp; 3 children. Twin brother taking part, sister too young to take part. Father not participating.</td>
<td>CFCS level II – Speech, unclear at times</td>
</tr>
<tr>
<td>Cooper</td>
<td>Libby - 12 yrs</td>
<td>James – father Catherine – mother Daniel – 13yrs, brother Joseph – 9 yrs , brother</td>
<td>Spastic bilateral CP GMFCS level V</td>
<td>Two parent family &amp; 3 children (all taking part)</td>
<td>CFCS level IV - Sounds, eye gaze, facial expressions, communication book</td>
</tr>
<tr>
<td>King</td>
<td>Brian* - 13 yrs</td>
<td>Matt – father Vicky – mother Ellen* - 12 yrs, sister</td>
<td>Dyskinetic: Choreo-Athetotic CP GMFCS level V Gastrostomy fed</td>
<td>Two parent family &amp; 2 children (all taking part).</td>
<td>CFCS level III - Sounds, eye gaze, facial expressions, voice output device (eye gaze system)</td>
</tr>
<tr>
<td>Gibson</td>
<td>Jacob - 6 yrs</td>
<td>Darren – father Anne – mother</td>
<td>Spastic bilateral CP GMFCS level V Epilepsy Gastrostomy fed</td>
<td>Two parent family. Jacob adopted at 2 years old. No other children.</td>
<td>CFCS level IV - Sounds, eye gaze, facial expressions, communication book</td>
</tr>
</tbody>
</table>

¹CP type based on the Surveillance of Cerebral Palsy in Europe (SCPE, 2000) classification system

²Gross Motor Function Classification System (GMFCS) (Palisano et al, 1997) is a standardised 5 level system to classify gross motor function in people with CP. A higher level number indicates a higher degree of severity.

³Communication Function Classification System (CFCS) (Cooley-Hidecker, 2010) classifies the everyday communication performance of people with CP. A higher level number indicates a higher degree of limitation. All methods of communication are considered in determining CFCS level.

The names of children in red are those children with CP who regularly (at least once every night) wake up at night and require assistance (usually a parent) to help them get back to sleep (at the time of the study).

The name of the parent who usually attends to the child with CP (at the time of the study) at night is in blue. Where both parent names are blue the ‘role’ of attending to their child at night was shared. In families where no parent name is highlighted in blue this denotes that parents did not need to regularly attend to their child with CP at night.

All names are pseudonyms. Where a * symbol is present next to the name the pseudonym was chosen by the young person.
6.3 Family participants and data collection details

This section will present general information about each family and the participating family members, starting with child with CP (as outlined in Table 6.1). Details concerning the data collection period will be included and a sleep overview for each family is provided using information provided, primarily, by the sleep questionnaires. These were the Pittsburgh Sleep Quality Index (PSQI) completed by parents, the Children’s Sleep Habits Questionnaire (CSHQ) completed by siblings (or by parents on their child’s behalf) and the Chailey Sleep Questionnaire completed by children with CP (or by parents on their child’s behalf). Information provided within the 2 week sleep diaries will also be drawn upon as will elements of the interviews when the sleep questionnaires and sleep diaries were used to facilitate discussion.

6.3.1 Baker Family

The Baker family consists of Robert, Lynn and their daughter Grace. All three family members took part in the research. The family live in a 4 bedroom house and all the bedrooms are upstairs. Lynn also has two older daughters (from her first marriage) who no longer lived at home at the time of the study so were not invited to participate in the research. The family have 2 pet cats.

Grace Baker

Grace was 13 years old and has mild unilateral spastic CP affecting her right side only (predominantly her right leg). Grace is able to walk, run and jump without assistance or aids but speed, balance and coordination are sometimes limited so she is at GMFCS level I. Grace is fully verbal and at CFCS level I. At the time of the study, Grace attended a private mainstream secondary school on a full time basis and required no additional educational support.

Lynn and Robert Baker

Lynn worked on a part time basis and also worked as a volunteer for 2 local organisations. Robert Baker worked in the IT sector and often worked from home.
**Data Collection**

All aspects of the 2 week data collection period were completed by Grace, Robert and Lynn. Grace and I completed her sleep questionnaire together when I visited to drop off the equipment for the 2 week data collection period and Lynn and Robert completed their own PSQI questionnaires during this time. Grace, Lynn and Robert all chose to word process their sleep diaries. Grace took all her own photographs. All three family members chose to be interviewed on their own.

**Sleep overview for the Baker family**

In their sleep questionnaires Grace, Robert and Lynn all reported that they generally had a good quality and quantity of sleep. Grace reported that she was sometimes reluctant to go to bed but once in bed she would fall asleep quickly and easily and she rarely woke in the night. Robert reported that occasionally he would wake in the night due to work-related issues.

**6.3.2 Hughes Family**

The Hughes family includes Chris and Sarah and their two sons, Thomas (age 8 years) and Charlie (child with CP, age 6 years). All the family members participated in the research. The family live in a 3 bedroom house. The bedrooms are located upstairs and Thomas and Charlie had their own bedrooms. They had 2 pet cats. The family had 14 nights a year allocated to them to stay at a local hospice. The hospice is a charitable organisation and the stays for the families that use them were paid through the charity’s funds. The family went together to the hospice and usually stayed for long weekends of 3 nights. When there, Charlie had his own bedroom and was monitored and checked on at night by the hospice staff. The rest of the family stayed in the family accommodation. During the day the hospice provided activities on site and opportunities for days out for the whole family to do together.
Charlie Hughes

Charlie was aged 6 years and has mild unilateral spastic CP affecting his left side only (predominantly his left arm). Charlie has very few difficulties in terms of his physical function and is able to walk, run and jump without assistance and he generally has good balance. His ability to co-ordinate the movements of his left hand, as well as his ability to grasp objects in his left hand is slightly impaired. Charlie’s GMFCS level is I. Charlie is fully verbal and at CFCS level I. Charlie could, on occasion, when we met be slightly distractible and his attention did wane but it was easy to re-focus him. Charlie also has epilepsy. At the time of the study Charlie was taking two different anti-epileptic medications. In the clinical section of the Chailey sleep questionnaire, Chris (father) reported that Charlie had minor epileptic seizures, known as absences, most days which lasted a few seconds and that Charlie’s most recent severe and prolonged seizure, known as a tonic-clonic seizure, happened 6 months previously resulting in hospitalisation. At the time of the study, Charlie attended a mainstream primary school on a full time basis with no additional educational support required.

Thomas Hughes

Thomas was 8 years old and did not have any physical disabilities or additional health needs. Thomas attended the same mainstream primary school as his brother, Charlie.

Sarah and Chris Hughes

Sarah worked part time and Chris worked full time. Chris had to commute for up to 2 hours each way for his job. Chris worked shifts and when on a late shift would not get back home until 1 am and if on an early shift he would leave the house at 5 am.

Data Collection

Unfortunately, at the beginning of the data collection period Sarah was taken unwell and had to stay in hospital. Therefore, Aciwatch data and sleep diary
information was not collected for Sarah. Because of the nature of Chris’ work it was not possible for him to wear his Actiwatch at the time of the data collection period. During this time, Charlie and Thomas stayed for a number of nights at relative’s houses and did not consistently wear their Actiwatches. Therefore, the Actiwatch data for all of the Hughes family members was not used to gather information, or to prompt discussion in the subsequent interviews. Chris completed his own written sleep diary and completed written diaries on both Charlie’s and Thomas’ behalf. However, there were few details noted in the sleep diaries. Chris also completed the sleep questionnaires for Charlie and Thomas but both boys took their own photographs. Chris was present for both Charlie’s and Thomas’ interviews, at the boy’s request. At the end of his interview, Charlie was very keen to show me his bedroom and, in particular, his cuddly toys. Thomas also wanted me to see his bedroom. I audio recorded the conversations that took place during these ‘tours’ of the children’s bedrooms. Chris and Sarah chose to be interviewed together a week after Sarah came out of hospital.

Sleep overview for the Hughes family

For Chris, Thomas and, in particular, Sarah sleep and the night-time were often problematic. Charlie, child with CP, appeared (from his questionnaire) to have the best quality and quantity of sleep in the household and was able to get to sleep, and stay asleep most nights. Sarah and Chris discussed in their interview how Charlie’s sleep had greatly improved in the last year and prior to that it had been much more disrupted. Sarah’s issues with sleep were long-standing. She had a diagnosis of insomnia and was prescribed, and regularly took, sleep medication. At the time of the study she had also been experiencing pain that affected her sleep and was linked to her hospital admission. Sarah also had worries in relation to Charlie, specifically his epilepsy, at night and this added to her troubles sleeping. These concerns were shared by Chris and his sleep was also affected. This is an area that will be explored in more detail in Chapter 10, when the subject of how parents monitor their child with CP at night is discussed. Chris reported on the CSHQ that Thomas (sibling) had issues related to sleep specifically with going to bed, falling asleep and waking up in
the night and moving to his parents’ bed. Chris made reference to this last point in his own questionnaire (and later in his interview) and raised it as a disturbance to his own sleep. Sarah did not raise Thomas’ night-time behaviour as having an effect on her own sleep.

6.3.3 Jackson/Jones family

The Jackson/Jones family consists of Greg Jackson, his mother Alice Jones and his step father Toby Jones. All 3 household members participated in the research. Greg, Alice and Toby live in a 3 bedroom house and all the bedrooms are located upstairs. They have a pet cat.

Greg Jackson

Greg was 13 years old and has spastic bilateral CP that affects both sides of his body. In particular, Greg’s legs are affected and although Greg is able to walk, he does have physical limitations. At the time of the study, Greg needed to hold on to a support in order to walk upstairs and, if expected to walk a long distance, Greg would use a wheelchair. Greg’s ability to run and jump and his balance and co-ordination are also affected by his CP and his GMFCS level is II. Greg is fully verbal and an effective communicator and at CFCS level I. Greg attended a mainstream secondary school on a full time basis and required no additional educational support.

Alice and Toby Jones

Alice was a full time student studying for a vocational degree. Alice and Greg’s father separated and later divorced when Greg was 7 years old and Alice married Toby when Greg was 11 years old. Toby worked in the IT sector and had to commute to work (approximately 1.5 hours each way). Toby had no previous children of his own.

Data Collection

Alice completed the Chailey sleep questionnaire on behalf of Greg as well as her own PSQI. Toby completed his own PSQI. Greg chose to audio record his sleep diary with a provided Dictaphone. Alice chose to write her sleep diary and
Toby chose to word process his. Greg took all his own photographs. Greg, Alice and Toby were all happy to wear their Actiwatchs, although some nights of data were absent for all 3 of them. Greg chose to be interviewed on his own as did Alice and Toby.

**Sleep overview for the Jackson/Jones family**

No pertinent issues regarding their sleep were reported by Greg, Alice or Toby at the time of the study. All reported that they generally slept very well.

### 6.3.4 Edwards Family

The Edwards family consists of Aileen and Mark and their 3 children Willow, Stanley (child with CP) and Alex. All 5 family members participated in the research. The family live in a 3 bedroom house. All 3 bedrooms are located upstairs in the house. Stanley and Alex shared a bedroom at the time of the study. At that time, discussions were taking place between the family and their local authority on extending and converting the ground floor to create a downstairs bedroom for Stanley. The family received some care help for Stanley through social services and the direct payment scheme. They had one carer every Friday after school that would take Stanley out for social activities and also help feed him his dinner at home. Another carer came one evening every other week from 7pm to 10pm. She would help get Stanley ready for bed. Sometimes when this carer was present Aileen and Mark would go out for the evening. Stanley also spent one night every half term at the residential unit of his school. The family also had 14 nights a year at a local hospice. The Edwards family usually stayed at the hospice all together as a family for 2 or 3 nights at a time. At the hospice, Stanley had his own bedroom and was looked after during the night by the hospice staff.

**Stanley Edwards**

Stanley, 7 years old, has severe bilateral (whole body involvement) dyskinetic (Choreo athetoid type) CP. Stanley is non-ambulant and uses a power wheelchair which Stanley was learning to self drive. Stanley was able to sit for varying amounts of time unaided and was able to move himself short distances
in a sitting position on the floor. Stanley is at GMFCS level IV. Stanley had limited verbal communication at the time of the study although he was able to clearly say the words ‘yes’ and ‘no’. He used some simple makaton sign language signs and would use his hands and his eyes to point to chosen objects. Stanley also made ‘choices’ by choosing between picture symbols that were presented to him by tapping his hand on the chosen symbol. For answering ‘Yes’ and ‘No’ questions, Stanley sometimes liked the questioner to put out their hands, with their right hand denoting ‘Yes’ and their left hand denoting ‘No’. Stanley would tap one of the questioner’s hands depending on his answer. Stanley’s CFCS level is IV. I found communication with Stanley became easier as I got to know him and his different ways of communicating better.

Stanley has epilepsy and Factor V Leiden thrombophilia. Aileen noted in the Chailey sleep questionnaire that Stanley has small seizures (myoclonic jerks and absences) daily. More severe seizures (which Aileen terms as ‘drop’ seizures as well as tonic seizures) occur approximately once a week. At the time of the study Stanley was taking one anti-epileptic drug twice a day. He was also prescribed an emergency medication to be administered when he had severe and prolonged seizures. Stanley was also prescribed Melatonin which his parents gave him before bedtime approximately twice a week. Both Aileen and Mark commented to me that they were unsure how much difference the melatonin made in terms of helping Stanley fall, and stay, asleep.

At the time of the study Stanley attended a special needs school on a full time basis.

Willow Edwards

Willow was 10 years old at the time of the study and has no disabilities or additional needs. At the time of the data collection, Willow found out she had passed entrance exams for a local private boarding school. She and her parents were deciding whether she would go to the private boarding school or to her local secondary mainstream school. At the time of the study, she attended a mainstream primary school.
**Alex Edwards**

Alex was 6 years old and has no disabilities or additional needs. Alex attended the same mainstream primary school as Willow at the time of the study.

**Aileen and Mark Edwards**

Aileen was a full-time ‘stay at home’ mother at the time of the study and Mark worked full-time in the IT sector. Aileen carries out the majority of care for Stanley which includes helping him in all aspects of daily living, for example, feeding, toileting, dressing, washing, moving and attending to him at night. At the time of the study she had a back injury and was unable to lift or carry Stanley so Mark undertook these tasks. Mark would also help settle Stanley to sleep at bedtime.

**Data Collection**

Aileen completed the Chailey sleep questionnaire for Stanley and the CSHQ for both Willow and Alex. Aileen and Mark completed their own PSQI questionnaires. Written sleep diaries were chosen. Aileen, Mark and Willow completed their own sleep diaries. Aileen completed Stanley’s and Alex’s diaries in consultation with them. Willow and Alex took their own photographs. Aileen helped Stanley take his photographs under Stanley’s direction. They were all happy to wear the Actiwatches and only one night of missing actigraphy data for Mark was noted. Aileen sat in on Stanley’s, Willow’s and Alex’s separate interviews. Stanley’s interview was carried out over two visits because he found the process of communication tiring, at times frustrating and his attention waned. I also carried out Alex’s interview in two parts. This was because Alex’s focus decreased after about 20 minutes and he said he was hungry. We took a break so Alex could have a snack and some time to play. While he was having a break I carried out Willow’s interview, after which I carried on with Alex’s interview. Aileen was interviewed alone but she also sat in on Mark’s interview, during which she also contributed.
Sleep overview for the Edwards Family

All members of the Edwards family reported that they had disturbed and disrupted sleep. Stanley was often reluctant to go to bed at bedtime and it would take him some time to fall asleep. During this time he was often very restless physically. In order to fall asleep he liked one of his parents to lie with him (usually Mark). Stanley usually woke between 1 and 3 times every night and required Aileen (and sometimes Mark) to attend to him and help him fall back asleep. It was not always clear why Stanley woke but often it was due to him moving into an uncomfortable position. Aileen also reported in the Chailey sleep questionnaire that Stanley sometimes woke in pain due to being constipated.

Bedtime was also difficult for Alex. Because Alex and Stanley shared a bedroom they often disturbed each other at bedtime, resulting in it taking prolonged periods of time for them to each fall asleep. To try and avoid this Aileen and Mark often staggered the children’s bedtime and had also recently made the decision that Alex should go to sleep at bedtime in their bed. Mark then moved Alex back to his own bed when he and Stanley were both asleep. Alex reported that he sometimes got woken in the night when Stanley woke up.

Willow was also reluctant to go to bed at bedtime and reported that she often took a long time to fall asleep. She often chose to secretly read after ‘lights out’ and also reported being disturbed at bedtime by both her brothers’ being noisy and disruptive. Although she did not report waking in the night she did feel that she was very restless at night.

Both Aileen and Mark felt that they generally had poor sleep. This was, in part, due to being woken up by Stanley needing assistance during the night. However, both reported that it often took them a long time to fall asleep. Both felt that stress negatively affected their quality of sleep. This stress was in part related to Stanley and his health needs, specifically his epilepsy, and also, for Aileen, the proposed plans to build a downstairs bedroom for him. Aileen and Mark also reported that stress related to other areas of their lives negatively impacted on their sleep. For Aileen this was related to the other children, her
own health issues and wider family factors. For Mark, work-related stress was highlighted as significant.

6.3.5 Davis Family

The Davis family includes Nicola and Tony and their son Oliver (aged 8 years). Also, living in the family home was Nicola’s daughter, Laura (from a previous relationship). Nicola and Oliver participated in the research and Tony and Laura chose not to. The family live in a 4 bedroom house on the outskirts of a city. Oliver sleeps in a bedroom downstairs whilst the rest of the family sleep upstairs. Oliver moved to his downstairs bedroom, from an upstairs bedroom, 3 years previously. The downstairs bedroom was built specifically for Oliver by extending the ground floor and the bedroom leads off from the main downstairs hallway. One night a month Oliver stayed overnight in the residential unit of his special needs school. Through the direct payment scheme a carer visited twice a week for approximately 4 hours to spend time with Oliver. This was usually at the weekend for either a morning or afternoon to do activities with Oliver, like arts and crafts or going out to a cafe or to the beach. If visiting in the afternoon the carer sometimes helped Oliver get ready for bed but did not usually settle Oliver to sleep (Nicola did this).

Oliver Davis

Oliver was 8 years old and has severe bilateral (whole body involvement) dyskinetic (dystonic type) CP. Oliver’s gross motor function is severely affected but he has, at times, good control of his head and trunk so is at level IV on the GMFCS. Oliver is non-ambulant and uses a power wheelchair that he is able to self drive using a head operated switch system. Oliver had good verbal communication although sometimes for me, as the listener, it was unclear and difficult to understand some of what he said. At these times, during his interview, he would look to his mother Nicola, who was present during the interview, who would then relay to me what he had said. Familiarity played a key part in understanding Oliver’s verbal communication and I found that as the interview went on I understood him better. At the time of the study Oliver attended two schools on a dual placement basis. Therefore, he spent 3 days a
week attending a special needs school and 2 days a week at a ‘mainstream’ school. Discussions and preparations were being made at the time of the study for Oliver to move full-time to his mainstream school. At the time of the study Oliver took 2 medications used to control muscle spasms. No other pertinent clinical or medical issues were noted by Nicola in the Chailey sleep questionnaire.

**Nicola Davis**

Nicola was a ‘stay at home’ parent. At the time of the study Nicola also did voluntary work at the local hospital. Nicola was the primary caregiver to Oliver when he was at home, providing assistance in all areas of his daily living including toileting, washing, dressing, feeding and attending to him when he woke in the night.

**Data collection**

Nicola completed the Chailey sleep questionnaire on behalf of Oliver and her own PSQI. Nicola and Oliver chose written sleep diaries and Nicola completed her own sleep diary and also completed Oliver’s on his behalf, in consultation with Oliver. Nicola took the photographs under the direction of Oliver. Both Nicola and Oliver were happy to wear the Actiwatches for the data collection period. Nicola was present at Oliver’s interview which took place in the sitting room of the family home. Nicola’s own interview took place in the garden of the family home as it was a very hot day.

**Sleep overview for the Davis family**

Oliver goes to bed at bedtime happily and, although Nicola reported that he is able to fall asleep on his own, Nicola often stayed with him until he fell asleep (sometimes falling asleep herself in the process). Oliver woke most nights between 1 and 3 times and required Nicola to assist him in order to get back to sleep. This was usually because Oliver had moved into an uncomfortable position and needed Nicola’s help in repositioning or adjusting his duvet. Sometimes Oliver reported that he woke up because he was thirsty and needed Nicola to help him have a drink. Despite waking up, and being woken every
night, both Oliver and Nicola reported that they slept well and Nicola reported that the waking periods were very short and that she and Oliver returned to sleep quickly. Oliver reported that in the morning he easily woke up and was ready and energetic for the day ahead and Nicola corroborated this.

### 6.3.6 Appleby Family

The Appleby family consists of Sue and John Appleby and their daughter Charlotte. Sue and Charlotte took part in the research. John decided not to take part due to work commitments and he reasoned, that as he rarely attends to Charlotte during the night, the study was less relevant to him compared to his wife. The family live in a 4 bedroom house in a market town. Charlotte’s bedroom is downstairs and was created by extending the ground floor and converting the garage 3 years previously. Charlotte’s bedroom is accessed via the sitting room. Sue and John sleep together upstairs. One night a month Charlotte stayed overnight in the residential unit of her special needs school.

**Charlotte Appleby**

Charlotte was aged 8 years and has severe bilateral (whole body involvement) dyskinetic CP. Charlotte’s GMFCS level is IV and she is non-ambulant and uses a power wheelchair. At the time of the study Charlotte had started to learn how to self-drive her power wheelchair using a switch control. Charlotte had limited verbal communication and communicated using a variety of different methods that were not always consistent in their effectiveness. Charlotte was able to verbally say ‘Yes’ and ‘No’ and also ‘mum’. Charlotte sometimes used her hands and/or her eyes to point to objects. Charlotte used a few ‘makaton’ sign language signs. Charlotte occasionally used a VOCA device (voice output communication aid) to make pre-set requests e.g. drink, snack etc. She also made ‘choices’ by choosing between picture symbols presented to her by tapping her hand on the chosen symbol. For answering ‘Yes’ and ‘No’ questions Charlotte sometimes liked the questioner to put out their hands, with their right hand denoting ‘Yes’ and their left hand denoting ‘No’. Charlotte would then tap one of the questioner’s hands depending on her answer. The effectiveness of Charlotte’s communication relied, in part, on the familiarity of
her communication partner. Consideration of all these factors resulted in Charlottes CFCS level being IV. At the time of the study, Charlotte had recently started taking one medication to help control muscle spasms and pain in her arms. She did not take any other medication. Charlotte attended two schools on a dual placement basis. Therefore, she spent 3 days a week attending a special needs school and 2 days a week at a ‘mainstream’ school.

**Sue Appleby**

Sue was a full-time ‘stay at home’ parent. Sue was the primary caregiver to Charlotte, attending to her needs during the day (when Charlotte was at home) and throughout the night. Charlotte required assistance in all areas of daily (and nightly) living.

**Data collection**

All aspects of the data collection were completed. Sue chose to complete the sleep diaries by hand and Charlotte chose which colour notebook they each had for their sleep diaries. Charlotte also decorated her sleep diary with stickers. Sue completed her own sleep diary and also completed Charlotte’s, on her behalf. The sleep questionnaires were both completed by Sue. The photographs were taken by Sue but Charlotte directed and showed Sue what she wanted to be photographed. The interview with Charlotte was conducted over 3 separate visits because Charlotte found it difficult to stay focussed for more than 20 minutes. Sue was present at Charlotte’s first interview visit and for part of the second visit. For the third interview visit, Charlotte did not want Sue present so Sue got on with household tasks in the kitchen. At the end of the second interview visit, Charlotte wanted to show me her bedroom so we all went and had a look whilst also referring to the photographs she and Sue had taken.

**Sleep overview for the Appleby Family**

Charlotte was happy to go to bed at bedtime and usually fell asleep quickly. She did not need a parent to stay with her in order to fall asleep. Charlotte always woke at least once a night, but usually it was up to 3 times a night and would
call out for Sue (heard via a baby monitor), who would then attend to Charlotte. The main reason for waking was that Charlotte had moved into an uncomfortable position and needed Sue to help move her and to re-adjust her duvet. Sue reported that her own quantity and quality of sleep was generally poor because she had to attend to Charlotte and because she had to get up to use the bathroom at night. She felt her poor sleep negatively affected her in the daytime as she often felt tired and lacked energy. Sue also felt her sleep was negatively affected because of worries and stress linked to Charlotte and her well-being.

6.3.7 Fletcher Family

The Fletcher family consists of Kate and Grant, their twin sons Sam and Alfie (aged 7 years) and Ruby, their baby daughter (aged 1 year). Kate, Alfie and Sam took part in the research. Ruby was too young to participate and Grant chose not to take part. The family live in a 4 bedroom house. All the family slept upstairs and Sam and Alfie had their own bedrooms. At the time of the study a downstairs bedroom had recently been created by extending the ground floor for Sam to move into. The bedroom had been decorated and a number of Sam's possessions and toys had been placed into the new bedroom but he had not yet slept in there. Kate reported that Sam was a little reluctant about moving into his new downstairs bedroom so they were taking the transition process very slowly. When I visited, Sam was keen to show me his new bedroom and reported to me that he was excited to move into it. A carer came for two hours 3 or 4 evenings a week to help with Sam during dinnertime and bedtime so that Kate could feed and get Ruby bathed and ready for bed. The carer had also been on holiday twice with the Fletcher family to help care for Sam, including during the night when Sam woke up.

Sam Fletcher

Sam was 7 years old and has severe bilateral (whole body involvement) dyskinetic (dystonic type) CP. Sam’s gross motor function is severely affected and he is at level V on the GMFCS. Sam is non-ambulant and uses a manual wheelchair which is pushed by the person who is attending to him. Sam has
good verbal communication although sometimes for me, as the listener, it was unclear and difficult to understand what he was saying. At these times he looked to Kate, who was present during all meetings, who would then relay to me what Sam had said. I found that the more time I spent with Sam, the better I understood him. Sam attended a special needs school on a full-time basis at the time of the study. Sam was on two medications for constipation but no other medical issues were noted in the Chailey sleep questionnaire.

**Alfie Fletcher**

Alfie is Sam’s twin brother so was also aged 7 years. Alfie does not have CP, other disabilities or additional health concerns. Alfie was a day pupil at a local private mainstream school for boys.

**Kate Fletcher**

Kate was a ‘stay at home’ mother at the time of the study and was caring for her baby daughter on a full-time basis during the day (and night) as well as caring for Sam and Alfie when they were not at school. During the night, Kate did not usually get up to attend to Sam (who woke regularly at night) but did attend to Ruby, who at nearly 1 year old was waking at night on occasion. Grant would get up at night and assist Sam when he woke.

**Data Collection**

At the start of the 2 week data collection period, Kate reported that Sam was very uncomfortable wearing the Actiwatch and did not want to wear it. We agreed that it was ok for Sam to continue in the study without wearing the Actiwatch. At the end of the 2 week data period Kate mentioned that she and Alfie had also not worn the actiwatch. No reason for this was given by Kate but it may have been a misunderstanding on Kate’s part that if Sam did not wear one then it was not necessary for anyone else to either. Written sleep diaries were completed for the two weeks, with both Sam and Alfie’s completed by Kate. Both of the boy’s sleep questionnaires were also completed by Kate. I completed Kate’s questionnaire with her when I visited to pick up the equipment. Alfie took his own photographs, whereas Kate took Sam’s
photographs under his direction. Kate was present at both Sam’s and Alfie’s interviews although she was quite distracted during both interviews as Ruby was also present and demanding some of Kate’s attention. This was also the case throughout Kate’s own interview.

**Sleep overview for the Fletcher family**

Sam goes to bed happily and will generally fall asleep quickly on his own. However, on occasion Kate reported that she or the carer have to help Sam move into a more comfortable position before he is able to fall asleep. Sam woke between 1 and 3 times during the night and called for parental assistance. In general, it was Grant who attended to Sam although on occasion Kate would go to him. When waking Sam required help with moving into a more comfortable position. Kate reported that sometimes it was difficult for her to physically move Sam as his body could be very rigid and he was getting heavier with age. This was why Grant was taking on the role of attending to Sam at night more often. Despite waking regularly at night Kate reported in the Chailey sleep questionnaire that she felt Sam got enough sleep and he seemed alert in the morning.

Alfie generally slept well and was happy to go to bed at bedtime, falling asleep quickly. No issues were noted by Kate on Alfie’s CSHQ and Alfie reported to me that he liked sleeping except for when he occasionally had bad dreams.

Kate reported that her own sleep was often disturbed and this was mainly due to either Sam or Ruby waking in the night. Although Kate did not always attend to Sam at night she reported that she always heard him when he woke up, and she would often have to wake Grant up to go to Sam. Kate reported that Sam and Grant often fell back asleep quickly but that it could take her some time to go back to sleep. Kate reported on the PSQI that her sleep was negatively affected by attending to her child’s health needs and because of experiencing stress related to her child’s health needs. I completed the PSQI with Kate and she rated her sleep during the last month as a being ‘somewhere between’ ‘fairly good’ and ‘fairly bad’. She commented to me that her sleep over
the last month had been ‘no better and no worse than normal’ and that she had got ‘used to it not being great’.

6.3.8 Cooper Family

The Cooper family includes James and Catherine and their children Daniel, Libby (child with CP) and Joseph. All 5 family members participated in the research. The family live in a 4 bedroom house. Libby's bedroom is located downstairs as part of an extension that was built 5 years previously and Libby's bedroom leads directly from the kitchen. The rest of the family sleep upstairs and Daniel and Joseph have their own bedrooms. Through the direct payment scheme, James and Catherine employed a carer who came to the house 2 Fridays every month and stayed the night. The carer slept in the sitting room downstairs and had the baby monitor, in order to hear Libby when she woke at night and attended to her. The carer had been employed for 5 years by the family and had also gone away on holiday to help care for Libby. Twice a week a different carer visited Libby for 2 hours each time after school to do activities, such as arts and craft with her. Catherine reported that this enabled her to do household chores such as prepare dinner, as well as spend time with Daniel and Joseph to help them with their homework. Libby also spent one night every other month at the residential unit of her special needs school.

Libby Cooper

Libby was 12 years old and has severe spastic bilateral CP (affecting her whole body). Libby's GMFCS level is V and she is non-ambulant and uses a manual wheelchair, which is pushed by the person who is attending to her. Libby has difficulty with keeping her head and trunk in an upright position so needs extra support in her wheelchair. Libby also has little control of her arm and leg movements.

Libby is pre-dominantly non-verbal and uses a range of methods to communicate. She has an established ‘yes’ response which is a higher pitched vocalisation and movement of her eyes and head upwards to the left. Her response for ‘No’ is more ambiguous. Sometimes she verbally responds with a clear ‘No’, other times a lower pitched vocalisation and movement of her eyes
and head downwards to the right means ‘No’ and sometimes no response is interpreted as meaning ‘No’. Libby is at CFCS level IV. Libby also uses a symbol book communication system. The system is based on the structuring of ‘20 questions’, requiring a ‘yes’ or ‘no’ response. The vocabulary is organised into 16 Categories (see Figure 6.1), which are then sub-divided into ‘Topics’ and then ‘Key Words’. To aid recognition of the Categories, the system is colour coded. In order for Libby to use this system she relies on a facilitator to read her out her category, topic and keyword choices. The facilitator allows enough time after each choice for Libby to indicate ‘Yes’ or ‘No’ using her established responses, as detailed above. When I first visited the Cooper family and met Libby it was clear that her communication system was quite complex. Both Catherine and James (Libby’s parents) were keen from the outset that neither of them should be present at Libby’s interview. However, I felt unconfident that a few visits would be adequate for me to learn how Libby’s communication system worked and I recognised that we needed someone who knew Libby well to help. As outlined above, a carer comes to the family home 2 evenings a week and it was decided, with Libby’s agreement that the carer, Sally (pseudonym), would act as communication facilitator during the visit to obtain consent and Libby’s interview.

Libby took 10mls of Chloral Hydrate every evening before bed to help her fall asleep. She did not take any other medication. Catherine noted in Libby’s Chailey Sleep Questionnaire that Libby had periods of constipation that could cause her pain but no other medical issues were noted.

At the time of the study Libby attended a special needs school on a full time basis.
Daniel and Joseph Cooper

Daniel was 13 years old and at the time of the study and attended the local secondary school. Joseph was 9 years old and attended the local primary school. Neither Daniel nor Joseph had a disability or additional health needs.

James and Catherine Cooper

Both James and Catherine worked in full-time jobs. When at home both Catherine and James shared caring for Libby, which included assisting her with all aspects of her daily living, as well as caring for Daniel and Joseph. They also shared the carrying out of household tasks such as laundry, cleaning, cooking etc.

Data Collection

James and Catherine chose to record audio sleep diaries for the 2 week period. Daniel and Joseph chose to complete written sleep diaries. James and Catherine completed a written sleep diary on Libby's behalf. Daniel and Joseph took their own photographs. Libby chose Sally, her carer, to take her
photographs under Libby’s direction. James and Catherine completed their own PSQI questionnaires and Daniel completed his own CSHQ. Catherine completed Joseph’s CSHQ and Libby’s Chailey sleep questionnaire. They were all happy to wear the Actiwatches but one night of data was missing for James and two nights missing for Daniel.

Informed consent was obtained from Libby during one visit but the individual interview was carried out over two visits. This was not because of Libby’s lack of focus but more to do with the time it took to use her communication system and, it appeared to me, that it was quite a tiring process for Libby. Libby’s interview took place in the dining area of the kitchen. Daniel and Joseph both chose to be interviewed on their own. Daniel’s interview took place in the sitting room but Joseph’s interview took place in Libby’s bedroom (downstairs) at the suggestion of Catherine, as the sitting room and kitchen/dining room were being used by the other family members. James’ interview was also conducted in Libby’s bedroom because the other downstairs rooms were being used. Catherine’s interview started in the dining area of the kitchen but it was raining and the noise of the rain on the conservatory style glass roof was loud and made the audio recording difficult to hear. Therefore, Catherine suggested we move to Libby’s bedroom instead. The use of Libby’s downstairs bedroom by other family members will be discussed in more detail in Chapter 9.

Sleep overview for the Cooper family

Libby is given a 10ml dose of Chloral Hydrate before bedtime to help her go to sleep. Libby has been on this medication for approximately 8 years. When discussing Libby’s sleep questionnaire Catherine described that, prior to being prescribed Choral Hydrate, Libby could take 3 to 4 hours to fall sleep and would often wake up 2 hours later often then staying awake for the rest of the night and throughout the day. Catherine and James, in their interviews, described this time as incredibly difficult for them and Libby. James described how desperate they were for help and how worried he became about Catherine because, at that point she was carrying out the majority of night-time care for Libby. Catherine described feeling desperate and depressed and at one point suicidal
and it was then that James rang social services to demand help. It was also at this point that their GP prescribed Libby Chloral Hydrate which made a significant difference to Libby’s sleep, specifically helping her to fall asleep much more quickly. However, she did still wake up approximately 4 times a night at the time of the study and call for James or Catherine (via the baby monitor) who would attend to her. These waking periods lasted up to 10 minutes and Libby would need help to change position or she woke because of pain from being constipated.

Catherine and James share the role of getting up to Libby in the night. Despite both having to get up 2 or more times and getting approximately 5 to 6 hours sleep a night, Catherine and James both reported on the their PSQI questionnaires that their sleep quality over the past month had been ‘fairly good’. When we discussed the questionnaire responses both Catherine and James remarked that their sleep was ‘fairly good’ in comparison to how disrupted their sleep use to be (before Libby was prescribed Chloral Hydrate). Both James and Catherine reported on the PSQI that they had had trouble sleeping because of attending to their child’s health needs and Catherine also reported that she had trouble sleeping because of experiencing stress related to Libby’s health and also stress related to other factors.

Both Daniel and Joseph felt that they slept well. However, for both there was a reluctance to go to bed at bedtime and to go to sleep when it was ‘lights out’ time.

6.3.9 King family

Matt, Vicky, Brian (child with CP, 13 years old) and Ellen (12 years old) are the King family. They all participated in the study. They live in a 3 bedroom bungalow in a large city. The bungalow is specially adapted for disabled people and has widened doorways and ramped access. The family moved into the bungalow 7 years previously from a flat. Brian and Ellen both have their own bedroom. The family did not receive any care help for Brian but would occasionally ask one of Brian’s teaching assistants from his school to babysit if Matt and Vicky wanted to go out in the evening.
Brian King

Brian was 13 years old and has severe Dyskinetic Choreo-Athetotic CP (affecting his whole body). This type of CP is characterised by fluctuations in muscle tone from high (stiffness and tension of the muscles) to low (floppiness of the muscles). Brian is non-ambulant and at GMFCS level V. With this level and type of CP Brian has very little control over the movement of his body and has great difficulty holding himself in an upright position and needs to be well supported in his manual wheelchair.

Brian is non-verbal. His main method of communication is via an eye-tracking activated symbol communication system called the My Tobii. Brian has a My Tobii computer screen mounted onto his wheelchair. Attached to the screen are forward- and rearward-facing infrared cameras which pick up the activity of Brian's eyes (specifically the cornea). The screen presents symbols arranged in a similar way to Libby Cooper's symbol communication book (as described above in section 6.2.8). Therefore, the front screen of Brian's My Tobii system is arranged into Categories. Brian then stares at the category symbol that he wants and this activates it (like a mouse click would activate a computer screen). The category symbols are then subdivided into topics and key words. There is also a keyboard screen which allows the user, if able, to spell out words using eye tracking. The system generates speech so that when Brain activates a symbol the choice is said out loud using a computer generated voice. The My Tobii system requires a substantial amount of concentration and can be tiring for Brian to use. When tired Brian will often use sounds and facial expressions to communicate, specifically to answer yes or no to questions. Despite meeting with Brian a number of times I did not feel confident in interpreting his sounds and facial expressions so Matt, Vicky or Ellen would facilitate this and we would then check with Brian that their interpretation was correct.

Brian had an operation 2 years previously to have a gastrostomy fitted and was entirely fed via the gastrostomy tube. The gastrostomy was decided upon because Brian had great difficulty co-ordinating the movements and muscles necessary to safely swallow food. He would often aspirate (when food
enters the airway and lungs) and choke on food and he also had severe reflux which would lead to pain and vomiting and further risk of aspiration.

At the time of the study Brian attended a special needs school on a full time basis.

**Ellen King**

Ellen was 12 years old and attended a mainstream secondary school. Ellen has no disabilities or additional health needs.

**Matt and Vicky King**

Matt and Vicky both worked in part-time jobs. Matt and Vicky shared the role of caring for Brian who needed physical assistance with all aspects and activities of daily (and nightly) living. They also shared the carrying out of household tasks such as laundry, cleaning, cooking etc.

**Data collection**

All of the King family members chose to complete written 2 week sleep diaries. Matt and Vicky completed Brian’s on his behalf. Ellen took her own photographs and completed her own written sleep diary and CSHQ. Brian’s photographs were taken by Matt and Ellen under Brian’s direction. Vicky completed the Chailey sleep questionnaire for Brian and her own PSQI and Matt filled in his own PSQI. All the family members wore their Actiwatches and no data was missing. Brian chose his dad, Matt, to be present for the visit when I obtained his consent and also for his interview. At one point Ellen joined Brian’s interview, checking with him that she could and Brian agreed. Brian was able to complete his interview in one visit which lasted 55 minutes. Ellen chose to be interviewed on her own and Matt and Vicky decided to have a joint interview.

**Sleep overview for the King family**

All members of the King family reported that they had disturbed and disrupted sleep. Vicky reported in Brian’s Chailey sleep questionnaire that Brian would fall asleep quickly but he usually woke during the night 4-6 times and would need
either her or Matt to attend to him. This usually involved physically repositioning him and the waking periods would usually last between 0-10 minutes. Both Matt and Vicky remarked in their interview that this was a huge improvement compared to what Brian’s sleep was like before having a gastrostomy because he was in pain with severe reflux leading to episodes of vomiting and aspiration. However, although improved, Brian still woke up a number of times and both Vicky and Matt recorded their sleep quality in the past month as ‘fairly bad’ on their PSQIs. They both reported that this was primarily because they had to get up to attend to Brian and Vicky also reported that she got up to use the bathroom during the night. In their interview, and as discussed further in Chapter 10, Matt and Vicky discussed how recently Matt had started occasionally co-sleeping with Brian (on a futon next to Brian’s mattress which is placed on the floor). Both Matt and Vicky felt that, although this was not an ideal situation, co-sleeping meant that Brian’s waking periods were much shorter as Matt could attend to, and reposition, Brian much more quickly.

Ellen also reported on her CSHQ that she had difficulty sleeping. In particular, Ellen reported that she was sometimes reluctant to go to bed and that it usually took her longer than 20 minutes to get to sleep. Ellen also reported in her CSHQ that she ‘sometimes’ woke more than once during the night and that she ‘usually’ felt tired in the day.

6.3.10 Gibson Family

The Gibson family are Darren, Anne and Jacob (6 years old). Darren and Anne adopted Jacob when he was 2 years old. The Gibson’s live in a 3 bedroom house. All 3 bedrooms are located upstairs. The house is fitted with a lift (by the local authority) which moves between the ground floor sitting room and Darren and Anne’s bedroom on the first floor. The lift was used to transfer Jacob up- and downstairs in his wheelchair. The family received some care help for Jacob through social/health services. They had one carer who came to the house 2 evenings a week to get Jacob ready for, and settled in, bed. Jacob also spent 2 nights a month at a NHS respite unit. Together the family also spent time at two different hospices and were allocated 10 nights a year at one hospice and 14 nights at the other. At the hospices Jacob stayed in his own
bedroom and was cared for at night by hospice staff allowing Darren and Anne uninterrupted nights.

**Jacob Gibson**

Jacob was 6 years old and the youngest participant in my study. He has severe spastic bilateral CP (affecting his whole body) and is at GMFCS level V. Jacob finds it very difficult to control his body, posture and movements and needs to be well supported in his wheelchair. Jacob is non-ambulant and at the time of the study Jacob was using a manual wheelchair but the family were hoping to acquire for him a powered wheelchair that he could learn to self drive. Jacob is non-verbal and communicates using a combination of sounds, facial expressions and head and eye movements. He has an established ‘yes’ response whereby he lifts his head up and raises his eyes whilst making a ‘hmmmm’ noise. Jacob’s ‘no’ response is denoted by him lowering his head and eye gaze and he makes a low pitched sound. At school and at home Jacob was beginning to learn how to use a symbol communication book (as used by Libby Cooper and described above). It was still a new concept for Jacob so Anne felt it was better not to use it for his interview.

Jacob has complex health needs and was on a number of different medications. Jacob has severe and complex epilepsy resulting in serious and sometimes prolonged seizures. Everyday Jacob would experience many absence type seizures and he also had longer lasting ‘tonic clonic’ seizures. The tonic clonic seizures would often occur in clusters so Jacob would experience a number of them within a period of a few days and then not have one for one to two weeks. Jacob was taking two medications to try and control his epilepsy. Jacob also took other medications to help control muscle spasms, lessen saliva production, and to reduce the build up of stomach acid. Jacob also took 9mg of melatonin every evening before bedtime to help him go to sleep.

Jacob has a gastrostomy fitted and was primarily fed via the tube, although very occasionally he would have ‘tastes’ (very small amount) of soft or puréed food in his mouth. Jacob also had a degree of hip dislocation (common in children with severe CP) and Anne reported in Jacob’s Chailey sleep
questionnaire that his hips could be a source of pain for Jacob, especially at night. Jacob attended a special needs school on a full-time basis.

**Darren and Anne Gibson**

Darren had a full-time job and worked night shifts. Anne was a full time ‘stay at home’ parent and carried out the majority of care for Jacob which includes helping him in all aspects of daily living. However, Darren helped if he was home and had not worked a night shift the previous night. When Darren works night shifts Anne attends to Jacob at night but when Darren is at home they share the night-time care of Jacob.

**Data collection**

Darren and Anne chose to complete written sleep diaries for the two week period and Anne recorded an audio sleep diary on behalf of Jacob. Anne also took photographs for Jacob, checking with him what aspects of his bedroom he wanted photographed. Anne completed the Chailey sleep questionnaire for Jacob and her PSQI and Darren filled in his own PSQI. Actiwatches were worn by all for the two week period with no issues reported. However, when I downloaded the Actiwatch data, Jacob’s watch had stopped working after one week of data collection, despite being fitted with a new battery before data collection started.

Jacob chose to have Anne present for his consent visit and for his interview. Because of his age, severe disabilities, and communication methods I was a little uncertain about Jacob’s level of understanding. However, he seemed to understand the consent form questions and was able to give his clear ‘yes’ response. I felt I had to adapt the interview topic guide slightly to try and make it, and my language, simpler. Anne appeared to be confident that Jacob understood the questions, although she would, at times, interject and rephrase questions. Occasionally, Anne would also answer the questions herself and I had to attempt to re-direct the question back to Jacob. We conducted Jacob’s interview in one visit, however, I did note in my research diary that Jacob’s concentration and focus dwindled near the end of the interview and that
I should have suggested coming back another time to finish the interview. Anne and Darren chose to be interviewed together.

**Sleep overview for the Gibson family**

Darren, Anne and Jacob all had disturbed and disrupted sleep. For Darren this was a result of working night shifts and, when home at night, being woken by, and attending to, Jacob. When Darren worked a night shift he tried to get at least 3 hours sleep the following day.

Jacob had 9mg of melatonin at bedtime but it could still take him more than 1 hour to fall asleep. Jacob woke every night, usually up to 3 times and these waking periods lasted up to 30 minutes but sometimes for much longer. Anne and Darren heard Jacob during the night via a baby monitor and Jacob also wore a SATs monitor clip on his finger. The SATs monitor measured Jacobs’s oxygen levels and if these dropped below a certain level the monitor triggered an audio alarm that Darren and Anne could hear. A drop in his oxygen levels could be indicative of Jacob having a prolonged seizure. However, often at night the finger clip fell off when Jacob moved and this also triggered the alarm. During the 2 week data collection period Anne reported in her sleep diary that the SATs monitor triggered the alarm 12 out of 14 nights (some nights it was up to 3 times) because the clip had moved or fallen off. Anne or Darren checked on Jacob each time the alarm sounded. On one day the alarm sounded at 6.15am and when Anne attended to him Jacob was having a severe seizure that required an ambulance to be called.

In their PSQI’s Darren and Anne both reported their sleep quality over the last month as ‘fairly bad’ and reported that they had 4-5 hours of sleep per night. Both reported that attending to their child’s health needs was the main reason for their trouble sleeping and Darren also reported experiencing stress related to Jacob’s health as a main contributing factor, although Anne did not.

### 6.4 Conclusion and overview of the data analysis chapters

The purpose of this chapter has been to provide an introduction to the participants, the families and their sleep. This allows understanding of pertinent
background and contextual information prior to presenting the following four analysis chapters.

The chapter outlined information about the participants, focusing specifically on the child with CP and included details about the child’s cerebral palsy and what this means in terms of the severity and type of CP, the effect on movement/posture and on communication using definitions from the GMFCS (Palisano et al., 1997), the CFCS (Cooley-Hidecker et al., 2011) and the Surveillance of Cerebral Palsy in Europe consensus report (SCPE, 2000). Information about the additional impairments and health needs of children with CP (where applicable), including details of prescribed medication, was drawn from the clinical section of the Chailey sleep questionnaire and has been outlined. The sleep questionnaires completed by, or on behalf of, all the participants were drawn on to also provide an overview of the sleep of the participants and the families.

As demonstrated all the participants and the families differed. This is particularly evident for those children with CP. As discussed in the introduction of this thesis, cerebral palsy must be considered as a descriptive term and the effects that it has on people with CP, with regards to movement, posture, communication and additional health needs will vary greatly from individual to individual. These differences and the differences between siblings and children with CP became a focus and important element in understanding the sleep of children with CP and their families, as will be discussed in the following data analysis chapters. Therefore, the aim of this chapter was to ‘set the scene’ and provide information that would help in the reading and understanding of the forthcoming analysis chapters.

The following four chapters present analysis of the qualitative interviews. Chapters 7 and 8 primarily draw on qualitative data from the interviews with children with CP and their siblings. Chapter 9 presents data from the children and the parents and Chapter 10 draws on interview data of the parents. Figures 6.2-6.5 present the themes and sub-themes for each of the analysis chapters.
Figure 6.2 Themes and sub-themes of Chapter 7

Chapter 7

Child interview data
- (non) Meanings of sleep
- Actions/interactions surrounding sleep
- The lie-in
- Delaying sleep and asserting autonomy

Parent interview data
- Impact of sleeplessness
- The bedtime routine
- Paid carers and bedtime

Figure 6.3 Themes and sub-themes of Chapter 8

Chapter 8

Child interview data
- Reasons for sleeplessness
- Impact of sleeplessness
- Physical needs
- Imaginary worlds
- Mum and Dad
- Toys and cats
- Stress and worry
- Disturbed by others
- Light and dark
- Independent techniques
Chapter 9

Child interview data

The bedroom

Bedroom use – siblings & mild CP

Bedroom use – severe CP

Downstairs location – severe CP

A shared space

Clinical Items

Hoists

Adapted bed

Parent interview data

Extension of public space

Chapter 10

Parent interview data

Night-time monitoring

Low level monitoring

Informal monitoring

Technological monitoring

Combination monitoring

Co-sleeping

Figure 6.4 Themes and sub-themes of Chapter 9

Figure 6.5 Themes and sub-themes of Chapter 10
Chapter 7 explores the meanings of sleep for children and emphasises the social context of sleep through the children’s discussions of the activities, routines and practices that precede and follow night-time sleep. Differences are highlighted based on the child’s age and for children with severe CP compared to those without. One difference explored in depth is the presence of paid carers to help children with severe CP at bedtime. The impact of sleeplessness on self and others within the family also emerged as a theme from the children’s interviews.

Chapter 8 also examines the social context of sleep children with CP. The focus of this chapter is on the actors, activities and artefacts that children discussed as either disturbing/disrupting or helping their sleep. Some of the hindrances to sleep include bodily and physical needs and being disturbed by other family members. Factors that help sleep include mum and dad, cuddly toys and pet cats. Differences are evident depending on the age of children and the presence and severity of CP. I make reference to the ‘younger’ and ‘older’ children throughout the rest of the thesis. ‘Younger’ children refer to those aged 6 to 8 years and ‘older’ children to those aged 9 years to 13 years.

Chapter 9 focuses on the bedroom (specifically children’s bedrooms) which emerged as an important theme from interviews with both children and parents. Factors relating to the use, location and meanings associated with bedrooms are highlighted as are the differences, related to these factors, between children with and without severe CP. A number of young people with severe CP have their bedroom located downstairs when the rest of the family have theirs upstairs. The reasons and meanings related to this and the concept of privacy are explored in detail.

Chapter 10 draws on the interview data of parents and focuses on their discussions of the night-time monitoring they undertake of their children with CP. The level and method of night-time monitoring differs between families and is determined by a number of factors including severity of the child’s CP, location of bedrooms and co-morbid health issues of the child with CP. The impact of night-time monitoring on the parents’ own sleep also differs depending on the method engaged in. For two families co-sleeping was discussed as a
useful (occasional) strategy to help their child with CP and to protect the sleep of the family.
Chapter 7 - The meanings and management of sleep for children with cerebral palsy and their siblings and the impact of sleeplessness

7.1 Introduction

As discussed in Chapter 2 there remains very little research on how children ‘do’ sleep and there is no literature on the lived experience of sleep for disabled children. Existing research focuses on the biological and psychological aspects such as diagnosis, cause and treatment of specific sleep problems/disorders in disabled children. Furthermore, there is no research from the perspective of disabled children themselves about their sleep. This chapter primarily draws on the children’s qualitative interviews (including the children with CP) focussing on their talk about the practices, interactions and management of their sleep, in particular the ‘when, where, what and with whom’ (Williams et al., 2007) aspects of their sleep. Rather than explicitly exploring and talking ‘about’ their own sleep the majority of the children talked ‘around’ their sleep. This highlights the social and relational context of children’s sleep. This chapter specifically focuses on the time that leads up to and follows night-time sleep as this emerged as significant for the children.

The focus on, and discussion of, these ‘transition phases’ (Schwartz, 1970) by the children in relation to the meanings and practices of their sleep corroborates the findings of Williams et al. (2007) and Moran-Ellis and Venn (2007). There were commonalities for all children in relation to the activities and interactions that preceded and proceeded going to bed. However, differences were also evident between children, for instance, with reference to developing autonomy and self-management with regards to sleep timings.

Sleep as embedded in family life is emphasised with the conceptualisation of the bedtime routine as a ‘family practice’ (Morgan, 1996; 2011). The concept of family is explored further when data on the presence of paid carers at bedtime for a number of children with CP is analysed. Although this chapter focuses primarily on the children’s data, the views of parents are also considered in the section on employment of paid carers to help at bedtime.
Furthermore, the social and interactional, as well as the embodied nature, of sleep is evident through the children’s discussions about the impact of sleeplessness. Sleep is understood and discussed in terms of the effect that sleeplessness has on the children themselves and also on the interactions and relationships with others.

### 7.2 The meaning and ‘non’ meaning of sleep for children

Williams et al. (2007) report that many of the young people in their study found it difficult to talk about their sleep especially in terms of whether or not they liked or disliked sleep. Williams et al. (2007) discuss that this may be because sleep, by its very nature, is a bit of a ‘blank’ in our lives and, therefore, remains a rather abstract concept for children to grasp and discuss. However, this was not entirely true for the young people involved in my research. Although some of the young people found it difficult to talk about the meanings of sleep per se, this did not seem to be because it was an ‘unknown’ aspect of their lives resulting in it being a difficult subject to conceptualise. For some of the young people there seemed to be more of an element of indifference about sleep. This was particularly evident when interviewing two of the siblings who, in general, accepted enquiry about the sleep of their disabled brother/sister but were impassive and unforthcoming by questioning of them about their own sleep.

*Interviewer*  Do you tend to sleep well?

*Daniel*  Yeah

*Interviewer*  Yeah? You don’t get disturbed? Or …

*Daniel*  Not really.

*Interviewer*  No? So you would generally say you’re a good sleeper?

*Daniel*  Uh huh (nodding)

*(Daniel Cooper, 13yrs old, older sibling)*
It may be possible that this attitude towards the subject of sleep demonstrated by some of the young people, particularly the siblings, reflects a perceived ‘uncoolness’ or ‘boringness’ related to the topic of sleep as proposed by Williams (2005). However, it may be that for those children and young people, for whom sleep is unproblematic and therefore, in their minds, a straightforward process, that there is simply little to discuss.

Other children were more able and more forthcoming in their discussion of sleep. This specifically emerged during the interviews when the children were asked directly if they liked or disliked sleeping. The majority of the children gave an affirmative answer with only two answering ‘no’ when asked. Both of these young people have severe CP and at the time of interview regularly woke at least once every night and required assistance (usually a parent) to help them get back to sleep. However, it was difficult for these two children to elaborate further on why they did not like sleeping.

Interviewer Do you like sleeping?

Oliver Noooooooo!

Interviewer Why not?

Oliver Don’t know

(Oliver Davis, 8yrs old, severe CP)

For those children who said they liked sleeping, two justified their positive answers by talking about the benefits or purpose of sleep. For instance, one young person with severe CP mentioned getting energy from sleeping and another said:

I like sleeping; it gives you sort of a rest

(Greg Jones, 13yrs old, mild CP)

The embodied nature of sleep discussed in terms of its perceived benefits was also drawn upon when children discussed the impact of sleeplessness (see Section 7.6).
For a number of the young people further details about what their enjoyment or dislike about sleep actually meant, felt like and involved was elicited by questioning about, for example, what a ‘perfect’ nights’ sleep entailed. In line with Williams et al. (2007), the young people were much more comfortable and able to discuss sleep with reference to the activities, processes and interactions that led up to, enabled and followed the period of night-time sleep. The words and symbols representing these aspects were also much more available for those young people using non-verbal communication methods.

7.3 Actions and interactions leading up to and following night-time sleep

The time periods leading up to and directly following night-time sleep, including the activities, actions and interactions that happen during these times, were discussed by many of the children. In particular, the concept of the ‘lie-in’ was deemed as significant for a small number of children and the ‘bedtime routine’ was discussed by all of the children. Schwartz (1970) labels the time leading up to sleep and the time following it as the ‘transition phase’ of sleep (p23) and Williams (2008) views pre- and post- sleep routines as ‘transitional practices and symbolic markers designed to ease us back and forth into waking life’ (p642). Schwartz (1970) defines sleep as ‘an important form of periodic remission’ (p19) which provides:

Relief from the discipline of social life, remissions make that life more bearable and are, for this reason, important modes of social control (p18).

The transition phase is one aspect of this social control and the transitions are important because they are not simply about experiencing the sensations related to sleepiness and wakefulness but they actually produce these states (Power et al. 2017). Williams (2005, 2008) discusses, with specific reference to pre-and post- sleep transition phases, the important role they play in the socialisation of children’s sleep in relation to family roles and routines and highlights the social pliability and plasticity of sleep. Further to this, the organisation and management of the transition phase pre-and post- sleep are
linked to issues of power, control and status. This is particularly evident for children whereby the transition phases are overseen and managed by parents. Williams (2005) argues that sleep is a ‘key site’ in which children’s minority group status is highlighted and ‘inter-generational power relations and issues of authority, autonomy and independence are played out’ (p79). The research of Williams et al. (2007) and Moran-Ellis and Venn (2007) found that bedtimes, in particular, were times of parent-child negotiations and conflict and as Moran-Ellis and Venn (2007) report it is often a time ‘replete with false starts, counter moves and resistances’ (para 3.1). As children grow older they take more control over the transition periods both preceding and proceeding their sleep (Williams, 2005) and are able to decide and dictate their own sleep timings. Moran-Ellis and Venn (2007) found that for the teenagers in their study, parents still regulated what time teenagers had to go ‘up to bed’ but the young people then had autonomy and flexibility in deciding when to actually go to sleep. Importantly, they also had privacy in their own bedrooms to engage in activities of their own choosing e.g. texting friends or reading, during this pre-sleep period.

Data from my own study in relation to the transition phases, leading up to and following sleep will now be discussed. Of particular interest are the differences that the discussions with the children highlighted in relation to age (i.e. older children compared to younger children) and disability (i.e. children with severe CP compared to children with mild CP or without CP). The analysis starts by focussing on the ‘lie-in’.

7.3.1 The Lie-in

As mentioned above the children in my study were asked if they enjoyed the act of sleeping with the majority saying they did. The children were questioned further about what they enjoyed about sleep and, in particular, what made a ‘perfect’ night’s sleep. For a number of the children, particularly those that were older and either siblings or young people with mild CP, the concept of the ‘lie-in’ was mentioned frequently in defining ‘a good nights’ sleep.

**Interviewer**  Do you enjoy sleeping?
Grace Yeah, I love sleeping.

Interviewer You love sleeping, OK?

Grace I love lie-ins.

Interviewer You love lie-ins, OK? Do you ever wake up and think ‘Oh I’ve had a really good night’s sleep?’

Grace Quite rarely but I do in the holidays, I’m like ‘Wow, I’ve had such a good night’s sleep’.

(Grace Baker, 13 years old, mild CP)

Grace goes on to describe the difference between being woken up by her alarm clock during term time compared to waking up without an alarm during holiday time. She also observes that even at weekends during term time she does not benefit from a true lie-in because she wakes naturally at her normal school day waking time and then finds it difficult to go back to sleep. This point is also discussed by Willow Edwards (sibling):

Willow On Saturday mornings I wake up early, like the rest of the week, but then Sunday morning I don’t and then Monday morning I don’t, and then I have to get used to running around again [to get ready for school]. I don’t like Monday mornings.

(Willow Edwards, 10 years old, older sibling)

The joy of school holiday sleep and lie-ins was reiterated by Joseph Cooper (sibling) but he also emphasised the benefit of being left alone to wake up naturally thus asserting some independence in managing his own time and his own sleep timings.

Interviewer Do you ever wake up and think ‘oh I’ve had a really good night’s sleep’?
Joseph

No, apart from in the holidays when my mum doesn’t drag me out [of bed].

Interviewer

Ok, so to make it a really good night’s sleep it would mean that you could stay in bed in the morning a bit longer?

Joseph

Until I actually feel like getting up.

Interviewer

Ok

Joseph

‘Cos usually [in the holidays] I get up when I want to, I open my eyes and sit in bed and read for 3 hours then go down and mum says ‘you’ve got to make your own breakfast now’.

(Joseph Cooper, 9 years old, younger sibling)

Joseph’s discussion of staying in bed and reading illustrates the concept of being ‘socially sleep’ (Schwartz, 1970; Williams, 2007) whereby the sleep role is still fulfilled and a periodic remission from social life is achieved despite ‘biologically’ being awake.

Lie-in’s were not discussed or used to define ‘good’ sleep by younger children or those with severe CP. On the contrary some of the younger children were proud to recall how early they woke up and for one pair of brothers there was rivalry about which brother woke the earliest.

Thomas

I wake up before Charlie now, he used to wake me up a lot but now I can wake up earlier than him.

(Thomas Hughes, 7 years old, older sibling)

There was little differentiation in the time of waking up and getting up on school days, weekends and school holiday days for younger children and children with severe CP irrespective of their age. The younger children (without severe CP) tended to wake early and unlike the older children they did not desire extra sleep or a ‘lie-in’, so instead would get out of bed and, therefore,
they had some control of when they started their day. This sometimes involved waking their parents too especially if they needed help to carry out their morning activities e.g. getting dressed or preparing breakfast. Therefore, the younger children were afforded some autonomy and choice as to when they woke and got out of bed but their actions potentially still had an impact on the sleep of others in the household i.e. parents. Williams (2005) purports that as children grow up their autonomy, control and decision making about sleep time (and timings) is likely to increase.

Physiological changes that occur at puberty are linked to changes in sleep timings with an evidenced shift towards later sleep times and delayed morning wake up times (Taylor et al. 2005). However, neither the increase in autonomy afforded with growing older or physiological changes are applicable or necessarily evident for young people with severe CP as with the unchanging nature of their disability they will always have an absolute reliance on others to physically remove them from their bed and, therefore, the end of their sleep and the start of their day are dictated by others. In this way, impairments are recognised as are ‘impairment effects’ (Thomas, 1999). Therefore, there are restrictions of activity because of impairments and they impact on the lived experiences of disabled children (and disabled adults). Of course, the children with severe CP woke up when they ‘naturally’ woke up but they had little choice about what happened next. The details of what happens in the mornings for children with severe CP were difficult to ascertain from the children themselves. The sleep diaries of the children offered some information but this was, in the main, from the parent’s perspective as they often completed the sleep diaries on behalf of the child with severe CP. One example of what happens in the morning for children with severe CP is illustrated by the following excerpt from Charlotte’s (severe CP, 8 years old) sleep diary, which was written by her mother but from Charlotte’s perspective i.e. the mother uses ‘I’ to refer to Charlotte herself:

I was awake and lying peacefully in bed when dad came down [Charlotte has a ground floor bedroom] at 8.15am and I gave him a big smile.

At the end of the diary entry Charlotte’s mother adds a N.B:
Not sure when Charlotte actually woke up, there was no sound over the monitor but [husband] said she was wide awake and quite happy.

This excerpt highlights how children with CP have very little control over what happens once they wake up. There is an element of passivity and acceptance that they need to wait for someone else and that despite being awake there may be very little they can physically do about it until a parent decides to take action. This is reiterated in another sleep diary entry, again written by the mother but from the perspective of her son, Oliver (severe CP, 8 years old):

I [Oliver] was awake when mum came down [Oliver has a ground floor bedroom] at 7.15am. I was just lying in bed chatting to myself and looking around my room.

Both of these excerpts also highlight the fact that some of the children with severe CP have ground floor bedrooms (and the rest of the family have bedrooms upstairs). The excerpt from Charlotte's diary also refers to the parental use of a monitor (in this case a baby monitor) in order to hear and monitor the child at night. Both of these important issues will be discussed in more detail in chapters 9 and 10 respectively.

The lack of independence and control for children who have severe CP in relation to sleep and, in particular, sleep timings is highlighted when bedtime and the activities leading up to night-time sleep were discussed by the young people.

7.3.2 The bedtime routine

The significance for children of what happens in the lead up to going to sleep at night is discussed by Williams et al. (2007) and Moran-Ellis and Venn (2007). Williams et al. (2007) found that children were much more forthcoming in their discussion of the processes leading up to going to bed and going to sleep as opposed to talking about the meaning of their sleep per se. Moran-Ellis and Venn (2007) describe the interactional processes leading up to night-time sleep as ‘specific rites, rituals and practices’ culminating in the physical relocation of the child from ‘shared public spaces of their home’, i.e. the living room to their
designated space for night-time sleeping, i.e. their bedroom. This relocation is accompanied by a series of activities and interactions signalling the end of the day and getting ready for sleep, such as brushing of teeth, as well as activities that aim to settle or calm children such as reading or being read to – the bedtime routine.

The bedtime routine can be conceptualised as a ‘family practice’ (Morgan, 1996; 2011). As discussed in Chapter 3, Morgan (2011) describes the six key features of ‘family practices’ which include a link between observers and the social actors, an emphasis on the active or ‘doing’, a sense of the everyday, a sense of the regular, a sense of fluidity and a linking of history and biography. The bedtime routine as a ‘family practice’ emphasises how family life is based on a set of activities that occur regularly, that may seem unremarkable or trivial, but which garner significance by being about ‘family’ and that also link into wider systems of meaning such as parenting. ‘Family practices’ emphasise relationships, activities and interactions as a way to define ‘family’ and the bedtime routine as a family practice highlights the relationship between family and sleep.

All the children with CP and the siblings made reference to or discussed their bedtime routine. The young people with severe CP using non-verbal or limited verbal methods of communication had access to a choice of words and/or symbols for the separate activities that happen in the lead up to sleep. To an extent they were, therefore, able to communicate the separate elements of their bedtime routine. However, the choice of words/symbols was still limited for these young people and dependent on the decisions of what words/symbols to include made by those adults responsible for putting together the communication system for the young person, e.g. parents, teachers, speech and language therapists. The following excerpt is from the interview with Charlotte Appleby (8 years old) who has severe CP when I was asking about what happens in the lead up to bedtime. Charlotte, as outlined in Chapter 6, uses a variety of methods to communicate including verbally saying ‘yeah’ and ‘no’ plus nodding or shaking her head and she can make choices between picture symbols by pointing at her chosen one.
Interviewer Can you tell me all the things that you do before bedtime?

Charlotte Yeah

Interviewer Can I show you some pictures? (Lays out on the floor 10 symbols of bedtime related activities and points to first one). Do you have medicine before bed?

Charlotte No (shakes head)

Interviewer No, Ok. (Points to next symbol) Do you read books before bed?

Charlotte Yeah (puts hand on book symbol)

Interviewer Yes. (Points to next symbol) Do you have a drink before bed?

Charlotte Yeah

Interviewer Yes! (Points to next symbol) Do you brush your teeth before bed?

Charlotte Yeah (puts hand on brushing teeth symbol)

Interviewer Yes! (Points to next symbol) Do you have a snack before you go to bed? Something to eat?

Charlotte Yeah.

(Charlotte Appleby, 8 years old, severe CP)

This illustrates that it is possible to obtain an idea of the schedule of activities leading up to bedtime but it is very difficult to elicit details and specifics. Furthermore, the bedtime routine is so much more than simply the activities that precede it. The bedtime routine as a ‘family practice’ is overseen and often directed by parents and thus involves complex and nuanced
interactions between the child and parents which may include negotiations, coercions, issues of power, autonomy and control. As with the subject of the lie-in the nature and extent of these interactions and resulting issues related to getting ready for sleep are different for children dependent on age and severity of CP.

7.4 Delaying sleep, asserting autonomy and covert activity

Previous studies have found a big difference between teenagers and younger children in terms of the flexibility and choice afforded to teenagers with reference to sleep timings (Moran-Ellis and Venn, 2007). Irrespective of the child’s age parents, in the main, retained control and supervision of ‘bedtime’ and the ‘relocation’ to the bedroom but once in their bedroom the teenagers decided for themselves what they did and when to actually go to sleep. Moran-Ellis and Venn (2007) discuss how this often allowed the teenagers the opportunity and privacy to socially interact with friends through the use of mobile phones and the internet. This section will discuss the autonomy, choice and control of the children in my research with reference to sleep timings and practices and highlight the differences evident between children with severe CP and those without (siblings and children with mild CP). This supports the work of Watson et al. (1999) and illustrates the heterogeneity of children with CP. The differences raised are most evident when comparing the older children that took part in the research.

The degree of autonomy and choice reported by Moran-Ellis and Venn (2007) was not as evident for the teenage participants taking part in my research, but this may be because the oldest participants were only 13 years old so at the lower end of the teenage age range. However, the ways in which autonomy and control, with reference to sleep timings, is coveted and the possible process by which it develops and increases was apparent in some of the discussions with the children, specifically those with mild CP and the siblings. Often a move towards independence in choosing when to go to sleep was demonstrated by the young people asserting themselves by small acts of rebellion against their parents as described by Joseph (9 year old sibling).
Interviewer: What’s your usual routine leading up to bedtime, what do you do?

Joseph: Um... play my DS, mum yells at me ‘Joseph, it’s 8 o’clock, go to bed’ so I go ‘OK’ and I get into my underwear, go into bed and read for 2 hours...

Interviewer: Two hours?

Joseph: Yeah, and I’m meant to go straight to sleep at 8.

Interviewer: Right, so does mum or dad come and check on you?

Joseph: No, because whenever they come up I just hide the book onto my chest.

(Joseph Cooper, 9 years old, younger sibling)

This provides an insight into how there is a real desire for more agency, independence and freedom of choice of when to go to sleep for siblings. This is further illustrated by Ellen (13 year old sibling), who describes how she sets about achieving the sleep time that, in her mind, is justified.

Interviewer: Tell me what happens leading up to bedtime?

Ellen: Ummm... usually I get ready and my parents tell me off as I am not in bed yet, and I say goodnight to Brian [older brother with CP], and I read for like an hour (laughs). My parents think I read for just a little bit but I use a torch afterwards.

Interviewer: Do you?

Ellen: Yeah.

Interviewer: So there is a lights out time?

Ellen: Yeah, it is usually bed at nine, and lights out at like half nine or something...
**Interviewer**  Ok, so bed at 9, lights out at...

**Ellen**  Between nine and half nine.

**Interviewer**  OK, but then not actual sleep until a bit later?

**Ellen**  Yeah, I am not tired at the time that my parents send me to bed, they don’t understand that teenagers at this age don’t go to bed that early anymore, they go to bed at half nine or ten.

*(Ellen King, 12 years old, younger sibling)*

Ellen justifies her secret torch use by claiming that she is not tired at the enforced ‘lights out’ time and by comparing (and thus identifying) herself with other teenagers, who she perceives, to stay up later. There are two points about Ellen’s justification that are interesting to note. Firstly, that at 12 years old Ellen already identifies herself as a teenager. Secondly, Ellen believes that other teenagers go to bed at half nine or 10 o’clock. This is only approximately half an hour later than Ellen herself is ‘sent’ to bed. Therefore, the difference between what Ellen believes to be an appropriate sleep time and what her parents ‘enforce’ is quite small.

It is less clear from the interviews how, and if at all, young people with severe CP could assert some independence in relation to their bedtime and night sleep. As discussed with reference to the ‘lie-in’ and morning time waking there is evidence of an age-based process whereby as children grow older their autonomy and choice about the timing of sleep increases. However, children with severe CP are unable to follow this path. In the same way that they are reliant on others to remove them from their beds, and thus dictate the start of the day they also have to fully rely on others (i.e. parents or carers) to facilitate getting ready for sleep whereby they are quite literally taken and ‘put to bed’. This is irrespective of their age, including teenagers. Children with severe CP are physically unable to do the activities that non-disabled children do to delay and ultimately control when they go to sleep, e.g. read a book, go onto the internet, watch TV and switch their own light off. Therefore, they cannot assert
their autonomy and control their sleep in this way because of ‘impairment effects’ (Thomas, 1999).

Furthermore, they are not afforded the same privacy as children without disabilities in the time between going to bed and falling asleep. Five of the families of children with severe CP employed a carer to help during the time period leading up to bedtime so often children with severe CP are taken and put into bed by a parent or an employed carer after a structured schedule of pre-sleep time activities (i.e. brushing teeth, being read a story) and then the parent or carer may stay with the child until they fall asleep. The next section discusses the use of paid carers at bed time in more detail.

7.5 Paid carers and bedtime for children with severe CP

As mentioned above, five of the seven families that included a child with severe CP used the direct payment scheme to employ a carer who helped care for the child with CP within the home at bedtime. Therefore, two families with a child with severe CP (the Appleby and King families) did not employ a carer to help within the home. The amount of care that the carers provided varied between families ranging from one evening every other week to 3 or 4 evenings every week to 1 whole night twice a month. The details for each family and the amount of care help they received is outlined in Chapter 6.

The use of employed carers, although not present every evening, highlights the differences between children with severe CP and siblings and children with mild CP at the time leading up to sleep. The presence of someone who is not a family member at the time leading up to sleep is significant as often this time is reserved and valued as ‘quality’ family time (Ben-Ari, 2008; Costa, 2012). Ben-Ari (2008) emphasises the bedtime routine (or as he labels it the bedtime ‘scenario’) as a cultural practice and that a child’s bedtime scenario as enacted within the urban middle class of Euro-American societies is characterised by four key features. Firstly, it takes place within the nuclear family, where the mother is usually the main caregiver. Secondly, it takes place in the private space of the bedroom, which where possible is not shared with siblings (or parents). Thirdly, it consists of a patterned or scheduled set of
activities culminating in tucking the child in and leaving them alone in their bedroom. Lastly, bedtime is perceived by parents as a last chance to make the child feel safe, secure and comforted, therefore, bringing to a close anything negative that may have occurred during the day and ‘so that children are made to feel good again’ (Ben-Ari, 2008: 176). However, a number of these features do not necessarily apply to the families who employ paid carers to specifically oversee and facilitate the bedtime of their disabled child. For instance, a paid carer is not a member of the family and their physical presence negates the privacy aspect of the child’s bedroom. It is relevant, therefore, to turn to the interview data of parents to ascertain the reasons for employing carers specifically to help with getting the disabled child ready for bed/sleep and also to explore the juxtaposition of this with the cultural values and features associated with the bedtime routine as outlined by Ben-Ari (2008) and with the conceptualisation of the bedtime as a ‘family practice’.

The main reason discussed by parents for employing carers in the afternoons and evenings was that this was the time when practical help was most needed. Particularly in the households that included siblings, the late afternoon and evening were busy times when parents had to negotiate and manage numerous and conflicting demands in the household. This busy period seemed to centre around dinner time and bedtime. As well as helping at bedtime, often the paid carers would come to help with dinner time as a number of the children with severe CP had feeding difficulties:

**Interviewer** How often does the carer come?

**Aileen** Every fortnight, they come at 5:00 and stay until 8:00 and they help us with the tea time and they enable us to, say, do something with one of the other children while... or both parents can do something with the other children, or we can do the cooking... and we know that Stanley [child with CP] is being entertained and the carer will help feed him his dinner.
(Aileen Edwards, mother of Stanley Edwards, interview)

Similarly, having paid carers at bedtime allowed parents to spend time, and carry out aspects of the bedtime routine, with their other children:

Interviewer How often do the carers come?

Kate Well I’d say we average about 4 evenings a week. The girls are here between 1½ and 2 hours.

Interviewer And what do they do?

Kate Well I tend to take her (indicates her baby daughter, Ruby who is sitting on her lap) up for a bath at 6:00. Sam [child with CP] has only been home [from school] for about 40 minutes or 45 minutes and so they [the carer] help Sam with his tea, play a game or something like that and then they get Sam ready for bed, that sort of thing.

(Kate Fletcher, mother of Sam Fletcher, interview)

Therefore, the employment of a paid carer at these busy household times was of practical help to parents and helped them manage the needs of all the family members. It must be highlighted again that paid carers did not attend every evening, therefore an assumption must not be made that parents prioritised the needs of their non-disabled child/children over that of their child with CP. The values attached to the bedtime routine and the features that characterise it are different for these families than those as outlined by Ben-Ari (2008). It is a busy time and it needs to be managed and carried out in a timely, efficient and practical manner. Perhaps then the portrayal of bedtime as a harmonious time for parent-child bonding and ‘quality’ family time is something of a myth (Power et al., 2017). This seems relevant for all families and for those with children with severe CP with additional care needs, whereby the bedtime routine may require extra time and attention to meet these needs, it is
understandable why a number of the families employed carers at this time of day. Furthermore, the cultural assumptions and values attached to the bedtime routine as a ‘family practice’ may not be totally forsaken if the employed carer is perceived by parents to be a ‘member’ of the family.

Two of the families had carers who had worked for them for a number of years. Both the mothers in these two families made reference to this fact and that they had grown very close to the carer. Kate Fletcher referred to the carer ‘as a friend really’ and Catherine Cooper referred to their long standing carer as ‘part of the family’. In the discussion with Catherine Cooper she went on to talk about how they had been invited to the carer’s wedding and they were the only ‘non-family’ members to be invited illustrating the mutual closeness that the carer and family felt for each other. The close bond that both the Kate Fletcher and Catherine Cooper felt for their carer was also highlighted through discussions about holidays and that on a number of occasions, in both families, the carer had been on holiday with the family:

**Interviewer** So when she [the carer] is here you and James [husband] can go out? Will she [the carer] look after the boys [non-disabled siblings] too [as well as looking after Libby, child with CP] or do you make other arrangements for that?

**Catherine** No, she will just watch all them, she’s really, really good. She’s more part of the furniture than anything now, so much so that we’ve taken her on holiday twice with us now.

**Interviewer** Oh really?

**Catherine** Yeah, first time we went I said to her ‘I can’t pay you for whole fortnight’, you know it’s too many hours out of direct payments so I said ‘I don’t want you to come and work every single day but if you just become part of us and if something needs doing, do it, if it doesn’t, don’t’. I said ‘But I’ll pay for your ticket,
your food, everything else’. So she went ‘Yeah, yeah definitely, where are we going?’ (laughs). She didn’t even know where we were going um, but she was up for it and it worked really well. We went to Florida and it was brilliant and what we did is we alternated nights, so one night James (husband) and I would get up [to attend to Libby, child with CP] and one night she [carer] would get up [to attend to Libby]. And that…oh it was great, it was really, really good.

(Catherine Cooper, mother to Libby Cooper, interview)

For these two families, who have had a long standing carer, there seems to a re-definition of what constitutes the family. Family is extended to include the paid carer and this supports the work coming from the field of the sociology of family as discussed in Chapter 3. Family is no longer about the ‘nuclear family’ and it is not a static and single unit. Instead it is fluid, diverse and changing in nature. The inclusion of carers in family practices that include the bedtime routine and going on holidays highlights the ‘doing’ of family through interactional activities that create and re-create what ‘family’ is.

It is difficult to ascertain how having an employed carer overseeing bedtime is perceived by children with CP. However, we get a sense of discontent from Oliver from his and his mother’s discussion of his bedtime routine and specifically the events that took place the night before the interview. Oliver has severe CP and can verbally communicate but it is often difficult to understand what he is saying. Oliver often relies on his mother to help interpret what he is trying to say to others.

**Interviewer**  What do you do to get ready for bed?

**Oliver**  As in what?

**Interviewer**  As in what? So when you start getting ready for bed, what do you do?
Oliver: Yawn... Wash teeth

Mum: You have your jim-jams [pyjamas] on?

Oliver: Yeah but with Lucy [carer] no...

Mum: You had your jim-jams on with Lucy didn’t you?

Oliver: No... (Oliver continues to speak but it is difficult for the interviewer to understand)...

Mum: (Mum listens while Oliver continues to speak) Oh, I see what you mean, yes. Lucy, the girl we have through direct payments, Oliver gets annoyed with her so he ends up with his t-shirt that he is wearing on in the end, because he definitely isn’t happy having her put his pyjamas on.

(Oliver Davis, 8 years old, severe CP)

The employment of a carer to help at bedtime was a relatively new arrangement for Oliver and his family. The novelty of the situation and the unfamiliarity of the carer may have been the cause of Oliver’s discontent and concern. However, it is clear that unlike Catherine Cooper, Oliver does not view his carer as part of the family. Getting ready for bed and the practice of getting undressed in order to put sleep clothes on is also quite an intimate and private activity. Therefore, for Oliver there is a blurring of the public and private divide and it is perhaps understandable why Oliver, especially considering the unfamiliarity of the carer, was not happy with the situation that occurred. Further to this, Oliver is use to his Mum helping him at bedtime so it was an unusual occurrence for him. Other young people with CP, who have employed carers overseeing bedtime, did not make specific reference to it perhaps reflecting that it was more of a familiar experience and one that they had grown accustomed to.
7.6 The impact of sleeplessness

As discussed in Chapter 2, Williams (2005; 2007) discusses how sleep can be analysed at three interrelating levels, the individual/(non)experiential level, the interactional level and the societal/institutional level. The first part of this chapter has been concerned with (mainly) the second of these levels and explored how sleep is ‘done’. Through an analysis of the ‘meanings, methods, motives and management’ (Williams, 2005) of children’s sleep, specifically related to the transition phases before and after night-time sleep, the social and interactional context of sleep has been highlighted. Through discussion of the use of paid carers and the differences highlighted for children with severe CP the third level of analysis has also been touched upon, especially with reference to issues around the regulating of sleep and the public/private divide. The next part of the chapter outlines the children’s views on the impact of sleeplessness which ties in with an analysis at William’s (2005, 2007) first level concerned with individual and (non)experiential matters. This section also considers children’s views about how other family members are affected by sleeplessness, providing an understanding of how the levels of analysis are interrelated as this discussion involves the second, interactional level of analysis.

Some children recognised ways in which lack of sleep negatively impacted on them and their daily lives. This seemed, in part, to depend on their age and gender. Specifically older girls including those with all levels of CP, discussed how a lack of sleep affected their ability to concentrate at school and affected them emotionally making them more irritable and grumpy with those around them. Some of the children with CP also remarked on how being tired impacted on their physical ability – slowing them down, adding to aches and pains and making it more difficult to co-ordinate their movements. Some older siblings recognised that when their disabled brother/sister had trouble sleeping this had a negative emotional impact on the child with CP and on their parents and, in turn, affected the whole family.
7.6.1 The impact of sleeplessness on self

Williams et al. (2007) found that a number of the children in their research were able to talk about sleep in terms of the ways lack of sleep had a negative functional effect on their lives and roles. My findings were similar as most of the older children in my research were able to reflect on how it feels for them when they are tired. The older girls, in particular, were more forthcoming in their discussion of the effect of tiredness on their emotions and how this impacts on their daily lives.

*Interviewer* If you haven’t had a good night’s sleep how does that make you feel?

*Willow* Grouchy, irritable, annoyed...

*Interviewer* And when you’re at school?

*Willow* I just feel like either putting my head on the table and falling asleep or if I’ve had a really bad night I feel like putting my head in a book... that helps or just falling asleep.

*Interviewer* Just falling asleep?

*Willow* Unless it’s my favourite subject...

*(Willow Edwards, 10 years old, older sibling)*

Some of the young people with severe CP were also able to communicate how being tired made them feel as they had access to picture symbols representing emotions. Libby Cooper (12 years old, severe CP) uses a complex and time consuming communication system as detailed in Chapter 6. When asked in her interview what it felt like when she was tired she chose a number of different words/picture symbols including ‘worried’, ‘cross’, ‘tired’, ‘scared’, ‘lonely’, ‘jealous’, ‘embarrassed’ ‘confused’ and ‘annoyed’. A full extract of this section of Libby’s interview is included in Appendix 13. Looking at the words she chose it is interesting and intriguing that she chose the words
‘lonely’, ‘jealous’ and ‘embarrassed’ as these are not emotions that would normally be associated with feeling tired. It is also difficult to really know why these words were chosen, however, both ‘lonely’ and ‘jealous’ were words chosen by Libby during another part of her interview when she was asked about what wakes her up at night and how she felt when she woke. This will be discussed in more detail in Chapter 9 about the bedroom. As discussed in Chapter 5 when analysing the interview data from Libby and the other children with severe CP who used non-verbal ways to communicate it was difficult not to start making assumptions about the meaning behind their symbol or word choices. However, I feel from the array of emotions chosen by Libby, as well as the ones not chosen, that she did understand the question and was able to communicate some of what it felt like for her when she was tired.

As well as the emotional impact of tiredness on self, the social impact was also discussed. Some of the older girls elucidated how being tired affected their relationships with others.

**Interviewer** If you have had a bad night’s sleep... how does it make you feel the next day?

**Ellen** I just feel really grumpy, and like I get really angry really quickly, like the slightest little thing that shouldn’t usually, wouldn’t usually annoy anyone that much…

**Interviewer** Ok and who might that be directed at?

**Ellen** My parents or my friends. It is never usually at my teachers or Brian [brother with severe CP]. I don’t know why. Well, teachers I know ‘cos they are teachers, and not Brian, I would never get angry with Brian really.

(Ellen King, 12 years old, younger sibling)
Despite feeling angry and having a quick temper when tired Ellen also insinuates that she has some control over these feelings as she is careful about who she expresses them to. Some of the older girls with CP were also aware of how feeling tired affected them physically and compounded some of the physical issues associated with their CP.

**Interviewer** Can you tell when you are tired?

**Grace** I guess I'm probably slower, I don't...I don't notice being slower but I can just notice my body feeling like 'Oh, I can't be bothered'...

*(Grace Baker, 13 years old, mild CP)*

This awareness of the effects of feeling tired was less evident in the interviews with the boys and younger children. Most of the boys and younger children did not feel that a bad night's sleep or feeling tired affected them in a negative way. For example, Daniel (older brother) only felt the effects of being tired if it had accumulated over a couple of days.

**Interviewer** When you are tired how does that affect you?

**Daniel** It doesn't, well except if I've got Maths then I'm nearly asleep anyway...

**Interviewer** (laughs)...Does it [being tired] affect your mood?

**Daniel** Sometimes but I'll only be a bit moody, a bit moody if I've been tired for a couple of days in a row. If I've just been tired for one day I might be a little bit [moody] in the morning and sort of brighten up a little bit...

*(Daniel Cooper, 13 years, older sibling)*

For some of the younger children it was difficult to ascertain how much they understood or were aware of the link between being tired and how they felt or behaved. This may be due to being young. However, it may also be about
the experiences the child has to compare in order to formulate their opinions on how being tired feels.

*Interviewer* And how do you feel after you’ve been awake in the night?

*Oliver* Fine

*Interviewer* You feel alright?

*Oliver* Yes

*Mum* He always wakes up bright as a button, don’t you?

*Oliver* I don’t know why.

*(Oliver Davis, 8 years old, severe CP)*

Oliver, who wakes at least twice every night, has some awareness that perhaps he should feel differently with his ‘I don’t know why’ comment at the end. However, young children that regularly and persistently wake in the night have little experience of feeling any different to how they usually do so it is difficult for them to comment or expand. There may also be an element of growing accustomed to having a broken night’s sleep and therefore the impact of sleeplessness is lessened. Similarly, young children who generally sleep well have little experience of feeling tired and cannot provide a narrative of how this feels.

### 7.6.2 The impact of sleeplessness on others

In families where child sleeplessness was a common and regular occurrence children and young people were asked about the possible impact on parents and other family members. This was particularly relevant for those families including a child with severe CP. Once again older children and girls were more aware and forthcoming of how it might feel for others in the family when they have had little sleep or are tired due to the child with severe CP waking during the night.
**Interviewer**  ...how do you think mum and dad are?

**Ellen**  They are pretty tired.

**Interviewer**  How can you tell if they have had a particularly bad night?

**Ellen**  ‘Cos they are grumpy and they are ratty with me.

**Interviewer**  But you know why they are tired, I guess?

**Ellen**  Yeah, I know why so I try not to get annoyed with them…

* (Ellen King, 12 years old, younger sibling)*

Ellen recognises the impact of her brother’s sleeplessness on her parents but it is also important for her to highlight how this then also impacts on her. Other siblings also discussed how their disabled brother or sister’s sleeplessness impacted on the family as a whole with specific reference to not being able to do activities together because of parental and child tiredness.

**Willow**  Because it [her brother’s sleeplessness] makes us all tired, more tired, so we don’t go out much. We are so tired.

* (Willow Edwards, 10 years old, older sibling)*

Furthermore for Willow, her brother’s sleeplessness also impacted on her own social life and having friends to stay overnight at her house.

**Willow**  And then I’m not that keen on letting anyone come to sleepovers at my house anymore, because of Stanley [brother with CP].

**Interviewer**  Why’s that?

**Willow**  I don’t want him to wake people up and I don’t, um…. if he does get to sleep, but then they are like a
bit like Izzy [a friend] and walk round waking everyone up, and if they open the door and wake Stanley... it will wake Alex [other brother] up and then I can’t get to sleep again.

*(Willow Edwards, 10 years old, older sibling)*

Some of the children with severe CP especially those who were older were able to recognise that their sleeplessness and requiring of parental assistance at night had a negative impact on their parents. Symbols chosen by some young people with severe CP in response to questioning about how their parents might feel when they have been awake in the night included 'tired', ‘don’t like’, ‘worried’, ‘confused’, and ‘dream’. The symbol for ‘dream’ was chosen by Libby:

*Interviewer* So when thinking about how mum and dad feel when they’re tired, the last word you chose was ‘dream’, is that right?

*Libby* *(Vocalisation and head movement upwards indicative of Libby’s Yes).*

*Sally*[carer] Do you want the word ‘dream’ Libby?

*Libby* *(Vocalisation and head movement upwards indicative of Libby’s Yes).*

*Interviewer* OK, so you think when they’re tired they dream... the next day?

*Libby* *(Vocalisation and head movement upwards indicative of L’s Yes).*

*Sally* Oh, like daydreaming?

*Libby* *(Vocalisation and head movement upwards indicative of Libby’s Yes).*

*(Libby Cooper, 12 years old, severe CP)*
Other young people and children were less aware of how their parents felt during the day as a result of being woken regularly and persistently at night. For those children whose parents get up in the night, every night, this is the norm and there may be no other situation with which to compare.

**Interviewer** Can you tell, Joseph, when they’ve [parents] had to get up a lot in the night [to Libby, his sister with severe CP], are they different in any way?

**Joseph** No, because they have to get up every night of all my life, so I can’t really see any difference.

**Interviewer** No, OK. Say they’ve had a really bad night, like they’ve had to get up loads does it affect them, do you see a difference then?

**Joseph** No

**Interviewer** No, ok, why do you think that is?

**Joseph** Because they’ve got use to it or sometimes I think different things. One thing is either they’ve got use to it or the other thing is they just fall asleep at work.

**Interviewer** (laughs)

*(Joseph Cooper, 8 years old, younger sibling)*

This also illustrates how Libby’s (child with CP) sleeplessness and the resulting sleeplessness for the parents has been long lasting and pervasive as Joseph cannot remember it being any different. This ties in with research, discussed in Chapter 2, that reports sleeplessness in disabled children as persistent over time (Quine, 1991; Wright et al., 2006; Wiggs, 2007). It also hints at the work parents do to protect their children from the reality of sleeplessness and the impact this has on daily life.
7.7 Conclusion

This chapter has outlined the analysis of data that highlights the social context of children’s sleep. In line with existing research (Williams et al. 2007) it was found that children were able to talk ‘around’ their sleep rather than explicitly ‘about’ their sleep. The practices, actions and interactions leading up to and following night-time sleep emerged as significant. This focus, specifically on the bedtime routine, allowed for differences to be examined between children with severe CP and siblings/children with mild CP. Differences were also dependent on age. Older children with mild CP and older siblings were beginning to utilise the time leading up to sleep to assert their independence and autonomy and to attain periods of privacy within the household. They were able to have some, increasing with age, control over their own sleep practices, especially regarding the timing of their sleep. This was not evident for younger children or for children with severe CP, irrespective of their age.

The bedtime routine is conceptualised as a ‘family practice’ and, as such, this example of ‘doing’ sleeping (Taylor, 1993) provides a lens through which to view ‘doing’ family and leads to a greater understanding of how sleep is embedded within family life. The employment of paid carers to help ‘manage’ the bedtimes of children with severe CP was an interesting topic of discussion and also provided insight into the meanings of family. When carers had been employed for a number of years there seemed to be a widening of the definition of ‘family’ to include them. This was especially evident in the discussion with Catherine Cooper (mother) who referred to their long-term carer as ‘part of the furniture’. However, for others, for whom the presence of a carer to oversee bedtime was a new experience, the carer was not considered as part of the family. This was evident from Oliver Davis’ (child with severe CP) experience and illustrates that familiarity and time (i.e. how long the carer has been employed for) play a key role in the definition of family and ‘family practices’. As the employment of paid carers to ‘manage’ bedtime is specific to children with severe CP, differences are once again highlighted between children with severe CP and siblings/children with mild CP with reference to sleep practices.
An exploration of the data on the impact of sleeplessness emphasised the embodied nature of sleep, with children referring to how sleeplessness made them feel and function, both emotionally and physically. Discussions focussed on the impact of sleeplessness on others emphasised, once again, how sleep (or lack of) is embedded in family life and how the sleeplessness of the child with severe CP can affect the family as a whole. However, this was not evident for all the young people as some children did not seem to be aware of the effects of sleeplessness (because of regular night waking to attend to their child with severe CP) on their parents. This may indicate that due to the persistent and long lasting nature of sleeplessness for children with severe CP, the negative effects on the parents are not recognised by children as there is not a time, when sleeplessness did not occur, to compare with.

An exploration of the sleep practices and organisation of sleep among children with CP and siblings is further discussed in the next chapter which analyses the data from children that focussed on the actors, activities and artefacts that helped or hindered their sleep. This chapter will continue to emphasise the social context of sleep and how it is embedded in family life. Furthermore, an analysis of the differences apparent between children with severe CP and those without, as well as differences based on age, will further highlight sleep practices as significant in the development of autonomy and independence.
8.1 Introduction

This chapter focuses on the actors, activities and artefacts that the children regarded as significant, helpful or obstructive in relation to sleep (or not sleeping). As in Chapter 7, the social and interactional context of children’s sleep is emphasised by their discussions of the practices and management of sleep, as is the way in which sleep is embedded in family life. For instance, a number of the siblings commented on being disturbed at night by their brother or sister with CP (but they were quick to add that it was not their siblings’ ‘fault’). The children also discussed who and what helped them when they woke during the night. For children with severe CP and younger siblings the greatest help to get back to sleep was mum and/or dad. For several children with CP the means of alerting their parents (i.e. through use of monitors) was also deemed helpful. Nearly all of the children took photos of cuddly/special toys and pets and talked of their significance with regards to promoting sleep. In line with the work of Moran-Ellis and Venn (2007) and Tipper (2011) special toys and children’s pets were regarded as ‘agents’ by children to be interacted with. The significance of pet cats in children’s discussion of sleep suggests flexibility and widening of the definition of the family and provides an example of ‘doing family’ in conjunction with ‘doing sleep’.

Individual, embodied and (non)experiential matters (Williams, 2005, 2007) related to sleep were highlighted by a number of children when they identified factors such as being too hot or too cold or being thirsty as reasons why they woke up at night. As well as these factors children with severe CP identified that their sleep was mainly hindered because of becoming uncomfortable in bed. Other factors that negatively impacted on sleep mentioned by a number of the young people centred less on physical or bodily needs and more on emotional experiences, e.g. bad dreams and worry.

Older siblings and older children with mild CP described ways that they help themselves to sleep (rather than relying on mum and dad), such as the use
of technology and relaxation techniques for their body and mind. This illustrates the embodied nature of sleep as well as a developing independence with reference to, and control of, their sleep and sleep practices.

8.2 Reasons for sleeplessness

All the young people were able to relay the reasons why they might wake up at night. For many of the young people these reasons centred on bodily needs and environmental factors.

8.2.1 Bodily and physical needs

The majority of young people commented that they often woke up because they were either too hot or too cold in bed, they felt thirsty or they were disturbed by external noises, e.g. a car alarm. Identification of bodily needs and/or environmental factors was easily achievable for those children with severe CP and limited verbal communication as they had the relevant picture symbols available to them. The identification and discussion of such factors also serves as a good example of the differences evident between children with severe CP and those with mild CP and the siblings. For instance, factors such as feeling too hot/cold or being thirsty were, in the main, considered by siblings and young people with mild CP as minor disturbances that they could easily remedy themselves. Hence the disturbance to their sleep was not long lasting and considered inconsequential, for example:

But sometimes I wake up and I am really thirsty and I have to get up to get a drink, or I always have a bottle of water on my kind of junk thing [shelving unit], which I always have there.

(Ellen King, 12 years old, younger sibling)

For young people with severe CP waking up because of these physical needs is more significant as they have to alert their parents or carers to assist them. They physically need the help of their parents or carers to have a drink or to rearrange a duvet or blanket that may have been kicked off or that they have slipped under too far.
Interviewer  Do you ever wake up in the night, Oliver?

Oliver  Yes.

Interviewer  And why do you wake up?

Oliver  Drink.

Interviewer  Drink? So you get a bit thirsty?

Oliver  Yes.

Interviewer  And what do you do when you wake up thirsty?

Oliver  Call.

Mum  You call me, don’t you?

Oliver  Yes.

(Oliver Davis, 8 years old, severe CP)

The seemingly innocuous need of quenching thirst then becomes an event that not only interrupts the sleep of the child but also that of the attending parent or carer. Additionally, the majority of children with severe CP communicated, or chose the symbol depicting, feeling uncomfortable as the main reason why they woke during the night. We all naturally move during the night, shifting our position or turning over to be comfortable. We are rarely aware of these movements as we do them at a barely conscious level. This is not the same for children with severe CP who often cannot move themselves sufficiently to a suitable or comfortable position. Furthermore, if they do move they often find themselves in an equally, or more, uncomfortable position than they were previously in. As with waking because of being too hot/cold or thirsty, there is a complete reliance on a parent or carer to attend to the child, who often will need to turn or adjust the child’s laying position in order for them to get back to sleep. The finding that needing help and parental assistance to change position at night was a common reason for waking at night for children with severe CP is in line with previous research. Wright et al. (2006) found that many of the
caregivers in their study who were looking after children with physical disabilities needed to change their child’s position at night. Furthermore, they found that 22% of the caregivers were getting up ten or more times per night to change their child’s position in order to prevent pain.

Therefore, bodily and physical needs were discussed by children as primary reasons why they woke up at night. Siblings and children with mild CP were able to independently deal with these issues whereas children with severe CP had to alert parents who would attend to the child’s needs. This impacts negatively on the sleep of the child with severe CP and the sleep of their parents.

8.2.2 Imaginary worlds

Many of the older siblings and those with less severe CP were keen to discuss their dreams, both good and bad. They were able to articulate how bad dreams or nightmares, affected their sleep and were a cause of waking up. For some of the young people the content of their dreams was intrinsically linked to events and happenings of their daily lives. For instance, Willow (sibling) was at the time of data collection waiting for the result of a school entrance exam which would determine her secondary school placement.

“This is my dream catcher and it catches all my really bad dreams”

(Grace Baker, 13 years old, mild CP)
Interviewer ...so when you were doing the data collection with the watch and diary, you’d had your exams, hadn’t you? I know in your diary you said that you’d had a dream about the school?

Willow Yes, that was the dream I had quite a lot.

Interviewer And what was that dream about?

Willow Well at [school name] the first day, like my favourite book character is Artemis Fowl and he was in the same school, and they were calling out the register and um... It’s embarrassing...

Interviewer It’s embarrassing?

Willow (laughs) And um... well I... he was, he was my lab partner, because we were in Science and um... I was quite pleased with that and on the way back, because it’s got these really steep steps I was asking ‘Are you really Artemis Fowl?’ and he like said ‘Yeah’, and then I fainted down the stairs! And it was... It was quite embarrassing!

(Willow Edwards, 10 years old, older sibling)

As mentioned by Willow in the excerpt above, dreams can often be recurring and persistent. When such dreams are nightmares or bad dreams this can be a source of worry and fear for young people which impacts on their sleep.

Interviewer So do you ever wake up during the night?

Joseph Only when I’ve had a bad dream or I’ve realised that I’ve been talking in my sleep.

[...]

191
Joseph  ...and there is this set of really bad dreams I have. It's about me waking up, every time it gets slightly worse, but the first time I wake up and come down and the family was shiny green zombies dressed very smartly and every time it gets slightly worse. The second time they were all creased, and third time they were quite scruffy and fourth time they went a darker shade and fifth time they had a couple of cuts, sixth time they had a bit of blood on them, seventh time they had loads of blood on them, eighth time they tried to kill me...

Interviewer  Oh, that sounds scary...

Joseph  I know, it's just like a series of dreams.

Interviewer  Yes and do you have these quite a lot?

Joseph  Yes

Interviewer  How often do you think?

Joseph  Once every week.

(Joseph Cooper, 9 years old, younger sibling)

Nightmares or bad dreams not only interrupted the sleep of the young people but also infiltrated and affected their emotions when they woke and on occasion, memories of the dreams and the feelings invoked were persistent across time. Thomas (sibling participant) described a cyclical relationship between daytime worries or anxieties generating bad dreams at night which in turn negatively affected how he felt on waking.

Interviewer  Do you ever get worried about things?

Thomas  Mmm (nodding) mmm...

Interviewer  Do you think that stops you sleeping?
Thomas Especially the night before when I had a really, really bad dream.

Interviewer Right?

Thomas Which made me woke [sic] up with tears a bit.

Interviewer With tears?

Thomas And it took me quite a while to get them off my, to get them off my face.

Interviewer Oh… and can you remember what that was about?

Thomas I can't remember now.

Interviewer Mmm...

Thomas Because I don’t want to talk about it.

Interviewer Ok, that’s ok

(Thomas Hughes, 7 years old, older sibling)

As will be discussed in the next section, anxiety, stress and worries were not only felt or recognised through the experience of bad dreams but were identified as directly affecting sleep by a number of the young people.

It was more difficult to gather information pertaining to dreams and nightmares from the young people with severe CP. A number of young people with severe CP did choose the word, or symbol depicting, nightmare when asked for reasons why they might wake up in the night, however, further details were then difficult to ascertain. On a couple of occasions when asked about dreams and nightmares the parent who was present during the interview commented that the young person might not understand the concept of a dream or nightmare.

Interviewer Can you tell me, Charlotte, can you tell me, do you have dreams when you are asleep? Do you have
dreams? [shows Charlotte the picture symbol for dream] Yes or no? [Holds out both hands, right hand for yes, left hand for no]

**Charlotte** [distracted and looking around] Aaiiiiii...aaiiiii...

**Interviewer** Have a think... Do you have dreams when you are asleep?

**Charlotte** Aaiiiiii [looks behind her towards her mum]

**Interviewer** Mum’s right there.

**Mum** You might have to explain what dreams are...

**Interviewer** Oh, right.

**Charlotte** Aaiiiiiiiiiii

**Interviewer** Shall I explain what dreams are?

**Charlotte** Aaiiiiiii [continues to be distracted and looking to mum]

*(Charlotte Appleby, 8 years old, severe CP)*

It was difficult to know, from the interview with Charlotte, if she understood the concept of a dream or whether she was choosing not to answer or if she was simply not interested or too distracted to answer. I did later try to explain what dreams are by describing them as ‘stories in your head’ but Charlotte did not answer again. This illustrates the difficulty of interviewing young people with severe CP and gauging not only their level of understanding but also their levels of interest and engagement. The influence of parents during the interviews with, in particular, those young people who do not verbally communicate is also highlighted.
8.2.3 Stress, worry and anxiety

Venn and Arber (2008) comment that stress and worry is generally, and in their view mistakenly, considered a cause of sleep interruption solely for adults and not for children and/or teenagers. However, just as Venn and Arber (2008) found with their group of teenage participants, stress and worry was also discussed by a number of young people in the present study as something that hindered sleep. The young people often described worries and stress as reasons why it was sometimes difficult to fall asleep (as opposed to reasons for being woken up). Often the worries discussed revolved around school, friendships or as Ellen (sibling participant, 13 years old) commented ‘general stuff’, and also concerns for family members.

**Interviewer** Ok, and what other things might keep you awake or stop you from going to sleep?

**Joseph** Sometimes there’s the stuff with my Nan, but I don’t really want to tell you about that.

**Interviewer** That’s ok, you don’t have to tell me about that.

*(Joseph Cooper, 9 years old, younger sibling)*

As with dreams and nightmares many of the young people with severe CP, who did not verbally communicate, chose words or symbols related to feelings of stress, worry and anxiety when asked for reasons why they might not sleep but it was difficult to then obtain further details as to the cause of such feelings.

**Interviewer** What wakes you up Stanley or stops you sleeping?

[lays out picture symbols for Stanley to choose] Is it sometimes too noisy and that wakes you up, or are you sometimes thirsty, or are you worried?

**Stanley** [lays hand on ‘worried’ picture symbol]

**Interviewer** Ok, sometimes you are worried?
It is interesting to note that after two different interviews in which the young person with severe CP chose ‘worried’ as a reason for not sleeping I added to my field notes that the parents present seemed surprised with their child’s choice.

As mentioned above, for siblings and young people with mild CP the reasons for them experiencing stress and worry that hindered their sleep was often discussed in general terms and as relating to school, friendships and family. Two young people, both siblings, discussed how sometimes they worried about their disabled sibling both during the day and also at night. Ellen and Willow both have brothers who have severe CP with additional health needs (Brian and Stanley respectively). The aspects relating to these additional health needs emerged as reasons for worry for both Ellen and Willow. For Ellen it was the worry of her brother Brian being sick in the night that concerned her. This not only caused Ellen to worry, but when Brian was actually sick it often disturbed and woke Ellen, as described in more detail in the next section. Willow worried about her brother, Stanley, having epileptic seizures, a worry that affected her during the day and at night. During the data collection period for the study Willow had witnessed her brother having a seizure, and although it was not the first time she had seen it happen, it was the first time she had been on her own with him.

*Willow* We were playing this game thing and we were trying to make his mini-robot do a cat walk and I went out to get something to measure, to make sure the... like it was the same all the way along and I thought I heard Stanley shout out and um... a big crash and I came back, all the things were like scattered and Stanley was on his side and he couldn’t move. When I sat him back up he started crying...

*Interviewer* And how did that make you feel?
Willow  A bit scared…. I didn’t know what to do.

Interviewer  So what did you do?

Willow  I just shouted until Mum came.

(Willow Edwards, 10 years old, older sibling)

For Willow sometimes the worry about Stanley having a seizure and being ill affected her during the day and impacted on her concentration at school but she also thinks about his ill health at night and this then influences her dreams.

Willow  I worry about [at night] if he [Stanley] like gets ill... Or if he’s like finding it hard or if he’s a bit ill, I don’t know really... and then I just have this weird dream...

(Willow Edwards, 10 years old, older sibling)

Willow also had concerns for her brother’s safety and health at night in relation to proposed plans to move his bedroom downstairs, (which will be discussed in more detail in Chapter 9 on bedrooms).

For other siblings of children with severe CP, worries or anxiety about their disabled brother or sister did not feature or have an impact on their sleep. For example, Daniel felt assured that it was not his role to worry about his sister at night and that if anything was wrong, his mum and dad would have the situation in hand.

Daniel  I know mum and dad get up to her [his sister Libby] and if there’s anything wrong they’ll find her...

(Daniel Cooper, 13yrs old, older sibling)

This section has outlined how stress, worry and anxiety did feature as a reason for sleeplessness for children with and without CP. Two children with severe CP chose the picture symbol for ‘worried’, however, details regarding
this choice were difficult to ascertain. Details were obtained from siblings and stress, worry and anxiety was often linked to school, friendships, family issues and, for two of the siblings, factors related to their disabled brothers’ additional health needs.

8.2.4 Being disturbed by others

Some siblings were disturbed and woken up at night by either the noise of their disabled brother/sister waking up or the noise of their parents who were attending to them.

Interviewer So, do you ever hear Libby [sister with severe CP] when she wakes up?

Joseph Yeah

Interviewer Does that wake you up?

Joseph Sometimes and sometimes I just sleep through it. But I know it’s happening.

Interviewer OK and who tends to get up to see to Libby?

Joseph Dad

Interviewer OK and do you ever hear dad get up?

Joseph Yeah I hear him go like this [makes groaning and mumbling noises]

(Joseph Cooper, 9 years old, younger sibling)

Daniel, who is the older brother of Joseph and Libby, also commented about hearing Libby and the attending parent at night. It is of interest that in the Cooper family home Libby’s bedroom is downstairs and the rest of the family have their bedrooms upstairs. The way in which the brother’s hear Libby at night (as is the way that the parents hear her) is through a baby monitor which is placed on the upstairs landing. Daniel has a strategy for minimising the noise
of Libby heard through the monitor, but is aware how it still affects his brother, Joseph.

**Interviewer**  Do you ever hear mum and dad getting up in the night?

**Daniel**  Sometimes I can hear them going up and down the stairs, sometimes I can hear her [Libby] through the monitor.

**Interviewer**  Ok, so sometimes you can hear?

**Daniel**  Yeah, the monitor’s on the landing in a plug so… Joseph [younger brother] keeps his door open when he’s asleep so I know he can hear it. But I keep mine shut, so I can’t always hear it.

_(Daniel Cooper, 13yrs old, older sibling)_

For Ellen, who’s older brother Brian has severe CP and wakes frequently at night, discussion of how he disturbs her sleep was initiated by discussion of the photos she took for the study.

**Ellen**  Um...so, I took a picture of my bedroom, ummm, and … here’s Brian [pointing at photo] because obviously sometimes he does disturb me in my sleep, not as often as he used to, since he has had the gastrostomy thing…. 

_(Ellen King, 12 years old, younger sibling)_

Ellen talked in detail about how sometimes at night Brian is sick (although this happens less since Brian had a gastrostomy fitted) and that this would disturb her. The King family live in a bungalow and the bedrooms are in close proximity to each other. In the discussion with Ellen she commented how often she was aware of Brian in the moments just before he is sick. Ellen is puzzled by this, but with further exploration it emerges that the sounds that Brian makes change
just before he is sick. Ellen feels in tune with these changes in sound and when she notices them she often takes responsibility to alert her parents.

Interviewer So do you ever hear Brian at night?

Ellen Sometimes, I mean sometimes I hear him, and like, if he is ever sick in the night, then every time he is, I always wake up a few minutes before he is.

Interviewer Ok.

Ellen Yeah most of the time, I don’t know why, it is like I know it is going to happen and then it does about three minutes later, if I am not asleep yet or even if it just wakes me up then... I don’t really understand why, and then I shout for Mum or Dad, and then they come in... But I don’t really know why [she wakes up just before Brian is sick], but, it hasn’t been for a while that that has really happened, but when it does, it is always a few minutes before he is sick, if he is, in the night. If it is really bad then I always wake up a few minutes before.

Interviewer Does he make particular noises if he is going to be sick that you sort of recognise?

Ellen Sometimes, like I can hear his breathing is sort of blocked a little bit and that is what I hear and then I think, ‘Oh no, he is going to be sick’ and then he is sick... and usually it is breathing that I can hear, it is kind of, it sounds like there is something in the way.

[...]

Interviewer Does it take you a while to then go back to sleep?
Ellen

Yeah, most of the time, especially because like I can hear my parents, I can hear them talking and helping and they have to switch the light on outside, so I can’t usually get back to sleep for a while afterwards.

(Ellen King, 12 years old, younger sibling)

As mentioned in Section 8.2.3 on stress, worry and anxiety the fact that Brian is sick in the night does cause Ellen to worry about him. Throughout the interview with Ellen it was apparent how close the sibling relationship is between her and Brian. Later in the interview she articulated clearly that Brian cannot help waking frequently at night and gives her views as to why she thinks he does wake. However, it is interesting to note that in the excerpt below (that directly followed the discussion about when Brian is sick) that she comments on feeling the unfairness of the situation but purely in relation to herself. For the majority of the interview Ellen talked with compassion and empathy for her brother and for the situation the family found themselves in.

Interviewer

Does it worry you when he [Brian] is sick?

Ellen

Yeah, sometimes. I mean, I don’t like it, it is not very nice.

Interviewer

No

Ellen

But, I just feel like, why does this always happen to me? It doesn’t happen to other families as often as this.

(Ellen King, 12 years old, younger sibling)

Many of the siblings, when disturbed by their brother or sister with severe CP, did not feel badly or blameful towards them. They all had their own ideas and thoughts on what caused sleeplessness for their sibling with CP and felt that often these causes were part of the cerebral palsy and so could not be helped. Causes such as being uncomfortable, unable to turn themselves, feeling ill and having nightmares were all cited by siblings as reasons why their
disabled brother or sister did not sleep well. Interestingly when asked what they thought might help their sibling with CP sleep better, all of them talked of medicine and sleeping pills with the view that if sedated the identified causes would not be so prominent or bothersome.

The compassion and understanding about being disturbed at night shown by siblings towards their brothers/sisters with severe CP was not so evident when disturbances to sleep, and through the night, came from other (non-disabled) siblings and family members. Willow talked of how she is disturbed by her youngest brother, Alex, as he is ‘annoying’ at bedtime and ‘messes around’. Young people were also disturbed by their parents, especially if they worked shifts, worked at night or had trouble sleeping. Grace was aware that her dad sometimes did not sleep well, and that on these occasions he could be noisy resulting in waking her up.

**Grace** ...Well sometimes like, if my Dad gets up, my Dad's a really bad sleeper, because he sometimes gets up in the middle of the night and decides, like, to put all the computers on and do work. He puts on like, all the lights on, and he flushes the loos and he is quite noisy and some nights, he gets up, and he wants his dressing gown to go to the study, so he like, 'cos my bedroom is like there and my Mum and Dad's bedroom there (demonstrating with her hands) and then you've got like walk-in wardrobes... so then they sort of meet, the walls meet. So my Dad sort of clatters around with the coat-hanger, it bangs against the wall and it echoes into my room, so that wakes me up.

*(Grace Baker, 13 years old, mild CP)*

Therefore, this section has illustrated that the night-time is far from being a time of isolation and, for many of the young people, it was a time full of disturbances and interactions. The interactional element of the night-time for the young
8.3 Actors and artefacts that aid sleep

Just as all the young people were able to relay reasons for their own sleeplessness, they were also able to identify the actors and artefacts that helped them sleep.

8.3.1 Mum and Dad

Many of the younger children (siblings and those with mild CP) and all of the young people with severe CP, irrespective of age, identified mum and/or dad as the greatest help in going, and getting back, to sleep. Nine out of ten of the families were two parent families with all the young people with severe CP living with both parents. For 4 of the 7 young people with severe CP both mum and dad were identified as helping and assisting them to get back to sleep during the night. For two young people with severe CP, it was always mum that came to help and for Sam Fletcher it was always dad that assisted at night. All the young people with severe CP woke at least once every night for, in the main, one or more of the reasons mentioned above i.e. being uncomfortable, too hot/too cold or thirsty. Therefore, parents would often need to reposition or rearrange their bedding.
For the younger children (siblings and those with mild CP) who identified and relied on their mum or dad to help them get back to sleep their needs during the night seemed to be fulfilled by parental comfort, reassurance and cuddles as opposed to the practical actions required by those with severe CP. However, the younger children without severe CP woke less frequently and less persistently compared to those with severe CP. It is also important to note that comfort and reassurance did feature and was provided by parents to their children with severe CP especially on nights when sleep was more disrupted than usual or where their ‘routine’ actions were not sufficient to remedy sleeplessness. As discussed in Chapter 10, a number of these parents and young people with severe CP, on particularly disrupted nights, would end up in a co-sleeping arrangement.

8.3.2 Ways to alert parents

*Charlie Hughes, 6 years old, mild CP*

For those children that relied on their parents to help them back to sleep at night, differences are evident in the way they alerted their parents. Alerting parents had two purposes, firstly, that they, the child, was awake and secondly, that they required parental assistance. Five young people with CP had baby monitoring devices in their bedrooms. The monitors featured in nearly all of these young people’s photographs and all were able to acknowledge and identify that this was the means by which they were able to alert their mum or dad if they needed them during the night. Oliver took a picture of his monitor, or as he calls it the ‘radio’:

*Interviewer*  Tell me again what that does [*pointing at photograph of the baby monitor]*?

*Charlie*  Um… I speak through it… at night

*Interviewer*  When you wake up?

*Charlie*  Yes

*Interviewer*  And who can hear you through that?

*Charlie*  Mummy.

(Charlie Hughes, 6 years old, mild CP)
Interviewer And what do you do when you wake up?

Oliver Call.

Mum You call me, don’t you?

Oliver Yes.

Interviewer How does mum hear you?

Oliver The radio (points to photograph of the baby monitor)

(Oliver Davis, 8 years old, severe CP)

From the quote and photograph at the beginning of this section it is interesting to note that Charlie, who has mild CP, has a baby monitor in his bedroom and sees it as a way of alerting or communicating with his mum. Charlie also has epilepsy and, according to his parents, it is for this reason that the baby monitor is in place. This will be explored in more detail in Chapter 10 when discussing parents' views on night-time monitoring and surveillance.

Although Charlie has a baby monitor in his bedroom if he wakes up at night, for reasons other than an epileptic seizure, he will often get out of bed and seek out his mum or dad. His brother Thomas will also do the same and both brothers (especially Thomas) will often get into their parents' bed for comfort and to fall asleep.

Interviewer And then what do you do [if you wake in the night]?

Thomas I go in Mummy's and Daddy's bed and then I fall asleep in their bed, and then Daddy might have to take me out, and put me back into my bed and then I have a Wallace and Grommit dream!

Interviewer Is that a good dream?

Thomas Yes.

(Thomas Hughes, 8 years old, older sibling)
Alfie Fletcher (sibling participant) also talked of how if he wakes during the night, because of a nightmare, he will get out of bed in order to find his mum:

*Interviewer* And what do you do when you wake up with a bad dream?

*Alfie* I just go in to Mummy’s bedroom and wake her up. And say that I’ve had a bad dream.

*Interviewer* And what does Mummy do?

*Alfie* She just comes and...

*Mum* Puts you back to bed

*Alfie* Back in bed!

*Interviewer* And then it’s ok?

*Alfie* Sometimes I have a cuddly, don’t I, Mummy?

*Mum* Yes.

*(Alfie Fletcher, 7 years old, twin sibling)*

In contrast, Alfie’s twin brother, Sam, who has severe CP, and is physically unable to get out of his own bed, has to call out and rely on being heard (as there is no baby monitor) by his parents in order for his dad (as it is always dad that assists Sam) to come and help him. As well as relying on his dad to help him and comfort him when he wakes at night, Sam also identified another nighttime interaction and activity that helps him when he wakes up at night and one that centres on artefacts mentioned by nearly all the children and young people interviewed – cuddly toys.
8.3.3 Cuddly toys and Pet Cats

“My cuddly toys – they are looking after me”.

(Charlie Hughes, 6 years old, mild CP)

Nearly all of the children and young people chose to take photographs of cuddly toys and other soft artefacts of comfort (e.g. special blanket) and identified these as being of great help in relation to sleeping. For many of these children there was one particular toy or item that held special significance. This significance was often related to how long they had had the toy or how they came to own it. For instance, it was important because they had had it since being a baby or because someone special had given it to them.

Often the stories relayed were not based on the children’s own direct memories but were obviously seemingly based on what they themselves had been told by their parents. Furthermore, for a number of children with severe CP it was the parent who was present during the interview that spoke of the significance of the toy, once again highlighting the influence of these parents during the interviews.

Interviewer Charlotte when you go to bed, do you have baby [baby doll] with you [pointing at picture of ‘baby’]?

Charlotte Yeah

Interviewer Does baby help you sleep?

Charlotte [points to mum]

Mum Tell you?
Charlotte: Yeah.

Mum: You’ve had baby since your very first day in the hospital, haven’t you? Baby was in your incubator when you were poorly...

(Charlotte Appleby, 8 years old, severe CP)

Age seemed to make some difference as to whether or not young people discussed cuddly toys as significant to their sleep. The young people who did not identify or take photographs of cuddly toys tended to be older in age with the exception of Grace Baker (13 years old) who was still very keen on her cuddly toys:

Grace: [Looking at photograph] But my cuddlies are, that’s Heebie, that’s my lionbear, my favourite. That’s my favourite ever and that’s one I got from my school – like a leaver’s present. That’s Tess, who I share with my friend – it was like year 4, and we both said ‘wow, I want a [cuddly toy] dog’ because we both like sheepdogs, I had a sheepdog, and it was like, I want that dog too, let’s buy a part share in it. So we sort of both bought it and now we share it...

(Grace Baker, 13 years old, mild CP)

One of the young people made direct reference to having outgrown cuddly toys and that the comfort they offered was no longer needed now that she was older.

Ellen: I have got a fluffy bunny but I don’t really cuddle up to him anymore ((laughs))

Interviewer: No?

Ellen: It is just there.

(Ellen King, 12 years old, younger sibling)
Cuddly toys and items of comfort are often conceptualised as transitional objects (Lee, 2008) and as such the expected norm is that children will at some point outgrow these and no longer need them for the purpose of comfort and security. However, for the majority of the children who did photograph and identify such transitional objects as important at night their purpose seemed to go beyond the transitional object definition. This is in line with Moran-Ellis and Venn’s (2007) assertions that cuddly toys can be viewed as ‘agents’ in children’s night worlds and as such are interacted with, highlighting again how, for children, sleep and the night is not a solitary time. The interactional aspect of the night, with specific reference to cuddly toys and special items, was clear in the narratives of many of the children and young people involved in my study:

*Interviewer* So if we think about when you wake up at night, Sam, what do you do when you wake up?

*Sam* Play

*Interviewer* You play?

*Sam* Talk [to] my teddy.

*Interviewer* What else do you do?

*Sam* Talk [to] my teddies!

*(Sam Fletcher, 7 years old, severe CP)*

There was also another ‘agent’ that was present and interacted with during the night and identified by a number of young people as important and helpful to sleep; the pet cat.

“Billy [the cat] is a sort of medicine, when she purrs and she’s really fluffy…”

*(Greg Jackson, 13 years old, moderate CP)*
Many of the young people who had pet cats photographed and identified them as providing comfort and company during the night. Some of the young people enjoyed playing and interacting with their cats, while others found simply their presence at the end of their bed a comfort and reassurance.

*Interviewer* Do they [the cats] ever come and sleep on your bed with you?

*Charlie* Yes… At the end.

*Interviewer* At the end, by your feet? And do you like that or would you rather that they didn’t?

*Charlie* Yes

*Interviewer* You like it?

*Charlie* They make me all snuggly and warm.

*Interviewer* They make you all snuggly and warm?

*Charlie* That’s how I get to sleep.

(Charlie Hughes, 6 years old, mild CP)

For some of the children, cats represented both a help and a hindrance to their sleep. A number of children discussed how, on occasion, their cats would wake them up by meowing or scratching at the door. However, in the main, the benefits of having their cats present and the comfort and company they provided far outweighed these occasional misdemeanours.

The importance attached to pet cats by the children in my research, both children with CP and siblings of all ages, is in line with existing research. Tipper (2011) reports that children often draw attention to the significance of pets when asked to talk about the relationships that matter to them in their everyday lives. Furthermore, Tipper (2011) comments that children include pet animals in their definition of their family and regard pets as ‘agents’ and ‘individuals in their own
right’ (p160). This consideration of pets as ‘part of the family’ was based on criteria such as cohabitation, quality and length of relationship which was also the criteria used by children when considering which humans counted as ‘family’ (Tipper, 2011). We are reminded once again of the fluidity, flexibility and diverse nature of ‘family’ and the concept of ‘doing family’ which emphasises activities, interactions, and practices.

Tipper (2011) discusses how the ‘physicality’ of relationships with animals dominated the discourses of the children with reference to animals in her study. This was also evident in my own research, as both the quotes above illustrate. Greg Jackson highlighted the fluffiness of Billy the cat and Charlie Hughes talked about how his pet cat made him ‘snuggly and warm’. This highlights what Tipper (2011: 153) refers to as ‘the tactile and embodied reality of knowing animals’.

Tipper (2011) concludes that by exploring children’s own perspectives, their relationships with animals can be understood within the social and relational context of children’s daily lives. My research illustrates that this is also applicable to children’s nightly lives. Tipper (2011) explains that the concept of ‘relationality’ emphasises the relationships themselves, by which, their richness is highlighted. She goes on to discuss how a relational approach ‘accommodates’ the way these relationships are embedded within, and constructed in relation to the many other social relationships in children’s life, for example, family. My research has also emphasised the relationality between children and their pet cats. I have also highlighted how the relationship is important with reference to sleep as interactions with pets aided sleep by being sources of company and comfort at night. This further emphasises the social context of children’s sleep embedded within family life.

This section has focused on the importance of cuddly toys and pet cats and has found that they are significant for children and their sleep practices. Cuddly toys and pet cats were framed as ‘agents’ and the interactions with them during the night, which provided company and comfort that aided sleep, highlights the social and relational context of sleep and the night-time. There were some age-based differences evident with reference to relationships with
cuddly toys. In the main (with the exception of Grace Baker) older children without severe CP did not identify or discuss cuddly toys in the same significant way as younger children and children with severe CP (irrespective of age). Age based differences were also evident in discussions about nightlights and children’s preference for light or darkness at night in order to aid sleep. This will be discussed next.

8.3.4 Nightlights and the preference for light or darkness during the night

There were differences between children in terms of whether they preferred to sleep with a degree of light or in complete darkness at night. The issue of light (and darkness) at night was also evident in the photographs taken by a number of the young people. Many of the younger children, with and without CP, photographed nightlights or toys that provided low level light at night (e.g. music and light show projection toys). For example, Alex’s nightlight in the shape of a ghost shown in the photograph below. The following excerpt occurred whilst looking at Alex’s photographs and discussing what happens in the lead up to going to bed. When the photo was discussed with Alex it quickly became clear why this was an important item to him.

*Mum* ...And you switch your little blue ghost light on, don’t you?

*Alex* Hmmm (nodding) because I’ll be scared...

*Interviewer* Scared?

*Alex* The dark, I don’t like the dark...

*Interviewer* Ok, so you like to have a light on?

*Alex* But not the very big light, just my little blue ghost light (points at photo)

*(Alex Edwards, 6 years old, younger sibling)*
Alex seems to understand that it would not be acceptable to have the ‘big’ light on, but it is ok to have a low level of light on during the night in order to mollify his fears of the dark. Alex’s mum also seems to authorise this by being the one to refer to the turning on of the little blue ghost light as being part of Alex’s usual bedtime routine. This suggests that there is a degree of negotiation and agreement between parent and child with regards to lighting levels at night. A similar finding was presented by Moran-Ellis and Venn (2007) who found that night lights were used and provided enough light to placate the children’s articulated fears of darkness and helped them in attaining sleep.

Older children (without severe CP) did not use equipment to provide light with most stating that they preferred complete darkness in order to sleep at night. This may illustrate older children’s awareness of age and age-appropriate behaviour and that having a nightlight is regarded as ‘childish’. James et al. (1998) discuss how age and age appropriate behaviour are central in children’s everyday sociality and are concepts that children readily engage with.

However, the majority of children with severe CP had some sort of low level lighting at night, irrespective of their age. For some this was a specific night light whilst others had their bedroom door open and a light on outside the room. For those children with CP that had a baby monitor in their bedroom the integral night light feature of the monitor was often turned on at night. It was difficult to elicit from the children with severe CP themselves the reason why they had low level lighting at night. For those that had taken a photo of their night light the question of whether this was something in their bedroom they liked was asked and all of them answered ‘yes’. The question of whether the night light helped them sleep was also asked and again the majority of them answered ‘yes’. However, whereas the younger siblings and younger children with mild CP, who used night lights, were able to explain their fears of darkness and the use of light to allay this, the young people with severe CP were unable to expound on this or other reasons why they liked having a light on at night. An interesting point to note is that in the interviews with parents a number of those with children with severe CP discussed how low level lighting in their child’s room or the external lighting from the hallway or bathroom was very useful to
them when getting up in the night to attend to their child. However, this was not something mentioned or discussed by the children with severe CP themselves.

This section has emphasised the significance of nightlights and the preference for light or darkness at night for children and highlighted how differences are evident dependent on age. Younger children preferred some type of low level light at night provided either through a specific nightlight or by having their bedroom door open and the hallway light on. Older children (without severe CP) preferred darkness at night to help facilitate sleep. This suggests that with increasing age preferences change and the transition from preferring light to dark may indicate an increase in autonomy and independence with reference to sleep practices. Having a light on symbolises a connectedness to the rest of the household by enabling children to see their surroundings and therefore, feel reassured that they are in a safe space and that others are near. Older children may not need this reassurance and instead desire the privacy, isolation, choice and independence that a closed bedroom door and darkness represents.

Differences are also evident between older children without severe CP (siblings/young people with mild CP) and older children with severe CP. Children with severe CP all had a nightlight or their bedroom doors open at night to allow for ambient low level lighting. There was no indication that, with increasing age, this situation would change especially when considering the practical usefulness of lighting at night for parents who have to attend to their child with severe CP on a nightly and long term basis. This once again highlights how older children with severe CP are not able to access the same levels of privacy and isolation as well as independence with reference to sleep practices when compared to older children without severe CP.

These differences are further highlighted in the next section when the ways and methods that older children without severe CP use to help themselves sleep are discussed.
8.4 Independent techniques to promote sleep

A number of the older children (both siblings and young people with mild CP) discussed techniques and strategies that they use, and ways that they had developed, to help themselves fall asleep (either at bedtime or if they woke during the night). It was generally the case that the young people who talked about these techniques were those that did not rely on, or seek, their parents help during the night. This highlights once more that autonomy and independence in relation to sleep develops with age and also illustrates the difference for young people with severe CP who, despite their age, have to continue to rely on parents or others to help them at night. The strategies used by the older siblings/children with mild CP ranged in complexity from simply reading to more elaborate and detailed practices:

*Interviewer*  ...if you can’t sleep or if you wake up in the night what do you tend to do?

*Daniel*  I’ll read most of the time, but the fuse has gone in my light or the bulb has gone in my light um... sometimes I just go the toilet for something to do, but other times I just read.

*(Daniel Cooper, 13 years old, older sibling)*

*Interviewer*  When you do wake up or you just can’t get to sleep what do you do to help go back to sleep?

*Willow*  Probably... I know this might sound weird but there’s this relaxation thing that I once did on sight training on the DS and it actually makes my eyes feel really sleepy after that, so that helps.

*Interviewer*  What sort of thing is that then?

*Willow*  It’s where you look as high as you can and then as low as you can, as far left as you can and then as far
right as you can. Then close your eyes. You feel really sleepy.

*Interviewer* Oh, Ok...

*Willow* I did it last night.

*(Willow Edwards, 10 years old, older sibling)*

The use of technology was deemed important by a number of the young people (without severe CP) when describing their strategies for promoting sleep. Furthermore, the idea that this caused their eyes to feel sleepy which in turn was an essential factor in them being able to fall asleep was reiterated by a number of young people. This was also something they recommended for others to try when they were asked what they would advise if other children or young people had difficulty sleeping:

*Interviewer* What things would you say to them [other young people] to help them to get a better night’s sleep?

*Grace* Like try and make your eyes tired ‘cos normally it’s my eyes that keep me awake…

*Interviewer* Mmmm…

*Grace* Like read or do like, watch like, something like…. If you’ve got like a laptop that you can take into bed or if you’ve got a computer in your room, or TV or stuff, watch something because that’ll make your eyes really tired…. Or do something like you have to concentrate on like, sometimes when I go on my Nintendo, I’ve sometimes gone on brain-training and do a Sudoku ‘cos like that makes my eyes tired… So, ‘cos I’m really like concentrating… I get really tired.

*(Grace Baker, 13 years old, mild CP)*
The embodied nature of sleep was also illustrated by children’s discussions that emphasised the need to relax their bodies or having to move their bodies into certain positions in order to achieve sleep:

Ellen  I usually scrunch myself up into a ball and get the covers up really close and yeah, then shut my eyes really tight, and go under the covers or something like that... That is usually how I get back to sleep.

( Ellen King, 12 years old, younger sibling)

The important link between the body and sleep is further extended to include the brain and how the ability to switch off or control one’s brain is essential when trying to achieve sleep:

Greg  I don’t normally have bad dreams, if I do, I normally I just fall... I just switch my brain to calm mode like this... it kind of goes off without me, it goes ‘weeeeee!’

( Greg Jackson, 13 years old, moderate CP)

This section highlights how older children without severe CP develop and utilise techniques and strategies to help themselves fall asleep. Discussion about these techniques often centred on the need to switch off or make tired parts of the body including the eyes and the brain as a way to induce sleep. Self-help techniques represent an independence that increases with age with reference to the management of sleep and sleep practices. This independence was not evident for younger children or children with severe CP, irrespective of their age and highlights, once again, important differences between these groups of children.

8.5 Conclusion

This chapter has presented data that highlights the social and relational context of children’s sleep. It illustrates that children are able and forthcoming in their discussion of sleep in relation to interactional aspects and the ‘meaning,
motives, method and management of sleep’ (Williams, 2005, 2007). These findings present a complex and rich picture of sleep from the point of view of children with CP and their siblings. By considering the actors, artefacts and activities that populate the young people’s night-time we can conclude that it is seldom solitary and often involves interactional practices throughout the night. Sleep is again shown to be embedded in family life.

Through an exploration of actors, artefacts and actions that hinder and help children sleep differences have been highlighted between younger and older children and also between children with severe CP and those without. For instance, differences between children with and without severe CP were illustrated by the reasons given by children about why they wake up at night. Reasons included being too hot or cold, thirst and, for children with severe CP, being in an uncomfortable position. Siblings and children with mild CP independently remedy these needs whereas children with severe CP have to rely on parental assistance to have their needs met. Mum and/or dad were also highlighted as the greatest help at night for younger children when they woke for other reasons such as bad dreams. In contrast, older children (without severe CP) had developed their own ‘self-help’ techniques to get to, or back to sleep. Certain artefacts and ‘agents’ were also discussed as significant with reference to sleep and highlighted differences between groups of children. Interactions with cuddly toys were important and helpful to younger children and children with severe CP but not, in the main, deemed as significant or ‘age-appropriate’ for older children. A similar finding was also discussed with reference to the use of nightlights and the preference for light or dark at night. Younger children and children with severe CP (irrespective of age) all had some degree of low level lighting at night and felt that this helped them to sleep better. Older children (without severe CP) preferred complete darkness in order to sleep. This may indicate a desire for privacy and isolation that shutting the bedroom door allows.

An examination of the differences found in the analysis of the actors, activities and artefacts that help or hinder children’s sleep illustrate that as children grow older they become increasingly independent in the management
of their sleep and their sleep practices. However, this is not evident for children with severe CP as they grow older. Furthermore, despite some of these independent sleep practices promoting a sense of privacy and isolation for older siblings/children with mild CP the night-time remained a social and interactional time, embedded within the family, for all children as illustrated by the disturbances to sleep caused by others and relationships with pet cats.
Chapter 9 - The bedroom: location, use, and significance of the sleep space

9.1 Introduction

Chapters 7 and 8 have focussed on the ‘when, what and with whom’ aspects of sleep for children (Williams et al., 2007). This chapter now explores the ‘where’ aspect and highlights the significance of the bedroom for children. As in the previous two chapters, differences between children with and without severe CP and differences based on age are highlighted.

The importance and significance of children’s bedrooms in terms of how they are viewed, arranged and used by the child themselves has been researched and discussed at both macro and micro levels, for example, by McRobbie and Garber (1976), Larson (1995), and Mitchell and Reid-Walsh (2002). The bedroom allows for privacy and it is an important space for children to explore and develop identity and autonomy (Mitchell and Reid-Walsh, 2002). Moran-Ellis and Venn (2007) found that the bedroom was an important private space for all their participants but the concept of privacy was different depending on their age. For instance, many of their teenage respondents chose to text or interact online with friends once they were in their bedrooms and prior to going to sleep, thus asserting autonomy and control in relation to the timing of their sleep. For their younger participants the opportunity for the ‘private moments of self’ that occurred in solitariness just before going to sleep or as part of the ritual of getting to sleep were important.

This chapter analyses the interview data from the children and illustrates how older siblings and older children with mild CP perceived their bedroom as a significant space that allows privacy within the household. Through discussion (including of their photographs) it was evident that their bedrooms were places in which to exhibit identity and autonomy. This was not so clear from the interviews of children with severe CP who tended to use their bedrooms for only sleeping and personal care needs. The location of the children’s bedroom is also identified as an important difference between children with severe CP and those without. The majority of children with severe CP had, or were going to
have, their bedrooms located downstairs whilst the rest of the family slept upstairs. This is discussed with reference to the perspectives of parents, children with CP and siblings. The chapter suggests that a downstairs bedroom increases the ‘public’ nature of this space for children with severe CP, which may have an effect on privacy, identity formation and autonomy for these children.

9.2 Bedroom use and location for siblings and children with mild CP

The perception of the bedroom as an important private space within the household discussed by Moran-Ellis and Venn (2007) is paralleled by the findings in the present study with a number of the young people (specifically siblings and those with mild CP) valuing what their bedroom represented and enabled. The bedroom was perceived by the siblings and young people with mild CP as an important place that signified privacy and a place where they could enjoy time to themselves either playing, reading, listening to music, computer gaming or watching TV. It was a place where autonomy, control and identity could be asserted, for instance, in arranging the room to suit their own personal preferences as discussed by Daniel who had distinct areas or zones (Lincoln, 2004) in his bedroom for the different activities that he used his bedroom for:

Daniel I’ve sort of got it [his bedroom] divided into three bits. I’ve got where my bed is, like where I sleep, and I’ve got a table with my stereo and stuff, so I can draw and just listen to music, and then I’ve got my Playstation area, where I sit and play that.

(Daniel Cooper, 13 years old, older sibling)

This zoning by Daniel reflects how the bedroom is a key identity space whereby he can assert control. Lincoln (2004: 97) describes a bedroom zone as:

...a physical and visual arrangement of furniture, technical equipment, beauty products, school books, in fact any item that is ‘contained’ within bedroom space. It is orientated by the social
activities that take place within that space, therefore it may not be fixed in physical or cognitive activities; zones can overlap and integrate.

Daniel identifies a clear ‘sleeping’ zone as did the teenage participants in Lincoln’s (2004) study and if we consider Lincoln’s definition of a ‘zone’ we can find support once more that sleep in itself needs to be considered as a social activity.

The bedroom as a place to form and display identities, as illustrated by the zoning of his bedroom by Daniel, was also evident in the discourses of the older siblings and older children with mild CP in relation to the objects present in their bedrooms. Bacon (2016) emphasises the importance of exploring the bedroom as a physical space because ‘the objects and spatial arrangements are the spaces that identities and relationships are lived in and through’ (p7). Bacon (2016) links this with the work of Smart (2007) and the ‘personal life’ perspective emerging from the sociology of family. Bacon (2016: 7) highlights Smart’s focus on the importance of considering ‘possessions, things and relationality’ and argues that objects in bedrooms are ‘invested with meanings’ that signify the displaying of identities and the practicing of social relationships. In his interview, Greg (child with mild CP, 13 years old) looked at and discussed in detail one of his photographs which depicted his ‘shelf of stuff’, a shelf of ornaments and artefacts that he had collected. He discussed the concept of being ‘cool’ in relation to his ‘shelf of stuff’:

**Greg**  
I wouldn’t really call myself cool, but I like my stuff. I’m really cool in my own way, I’m not cool like all the, like cool people think is cool, even though most of the cool people are total jerks!"

*(Greg Jackson, 13 years old, mild CP)*

Items and objects present in the bedroom also reflect the transistional nature of children’s identities and Bacon (2016) comments how children’s bedrooms often contain a mixture of items from the ‘past’ and ‘present’. Bacon (2016: 9) goes on to describe bedrooms as ‘constantly evolving material..."
spaces’. Grace (child with mild CP, 13 years old) discussed in detail the objects and artefacts present in her bedroom when looking through the photographs she had taken. The objects that she had photographed were a mixture of items from her past and present and reflects Smart’s (2007: 166) assertion that ‘things can throw light on social relationships’.

**Grace**
That’s my bed (pointing to one of her photographs) and that’s the curtains and there’s the window and there’s my wall hanging, there’s my computer. And there’s my collection of frogs [ornaments]. They look quite weird there but you see, I have a little obsession with frogs just like my Dad. [When] I was, like, younger and my Dad was, like, ‘Oh I liked frogs too when I was a child’ and I was like ‘you never told me that!’. Yeah, so like my little collection of frogs and that’s (pointing) like the sort of Buddha frog, and it’s actually like a Buddha frog, and then there’s my little collection of frogs that my Dad gave me. Then that’s (pointing to photo) like my trinkets and how cool is that, my cupcake candle from my friend!

*(Grace Baker, 13 years old, mild CP)*

The privacy that the bedroom space afforded the older siblings and children with mild CP was revered as was the autonomy, ownership and control that they had in relation to it. The fact that many of the bedroom doors had the children’s names displayed on them with a few having additional hand written signs with messages such as ‘keep out’ reflects the young people’s feelings of ownership about their bedroom space, as well as control over who accessed it. The bedroom space was often ‘off limits’ to parents and siblings, as Daniel strongly demonstrates when asked, following his description of his bedroom ‘zones’, if his family respected that his bedroom was *his* space:

**Daniel**
...if they don’t, I tell them to push off...especially Joseph [younger brother].
This control of access to their bedroom was not extended to everyone as a number of the siblings and young people with mild CP enjoyed using their bedrooms as a physical social space to invite and share with friends, highlighting the importance of the bedroom as a place where friendships are practiced and established (Lincoln, 2004; Bacon, 2016), as described by Ellen:

**Interviewer** And in terms of how you use your bedroom, apart from sleep in your bedroom what do you use it for?

**Ellen** I like to go watch iPlayer in there on my iPad and when my friends come around, we mostly hang out in there and listen to music and stuff.

The bedroom was a place located, in the main, upstairs and away from the public spaces of the household where the siblings and the children without severe CP could choose and were able to go by their own volition and without having to necessarily check with, or get permission from, their parents. This, once again highlights a degree of autonomy and control within the household for these older children (i.e. with mild CP and the siblings). The location and use of bedrooms as well as the privacy, autonomy and control that they signify for the siblings and young people with mild CP contrasts greatly with the experiences of children with severe CP.

**9.3 Location of the bedroom for children with severe CP. The downstairs bedroom: a disability norm?**

A number of the children with severe CP had their bedrooms located downstairs on the ground floor of the home. Table 9.1 outlines details of the children with CP who took part in the study and the location of their bedroom in relation to other family members. It also details if, at the time of the interviews, there were plans to move or change the location of the child’s bedroom.
<table>
<thead>
<tr>
<th>Name, age and severity of CP</th>
<th>Location of bedroom</th>
<th>Future plans to relocate bedroom of child with CP</th>
<th>Location of family member’s bedrooms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charlie Hughes, 7 yrs, mild CP</td>
<td>Upstairs</td>
<td>No</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Grace Baker, 13 yrs, mild CP</td>
<td>Upstairs</td>
<td>No</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Greg Jones, 13 yrs, moderate CP</td>
<td>Upstairs</td>
<td>No</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Jacob Gibson, 6 yrs, severe CP</td>
<td>Upstairs (accessed via a lift)</td>
<td>No</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Stanley Edwards, 7 yrs, severe CP</td>
<td>Upstairs</td>
<td>Yes</td>
<td>Upstairs (Stanley and younger brother Alex share a bedroom upstairs)</td>
</tr>
<tr>
<td>Sam Fletcher, 7 yrs, severe CP</td>
<td>Upstairs</td>
<td>Yes</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Charlotte Appleby, 8 yrs, severe CP</td>
<td>Downstairs (accessed via living room)</td>
<td>No</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Oliver Davis, 8 yrs, severe CP</td>
<td>Downstairs (accessed via hallway)</td>
<td>No</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Libby Cooper, 12 yrs, severe CP</td>
<td>Downstairs (accessed via kitchen/diner)</td>
<td>No</td>
<td>Upstairs</td>
</tr>
<tr>
<td>Brian King, 13 yrs, severe CP</td>
<td>Downstairs (bungalow)</td>
<td>No</td>
<td>Downstairs (bungalow)</td>
</tr>
</tbody>
</table>
As Table 9.1 details, 4 out of the 7 children with severe CP had their bedrooms located downstairs on the ground floor of the home. Furthermore, plans for 2 of the children with severe CP were being made to move their bedrooms downstairs resulting in 6 out of the 7 children with severe CP having their bedrooms located downstairs. The seventh child with severe CP, Jacob, has his bedroom upstairs, but this is accessed via a lift that was fitted by the Local Authority specifically for transferring Jacob, in his wheelchair, upstairs.

The bedrooms that are downstairs were, in the main, created specifically for the young person with severe CP by means of building a single storey extension to the main house. The exception to this was Brian, whose bedroom and the bedrooms of his family members are all downstairs because their house is a bungalow. The move to a bungalow, facilitated by the Local Authority and local Housing Association, happened 7 years previously and a bungalow was selected specifically because of Brian’s disabilities and his use of a wheelchair (the bungalow has wide doorways and ramped entry points). As Matt King, Brian’s father, explains in his interview the move to a bungalow was prompted by the practical implications of Brian growing older and getting heavier:

*Matt* It was getting to the point where we just couldn’t do stairs anymore; the carrying of him upstairs was getting impossible*”

*(Matt King, interview, father of Brian, severe CP)*

The downstairs location of the bedrooms of children with severe CP bedrooms will now be discussed in more detail, firstly from the parents’ perspective.

### 9.3.1 The downstairs bedroom: the parent perspective

The practical and physical difficulty of lifting a child who is getting heavier with age, as discussed by Matt King above, was the main reason given by all the parents for having a bedroom downstairs for their child with severe CP. The building of a single storey extension to facilitate a downstairs bedroom seemed also to be the preferred option of the Local Authorities who are responsible for the planning and part funding of such a build. The option of installing a lift was
often the preferred choice for the families, but the reality and practicalities (and perhaps the greater cost) made this a less preferred option for the Local Authorities. For instance, often a two storey extension would be needed in order to house a lift and a restructuring of the first floor necessary to account for the extension and to be fully accessible for a wheelchair (e.g. widening of doorways and landing areas):

**Sue** I can’t get her [daughter with severe CP] up the stairs any more. John [husband] struggles to lift her up there. We did initially look at doing a 2-storey extension which would have had a lift up, but that was refused planning permission. Maybe that was the best thing; it’s difficult to know...um... because it does work very well as it is now [with daughter’s bedroom downstairs].

*(Sue Appleby, interview, mother of Charlotte, severe CP)*

The view that having a downstairs bedroom for their child with severe CP was a positive and practical solution to the difficulty of lifting their child upstairs was reflected by most of the parents for whom it was relevant. However, one negative aspect was mentioned by nearly all parents. With the relocation of their child’s bedroom downstairs the distance between the parents’ bedroom and the bedroom of the child with severe CP becomes greater. All the children with severe CP woke at least once every night and required parental or carer assistance in order to get back to sleep (as discussed Chapters 6 and 8). Many of these parents mentioned that the greater distance led to them, the parent, being more fully woken up at night when they had to go downstairs to assist their child with severe CP in their bedroom at night. Sue Appleby explains how the level of her own waking at night differs when it is due to having to go downstairs to attend to her daughter Charlotte as opposed to, for instance, going to the (upstairs) lavatory herself. Sue also contrasts the level at which she wakes up attending to Charlotte downstairs with how it was when Charlotte’s bedroom was still upstairs:
For Sue, coming downstairs and being woken more fully is exacerbated by having to turn the lights on to negotiate the stairs. Catherine Cooper (mother to Libby) also feels that she is woken to a greater degree by having to go downstairs to attend to her daughters’ needs at night and this is compounded by feeling the cold:

**Sue**

I mean if I get up to go to the loo, I do basically do it in the dark, because you do just find the path, you just kind of know it. And I think it used to be like that when she [Charlotte] was upstairs, I could just go in the dark, listen to the door, just listen or double check and go back to bed and you didn’t, you didn’t rouse as much. In having the lights on and coming down[stairs], it definitely wakes me up more. I don’t think... it probably doesn’t have any impact on her [Charlotte], but I think it definitely does on me.

*(Sue Appleby, interview, mother of Charlotte)*

For Sue, coming downstairs and being woken more fully is exacerbated by having to turn the lights on to negotiate the stairs. Catherine Cooper (mother to Libby) also feels that she is woken to a greater degree by having to go downstairs to attend to her daughters’ needs at night and this is compounded by feeling the cold:

**Catherine**

When we get up in the night to Libby [daughter with severe CP] it is really cold, ‘cos we don’t have the heating on at night and that’s kind of the hardest thing in the winter, ‘cos you get out of bed and it’s freezing and you have to go downstairs and you get cold, and it wakes you up and then by the time you get back up to bed, you might just get warm and she [Libby] starts again and you think ‘arghh’.

*(Catherine Cooper, interview, mother of Libby, severe CP)*

The proximity of the bedroom of the child with severe CP to that of the parents also impacted and made a difference to the level and means of monitoring the child during the night. For those children where there were proposed plans to move them to a downstairs bedroom the parents accepted that the level of monitoring at night would need to change. This will be discussed in more detail in the next chapter.
As well as a change to the level of monitoring Aileen Edwards also voiced her concerns about the safety of her son, Stanley, in relation to the proposed plans that were being drawn up by the local authority for his downstairs bedroom. Although she accepted that a downstairs bedroom was now necessary, as she could no longer lift Stanley upstairs, and her husband had ongoing back trouble, she also found it hard as she felt that she was not being listened to in terms of the planned building work, both in terms of Stanley’s safety, but also because of the impact on the rest of the family and for her this led to feeling a loss of control:

_Aileen_ One of the plans that they were drawing up had three doors between him and us and they can't see why we were uncomfortable with that [if Stanley has a seizure]... We are going to have problems with just the fact that he is going to be downstairs, rather than upstairs... It is one of those things, a compromise you have to make, but three doors between him and us isn’t on... then their other idea is for him to actually go through the kitchen into his bedroom, so past the oven, to get to his bedroom and they can’t see that actually, as a parent, you feel very uncomfortable with that... So you know, it will be out of my control... and I have to think of the other people living here in the house, it’s not just him [Stanley] and me, so I cannot guarantee that he will [not] be coming through the door as say Alex [youngest child] is opening the fridge freezer and helping himself to something in there and may knock him [Stanley] out [of wheelchair]! And they [local authority] can’t get that! That actually, as a parent, you are looking at all the hazards within the house not just the ones relating to your child’s disability.

_(Aileen Edwards, mother, sibling interview)_
All of this was said during the interview with her eldest child, Willow, and as discussed in the ‘Sibling Perspective’ section below it is clear how the concerns of Aileen directly influenced those of Willow. For Aileen the prospect and the planning of the building work was obviously stressful, but it was a necessary and practical solution to not only the difficulty in lifting Stanley upstairs but also in order to create an extra bedroom so that Stanley and his younger brother Alex no longer had to share a bedroom. The brother’s sharing a bedroom was an arrangement that the whole family felt negatively impacted on the sleep of both boys (discussed in more detail in the Section 9.7).

Most of the parents whose children with severe CP already had their bedrooms downstairs commented on how they felt their child with severe CP preferred the downstairs location and enjoyed being closer to the public spaces of the household especially during the evening time.

**Interviewer** And when did the extension get done and he [Oliver] move downstairs?

**Nicola** It’s been about 3 years now that it’s been done.

**Interviewer** And how was it when he first slept down there?

**Nicola** He loved it ‘cos we were just, rather than him being upstairs on his own in the evening, he was just there, across the corridor. And he loved having his own room [Oliver was previously sleeping in same bedroom as his mum and dad] and it was big...

*(Nicola Davis, interview, mother of Oliver, severe CP)*

Similarly, Sue Appleby, mother of Charlotte, describes how being closer to the general noise of the household during the evening since moving to a downstairs bedroom helps Charlotte initially fall asleep at bedtime.

**Sue** I think because she [Charlotte] knows that we are here [in living room], she can hear us, she tends to go to sleep better if there’s a noise, than if there is
quiet, because when I’ve been in there [Charlotte’s bedroom] with her, John [husband] has turned the television down and she jumps every time he coughs or anything... She jumps, so I think she prefers a little bit of background noise, because it takes that startle out.

*(Sue Appleby, interview, mother of Charlotte, severe CP)*

The reassurance of noise and the resulting benefit to sleep was also outlined by Venn and Arber (2008) who found that during the night something as innocuous as a squeaky floorboard outside a bedroom door provided comfort and reassurance that family members were close by. However, for those children with severe CP who have their bedroom downstairs the proposed comfort and reassurance provided by close proximity and ‘background’ noise does not continue through the night. The benefits of close proximity during the evening time as stated by the mothers, Nicola and Sue, above cannot and does not continue through the night. As the rest of the household get ready for sleep they migrate away from the public spaces of the household to their own bedrooms upstairs and thus the distance to the child with severe CP sleeping downstairs increases. As discussed above a number of parents acknowledge this increased distance between their own bedroom and the downstairs bedroom of their child in relation to the impact it has on their own (i.e. the parents’) sleep when they have to attend to their child during the night. However, the majority of parents did not discuss how this increased distance and the absence of ambient and background noise may affect the child themselves when they wake during the night, as opposed to the benefits highlighted above in relation to the evening time and in getting to sleep.

### 9.3.2 The downstairs bedroom: the perspective of children with severe CP

It is only the child with severe CP themselves that can comment on how they feel about having a downstairs bedroom when the rest of the family have their bedrooms located upstairs. However, once again this type of in-depth reflection
was difficult to ascertain from the children with severe CP who used non-verbal methods of communication. Each child with severe CP who had a downstairs bedroom was asked if they liked their downstairs bedroom and the majority did answer ‘yes’. However, additional information about why they had a downstairs bedroom and the reasons why they liked it was not obtainable.

When asked the slightly reworded question of whether he liked having his bedroom downstairs Oliver Davis (severe CP, 8 years old) verbally and clearly answered ‘I don’t know’. However, it was not possible to question him further about this as he quickly became distracted and keen to talk about something else. Libby Cooper (12 years old) was also less affirmative when asked about her downstairs bedroom and it was difficult to obtain a clear answer as to whether she liked her downstairs bedroom or not. However, she was much clearer when choosing words from her communication book (with the help of her communication facilitator, Sally) to reflect reasons as to why she woke up at night as she clearly chose ‘don’t like’, ‘lonely’ and ‘jealous’ from a wide selection of choices:

*Interviewer*  Why do you wake up during the night?


*Libby*  (Vocalisation and head movement upwards indicative of Libby’s Yes)

*Sally*  I’ll read through them once more and when you get to the word that you want either say ‘yes’ or you can put your head up and Jessica can look for your
answer ‘cos Sally’s reading. Ok ready, you got ‘sad’…’don’t like’…

**Libby**  (Vocalisation and head movement upwards indicative of Libby’s Yes)

**Interviewer**  Don’t like? Ok. We’ll remember that one, shall we read some more?

**Sally**  Ok we’ve got ‘bad’… ‘worried’… ‘upset’… ‘cross’… ‘bored’… ‘hungry’… ‘thirsty’… ‘scared’… ‘fed up’… ‘puzzled’… ‘homesick’… ‘lazy’… ‘lonely’…

**Libby**  (Vocalisation and head movement upwards indicative of Libby’s Yes)

**Interviewer**  Lonely?

**Sally**  Was it yes to lonely?

**Libby**  (Vocalisation and head movement upwards indicative of Libby’s Yes)

**Sally**  Then we’ve got ‘jealous’…

**Libby**  (Vocalisation and head movement upwards indicative of Libby’s Yes)

**Sally**  Jealous?

**Libby**  (Vocalisation and head movement upwards indicative of Libby’s Yes)

**Sally**  Do you want that word? You want the word jealous?

**Libby**  (Vocalisation and head movement upwards indicative of Libby’s Yes)

*(Libby Cooper, 12 years old, severe CP)*
Sally then carried on and read each of the rest of the words out to Libby and Libby remained in a head down position which is indicative of Libby’s ‘no’ response. Libby’s choice of the words ‘don’t like’, ‘lonely’ and ‘jealous’ in relation to why she woke in the night was checked again with Libby later on in the same interview visit and then a third time when I returned a week later to continue the interview as I recapped what we had talked about at the previous interview visit (Libby’s interview was scheduled over 2 separate visits because of the time consuming nature of her communication system):

*Interviewer*  When I asked you why you woke up [at night], the words you chose were ‘don’t like’, ‘lonely’ and ‘jealous’, is that right?

*Libby*  (Vocalisation and head movement upwards indicative of Libby’s Yes)

*(Libby Cooper, 12 years old, severe CP)*

As noted in my research diary, at this point I was beginning to wonder if the feelings chosen by Libby related to where her bedroom was located in comparison to the rest of the household but without asking Libby potentially leading questions that could only require ‘Yes’ or ‘No’ answers it was very difficult to ascertain from Libby if this was the case. I did follow up with one question about if feeling lonely was because she was on her own in her bedroom at night, as a way to check Libby’s understanding of the word lonely and Libby gave her ‘yes’ response. I also asked Libby to confirm that her bedroom was downstairs which she did, and I then asked her if each of her family member’s bedrooms were downstairs. To each of these questions Libby gave her ‘No’ response. But it was then very difficult and potentially unethical to ask Libby about a direct link between having a downstairs bedroom and feeling ‘jealous’ and ‘lonely’.

As outlined in the Chapter 5, the level of information that can be obtained, and the analysis of the data, from a participant who uses a communication system such as Libby’s is limited and frustrating for both the interviewer and no doubt the participant themselves. This was accentuated by
my feeling that Libby's understanding of complex emotions and feelings such as jealousy and loneliness was good.

9.3.3 The downstairs bedroom: the sibling perspective

As discussed above the reasons for relocating the bedroom of the child with severe CP downstairs (or in the case of the King family being re-housed in a bungalow) were clear for the majority of parents (Section 9.3.1). As their children with severe CP became older they also became heavier and the difficulties and potential impact on parents' physical health involved in carrying their children upstairs motivated the build of, and relocation to, the bedroom downstairs. The reasons for having a downstairs bedroom and the potential feelings about having a different bedroom location compared to other family members were difficult to ascertain from the children with severe CP themselves (Section 9.3.2).

The siblings of children with severe CP were asked in their interviews to highlight the differences between their own bedrooms and that of their sibling with severe CP. The majority of siblings made no mention of the fact that their sister or brother with severe CP had their bedroom located downstairs. The differences most often focussed on the size of the bedroom and the difference in the type and size of their beds (see Section 9.6). One younger brother, Joseph Cooper (brother to Libby) did note that his sister's bedroom was downstairs and when asked why he thought this was, he answered:

*Joseph*  
She [Libby] sleeps downstairs because if there is a fire upstairs and she sleeps upstairs, she's disabled, so it would be harder to get up, walk past the fire without getting touched, pick her up, hold her over our head, put her through the window very gently and by that time the fire would have burnt us all wouldn't it? So we just have to run downstairs, get out the door, grab her on the way and get out. So it's easier.

*(Joseph Cooper, 9 years old, younger brother)*
Joseph’s stated reason for his sister Libby’s bedroom being downstairs is, like the parents, principally a practical one but it is also one that keeps all the family, including Libby, the safest. He knows that it is intrinsically linked to Libby being disabled and in his reasoning there is an element of him feeling that he, and the family, need to protect her especially with his use of words such as ‘very gently’.

Safety was also an important aspect considered and talked about by Willow Edwards when she discussed her worries about the potential building of, and subsequent move to, a downstairs bedroom for her younger disabled brother Stanley. This followed a discussion about why Willow thought her brother Stanley does not sleep well with Willow identifying that Stanley and her youngest brother Alex sharing a bedroom has a negative impact on both the brothers’ sleep:

**Interviewer** So do you think that would really help [Stanley and Alex to sleep better] when Stanley has his own bedroom downstairs?

**Willow** Maybe, but that also means that Mum is upstairs and there will be quite a lot of doors between them and Stanley, which will mean if Stanley has a really bad seizure, we won’t be able to tell.

**Interviewer** That worries you does it?

**Willow** Yes, I don’t want him to get ill and no-one realising.

**Interviewer** Ok

**Willow** Because at the moment he will sort of give out a cry, or start crying or something if he falls over, or got his head stuck between the side of the mattress or something and then we will come and sort him out, and yes…but if he was downstairs and we couldn’t hear him it’s not going to be good….
(Willow Edwards, 10 years old, older sibling)

Willow’s worries about the safety of her brother when he moved downstairs were somewhat alleviated when her mum (who was sitting in on the interview) assured her that they would have a ‘baby monitor’ to hear Stanley when he moved downstairs. But it was also clear that Willow’s worry and uncertainty about the move downstairs was also shared and perhaps influenced by the worries of her mum. As the interview with Willow continued Aileen, her mum, interjected about her own frustrations about how the potential conversion of downstairs to accommodate a bedroom for Stanley was being handled by the local authorities as discussed in Section 9.3.1. With Aileen voicing her concerns and frustrations in the presence of Willow it is understandable why Willow has the worries she does. It is also understandable from the point of view of Aileen who accepts that a practical solution is needed, but also feels a lack of control over the changes proposed for her and her whole family’s home.

9.3.4 Section summary

The location of the bedroom downstairs may in many ways be seen as a way to enable accessibility for children with severe CP. Because access to an upstairs bedroom becomes difficult with the child’s increasing age and weight, a downstairs bedroom is considered a practical option. It is important to note that with the building of, and move to, a downstairs bedroom for children with severe CP the upstairs part of the house becomes an area never to be accessed by them again. From discussion with parents, siblings and children with severe CP who have their bedrooms downstairs, this was not an aspect reflected on. But it is significant as this differentiates those children with severe CP and downstairs bedrooms from most other children living in their family home. It is an unusual situation for a whole area of a home not to be accessible or frequented by a member of the family. The lack of discussion by parents about this particular aspect may reflect that it is just the way it has to be, as for the most part having a downstairs bedroom for their child with severe CP was viewed by parents (and Local Authorities) as a solution to a practical problem. As Aileen Edwards stated having a downstairs bedroom for her son was a compromise that they had to accept.
Many of the parents also felt that their children liked and favoured the downstairs location of their bedroom because of the close proximity to the rest of the family in the evenings. However, the greater distance did lead to parents having to wake more fully when attending to their child’s needs during the night. How the children with severe CP felt about having their bedroom downstairs (as well as no longer being able to access the upstairs of the house) was difficult to ascertain. The majority of the siblings did not comment or reflect on their brother/sister with severe CP having, or about to have, a downstairs bedroom. Out of the two that commented, one reflected that it was safer for his sister to be downstairs in case of a fire, whilst the other sibling was concerned about her brother’s safety when he moved to a planned downstairs bedroom.

Concepts such as privacy, control and solitariness that the bedroom affords children and young people without severe CP, as discussed at the beginning of this chapter, may not be attainable for children with severe CP. As discussed in the next section, rather than making the bedroom and all that it encompasses accessible, a downstairs location may actually become a barrier to this.

9.4 The use of the bedroom by children with severe CP

One of the biggest differences evident for children with severe CP compared to their siblings and children with mild CP with regard to their bedrooms was how little time they spent in them. Unlike their siblings and the young people with mild CP, children with severe CP did not or were not able to spend their ‘free’ time in their bedroom and therefore, would often remain, during the day, in the public spaces of the household, i.e. living room, kitchen and dining room. Their bedrooms were used, in the main, only for the purpose of sleep. For a number of young people with severe CP their bedrooms were attached to an en-suite bathroom (especially those young people that had their bedrooms located downstairs). Therefore, the bedroom was also a place associated with personal care needs during the day (e.g. toileting and pad changes). Because of their physical mobility limitations in combination with their verbal communication difficulties moving themselves or asking to be moved to their bedroom was difficult. It is also important to add that for these children the activities available
to them within their bedrooms were limited compared to that of their siblings and the children with mild CP. The activities enjoyed by the siblings and those with mild CP in their bedrooms such as playing, listening to music, watching TV, and hanging out with friends were not activities that children with severe CP would generally be able to participate in without the assistance of someone else representing, once again, the concept of ‘impairment effects’ (Thomas, 1999). Therefore, the solitariness and privacy that the bedroom affords siblings and children with mild CP is not attainable for those with severe CP.

9.5 The downstairs bedroom: an extension of the public space

As discussed above, the bedroom for children with severe CP may not be utilised as a private space to spend time participating in solitary leisure or ‘downtime’ activities, because the bedroom itself and the activities are often inaccessible to them. This is further compounded by the fact that for a number of the young people with severe CP their bedrooms, far from being private spaces are actually very public ones (within the household).

One example of this is highlighted by the employment of paid carers to help with the care of a number of the young people with severe CP. As discussed in the Chapter 7, many of these families had help from a paid carer in the early evening and specifically to help get the child with severe CP ready for bed and sleep. By being so involved in the process of getting the young person ready for bed it can be assumed that the carer has a significant presence within the child’s bedroom. This contrasts greatly with the older children (siblings and those with mild CP) who are beginning to assert autonomy and control in the physical relocation and process that takes place in the lead up to bedtime and sleep and who value the privacy and opportunity to be by themselves at this time. The contrast is evident when considering the fact that older children with severe CP need parental assistance at bedtime but with the employment and presence of paid carers it is made all the more apparent.

A further way that the bedroom of children with severe CP can be viewed as a public space is highlighted by how it is used by the rest of the family. This was particularly evident for those children with severe CP who have their
bedrooms located downstairs. An example of the ‘public’ use of the downstairs bedroom of a young person with severe CP occurred when I visited the Cooper household to carry out the individual interview with Catherine, the mother. The interview started in the dining area of the kitchen which is located in a conservatory extension of the house. At the beginning of the interview the mother, Catherine Cooper, noted that it was raining and as the interview commenced she said:

*Catherine*  Can I just check you can hear this [interview on the digital recorder] with the noise of the rain [on the conservatory roof], because if not we can go into Libby’s [daughter with severe CP] room”

*(Catherine Cooper, Mother of Libby Cooper, interview)*

The noise of the rain was noticeable when I played back the digital recording, so Catherine decided that we would relocate and continue the interview in Libby’s bedroom which was located downstairs and accessed via the kitchen/diner. A similar example occurred when I returned to the Cooper household to carry out the interview with Joseph Cooper (sibling), who is the youngest child in the family. As noted in my research diary it was early evening and the household was busy with Libby and her older brother in the living room watching television and Catherine Cooper cooking dinner in the kitchen. Catherine suggested that Joseph and I go into Libby’s bedroom to carry out the interview which we did. It is perhaps interesting to note that Libby’s own interview did not take place in her bedroom but in the dining area of the kitchen. These are examples of how a bedroom (particularly one located downstairs) can become a public space used by different members of the family. It is difficult to perceive such an occurrence happening with bedrooms that are located upstairs and even in bungalows where, although the bedrooms are located downstairs they tend not to be accessed via the more ‘public’ spaces of the household e.g. via the kitchen or living room.

A third example of how the downstairs bedrooms of children with severe CP become part of the public sphere of the household is illustrated by the use
of monitoring and surveillance equipment carried out by parents of their children during the night. As discussed in more detail in Chapter 10 all the parents of children with severe CP who had a downstairs bedroom, used a ‘baby monitor’ in order to hear their child and monitor if they were required to provide assistance during the night. The use of a ‘baby monitor’ represents a constant listening presence from within the child’s bedroom and therefore prevents true privacy from being achievable.

A final reason, and one linked to Section 9.6, relates to the amount of disability-related equipment often stored in the bedroom of children with severe CP, especially when the bedroom is located downstairs. On the whole the equipment is for use during the bedtime routine and the night so it makes sense for it to be present in the bedroom. However, other items of equipment such as spare wheelchairs, battery chargers for wheelchairs, standing frames etc. were often also visible in these children’s bedrooms. Such items are required and needed during the day, so the child’s bedroom would need to be accessed by others in order to retrieve these pieces of equipment. Furthermore, by storing the equipment in the bedroom of children with severe CP other areas of the household are kept free of such items. Because the bedroom is viewed as suitable for storage of such items throughout the day, it further highlights the fact that children with severe CP rarely used their bedrooms as their own personal space to be in during their free time or for other activities apart from sleeping.

9.6 Contents of the bedrooms of children with severe CP: a clinical space

As mentioned above the bedrooms of children with severe CP often contained items and equipment related to having a disability and for use in getting ready for bed and for sleep. The two items most discussed in the interviews and photographed were the adapted bed and the hoist in the bedrooms of children with severe CP.
9.6.1 The ‘hospital’ or ‘adapted’ bed

During the interviews siblings were asked to identify any differences between their own bedroom and that of their brother/sister with severe CP. As discussed in Section 9.3.3, very few commented on the downstairs location of the bedroom of the child with CP, but one aspect was mentioned by nearly all the siblings - the bed. Many of the siblings commented on the size difference of their bed compared to that of their brother/sister with severe CP, with their own often smaller in comparison:

*Interviewer* What is the biggest difference between Brian’s [child with CP] bedroom and your room?

*Ellen* His bed is pretty much on the floor and it’s like a huge double bed, whereas my bunk bed is pretty much on the ceiling and it is a single bed so it’s much smaller...

*(Ellen King, 12 years old, younger sister)*

Brian’s (aged 13 years) bed is low to the floor as he does not like there to be sides on his bed, a feature common to the beds of children with severe CP to stop them from falling out of the bed. As well as the size of the bed, other siblings noted the mechanical aspects of the bed of their brother/sister with severe CP as something that was different to their own:

*Interviewer* Is there anything different about his [Stanley’s] bedroom compared to yours?

*Willow* ...there is sort of the bed, which is a big one and then it goes up and down like that and stuff...

*(Willow Edwards, 10 years old, older sister)*

The difference between the beds of children with severe CP and those of the siblings and children with mild CP was also evident from the photographs taken by the children which showed beds with sides and with electronic
functions (Figure 9.1). This difference is particularly highlighted in the photo of the shared bedroom belonging to Stanley Edwards (child with severe CP) and his younger brother Alex (Figure 9.2):

The mechanical and additional features of the beds of the majority of the children with severe CP were required for practical reasons. As mentioned above, many had sides to stop the children from falling out, similar to what would be used for young children when they transition from a cot to a first bed or like the sides that can be erected on a hospital bed when transporting patients. The function of being able to move the bed up and down was also common and an useful and protective feature for parents and carers when having to physically move and attend to their child with severe CP. Often the bed was also used as a place to change the child’s nappy or pad (the majority of children with severe CP wore nappies or incontinence pads throughout the day and night), therefore adjusting the height of the bed was helpful to parents as they did not need to bend and put undue pressure onto their backs. During the 2 week data collection period of the study Libby Cooper, got a new bed and as Catherine, her mother explains, this was very beneficial:
Catherine

It’s a lot better for our backs now we’ve got a proper bed [for Libby]. We did have a hospital bed before that went up and down, but it was so noisy that we tended not to use that [function]...the new bed is quiet, it’s easy to move up and down um, and she [Libby] is getting use to it”.

(Catherine Cooper, interview, mother)

Catherine’s comment that Libby ‘is getting use to it’ refers to the fact that for the first couple of nights in her new bed Libby was quite unsettled and both Catherine and James (father) felt this was because of the new bed, specifically the fact that it had sides on it, which was something Libby was not use to.

It is interesting that the feature of being able to adjust the height of a bed was deemed important and was used by many of the parents as a protective function against back injuries. This same acceptance and utilisation was not so evident in relation to hoists which were provided to help in the lifting and moving of their child with severe CP and present in nearly all of these children’s bedrooms.

9.6.2 The hoist

A hoist is a device used to lift, move and then lower people who are unable to move themselves. In the bedrooms of the children with severe CP, two types of hoist were generally present. The first is a mobile hoist that is on wheels so can be moved anywhere within and between rooms (that are on the same level). An example of a mobile hoist is the one belonging to, and photographed by, the Appleby family (Figure 9.3). A second type of hoist that was present in a number of the bedrooms of children with severe CP was a fixed ceiling type. This can only be used in the place that the ceiling track runs along. A number of children with severe CP and downstairs bedrooms had en-suite bathrooms. In this situation the hoist ceiling track would run from the bedroom through to the bathroom to aid the transfer of the young person between these two places. An example of a ceiling hoist is the one photographed in Libby Cooper’s bedroom (Figure 9.4).
Unlike the acceptance of needing a downstairs bedroom for their child with severe CP and the use of the height adjustable function on the beds, because of the difficulties in lifting and moving their child, there was a lot more reluctance on the parent’s part to use the hoists despite them being present and available within the home. A number of parents seemed quite embarrassed to admit that the hoists were hardly used:

Sue  We very naughtily haven’t used it [the mobile hoist in daughter, Charlotte’s, downstairs bedroom] up to this point, but I am going to have to now [because of a bad back]. It will primarily, I think at this stage, be for getting her [Charlotte] off the shower chair because that is a difficult lift for me. John [husband] lifts her into bed and the other difficult lift I’ve got is up the bed in the middle of the night, and we are going to get slip-sheets for that”.

(Sue Appleby, interview, mother to Charlotte Appleby)

Other parents felt that using a hoist was simply too time consuming despite knowing the risks of damage to their own backs and often (especially a ceiling hoist) was fitted as a requirement of local authorities for when paid carers visited and attended to the child in the home:
Interviewer And do you use the hoist to move her [Libby] in and out of bed?

Catherine No (laughs), no, we don’t use it very often um... but we have got that option if we want, but to be honest by the time we got the hoist and faffed around, it’s just easier to lift her

Interviewer So is this [the hoist] used by the carers?

Catherine Um, officially yes, but when they [local authority] came to service it last they pulled it down and a big lump of dust fell out (laughs), so they know we don’t use it.

Interviewer Ok, so if you need to get Libby out of bed you’ll…

Catherine I’ll tend to pick her up... I’ll tend to lift her and um, getting her into her wheelchair it’s just as easy to lift her as it is to use the hoist

(Catherine Cooper, mother of Libby, interview)

Vicky and Matt King, at the time of the study, had recently started to routinely use the ceiling hoist to transfer their son Brian (aged 13 years) in and out of his bed because of his increasing weight. As well as citing the benefits that this was having for themselves physically, in terms of their backs, necks and shoulders, they also felt that it was more comfortable for Brian himself:

Interviewer How does he [Brian] feel about the hoist?

Vicky He is quite happy with it.

Matt He is ok with it.

Interviewer Is he use to it, as do they use hoists at school?

Matt Yeah, before we used them at home.
Vicky Yeah, long before and I think because of his increase in weight, I think us lifting him had got less comfortable for him.

(Vicky and Matt King, mother and father to Brian, joint interview)

How the children with severe CP felt about the presence of the hoists as well as the (non-)use of them was not clear from their interviews. They were certainly aware of them as photographs of the hoists were common. One aspect related to the ceiling hoist was referred to by Brian King and explained more fully by his father Matt during Brian’s interview:

Matt He [Brian] doesn’t like to have the light on above his head that shows that the hoist is charging. He doesn’t like any of those things on, you have to turn the light off, that is on his stereo as well. That’s right, isn’t it Brian?

Brian Yes (answered via his eye-gaze voice output device)

(Matt King, father, and Brian King, 13 years old, child with severe CP)

Therefore, differences between the bedrooms of the children with severe CP and that of their siblings and other children with mild CP are illustrated. The main difference discussed by siblings was in relation to the larger bed of the child with CP as well as the mechanical functions of the bed that enabled it to be moved up and down. Such a function was noted by parents as useful when needing to move and attend to their child with severe CP and in benefitting them physically, in terms of preventing potential injury to their backs. The hoist was an item of equipment that was present in nearly all the bedrooms of children with severe CP. However, the extent to which they were actually used by parents varied with a number being reluctant to use them at all. It was difficult to ascertain how the children with severe CP felt about the presence and use of the hoists.

The presence of clinical equipment in the bedroom emphasises that the child to who it belongs is disabled. Section 9.2 discussed how the bedroom of
siblings/children with mild CP was an important place for privacy but also for forming and displaying identity. This was illustrated by the ‘zoning’ of bedrooms and by the meanings invested into objects and items chosen and displayed in bedrooms by siblings/children with mild CP. The displaying of identity through the use of, and items contained in, their bedrooms was not as evident for children with severe CP. As discussed, children with severe CP rarely used their bedrooms for activities or spent time in bedrooms except to sleep or, for some, to have their care needs attended to. Despite their bedrooms containing personal items such as toys, photographs and soft furnishings the space was dominated by equipment such as the ‘adapted’ or ‘hospital’ bed and the hoist as well as equipment including airway suction machines, oxygen cylinders, power wheelchair battery packs, feeding tubes, standing frames as well as items including latex gloves, incontinence pads/nappies and wet wipes. This led to the space feeling clinical and the identity of the child with severe CP bound up with meanings of being disabled and different.

9.7 The bedroom: a shared space

Amongst all the families that took part in the study only one pair of siblings shared a bedroom at the time of the data collection. The two brothers that shared a bedroom were Stanley (child with severe CP) and Alex Edwards. From discussion with both boys the sharing of a bedroom was viewed in negative terms. In his interview, Alex voiced a number of times his frustrations at having to share a bedroom with Stanley, especially in relation to being woken up by him:

*Interviewer*  Is there anything you don’t like about your bedroom?

*Alex*  Stanley [his brother with severe CP]. Because he wakes me up.

*Interviewer*  Would you rather have your own room?

*Alex*  Yes

*Interviewer*  And for Stanley to have his own room?
Alex                      Yes

Interviewer  Do you think that you would miss Stanley a little bit?

Alex                      No.

(Alex Edwards, 6 years old, younger brother)

Stanley, in his own interview, demonstrated that he was also keen to have his
own bedroom and not to share with Alex:

Interviewer  Do you like sharing a bedroom with Alex [younger
brother]? Yes (holds out right hand) or no (holds out
left hand)

Stanley       (chooses left hand – no)

Interviewer  Would you like your own bedroom? Yes (holds out
right hand) or no (holds out left hand)

Stanley       (chooses right hand – yes)

(Stanley Edwards, 7 years old, child with severe CP)

As discussed above, at the time of the study, plans were already
proposed to build Stanley a downstairs bedroom and it seemed to be the
consensus viewpoint of all family members that it would be best for Stanley and
Alex to no longer share a bedroom. It is important to note that as well as
Stanley disturbing the sleep of Alex, vice versa also happened.

Sharing a bedroom was also something that, although no longer
occurring, had happened in the past for two other pairs of siblings. As discussed
by Ellen, her and her brother, Brian, had previously shared a bedroom:

Interviewer  And have you ever shared a bedroom with Brian?

Ellen     I did. I have only had my [own] bedroom for probably
         about 4 years or something. So I use to share with
         Brian most of the time, but I started getting really
disturbed [by Brian] in the night, as he was waking up really often.

*Interviewer*  OK

*Ellen*  So I decided to get my own... my room used to be my parents’ music room, well my dad’s music room. But then I still, sometimes me and Brian still like to have kind of mini sleepovers, like I will go into his room and sleep there for a night or he will come to my room. We haven’t done it this [school] holiday, as I haven’t had time, but I do like sleeping with him, but when I do I don’t get much sleep.

*(Ellen King, 12 years old, younger sister)*

Ellen and Brian’s ‘mini sleepovers’ are facilitated in part by the family living in a bungalow so access to Ellen’s bedroom is possible for Brian.

Daniel Cooper and his younger sister Libby also previously shared a bedroom but deterioration in Libby’s sleep as well as the occurrence of seizures meant that this did not continue:

*Interviewer*  Have you ever shared your bedroom?

*Daniel*  I don’t think I’ve ever shared with Joseph [younger brother] but I’ve shared with Libby [younger sister with CP], but that’s before she started waking up and crying all the time and I think it was when I was sleeping with her, but I’m not sure, she had a fit one night and so we stopped [sharing]... I’m not sure if I was there at the same time, but I do remember her having the fit and stuff.

*(Daniel Cooper, 13 year old, older brother)*
Therefore, for all 3 of these families one of the main reasons for stopping the siblings from sharing a bedroom was the negative impact the sleep disturbance of the child with severe CPs has or had on the sleep of their sibling.

9.8 Conclusion

This chapter has explored the location, use and items contained within the bedrooms of children with severe CP. Firstly, these aspects in relation to the bedrooms of the siblings and children with mild CP were discussed, and the differences were highlighted in relation to the bedrooms of children with severe CP. The majority of the children with severe CP had, or were going to have, their bedroom located downstairs while the rest of the family had upstairs bedrooms. The practical reasons for this were outlined from the parent’s point of view as were their opinions as to how their child with severe CP felt about the downstairs location. However, the viewpoints of the children themselves were less clear. The use of the bedroom was very different for children with severe CP. It was predominantly a space for sleeping and personal care compared to siblings and children with mild CP, who used their own bedrooms more frequently for a range of play, relaxation and social activities as well as for sleep.

The bedrooms of children with severe CP especially when located downstairs, were often public spaces for a variety of reasons including the use of paid carers and parental monitoring via a baby monitor at night, as well as their use by other family members and the range of disability equipment often stored in them.

Two items present in the bedrooms of children with severe CP were discussed in detail – the specially adapted bed (which was height adjustable and often had sides) and the hoist. The presence of the ‘adapted’ bed and hoist, as well as other care related equipment made the child’s bedroom feel clinical as a space and the identity of the child and their ownership of the bedroom were not as apparent when compared to siblings and children with mild CP.
Lastly, the bedroom as a shared space was discussed. The sharing of a bedroom was not a common occurrence with only one pair of siblings doing so at the time of the study. Sharing a bedroom was negatively viewed by both the siblings who were keen to have their own bedroom. The main reason for this negative view, and why other pairs of siblings had stopped sharing a bedroom, was due to the sleeplessness of the child with CP disrupting the sleep of their sibling.

The location, use and the items contained within the bedrooms of children with severe CP raises important questions about the impact on their identity formation, autonomy and control in their everyday lives and on the opportunities they have for privacy within the household. The bedroom serves as an important and symbolic identifier of the differences between children with severe CP and those without.
Chapter 10 - Parental night-time monitoring of children with CP

10.1 Introduction

This chapter focuses on the topic of parental night-time monitoring of their child, specifically their child with CP, which emerged as a salient theme from the parent data. Night-time monitoring refers to the hearing, checking and/or surveillance by parents of their child at night. Four levels/methods of parental night-time monitoring of children with CP emerged from the interviews with parents. Differences evident in terms of the level and type of monitoring that parents undertook of their children during the night were dependent on a number of intersecting factors. Differences were also evident in terms of the impact on parents’ sleep that different methods of monitoring had.

The severity of the child’s CP (including how the child was able to communicate) was one important differentiating factor that influenced the level and method of monitoring practiced by parents at night. However, it was not as simple as the more severe the child’s CP the greater the level of parental night-time surveillance. Other factors, for instance, the child regularly waking at night, location of the child’s bedroom, additional health issues concerning the child with CP, and past experiences all intersected and influenced the level and the means of night-time monitoring that parents deemed necessary. How the intersection of such factors was interpreted by parents was also of paramount importance for the type of monitoring chosen. As well as practical considerations, this interpretation was also associated with the perception of risk and danger to the child with CP with each factor interplaying and signalling differing levels of potential of risk.

The perception of risk, as well as the act of surveillance used to minimise perceived risk, is important to consider in the context of night-time monitoring of children with CP. Theorists in the field have noted that surveillance practices are almost always motivated by perceptions of risk (Howell, 2010). An increase in surveillance at a societal level has been linked to a rise of a more generalised anxiety which in turn has been attributed to the emergence of what Beck (1992)
termed a ‘risk society’. As outlined by Nelson (2008), much of the theoretical work on surveillance is concerned with its practice within the public sphere, but there is a need to also consider it within the private (including the family) realm. Emerging work on surveillance proposes that it is not simply about a one sided exercise of power and control but is also about care and protection (Lyon, 2001; McIntosh et al., 2010). This is an important consideration in the study of parental surveillance of children. This does not detract from the fact that elements of control and power still play a part in parental surveillance, but that concepts of care and protection need reflecting on as they may often be central to parents’ own justification for monitoring. McIntosh et al. (2010) also note that awareness that you are being ‘watched over’ can be positive and reassuring for children. This seems especially pertinent if children are aware of their own health issues and potential status of ‘at risk’ and is an important consideration with reference to children with CP and additional health issues.

10.2 Four levels of parental night-time monitoring

Amongst the 10 families 4 levels of night-time monitoring adopted by parents in order to monitor the night-time activity of their child with CP were identified:

- Low level monitoring
- Informal monitoring
- Technological monitoring
- Combination monitoring

Table 10.1 shows information about which families adopted each approach.
Table 10.1 Method of parental night-time monitoring

<table>
<thead>
<tr>
<th>Method of parental monitoring</th>
<th>Name, age and severity of CP</th>
<th>Regular night waking of child with CP that requires parental attendance</th>
<th>Location of bedroom</th>
<th>Additional health needs of child with CP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low level</td>
<td>Grace Baker, 13 yrs, mild CP</td>
<td>No</td>
<td>Upstairs</td>
<td>None</td>
</tr>
<tr>
<td>Low level</td>
<td>Greg Jones, 13 yrs, mild/moderate CP</td>
<td>No</td>
<td>Upstairs</td>
<td>None</td>
</tr>
<tr>
<td>Informal</td>
<td>Stanley Edwards, 7 yrs, severe CP</td>
<td>Yes</td>
<td>Upstairs</td>
<td>Epilepsy Thrombophilia</td>
</tr>
<tr>
<td>Informal</td>
<td>Sam Fletcher, 7 yrs, severe CP</td>
<td>Yes</td>
<td>Upstairs</td>
<td>None</td>
</tr>
<tr>
<td>Informal</td>
<td>Brian King, 13 yrs, severe CP</td>
<td>Yes</td>
<td>Downstairs (in a bungalow)</td>
<td>Gastrostomy fed</td>
</tr>
<tr>
<td>Technological: Baby monitor</td>
<td>Charlotte Appleby, 8 yrs, severe CP</td>
<td>Yes</td>
<td>Downstairs</td>
<td>None</td>
</tr>
<tr>
<td>Technological: Baby monitor</td>
<td>Libby Cooper, 12 yrs, severe CP</td>
<td>Yes</td>
<td>Downstairs</td>
<td>None at present (past history of epileptic seizures)</td>
</tr>
<tr>
<td>Technological: Baby monitor</td>
<td>Oliver Davis, 8 yrs, severe CP</td>
<td>Yes</td>
<td>Downstairs</td>
<td>None</td>
</tr>
<tr>
<td>Combination (informal and baby monitor)</td>
<td>Charlie Hughes, 7 yrs, mild CP</td>
<td>No</td>
<td>Upstairs</td>
<td>Epilepsy</td>
</tr>
<tr>
<td>Combination (Oxygen SATs monitor and baby monitor)</td>
<td>Jacob Gibson, 6 yrs, severe CP</td>
<td>Yes</td>
<td>Upstairs (via lift)</td>
<td>Epilepsy Gastrostomy fed</td>
</tr>
</tbody>
</table>
As suggested by Table 10.1, the method of monitoring adopted by parents varied between families and depended on a number of compounding factors:

- Severity of the child’s CP
- Regular child sleeplessness
- Age of the child
- Location of the child’s bedroom downstairs and proximity, at night, to parents.
- Presence of additional health needs, specifically epilepsy.

How the child with CP communicated and the effectiveness of their communication methods also made a difference to how parents chose to monitor their child with CP at night. Past negative experiences, especially past times when their child with CP had been taken ill during the night, e.g. severe epileptic seizures, also influenced some parents in their choice of night-time monitoring method. Bound with the interplay and interpretation of these different factors was the parental perception of risk to their child with CP with the aim to minimise such perceived risk. This also influenced the parental choice of monitoring method.

**10.3 Low level monitoring**

Two sets of parents (the Bakers and the Jones/Jacxons) felt that they did no, or very little, night-time monitoring of their child with CP. Both the disabled children, Grace and Greg respectively, were mildly affected by CP, had upstairs bedrooms (i.e. close proximity to that of their parents), slept well and neither had additional health needs. Both Grace and Greg were 13 years old and their parents felt that as their child had got older the need to monitor at night had become less.

*Interviewer*  Ok, and when you go up to bed and get ready for bed, do you check in on Greg or…?
Alice ... I generally... if he is asleep he’s ok. You get to that point, don’t you, when you don’t need to check anymore.

(Alice Jones, interview, mother of Greg Jackson, 13 years)

Only in certain and exceptional circumstances did a higher level of monitoring of these two children become necessary, for instance, when a child was temporarily unwell. Both Robert and his wife Lynn, felt that they did very little night-time monitoring of their daughter, Grace, however, Robert did concur that there were times when he was aware of Grace’s behaviour during the night:

Interviewer So, if Grace is ever awake or restless during the night, are you ever conscious of her being awake?

Robert No, no... I mean the only time that I would be conscious of Grace being awake is the very few times, you know, when she really is ill, and she will come into our bedroom and say “I think I’m going to be sick” (laughs)...

(Robert Baker, interview, father of Grace Baker, 13 years)

Low level monitoring, therefore, also relies on the ability of the child to alert or let their parents know if they need assistance or help. If Grace is feeling unwell, she is able to go to her parents’ bedroom and communicate her needs. So another reason why these parents felt reassured that the risks to the child at night were minimal was that they could rely on their child communicating clearly any occasions when they might need parental assistance. In this way the experiences of both these sets of parents can be aligned with those parents of children with no disabilities, whereby as children grow older, less night-time monitoring by parents is seen as necessary, and if it is necessary at specific times the child can communicate this need clearly and effectively. Overall, the topic of monitoring was not a predominant one for the Bakers or the Jones/Jacksons and the discussion of it was not extensive. The risks to the child during the night and the likelihood that the parent would need to attend to
the child were perceived as low, therefore monitoring was not required. This was also the case for most parents with reference to any child or children without CP (i.e. the siblings), whereby monitoring at night of siblings was often only mentioned with reference to exceptional circumstances, such as when their child (without CP) was unwell.

**Interviewer** And what about checking or hearing Daniel and Joseph [non-disabled siblings] at night?

**Catherine** No, neither [of them] has any problems sleeping so... it’s very rare that one of them will wake up, only if they’re unwell.

*(Catherine Cooper, interview, mother of Libby Cooper)*

For Catherine not needing to monitor or ‘check’ her (non-disabled) sons at night is related to them not having ‘problems sleeping’ and, therefore, not requiring parental assistance during the night. Venn and Arber (2008) comment that as children grow older the need for parents to attend to them to meet their physical demands at night (for example, hunger, thirst, illness etc.) declines, however, this is not the case for children with severe CP. Despite their increasing age children with severe CP still woke at night frequently and depended on parental assistance at night for their physical needs and comfort. Additional health needs of a number of the children meant that the night continued (indefinitely) to be perceived as a risky time by parents often exacerbated by other interrelated concerns such as a lack of proximity of the child to them at night. For these children monitoring at night was discussed in more detail by parents and was either ‘informal’ monitoring, ‘technological’ monitoring, or ‘combination’ monitoring.

### 10.4 Informal monitoring

Informal monitoring through ‘keeping an ear open’ was discussed in detail by parents in 3 of the families. This type of ‘informal’ monitoring is at a much higher and explicit level than the low level monitoring outlined in Section 10.3 and the parents that engaged in it did so every night.
This contradicts my expectation of the sort of monitoring that the parents in these 3 families would practice. I assumed, because of various factors relating to the child with CP that some sort of technological monitoring device would be used. For instance, the children in these three families each had severe cerebral palsy that affected their ability to move and reposition themselves. All three children regularly woke more than once during the night and required some sort of assistance from their parent/s. Two of the children had no or very little verbal communication (although as discussed later they are vocal). Stanley Edwards has epilepsy with seizures occurring relatively frequently and one child Brian King vomited during the night on a regular basis due to reflux and difficulty clearing his own airways. Therefore, when I considered these factors my assumption was that a technological monitoring device would be employed. However, this was not the case and instead the parents relied on what I term the ‘keeping an ear open’ approach to monitoring and hearing their child during the night.

For these parents the main reason why this level of monitoring had been chosen was the proximity of the child to the parents, during the night. They felt that this type of informal monitoring was adequate because their child was close enough during the night for them to hear without the use of a baby monitor.

*Interviewer*  And do you have a monitor for Sam?

*Kate*  No, we don’t have a monitor for Sam anymore because obviously he is just across the hall.

*(Kate Fletcher, interview, mother of Sam Fletcher)*

Not only were these children located in close proximity to their parents but parents also used strategies such as keeping bedroom doors open at night, so they could hear their child.

By relying on this informal way to monitor, parents were also relying on the knowledge that their child had an effective way to alert them during the night. Even the children with no verbal communication had an ability to vocally communicate their needs and similarly the parents had the skill to interpret
these vocalisations as a call for assistance. This parental skill was based on experience and knowledge of the ways in which their child communicated and, to some extent, parental intuition that allowed parents to differentiate between the noises, and their meaning, heard during the night:

**Matt** Usually he cries out when he needs us in the night, he will shout out.

**Vicky** Yeah, he has particular shouts.

**Matt** Yeah, usually you can tell the difference between when he is just being noisy in his sleep and when he actually wants you.

*(Vicky and Matt King, joint interview, parents of Brian King)*

Therefore, proximity is important in choosing this level of monitoring as is reliance on the child with CP having an effective, interpretable and, presumably, loud enough way to alert their parents. However, an interesting juxtaposition exists here in relation to the noisiness of their child. The main reason, along with proximity, given by these parents for adoption of the ‘keeping an ear open’ approach, instead of using a baby monitor, related to the impact of their child’s ‘noises’ at night on their own (i.e. the parents’) sleep.

**Interviewer** And do you have a baby monitor?

**Vicky** No, no. We did try it once, years and years ago, but all I could hear was (Vicky breathes heavily, snorts and gasps and then laughs)

**Matt** Even when he is asleep, it is pretty noisy.

**Vicky** It is too, you know, I don’t think we would ever get to sleep because every little thing you would hear.

*(Vicky and Matt King, joint interview, parents of Brian King)*
These parents trust that they will be alerted and know when they need to attend to their child with CP by relying on the fact that their child is close enough, and loud enough, to hear. Parents also relied on being able to differentiate and attach the right meaning to the noises their child makes. By adopting these strategies they go some way to protecting their own sleep. They feel, for the sake of their own sleep, that they do not need to hear every snuffle and grunt that their child makes. However, it is important to note that there must be some level of sleep disturbance for parents in order to consciously differentiate between ‘good’ noises that signal normative sleep behaviour and ‘bad’ noises that signal a need for parental assistance. This is made clearer when comparing the informal monitoring of the child with CP to the lack of monitoring of children without disabilities. In the following quote Mark Edwards recognised that he did not explicitly monitor or ‘hear’ his non-disabled children at night and compared this to the higher level, albeit subconscious, monitoring that he engaged in of his child with CP:

Mark And even though I sleep very deeply, as soon as I hear Stanley [child with CP] I wake up.

Interviewer So you wake when you hear him?

Mark Yes, quite easily.

Interviewer So you are very aware [of Stanley]?

Mark Yes, because with the other ones [other children without CP], if they wake up in the middle of the night I don’t hear them but, it’s for some reason, with Stanley that I’m straightaway awake.

(Mark Edwards, interview, father of Stanley)

Mark Edwards is alert to his son, Stanley’s, noises and wakings at night. Although those noises might not always signal the need for assistance they do still at some level wake and interrupt Mark’s sleep. This was also touched upon by Vicky and Matt King, as discussed in Section 10.5 on co-sleeping. Vicky
made it clear that she was often the one woken by her son Brian’s noises as Matt slept more deeply. Therefore, it was Vicky’s role to differentiate and decide what the noise might mean. If the noise signalled a need for help then she would either attend herself or wake Matt for him to attend.

Informal monitoring also represented a more flexible approach and was less ‘fixed’ compared to the approaches using technology. This was apparent in discussions about when certain aspects, such as proximity of bedrooms, were going to change. A downstairs bedroom had already been created and decorated for Sam Fletcher to move into, but at the time of the study he had not yet spent a night in his new downstairs bedroom.

_Interviewer_ ...and when Sam moves downstairs, will you have a monitor?

_Kate_ Yes, we’ll have to have a monitor for him.

*(Kate Fletcher, interview, mother of Sam Fletcher)*

The move to a downstairs bedroom for Sam was going to be a permanent one (for as long as he lived in the family home). Because of this and because Sam woke every night and required parental assistance (to change position) the change to using a baby monitor was also going to be permanent. This is the opposite of what would be expected for children without CP whereby the use of a baby monitor would cease as the child got older and be replaced by informal and then low level monitoring. The permanence of the use of a baby monitor for older children with CP will be discussed in more detail in Section 10.6. Informal monitoring was also liable to temporary changes whereby parental monitoring was adapted when other aspects relating to the child with CP changed. For instance, when the child was unwell or going through a period of waking more often.

Two sets of parents who usually engaged in the ‘keeping an ear open’ informal monitoring approach discussed how, on occasions, they co-slept with their child with CP, which will be discussed in the next section.
10.5 Co-sleeping

Co-sleeping refers to when a parent and child sleep in the same bed or same room together. The act of parent and child co-sleeping is one layered with conflicting and vying social, cultural, behavioural and medical constructions and meanings. Lupton (2012) describes co-sleeping as an influential interembodiment practice between carer and child citing research carried out in cultures where co-sleeping is a normative act throughout a child’s infancy and childhood. For instance, in Japan where parent and child co-sleeping is a common phenomenon, research has found that it plays an important role in the development and maintenance of family intimacy (Tahhan, 2008, cited in Lupton, 2012). Co-sleeping enables ‘skinship’ (a concept that describes relational states created by close physical proximity, touch and intimacy) and this may provide the relaxation, comfort and security that a baby or child requires to fall asleep peacefully.

However, as discussed by Lupton (2012), in Western societies co-sleeping with children is not a promoted practice and is, in general, frowned upon by health professionals with ‘risks’ of co-sleeping (i.e. risks to the health of the child, as well as behavioural risks related to creating ‘bad’ sleep habits) highlighted by doctors, childcare advice books and media coverage. For example, the headline ‘The new parenting fad experts fear could KILL your baby: Mothers are jeopardising their child’s safety by co-sleeping’ (Hoyle, 2013) appeared in The Mail on Sunday newspaper.

Advice in many childcare and sleep manuals maintains that parents and children should sleep in separate spaces to promote good sleep for both parties and to ‘teach’ babies and children to ‘self settle’ to sleep to avoid creating and maintaining bad sleep related habits. One notable exception to this is the work and advice of the paediatrician William Sears (1999) who as part of his ‘attachment parenting’ approach encourages co-sleeping between parent and child and advocates the same benefits as highlighted by research from Japan (Tahhan, 2008, cited in Lupton, 2012). An eighteen-year longitudinal study of co-sleeping (Okami et al., 2002) identified results that neither supported the
benefits as highlighted by co-sleeping supporters nor the risks as identified by those opposed to it.

A focus on the medical based research exploring sleep in disabled children finds parental co-sleeping as a common practice that has a negative impact on the sleep of the parent (Jacquier and Newman, 2016). Interestingly the impact on the child’s sleep has been found to vary with some parents reporting a positive impact and others reporting negative consequences for the child’s sleep (Jacquier and Newman, 2016). Overall, the literature presents co-sleeping in a negative light and, specifically, co-sleeping is, itself, labelled a sleep problem, for example:

Night settling, co-sleeping, and night waking are the most common sleep problems experienced by both typically developing children and children with an intellectual disability (Robinson and Richdale, 2004: 139).

In my study, for the parents of children with CP who engaged in occasional co-sleeping it was not viewed as a problem, but rather as a solution or strategy. Firstly, it was a strategy to use when a higher level of night-time monitoring was required because the child with CP was unwell. Secondly, it was used to attend to the child with CP more quickly in order to protect the sleep of others in the household.

At the time of her research interview Aileen Edwards was sharing her bed with her son Stanley as he was experiencing severe muscle spasms that were causing him pain at night:

_Aileen_ ...I was woken up when Stanley was having spasms, because he had a few last night...

_Interviewer_ Did he?

_Aileen_ And he woke me up.

_Interviewer_ And how did he wake you up with that?
Aileen Well with these, what he is doing at the moment, he is screaming and then going very rigid, so I hear the scream, because he is in bed with me, we’ve turfed Mark [husband] out onto the sofa at the moment.

Interviewer Ok, so he [Stanley] is in bed with you at the moment?

Aileen Yes, so he is actually really quite warm, quite snugly and I know that he is quite comfortable, but then he will suddenly scream and he will go very stiff and then I can massage him before it [the spasm] gets too bad.

(Aileen Edwards, interview, mother of Stanley Edwards)

For Aileen monitoring Stanley closely through co-sleeping at this time provided her with reassurance that Stanley was comfortable and comforted by being in such close proximity, and it meant that she could respond immediately to help him when he had a spasm. It is less clear what the impact of this co-sleeping arrangement had on her husband Mark who was ‘turfed’ out of the marital bed onto the sofa. However, Aileen’s use of the term ‘at the moment’ indicates that co-sleeping was only temporary and, therefore Mark’s relocation to the sofa at night should be short lived.

Recognition and consideration of the effect of co-sleeping on the marital relationship was touched upon by Matt and Vicky King. In the recent weeks preceding the study interview either Matt or Vicky (but usually Matt) had been co-sleeping with their son Brian (13 years) in Brian’s bedroom on occasion. This was a strategy used to protect the other (not co-sleeping) parent’s sleep, as discussed in more detail below. Both Matt and Vicky made it clear that co-sleeping was not an option on a regular or long term basis because it was important for them to maintain their own private sleep space as a couple:

Vicky It [co-sleeping with son Brian] doesn’t happen very often, because we have got our own bedroom and
our own bed. We don’t really want to be doing that [co-sleeping] every night, ummm, but sometimes one or other of us, usually me, just gets so tired, that I just really, really need some sleep.

*(Vicky King, mother, joint interview)*

This was affirmed again by Vicky later on in the interview:

**Vicky** The main thing I think about it [co-sleeping with Brian] is that we [her and Matt] have got our own bed and our own bedroom and we [her and Matt] are supposed to be in bed together.

**Matt** Well, and it is a more comfortable bed.

**Vicky** Yeah, so it [co-sleeping with Brian] is not something where I would want to have to do it every night or anything like that.

*(Vicky and Matt King, parents, joint interview)*

Vicky’s worry about co-sleeping becoming a regular occurrence was related in part to the experience they had when Brian was a baby. Vicky related, during the interview, how as a baby Brian would only fall asleep if held and rocked by a parent. Brian eventually learned how to ‘self settle’ when Vicky and Matt introduced a ‘gradual retreat technique’ that involved moving gradually further away from his bedside at bedtime. For Vicky the thought of co-sleeping on a regular basis indicated a regression in terms of Brian’s sleep and a fear that ‘bad habits’ would once again become engrained, if Brian relied on a parent being present to fall asleep:

**Vicky** So, we did investigate it [Brian not self settling] at the time, you know, we looked up what to do about these things and so, with him going to sleep, we gradually retreated from the room and then I sat outside reading, and all that kind of thing, ((Matt
laughs)). So, that it would feel like such a backward step to be sleeping in with him now all the time, but it is just necessary sometimes.

(Vicky King, mother, joint interview)

We are reminded here of the Western societal norm, as outlined above, that promotes ‘self settling’ as a skill that must be learned by babies and children in a separate sleep space to that of their parents. Vicky, in particular, was mindful of how co-sleeping may be perceived by those observing from the outside, including me as researcher and perhaps, in her eyes, as a ‘health professional’. At one point Vicky assured me that co-sleeping was not as ‘disastrous’ as it seemed, indicating an expectation that I would view it negatively. However, for Matt and Vicky, at the time of the study occasional co-sleeping had become a necessary strategy to help protect their own sleep. Despite advocating strongly for their informal approach to monitoring, as opposed to using a baby monitor, Vicky was most often woken by Brian at night as Matt conceded he slept more deeply. Therefore, Matt co-sleeping with Brian enabled Vicky to get a better night’s sleep:

Vicky I suppose the best night’s sleep I have had recently is if you [Matt] have been in with him, um, so then I could probably get 5 or 6 hours undisturbed sleep.

(Vicky King, mother, joint interview)

Co-sleeping provided a way for Matt to monitor, and attend to, Brian before he disturbed and woke Vicky. As Aileen Edwards also highlighted the close proximity that co-sleeping afforded enabled a quick response by the parent to the child and for Matt this protected his own sleep and Brian’s sleep, as well as Vicky’s.

Matt So you know, if you are next to him he [Brian] doesn’t wake as much

Interviewer So he doesn’t call out as much?
Matt  No, more because you hear him quicker and you get him settled down quicker and then I am straight out [asleep] like that (clicks fingers), you know I am probably only awake for a minute and then you are back to sleep, you really don’t wake up much to do it. It’s a practical thing, but it is not ideal and it’s not as comfy as your own bed.

*(Matt King, father, joint interview)*

Matt and Vicky also considered what co-sleeping meant for Brian himself. Matt voiced his concerns that he did not want Brian to become use to, or to expect, parental co-sleeping as a regular practice. This was a concern that appeared to be related to their experiences of when Brian was a baby, because Matt quickly negated his own concerns by saying that Brian was now older and at 13 years old he was very rational and was able to empathise with how co-sleeping may impact on his parents.

Matt  I think there is an element of whereas he [Brian] is sometimes relieved when you have come in, I also feel that, he also feels a bit guilty about the fact that you are in with him as well, he is old enough to... He empathises, he empathises way beyond his years I am sure... he is very empathetic, yeah, so... So, it is possible to rationalise with him because he understands that you don’t necessarily want to be there, and you are doing it for him, so... Hopefully it [the co-sleeping] will remain controllable.

*(Matt King, father, joint interview).*

Some indication of how Brian himself felt about co-sleeping was obtained in his interview whilst looking at the photographs of his bedroom. When a photo of his bed (a double mattress on the floor) along with a futon next to it (placed there in case Brian rolls off the mattress and also for either Matt or Vicky to sleep on) was shown to Brian he used his eye tracking speech generating
device to ‘voice’ the word ‘embarrassed’. Matt questioned Brian about what he was embarrassed about and ascertained that it was related to the beds and more specifically the futon. Matt then made the link to it being about co-sleeping and Brian agreed.

**Matt** Are you embarrassed that maybe Daddy has to sleep in there sometimes. Is that what you are embarrassed about?

**Brian** Yes (eye gaze speech generating device)

**Matt** Is that right?

**Brian** Yes (eye gaze speech generating device)

**Interviewer** Daddy being there, does that help you?

**Matt** Tell the truth (((laughter))) Because I really come in for me not for you. (((laughter))). Does it actually help you?

**Brian** Yes (eye gaze speech generating device)

**Matt** Good

**Interviewer** That’s good.

*(Brian King, severe CP, 13 years, interview, Matt King, father, also present)*

Caution needs to be exercised as to whether this is the exact reason for Brian voicing the word ‘embarrassed’ and the leading nature of Matt’s questions needs to be highlighted. However, it does raise questions about the appropriateness of co-sleeping as a strategy for older disabled children and teenagers. The excerpt above does imply an awareness that older children with CP may have of being different compared to non-disabled peers and, in the case of Brian, a non-disabled sibling. For Brian there may be a struggle
between what is expected for a child of his age, 13 years old (in terms of sleep and sleep practices) with his need for parental attendance and help at night.

Co-sleeping is an example of how the ‘informal’ approach to monitoring is flexible. Parents who take this approach are able to evaluate and take action if another way of monitoring is required because circumstances change – either temporarily or permanently. As outlined in the next section parents who used a technological device to monitor were more fixed in their approach.

10.6 Technological monitoring: The ‘Baby’ monitor

Despite widespread use by parents of babies and young children there has been very little research into the use, and meanings of use, of the ‘baby’ monitor (Nelson, 2008). Regardless of their relatively recent appearance in the marketplace, Nelson (2008) comments that their use by parents of babies and young children is ‘assumed’ rather than ‘explained’, which she attributes to the normalisation of parental anxiety. In her study of product reviews of baby monitors, Nelson (2008) found that parents identify anxiety as part of what it means to be a parent, especially first time parents and in the first year of their baby’s life. Baby monitors enable an awareness of the baby at all times and this, in turn, helps to alleviate parental anxiety. Babies are conceptualised as fragile beings, therefore, it follows that parental anxiety concerning their care is appropriate as is the use of a baby monitor to allow the minimisation of risk and the resolution of anxiety.

The practice of parental surveillance in order to minimise risk and to protect children is strongly linked to an expectation and assumption about what a ‘responsible parent’ should be and do. For example, Lupton (2012) discusses the expectation that mothers are primarily responsible for the care and protection of their children by constant surveillance, which has resulted in the image of the ‘ever-watchful’ mother being positioned as the ideal type.

In the first months of parenthood, Howell (2010) describes how parents are particularly focussed on biological and health-related dangers that might befall their baby. For instance, in many of the reviews analysed by Nelson (2008) parents discussed their fear of Sudden Infant Death Syndrome (SIDS)
and how baby monitors were purchased specifically to help minimise and protect against this risk. As Howell (2010: 207) comments, parents are most concerned about ‘the inherent unpredictability of nature in the form of unpredictable biological events that might occur when they are physically apart from their children’. Surveillance, and use of baby monitors, symbolises for parents a method to protect against this unpredictability.

There is an expectation that the intensity and the ways by which parents monitor their child changes with age and throughout the child’s development. High level monitoring is assumed ‘normal’ in the early months of a baby’s life and is associated with the ‘routine’ worry and anxiety expected for all new parents (Nelson, 2008). As the child gets older such high intensity monitoring decreases, although it may rise again temporarily when children reach an age when they are independently ‘mobile’ (Fotel and Thomsen, 2004). The fragility and uncertainty linked to the image of the baby and the experience of early parenthood which necessitates the use of the baby monitor changes and for most parents, baby monitors are abandoned after infancy.

However, this is not the case for a number of parents of children with CP. The parents in 5 families used a baby monitor to hear their child with CP (ranging in age from 6 to 12 years) at night. For 3 of these families the baby monitor was, primarily, discussed in terms of overcoming the practical issues of lack of proximity and the need to hear a child who woke and required attendance on a regular basis. Their children all slept in a downstairs bedroom (in extensions specifically built for this purpose, as discussed in the previous chapter) whilst the rest of the family slept upstairs. This, in conjunction with the fact that all 3 regularly woke on a nightly basis and required parental attention, led parents to need a ‘reliable’ way to hear their child. The use of a baby monitor reduced the risk of not hearing their child and allowed an acceptable approximation of ‘technological proximity’ when actual physical proximity was not attainable (Howell, 2010). Because of these issues the use of baby monitors by parents of children with CP is unlikely to be a temporary measure. In all likelihood these aspects relating to proximity and persistent night waking will not change and, therefore, the use of a baby monitor becomes a permanent fixture.
Parents of children with severe CP seem to accept this as the way it is and the way it will continue to be because of the physical needs of their child and the decision to have their child’s bedroom downstairs:

**Nicola**  He’ll [Oliver] either want a drink or, you know… and anyone else would, they would just, you know if they were able… would get themselves a drink, pull the covers up or turn over wouldn’t they? So that is the only problem… he’s not awake worrying about anything, he’s not awake because he can’t sleep or anything, it’s literally if you laid there and you had no covers, and you couldn’t pull them up, you’d call someone to pull them up wouldn’t you?”

*(Nicola Davis, interview, mother of Oliver Davis)*

Although the baby monitor provided a practical solution to the problem of a lack of spatial proximity there were also risks and issues related to its use. One such issue was the difficulty parents had in differentiating the sounds, and their associated meanings, emitted through the device. Baby monitors are highly sensitive in picking up even the smallest of sounds and along with added problems such as sound interference and time delays it meant that parents were required to pay focussed attention to what the sounds may signal.

**Interviewer**  Is it more difficult for you [when Charlotte wakes] because you are obviously upstairs…?

**Sue**  I would have to say yes, I would have definitely said yes. Um… I think when she was upstairs, with the closer proximity, sometimes you could discern the noises better and sometimes the gadget [baby monitor] takes a couple of seconds to click in or it has a little bit of distortion on it and you think “was that her?” and that wakes me up… “was that her calling me or not?” And so I wait and you can tell whether it was her actually turning over, which that
[the baby monitor] would pick up on in the silence or whether it is then her actually calling “mum”, and sometimes I have waited one or two minutes and she has got herself off [to sleep] again.

(Sue Appleby, interview, mother of Charlotte Appleby)

As intimated by Sue Appleby the use of a baby monitor by parents can have a negative impact on their own sleep. Being able to hear every movement their child makes, as well as other sounds the monitor picks up, means that parents are awoken and on alert for periods of the night. Further to this, these children woke regularly every night in need of parental assistance. Therefore, the expectation and anticipation of being woken and needing to attend at some point every night was experienced, perhaps making parents more alert to every sound emitted by the monitor and further negatively impacting on their own sleep.

Another issue apparent in the use of baby monitors is the risk that the technology will fail.

Interviewer …even without the monitor can you ever hear Libby [from] upstairs?

Catherine Um, no, the only time we ever did was, um, the monitor broke down, um… We used to have a camera in here [Libby’s bedroom] and it broke and of course it was Sunday evening and we couldn’t get anything, um… So we left all the doors open and we did hear her but she was at screaming pitch by the time we heard her, um so we don’t... I mean she is completely the opposite side of the house, so we don’t hear her.

(Catherine Cooper, interview, mother of Libby Cooper)
Catherine’s description of what happened when their video monitor failed illustrates, to an extent, the reliance parents have on their ‘one and only’ way of hearing their child at night and raises the question of whether such a reliance limits parents in their resourcefulness to find other effective strategies to monitor their child on these occasions. As discussed in Section 10.5 when factors temporarily or permanently changed, parents who used an informal approach adapted their strategy for monitoring (i.e. co-slept) but this is something that appears more difficult for parents who rely on a technological device alone. This is further illustrated by Sue Appleby when she explains what happens on ‘bad’ nights:

**Sue**

On the very bad nights when she [Charlotte] just won’t go back to sleep and she does just yell and scream and call out continually, obviously because John [husband] has to get up and go to work, if it goes on for more than an hour and it’s disturbing him as well, sometimes he can sleep through it, sometimes he can’t... I must admit what we sometimes do is turn the monitor off and leave the door open and I can’t sleep then anyway, so I am laying awake listening and I can come down and check that everything is ok. Um...just so that he [John] can get some sleep”.

*(Sue Appleby, interview, mother of Charlotte Appleby)*

The above quotation demonstrates again the difficulty that users of technological devices, especially when their child has a downstairs bedroom, have in adapting their approach when they cannot use the baby monitor. In both examples above it may have been more beneficial for Catherine and Sue to seek ways to increase the proximity between themselves and their child, for example, by sleeping downstairs or co-sleeping. By choosing this alternative Sue would have been as successful in protecting her husband’s sleep as well as minimising the impact on her own. As it stands Sue places the protection of her husband’s sleep above her own. This is an example of the ‘political
economy’ of family life which, when related to sleep predicts that as the ‘breadwinner’ in the household, John, is not expected to get up to attend to wakeful children at night whereas Sue as a ‘stay at home’ mum is (Pahl, 2007). The family expectation and practice is for Sue to carry out the night-time care of their child. It also illustrates the gendered nature of caregiving at night, which relates to the work of Venn et al. (2008) who explored the gendered nature of sleep disruption among couples who have children. They found that in general women provided the emotional and physical night-time care for children. This even applied to mothers who had returned to paid employment and that this was an extension of their daytime role. The authors label this as the ‘fourth shift’ as they see night-time activity as continuation of Hochschild’s (1997, cited in Venn et al., 2008) notion of the three shifts that exist for women, namely paid daytime work, evening domestic work and emotion work. The result of this is significant sleep disruption for women who have children.

As discussed, at the beginning of this section, the use of baby monitors in the first months of a baby’s life is often a strategy used by parents to minimise perceived risks associated with the image of babies as fragile and vulnerable to biological and health related dangers. As these fears reduce as part of the expected passing of routine new parent anxiety, and children grow older, the use of baby monitors also ends. The continued use of baby monitors by parents of children with CP was often framed in the context of being a practical solution to the problem of a lack of proximity at night. However there was also some indication of their use because of the persistent and long lasting anxiety related to the unpredictable nature of CP and its associated health issues:

**Catherine**  Um, Libby [daughter with CP] hasn’t had a fit since she was a year old but she is epileptic um... It’s always in the back of your mind what if, what if, she has a fit at night, what if something happens to her and obviously with the nature of the children at XXXXX [Libby’s special needs school] we sometimes get a letter home that such and such has
died... and I do worry that, you know, we’re going to get up one morning, particularly if she has a really good night... that actually causes me a lot of anxiety when I get up um... We had one day when she didn’t wake up until about half past nine... and we woke up and it was about quarter to nine and I woke James [husband] up and made him come down and check ‘cos I was frightened something had happened ((laughs)), um so that was... that is a big worry for me... The first thing we [her and James] say to each other when we get up is how many times were you up in the night [with Libby]? What sort of night did she [Libby] have? Cos sometimes I might get up four or five times and James not stir at all or vice versa, um, and you know, we always sort of check what sort of night and if it’s like “urr I didn't get up to her” and “nor did I” we're both “can you hear her” and we'll turn the monitor really loud and just see if we can hear her”.

(Catherine Cooper, interview, mother to Libby, 13 years)

This clearly illustrates the very real anxiety and fear that parents of children with severe CP experience throughout the life of their child. The nighttime is perceived by parents as an inherently risky time for these children and although, on the whole, monitor use minimises this risk it may also draw attention to the potential dangers. Some research has concluded that use of monitors may actually at times increase parental stress. Nelson (2008) discusses that monitor use can lead to ‘heightened attention’ which in turn emphasises the perceived potential risks. For Catherine a ‘good’ night sleep is symbolized by not hearing her daughter via the monitor and this, in turn, is a cause for concern and anxiety. Therefore monitoring and hearing your child at night becomes so habitual that when parents do not, the situation is disconcerting and worrying.
The fear and anxiety about health-related dangers was discussed in more detail by two sets of parents who employed a combination of ways to monitor their child with CP at night. For these parents this combination approach offered reassurance and a perception of safety that they felt outweighed the negative issues of ‘heightened attention’ and also the negative impact on their own sleep.

10.7 Combination monitoring

For some parents reliance on ‘keeping an ear open’ or a baby monitor alone was not considered enough. Despite having their children sleeping close by, anxieties about their child’s health specifically about epileptic seizures, meant that 2 sets of parents used a combination of ways to monitor and hear their child at night. Interestingly the two children to whom this applied differed greatly in their epileptic and seizure status. One child (Jacob Gibson) regularly, more than once a week, had seizures, most often at night, which caused his oxygen saturation levels to fall to a dangerous level and sometimes resulted in his parents administering oxygen and emergency medication and on occasion led to hospitalisation. For his parents, Anne and Darren, having a baby monitor alone was not an option as they were unable to rely conclusively on the vocalisations of Jacob as a way to monitor if and when a seizure happened, so they also had a device to monitor Jacob’s oxygen saturation levels (SATs monitor). This monitor consisted of a probe that was worn on Jacob’s finger and monitored and continuously recorded his oxygen saturation levels. If these levels fell below a certain figure then it indicated the occurrence of a seizure and the monitor sounded an alarm which was heard by the parents through the use of the baby monitor. However, it was a common occurrence for the probe on Jacob’s finger to slip or fall off which triggered the alarm when a seizure was not occurring. This happened most nights.

The other child (Charlie Hughes) had had only a few major seizures during his life but the last major one resulted in hospitalisation and happened at night. He had not had a major seizure for over two years. His parents relied on a baby monitor to ‘hear’ Charlie in case he had another major seizure but they also explicitly referred to adopting a ‘keeping an ear open’ approach and
purposely kept bedroom doors open in order to hear their child if he had a seizure.

So for both sets of parents the fear of their child having a seizure was very real, whether it was based on current or historic events and this had a negative impact on their sleep.

Interviewer So we’ve talked a bit about Charlie and his seizures… so would you say that your sleep is disrupted because of those sort of things or…

Sarah Yes

Interviewer Yes? Ok, so because you’re thinking about his seizures and things…

Sarah Yes, I think there is the worry that I won’t hear it… um, yes I think will he… will I not, will I go to sleep and not hear it…

(Sarah Hughes, interview, mother of Charlie Hughes)

Despite Charlie not having a major seizure for over two years the fear of it happening and the perceived need to monitor in order to minimise the risk to him was constant for Sarah. Research has found that people overestimate the likelihood of dangerous events when the risks are highly imaginable and/or readily available in memory (Tversky and Kahnerman, 1974, cited in Howell, 2010). In addition, parents needed to know that they were doing everything possible in order to ‘hear’ in the event that a seizure occurred at night. However, by monitoring in multiple ways the impact on parents’ sleep was inevitable.

By monitoring at such a high level parents may be aware and alert to their child for most of the night. As mentioned in Section 10.6, this ‘heightened attention’ created by use of technological monitoring can lead to an increase in parental stress. Although research on use of baby monitors is scarce there is a body of research exploring the use of cardio-pulmonary monitors often given to, and used by parents of babies identified as at high risk for SIDs (Abendroth et
As with the expected use of the baby monitor the use of cardio-pulmonary monitors for this reason would also be relatively short term (first year of a baby’s life), but some parallels between this short term use and the more long term use of monitors, such as SATs monitors, by parents of children with CP can be made. The research on the use of cardio-pulmonary monitors has found that often the use of such monitors resulted in an increase in parental stress but a number of studies reported benefits of their use in terms of the reassurance and comfort they provided to parents. For Anne and Darren Gibson, the use of the SATs monitor was viewed in a predominantly positive way. Anne described how it had been instrumental in reducing the stress she had felt in relation to Jacob’s epilepsy.

**Anne** The SATs monitor is, for me, is the biggest... best and biggest thing that I think has helped, and the fact that we’ve got oxygen as well, so you don’t feel helpless and things...

*(Anne, Gibson, joint interview, mother of Jacob, 6 years)*

As well as being able to administer oxygen immediately, the SATs monitor was important for Anne and provided her with a sense of control over the inherently unpredictable nature of epilepsy. For Sarah and Chris monitoring at night provided great reassurance and comfort as the fear of what might happen if they did not hear Charlie have a seizure was considered unimaginable.

**Chris** When he had his seizures, then we didn’t sleep too well because he was in bed with us when he had his seizures and so that was the only reason we knew he was having them. So after that, when he went back to his own bed it was a bit tricky for a while as well.

**Interviewer** Yes, and now... because you’ve still got the baby monitor haven’t you?
Chris  Now, not so bad because we’ve got the baby monitor.

Interviewer  Do you think you would hear him?

Sarah  Yes

Chris  He makes a very loud noise, doesn’t he?

Sarah  I don’t think we would hear small little ones but if he had a big one, ones that are life threatening we would hear… that noise I can hear… I would hear throughout the house that sound… we could hear. And his bedroom with the plaster board walls… his bed is about that far away from my head board (indicates a small gap between her thumb and forefinger), so we would hear… we would definitely hear his... definitely...

Interviewer  So that’s reassuring in a way…?

Sarah  Yes... yes, I think it’s more for me… it’s a long term, sort of… I think, you know... God forbid I missed a fit, what does that mean long term and I think um… things like that…

(Chris and Sarah Hughes, joint interview father and mother of Charlie Hughes)

Both Charlie and Jacob were aware of the monitoring that their parents practiced at night. Although it was not clear if they were exactly aware of the extent of the dangers that their parents perceived and were attempting to minimise. Charlie referred to the baby monitor in his bedroom as a ‘radio’ and commented that he could speak through it and that his ‘mummy’ could hear him. Jacob, who was a non-verbal communicator, was asked about his favourite and least favourite belongings in his bedroom. Using the photos that he and his mum had taken Jacob clearly indicated that the SATs monitor was a
favourite item (as opposed to his suction machine used to clear mucous secretions that Jacob is unable to clear himself). Although tenuous it is possible that Jacob, like his parents, felt reassured by the use of the SATs monitor and its ability to alert his parents if a seizure occurred. This is also in line with the findings of McKintosh et al. (2010) who describe how some children perceive adult monitoring as positive and reassuring.

For parents the reassurance and control that monitoring at this high level provides outweighs the inevitable adverse impact on parents’ own sleep. Anne and Darren Gibson were constantly woken by the SATs machine alarm throughout the night. The alarm not only signified the occurrence of a seizure but on many occasions the alarm sounded because the probe had slipped and lost skin contact. However, these false alarms were not perceived negatively by Anne and Darren because of the benefits outlined above and because the consequence of not monitoring and missing a ‘real’ seizure was seen as too great. They saw no alternative to monitoring at this all encompassing level even if it meant that their own sleep was severely affected:

*Interviewer* So when you first go in to him, do you feel like you are on that sort of auto pilot …

*Darren* Yes, but you’re expecting the worse…

*Anne* Never really thought about it… it is auto pilot, you just think, hear the beep…

*Darren* If it [SATs monitor] goes off two or three times, you will go in there expecting him to be fitting and if he isn’t it’s a bonus…

*(Darren and Anne Gibson, mother and father of Jacob, joint interview)*

It is difficult to see how the impact on parents sleep could be reduced as it was not just the fear of a seizure that kept them awake but the actual process of high level monitoring and the devices used (i.e. the alarm of the SATs
machine). Even if there was a dramatic improvement in their child’s health status the level of monitoring would not necessarily change because parents continued to fear that seizures may occur.

10.8 Conclusion

This chapter has explored how parents of children with CP monitor or choose to ‘hear’ their child during the night. Four levels of monitoring have been identified as have a number of factors that affect the choice of monitoring level.

Two main areas of concern are highlighted by the exploration of the methods of night-time monitoring practiced by parents of children with CP. The first is related to different methods impacting, in varying degrees, on the parents’ own sleep. The parents of the young people that are mildly affected by their CP (who sleep well and have no additional health needs) felt they performed low level night-time monitoring, except on the rare occasions when their child was unwell and therefore, there was minimal impact on the parents’ own sleep.

The ‘keeping an ear open’ informal approach to monitoring, despite being used with children with severe CP, who needed parental attendance every night, also had a low impact on parents sleep when compared to technological and combination monitoring. Parents who practiced informal monitoring were confident that they would hear, and be able to quickly determine, when and if their child with CP required parental attendance. The main facilitating factor in being able to monitor at this level concerned the close proximity of the child to the parent at night.

In contrast, for the three families that used (solely) baby monitors proximity was an issue, as the child with CP had a downstairs bedroom whilst the rest of the family slept upstairs. Use of a baby monitor led to a heightened sense of alertness because of the noises that it emitted, in conjunction with the parental expectation that they would need to attend to their child at some point. The significance of the location of the child’s bedroom was also highlighted by the discussion that technological monitoring would need to replace informal monitoring when disabled children moved to a downstairs bedroom. This also
highlighted that technological monitoring was a permanent strategy for as long as the young person remained in the family home. Furthermore, there was an inflexibility associated with this approach illustrated by parents not exploring other strategies to monitor or ways to increase proximity when circumstances changed, for instance, if the technological monitoring equipment failed or if the child was having a very disturbed night.

Flexibility in their approach to monitoring was found for some parents who usually undertook the informal method. An example of this was illustrated by two of the families who chose co-sleeping as a short term or occasional strategy in order to monitor their child with CP more closely at night and to respond to them more quickly. For these families co-sleeping was very much seen as a strategy rather than a problem. For the King family, a quicker response to Brian waking up meant that the period of wakefulness was lessened for him and the parent attending, and it also meant that the impact on the sleep of the other (non co-sleeping parent) was minimised. Both families emphasised that co-sleeping was not a permanent practice. Brian King (child with severe CP) used the word ‘embarrassed’ in relation to the co-sleeping arrangement, although he did confirm that his dad’s presence at night was helpful to him. This raises questions about, and a need to consider, how age and gender affect the practice of co-sleeping. For instance, when the child reaches a certain age does co-sleeping become inappropriate? Similarly, is there an age when children should only co-sleep with their same-sex parent? Co-sleeping was a useful strategy for these families in order to provide immediate comfort when the child was ill and, also, to protect the sleep of the child and parents, however, consideration of these questions is important.

For two sets of parents there was a need to monitor and be able to ‘hear’ their child using a combination of monitoring strategies because their child had, in the past, or was currently having major epileptic seizures. For these parents the use of such strategies provided reassurance and control, however, the impact on the parents’ sleep was substantial. The fear of not hearing a seizure and the perceived danger that this posed to their child outweighed all need to protect their own sleep. For Anne and Darren Gibson, the acquisition of the
SATs monitor was viewed as entirely positive, despite it being the cause of ‘false alarms’ and numerous awakenings every night. The monitor provided the Gibson’s with a sense of control to counterbalance the unpredictability of Jacob’s complex epilepsy and, at the time, this was more important to them than a consideration of the impact on their own sleep.

The second area of concern that needs consideration is about how parental night-time monitoring impacts on the privacy needs and rights of children with CP. In the Watson et al. (1999) study, in which high levels of adult surveillance of disabled children were identified, a number of young people commented on the negative impact this had on their need for privacy. However, in my study there was no mention or discussion by children or parents about the possible consequences for privacy that night-time monitoring may have.

The potential impact that night-time monitoring has on the privacy of children with CP may depend on the method of monitoring engaged in by parents. Once again, as with the impact on parents’ sleep, technological monitoring and combination monitoring may have a greater impact on the privacy of children with CP. Monitoring, via a baby monitor, was constant throughout the night and did not allow for any periods of complete seclusion and privacy for the child. In contrast, informal monitoring allowed for periods of privacy, broken only when the child indicated (and voiced) their need for parental attendance. As discussed earlier the main reason for using a baby monitor was due to the lack of proximity between the parents’ bedroom and the downstairs bedroom of the child with CP. Therefore, as discussed in Chapter 9, the way in which a downstairs bedroom impinges on the privacy and autonomy of children with severe CP is highlighted again by the need to monitor via a technological device. It should be noted, however, that for some children, specifically those with severe CP and additional health needs, the knowledge that parents are monitoring them at night may provide comfort and reassurance (McKintosh et al., 2010). This was intimated by Jacob Gibson choosing the photograph of his SATs monitor as one of his favourite things in his bedroom.

Furthermore, for parents undertaking informal, technological and combination monitoring it is done in a context of care and protection for their
disabled children. The children concerned all wake regularly during the night and require parental attention and/or they have epilepsy which the parents perceive as a serious risk to the child if they are not monitored or 'heard'. However, monitoring at night solely via a baby monitor (as opposed to combination monitoring) is necessitated by the child having a downstairs bedroom when the rest of the family sleep upstairs and, as a monitoring method, has a substantial negative impact on parents’ sleep. Additionally, because of the constant and continual nature of monitoring via a baby monitor, the potential impact on the privacy of the child with CP may be greater.
Chapter 11 - Discussion

11.1 Introduction

The original primary aim of my research was to explore the experiences of sleep directly from children with cerebral palsy (CP). As discussed in Chapter 2, children with CP are more likely to experience sleeplessness but no previous research has obtained disabled children’s own views about their sleep. To date all research examining disabled children and sleep has relied on the viewpoint of parents, mainly mothers. Inspired by the literature on methods to include children (emerging from the ‘new’ sociology of childhood), and specifically research involving disabled children (Watson et al., 1999; Connors and Stalker, 2003), my study enabled children with CP to provide their views and understanding of their own sleep. The sociology of sleep and the sociology of family influenced my thoughts and, building on the sociological research of Moran-Ellis and Venn (2007) and Williams et al. (2007), my study has emphasised how sleep and the night-time for children is one of activity and interaction, bound up within a family context. No research to date has explored sleep from the multi-perspectives of family members. Therefore, by obtaining the viewpoints of children with CP, their siblings and their parents my research has achieved an inter- and intra-generational family perspective. This allowed for differences, as well as similarities, in aspects relating to sleep to be explored between disabled children and their non-disabled siblings. In particular, there was an exploration of elements related to sleep that existed because of the severity of the child’s disability and how sleep practices were related to the child’s age. Parent viewpoints allowed an examination of their own sleep from a variety of perspectives - as individuals, as parents, and as carers of a disabled child.

Ten families took part in the study (including 3 pilot families) which represented 34 participants - ten children with CP, seven siblings (from 5 families) and seventeen parents. For a family group to be included in the study there had to be at least one young person with CP (aged 6 to 13 years) and one parent, fulfilling the relevant inclusion criteria, agreeing to participate in the study. A qualitative approach was adopted and semi-structured interviews were
conducted with each participating family member. Supplementing this approach was the use of task-based methods prior to the interview taking place during a two week information collection period. All the children in the study (children with CP and their siblings) were asked to take photographs of aspects related to sleep using a provided disposable camera. Additionally, all participants (children with CP, siblings and parents) were asked to complete daily sleep diaries for two weeks and could choose to do this by either audio recording with a Dictaphone, hand writing or word processing their diary entries. During this two week period, participants were also asked to wear an Actiwatch and to complete a one-off sleep questionnaire. The information collected via these activities was used to facilitate, and prompt, discussion during the interviews.

This chapter draws on the accounts of family members to discuss how sleep is viewed, conceptualised and practiced or ‘done’ within and across families of children with cerebral palsy. The key findings that have emerged from the preceding analysis chapters will be outlined in this chapter and discussed with reference made to the sociological literature concerning sleep, children, childhood, disability and families.

11.2 The social context of (disabled) children’s sleep

Findings build on previous work from the sociology of sleep and emphasise how sleep and the night-time is a time of activity and interaction, thus supporting the notion of ‘doing’ sleep (Taylor, 1993). The social context of children’s sleep, in particular the ‘when, where, what and with whom’ (Williams et al., 2007) aspects of sleep were explored. This level of exploration is labelled as the social/interactional level by Williams (2005, 2007), who purports that a sociological analysis of sleep can take place at 3 interrelated levels. My research primarily explored the social and interactional aspects and practices associated with the ‘meanings, methods, motives and management’ (Taylor, 1993) of sleep. This was especially relevant for the children, who were able to articulate their attitudes, experiences and feelings about these matters. An example of this are the findings related to the transition phases of sleep for children and, in particular, the bedtime routine and the interactions that occurred
during the night. However, the two other levels of analysis proposed by Williams (2005, 2007) also feature in my research.

The first is the individual/(non)experiential level which concerns notions of the ‘dormant, dreaming or drowsy body’ (Williams, 2005: 4) and so includes (non)experiential aspects and the embodied nature of sleep. For instance, the embodied impact of sleep, specifically sleeplessness, was discussed by a number of children. The interrelation with the second, social/interactional, level was also clear from these discussions as the topic moved from the negative impact of sleeplessness on self to that on others.

The third level of analysis suggested by Williams (2005, 2007) is the societal/institutional level and once again themes pertaining to this level were evident in my research. One example of an issue raised and relevant to this level was the use and location of the bedrooms of children with severe CP. The downstairs bedroom of a number of children with severe CP represented a lack of a clear public/private divide within the household which may have compromised the privacy (as well as autonomy) for these children. Location and proximity to household public spaces of the downstairs bedroom played a key part in this potential compromising of privacy, as did its use by other family members, presence of paid carers and the installation and use of monitoring equipment. This finding was emphasised by discussion with siblings and older children with mild CP about what they used their bedrooms for and the associated meanings, as well as through discussion with parents about the night-time monitoring they engaged in of their child with CP. Therefore, although the main focus of my research was on the social and interactional dimensions of sleep as embedded within family life, the individual and the societal levels are pertinent and evident in the findings of my research. An overview of the findings will now be presented.

11.3 Overview of findings

Chapters 7, 8 and 9 presented the findings gained primarily from the accounts of the children participating in the study, which in part were prompted and facilitated by the photographs taken by the children. Chapters 7 and 8
specifically focussed on the meanings of sleep for children, reasons for sleeplessness and the impact of this on the child and others. A dominant theme that emerged concerned the time leading up to sleep and the activities and interactions that took place at this time - the bedtime routine. The bedtime routine is discussed in more detail in Section 11.4. Interactions during the night also emerged as important, specifically how parents helped younger children (siblings and the younger children with mild CP) and those with severe CP during times of sleeplessness. Other interactions and artefacts were viewed by the younger children and children with severe CP as helpful in getting to, or resuming, sleep and these included night lights and cuddly toys. Older children (siblings and those with mild CP) discussed strategies that they used to help themselves fall asleep which included relaxation techniques and the use of technology, for example, watching TV or playing computer games. Chapter 9 focussed on the ‘where’ aspect of children’s sleep – the bedroom. This chapter explored the use, location and items contained within the children’s bedrooms, with differences, with regard to these factors, between children with severe CP and those without (siblings and children with mild CP) being highlighted and the potential adverse impact on displays of identity and on privacy for children with severe CP emphasised. This will be further discussed in Section 11.5.

Findings from the parent data presented in Chapter 10 also highlighted the social and interactional aspects of sleep and the night for families, specifically those including children with severe CP. The findings illustrate that night-time parental monitoring of children with CP is common but differs in terms of level and type between families and depends on a number of intersecting factors. Severity of the child’s CP, whether the child with CP regularly woke at night, location of the child’s bedroom, additional health issues concerning the child with CP and past experiences were all factors that intersected and influenced the level and the means of night-time monitoring that parents deemed necessary. Parental night-time monitoring of children with CP is discussed in detail in Section 11.6, with a specific focus on the impact of this on the sleep of the parents and on the privacy rights of children with CP. Co-sleeping was engaged in by a small number of the parents with their disabled child at certain times evidencing again the interactional nature, and
management, of sleep as co-sleeping was used as a strategy to monitor their child and, also, to protect the sleep of others in the family. The practice of co-sleeping is discussed in Section 11.7.

11.4 The bedtime routine

Many of the children found it difficult to articulate their thoughts about the meanings of sleep per se. As Williams et al. (2007) also found the children were much more confident and comfortable in the discussion of the time leading up to and the time following sleep, ‘the transition phases’ (Schwartz, 1970) and to the ‘myriad of social activities which both precede and proceed it [sleep]’ (Williams et al. 2007: 3.3). Moran-Ellis and Venn (2007) also found that the lead up to bedtime was a significant time in their exploration of the sleeping lives of children and teenagers. They conceptualise this time, the bedtime routine, as ‘domestically institutionalised through specific rites, rituals and practices’ (para 3.1). Moran-Ellis and Venn (2007) discuss how for the children in their study the process of going to bed was one that was highly embodied as it involved the physical relocation of children from the ‘day world’, and the shared physical spaces this included, to the ‘night world’ that their bedroom encompassed. The activities that took place during this time of relocation were often hygiene-related (for example, brushing teeth, washing and using the toilet) and activities that promoted calmness, stillness and quiet such as reading a book or being read to.

Focusing on these aspects and activities of sleep, encapsulating going to bed and going to sleep, highlights the social context of sleeping for children embedded within family life. As discussed by Williams et al. (2007), Moran-Ellis and Venn (2007) and corroborated by my own findings the activities and elements that make up the bedtime routine are led and co-ordinated by the adults in the household (most often the parents but for a number of families in my study by paid carers also). However, this time is also characterised by child and adult interactions, negotiations, and as Moran-Ellis and Venn (2007) state ‘replete with false starts, counter-moves and resistances’ (para 3.1). The interactional aspect of the bedtime routine was evident for all the children that took part in my study, however, elements involving negotiations and resistance
between parent and child, for instance about the timings of going to bed and timings of sleep was not (see Section 11.4.3). Therefore, the ‘transition phases’ (Schwartz, 1970) discussed by the children highlighted the differences between children with severe CP and those without.

11.4.1 The bedtime routine: a family practice

A close examination of the bedtime routine reveals a time that is complex and interwoven with interactions, negotiations and, for some children, resistances and power play and embedded in family life. However, at a surface level as Moran-Ellis and Venn (2007) comment the bedtime routine is ‘so culturally familiar and mundane as to be unremarkable’ (para 3.1). Unremarkable until explored further and a transition period that is all about the ‘meanings, motives, methods and management’ of ‘doing sleep’ (Taylor, 1993) and also of ‘doing family’ (Morgan, 1996, 2011) is revealed. In this way the bedtime routine can be described as a ‘family practice’ (Morgan, 1996; 2011). Family practices convey a sense of the active, a sense of everyday, a sense of the regular and a sense of fluidity (Morgan, 2011) which is applicable to the practice of the bedtime routine. Viewing the bedtime routine as a family practice emphasises the relationship between sleep and family. There is an interconnectedness whereby sleep is a lens through which to view family and family is a lens through which to understand sleep. An exploration of the separate elements of children’s bedtime routines emphasised a commonality of family experiences and an understanding of the interactions, power relations and negotiations that highlights the relationality of family practices, whereby ‘family practices are carried out with reference to some other family member’ (Morgan, 2011:10). My research clearly showed how the bedtime routine differed for children with severe CP compared to siblings and children with mild CP. This had implications for the amount of choice, control, autonomy and privacy that children with severe CP were able to experience, which is discussed in Section 11.4.3.

Furthermore, for a number of families the bedtime routine did not exclusively involve ‘family’ members as paid carers were employed often at this time to help with children with severe CP. The inclusion of paid carers does not
necessarily negate the ‘family’ aspect from the practice of the bedtime routine. As Morgan (2011) comments it depends on how we define ‘family members’. This will be discussed in more detail in the next section.

11.4.2 Paid carers and the bedtime routine as a family practice

One way that Ben-Ari (2008) defines the bedtime routine from a Western cultural perspective is that it always takes place within a nuclear family context. However, this was not necessarily the case for a number of the families with children with severe CP. Five families used their direct payments to employ a paid carer to come in regularly and help in the afternoon and evenings and, specifically, to help the child with severe CP get ready for and into bed and thus manage and supervise the child’s bedtime routine. Reasons given by parents for using paid carer at this time included it being difficult to organise and manage bedtimes for multiple siblings and the need to multi task at this time of day i.e. cook dinner, tidy up, help siblings with home work etc.

A key issue is whether the presence of a paid carer at bedtime means that the bedtime routine can no longer be considered a ‘family’ practice? This, in part, depends on how ‘family’ is defined. Parents in two families referred to their paid carers, who had been working for them for a number of years, as ‘one of the family’ or ‘as a friend’. With this widening of the definition of ‘family’ to include paid carers (for these two families at least), the sense of fluidity and flexibility that Morgan (2011) ascribes to the concept of family practices is evident. It also reflects Smart’s (2007) personal life perspective which focuses on people’s meanings of ‘family’ and highlights the range of different personal relationships that are important to people, even though they may not be conventionally defined as ‘family’. These include all kinds of relationships that individuals see as significant. This was particularly evident from Catherine Cooper’s (mother) discussion about their carer who had been employed by them for several years. At one point in her interview Catherine Cooper described the carer as ‘being part of the furniture’ and when she invited the carer to go on holiday with the family she instructed her ‘to become part of us [the family]’.

292
The length of time that a carer had been working for the family seemed to be significant in terms of how they were viewed and the nature of the relationship. For some families the employment of a carer to help at bedtime was a relatively new experience and for others there had been a frequent change of carers. It also depends on whose viewpoint or perspective is considered. Therefore, the viewpoint of a parent regarding family membership of a carer may be very different to a child’s perspective. For instance, Oliver Davis (child with severe CP) did voice some discontent about his recently appointed paid carer helping him at bedtime and had refused to let her help him put his pyjamas on. The lack of familiarity and the intimate nature of being undressed and redressed in preparation for sleep clearly crossed the boundary of the public and private divide for Oliver. He was use to (familiar with) his mother managing this element of bedtime and in this circumstance Oliver clearly did not perceive the carer as ‘part of the family’. It also serves as a reminder of the high level of surveillance and ‘management’ by adults that disabled children are subjected to throughout all areas of their lives as highlighted by Watson et al. (1999). Oliver was able to voice his discontent but for many disabled children who are non-verbal this is not possible.

Therefore, in situations when the employment of a paid carer is a new experience or when they are perceived as unfamiliar, questions do need to be asked about the bedtime routine as a family practice. This then potentially impacts on the privacy rights of, primarily, the child with CP but also the family as a whole. This will be explored in more detail when the bedroom of children with severe CP is discussed in Section 11.5.

11.4.3 The bedtime routine and developing autonomy

Children with severe CP had little say, choice or control about when they went to bed (or when they got out of bed) and therefore, autonomy was lacking and little privacy was achieved. Because of their complete physical reliance on others to transfer them in and out of bed they were unable to exercise choice in relation to sleep timings. The inclusion of siblings and older children with mild CP in my study highlights how family and sleep practices, for these children, facilitate the development of independence and allow for increasing (with age)
periods of privacy within the family household. Moran-Ellis and Venn (2007) discuss the privileges that an increase in age affords children with reference to choosing when to go to sleep. Often for the teenagers in their study there was greater flexibility about what bedtime, specifically sleep time, meant. So although the relocation from the public household spaces of the day-world was dictated by parents, once in their bedrooms older children were able to choose when to go to sleep. There were indications of increasing autonomy in my own findings with reference to sleep timings and age for siblings and children with mild CP. For instance, a number of the older siblings discussed how they secretly read in their beds to delay sleeping and also a discussion of techniques that were utilised to self-manage and help themselves fall asleep.

Age appeared to make no difference to the experience of children with severe CP who were unable to, and perhaps not facilitated to, demonstrate autonomy with regard to their own sleep timings. Children with severe CP are unable to physically perform the activities that non-disabled children do in order to delay sleep. Therefore, this finding recognises how 'impairments' and resulting 'impairment effects' (Thomas, 1999) impact on the sleep practices and management of sleep for children with severe CP which also affects their sense of autonomy and control. Some parallels can be drawn with the literature on the sleep of older people living in care homes. For instance, Luff et al. (2011) found that the bedtimes and getting up times of physically disabled elderly residents in care homes, who relied on caregiver assistance at these times, were affected by the availability and shift patterns of the care staff. One consequence of this was that these residents spent longer in bed compared to more independent residents and a greater proportion of this time was spent awake. Luff et al. (2011) question how resident's experience the hours spent awake, especially as they are physically reliant on others to assist them in activities that independent others may partake in at these awake times e.g. reading a book, watching television, making a drink. The authors suggest this as an area for future research. For the children with severe CP in my own research, who had little control and choice over bedtimes and get up times, there may also be a discrepancy between the time spent in bed and the time spent asleep. This may particularly be the case for older children where physiological changes have
been shown to shift the sleep timings of teenagers to a later sleep time and a later morning awakening (Taylor et al., 2005).

From the parent data about monitoring it may be that parents are much more aware of when their child with severe CP is awake and can assist the child (especially if the child vocalises their awake state) compared to staff in care homes for older people. However, in a number of diary entries, that parent’s wrote on behalf of their child with severe CP, comments were made about the child being wide awake when checked on in the morning and that they (the parents) were not aware of when the child had woken. A priority is to research this further and, in particular, gain an insight from the disabled children themselves about how these awake (but quiet) times are experienced. Exploration could reveal whether these are times of frustration and another example of the lack of choice and control experienced by children with severe CP or if they are, in fact, calm, solitary times valued ‘as opportunities to be disengaged from the demands of interactions with others and instead enjoy time to themselves’ (Moran-Ellis and Venn, 2007: para 5.6) and thus an opportunity to display agentic qualities.

My findings also raise broader issues in relation to the life experiences of children with severe CP. As Watson et al. (1999) found, disabled children are subjected to high levels of adult surveillance and adult control throughout their lives. Watson et al. (1999) report that disabled children are often in the company of adults rather than other children and that in their project (mainly based in schools) they observed very few child-child interactions. Applying these observations to my own sleep-related findings, specifically with reference to the bedtime routine, raises questions about the level of awareness children with CP may have of the normative expectation that autonomy and control, in terms of sleep, increases with age. This may be particularly pertinent when children with severe CP are the only children in a household as children are unlikely to observe the sleep practices of other non-disabled children outside of the family. For children with severe CP who have siblings it may be compounded by having a downstairs bedroom, when the rest of the family sleep
upstairs, as they are unable to observe the sleep practices and activities of siblings that signify increased choice and autonomy (see section 11.5.1).

11.5 The bedroom

The bedroom, particularly the children’s use of their bedroom and the location of their bedroom, clearly captured the concept of difference between the sleep practices and organisation of sleep for children with severe CP compared to those with mild CP and the siblings. For siblings and children with mild CP the bedroom was regarded as an important place that represented privacy within the family household and a space in which to exhibit identity and autonomy. This contrasted with the findings, in relation to bedroom use, of children with severe CP who tended to use their bedroom only for the activity of sleep and for some, personal care needs.

The location of children’s bedrooms also highlighted differences between children with severe CP and those without and had an impact on the privacy afforded to children with severe CP. Four out of the seven children with severe CP had their bedrooms located on the ground floor of the family home. For three of these children the rest of the family slept in upstairs bedrooms (whereas, Brian King, lived in a specially adapted bungalow so all the family had bedrooms on the ground floor). For two other younger children with severe CP, there were plans for them to move to bedrooms on the ground floor in the near future. Converting the downstairs space to create a bedroom for physically disabled children seemed to be the preference of Local Authorities as opposed to, for example, installing a lift.

From the parent viewpoint the reasons for having a downstairs bedroom for their child with CP were practical ones and based on the difficulty of physically carrying their child to an upstairs bedroom. However, a number of mothers acknowledged that when having to attend to their child at night the negative impact on them (the mother) and their sleep was greater compared to when the child had an upstairs bedroom. The decision to move a child with CP into a downstairs bedroom was not always an easy one for parents. Aileen Edwards (mother) was experiencing significant stress in relation to plans that
were being made to create a downstairs bedroom for her son Stanley. However, she acknowledged that with the increasing size and weight of Stanley and the difficulty in carrying him up stairs the family had little choice. The Local Authority would only fund a downstairs conversion rather than a two storey extension and lift, therefore Aileen felt she had ‘no choice’ and had to ‘compromise’.

However, a number of parents commented that they believed having a downstairs bedroom was favoured by their child with severe CP because they (the child) were comforted by the familial noises of the household during the evening time. Although the perspective, with reference to having a downstairs bedroom, of the children with severe CP was considered it was difficult to obtain detailed responses. Libby Cooper (12 years old, severe CP) did choose the words/symbols ‘don’t like’, ‘lonely’ and ‘jealous’ from her communication book when asked how she felt when she woke in the night but, as discussed in Chapter 9, it was difficult to know whether this was related to having a downstairs bedroom and being separate from the rest of the family or not.

The location of the bedroom, specifically a downstairs bedroom, increased the ‘public’ nature of this space for children with severe CP. This was further compounded by the employment of paid carers at bedtimes, storage of disability related items in the disabled child’s bedroom and parental technological monitoring of children with severe CP at night. The potential impact of this on the concepts of privacy, identity formation and autonomy will now be discussed in more detail.

11.5.1 The bedroom: a place for developing identity and enjoying privacy for ‘some’ children

Williams (2005) details how throughout history sleep, and the bedroom, has become increasingly part of the private sphere. Mitchell and Reid-Walsh (2002:113) comment that ‘the child’s bedroom is the one official place of some privacy – and a place where there can be at least some expression of individual taste’. Having opportunities for privacy has been found to be important in the development of individuality, independence and responsibility which in turn
facilitates the development of a sense of self in children (McKinney, 1998; Shmueli and Blecher-Prigat, 2010). With specific reference to disabled children Weigel-Garrey et al. (1998) stress the importance of privacy in developing self-identity and autonomy. However, in my study the bedroom and what it represented highlighted vividly the differences between, in particular, older children with severe CP and older children without, in terms of access to privacy. For the older children with mild CP and the older siblings their bedrooms represented for them a place of privacy, identity and agency. Apart from Stanley Edwards (who has severe CP) and his younger brother, all the other children in the study had their own bedrooms. Having one’s own space provided, specifically the older children without severe CP, opportunities for privacy and autonomy within the household. In arranging and ‘accessorising’ their own bedrooms these children also displayed identity and agency. This was clearly illustrated by Daniel Cooper (13 years old, older brother) who explained how he had his bedroom arranged into different ‘zones’ (Lincoln, 2004).

The bedroom as a place to form and display identities, as illustrated by the zoning of his bedroom by Daniel, was also displayed through the discourses of the older siblings and older children with mild CP in relation to the objects present in their bedrooms. Bacon (2016:7) emphasises the importance of exploring the bedroom as a physical space because ‘the objects and spatial arrangements are the spaces that identities and relationships are lived in and through’ and links this with the work of Smart (2007) and the ‘personal life’ perspective. Bacon (2016:7) highlights Smart’s focus on the importance of considering ‘possessions, things and relationality’ and argues that objects in bedrooms are ‘invested with meanings’ that signify the displaying of identities and the practicing of social relationships. One example of this (discussed in Chapter 9) was Greg Jackson’s (child with mild CP) discussion of ‘being cool’. Furthermore, the objects in these children’s bedrooms illustrated the transitional nature of children’s identities with objects from the past as well as the present being discussed and represented as significant. This was not evident and there was little sense of children with severe CP displaying their identity, individuality and agency through their bedrooms. As explained by Mitchell and Reid-Walsh
(2002: 123) age is (usually) linked to agency in terms of use and claim over the decor of the bedroom:

Clearly the infant or toddler has virtually no say over space, while the older child is gaining some autonomy over his or her space. Thus, the rooms of infants and young children...are not really private spaces the way the bedrooms of older children, adolescents, or adults might be; rather, they are more likely to be reflections of adult taste – or “repositories” for what parents want for their children.

However, an increase in age made little difference for children with severe CP and instead the description of the bedrooms of toddlers and infant’s bedrooms by Mitchell and Reid-Walsh (2002) can also be applied to the bedrooms of older children with severe CP which did not pervade a sense of them, the child, their identity or their interests.

This was further compounded by items related to clinical care needs being present in the bedrooms of children with severe CP, for instance, ‘hospital’ beds and hoists (discussed in Chapter 9) and equipment such as airway suction machines, oxygen cylinders, power wheelchair battery packs, feeding tubes, standing frames as well as items including latex gloves, incontinence pads/nappies and wet wipes. Kirk et al. (2005) report that the parents, caring for their technology-dependent children, in their study felt that their homes were dominated by pieces of equipment and one mother described her child’s bedroom as a ‘mini-hospital’. Kirk et al. (2005:459) discuss how all the parents experienced the ‘intrusion of equipment and spatial alteration’ and, how in some cases, the entire home environment could be dominated by medical equipment. In my own study there was no evidence of the rest of the home being ‘dominated’ by clinical equipment and related items. Instead these artefacts appeared to be contained to the disabled child’s bedroom, especially if the child’s bedroom was downstairs. Furthermore, Kirk et al. (2005) did not consider the impact of the presence of medical equipment from the child’s perspective. Gaining more insight from disabled children about their feelings towards having medical equipment and items in their bedrooms would be an
interesting topic for further research, especially given the importance of the bedroom for the development of identity and independence as I have discussed above.

Past sociological research that has focussed on children and sleep has highlighted the importance attached to the privacy bedrooms afford older children (Williams et al., 2007), but that privacy for some young people did not necessarily mean isolation. Moran-Ellis and Venn (2007) found that bedrooms for their teenage respondents were often used for socially interacting with friends in virtual ways, and that by using their own bedrooms such interactions were kept private from the rest of the household (and sometimes were carried out covertly when older children were assumed, by parents, to be sleeping). In my study there was no evidence of the older children without severe CP engaging in virtual interactions with friends within their bedrooms, although bedrooms were used as a social space when friends visited which can be seen as examples of ‘practicing of relationships’ (Bacon, 2016: 7) and an important part of the development of identity and autonomy. However, privacy and independence enjoyed by the older children without severe CP was not shared by those with severe CP.

Although all the children with severe CP had their own bedrooms (except for Stanley Edwards) there was a lack of evidence of them being private spaces used to display agentic and autonomous qualities. Furthermore, there was little discussion from parents that their children with severe CP needed or desired the privacy that time alone in their bedrooms could offer (the exception to this was Brian in the King family, discussed in more detail below). This is akin to the findings of McKinney (1998) who found that parents of pre-schoolers did not consider privacy or the facilitating of privacy for their young children as an important aspect of home life. However, this is in contrast to Weigel-Garrey et al. (1998) who found that parents of disabled children in the United States were highly aware and supportive of the privacy needs for their disabled children. In this study parents tried to actively facilitate opportunities for privacy for their disabled children but felt it was restricted by access and control in the environment. In many ways a downstairs bedroom should facilitate access for
children with CP and, therefore, provide opportunities for privacy but as discussed next this may not be so. In light of my own findings and how they contrast to those of Weigel-Garrey et al. (1998), further questions need to be asked about how parents view the privacy needs and rights of their children with severe CP as they grow older, particularly when compared to non-disabled siblings of a similar age. Additionally, future research should focus on how disabled children themselves view their privacy rights and their opportunities for access to privacy within the home.

The lack of privacy afforded older children with severe CP in my research was compounded by their bedrooms, especially those downstairs, being often located in, and used as, public places. For example, often the downstairs bedrooms were located directly next to a household ‘public’ space such as the sitting room or the kitchen. The presence of paid carers in the child’s bedroom to help get the child with severe CP ready for bed and the use of the downstairs bedroom as an extra or additional household or family space also highlights the public nature of the bedroom of children with severe CP and a blurring of the public/private divide.

Children with severe CP spent little time in their bedrooms apart from designated (by parents) sleep times and for a number of children with severe CP personal care activities, for instance, changing of nappies/incontinence pads. One exception to this was Brian King, who did spend some leisure or relaxing time in his bedroom listening to music. However, the autonomous nature of this was difficult to gauge as the information pertaining to this came from his parents and not directly from Brian. In their interview, both Matt and Vicky King (parents) specifically discussed the importance of Brian having time alone to ‘chill out’ in his bedroom. They were also parents, despite Brian having severe CP and complex needs, who chose not to use a baby monitor to ‘hear’ Brian at night. One way that Brian may have been more enabled to use his bedroom for privacy and time relaxing (and that affected his parents’ choice to not use a baby monitor) is that the family live in a specially adapted bungalow and all the bedrooms are downstairs. Therefore, it is not necessarily the fact that the downstairs location enabled autonomy over bedroom space as a
number of the children with CP had downstairs bedrooms. However, what makes the King family different is the fact that all the bedrooms were downstairs. In the interview with Ellen King (Brian’s younger sister) she talked about how often Brian and she would go in and out of each other’s bedrooms. If Ellen had friends over then Brian would often join them ‘hanging out’ in Ellen’s bedroom. She also mentioned how in the school holidays Brian and she would have mini-sleepovers together in each other’s bedrooms. By being able to observe and take part in Ellen’s ‘normal’ use of her bedroom, Brian was aware of how his own bedroom could be used and how this changes with age. Although he cannot physically move himself into his own bedroom he does have the means of communication to ask to be taken to his bedroom at times other than sleep times.

### 11.5.2 The downstairs bedroom: ‘barriers to doing’ and ‘barriers to being’

As discussed above the public nature of downstairs’ bedrooms for children with severe CP (specifically, when the rest of the family sleep upstairs) and the lack of opportunity to access their bedrooms may impede the privacy rights of the child. As discussed in Section 11.5.1, restricted opportunities for privacy may negatively affect the development of independence, autonomy and self-identity in children (McKinney, 1998; Weigel-Garrey et al., 1998; Shmueli and Blecher-Prigat, 2010). Therefore, the downstairs bedroom may potentially be both a ‘barrier to doing’ and a ‘barrier to being’; terms proposed by the social relational model of disability (Thomas, 1999). ‘Barriers to doing’ describe structural, physical and environmental barriers that prevent disabled people from accessing facilities, services and support. This can be applied to downstairs bedrooms if we consider that once created and used, the child with CP is no longer able, or facilitated, to access the first floor of the household and they no longer ‘go up’ to bed with the rest of the family. The downstairs bedroom, therefore, represents segregation from the rest of the family at night.

‘Barriers to being’ refer to behaviour that is directed towards a disabled person (wittingly and/or unwittingly) that is hurtful or inappropriate and leads to ‘psycho-emotional disablism’ (Thomas, 1999) which, in turn, has a negative impact on the disabled person’s self confidence and self esteem. The public
nature of the downstairs bedroom including its use by other family members has a direct impact on the attainment of privacy for children with severe CP which may affect the development of their independence and identity which have been closely linked to aspects of personality such as self confidence (Weigel-Garrey et al., 1998). Furthermore, a downstairs bedroom, when the rest of the family sleep upstairs, may cause feelings of loneliness and a sense of difference from siblings and the rest of the family for the child with CP. Connors and Stalker (2007) suggest that disabled children face greater ‘barriers to being’ than ‘doing’ and these barriers may be of particular importance to young people:

Our findings suggest that [barriers to being] may have particular significance during the childhood years [for disabled children], when young people are going through important stages of identity formation, which may lay the foundations of self-confidence and self-worth for years to come. (p. 31)

It is important to highlight the word ‘unwittingly’ in the above discussion of ‘barriers to being’ as I do not want to convey that parents purposely or knowingly cause ‘barriers of being’ for their children. Often, as emphasised by Aileen Edwards (mother), parents are given little choice or options about having to have a downstairs bedroom for their disabled child. Local Authorities (in the area where the research took place) seemed to favour building a downstairs bedroom rather then, for instance, installing a lift or a two storey extension to house a lift. Therefore, for parents facing the difficulties of lifting, carrying and moving their growing disabled child upstairs there is little choice but to ‘compromise’ with the option of a downstairs bedroom.

The examples given above of the King family and Brian (child with CP) and Ellen’s (sibling) use of their bedrooms suggest that when bedrooms are all on the ground floor the barriers to ‘doing’ and ‘being’ may be reduced.

11.6 Parental night-time monitoring of their disabled child
Chapter 10 presented the findings gained from the accounts of the parents and focused on the salient theme of parental night-time monitoring of children with CP. The level and type of night-time monitoring of disabled children differed in
terms of level and type between families and was dependent on a number of intersecting factors, particularly the severity of the child's CP, likelihood of the child waking at night, location of child’s bedroom, current and past health issues (for the child with CP) and parental perception of risk. How the intersection of these factors was interpreted by parents was also an important determinant in terms of level and type of night-time monitoring.

Four levels of parental night-time monitoring emerged from the parent interviews; low level monitoring, informal monitoring, technological monitoring and combination monitoring. Low level monitoring was performed by parents of children with mild CP, who sleep well and have no additional health needs. This minimal level of monitoring was also undertaken by parents of their children who did not have CP (i.e. the siblings). Informal monitoring or the ‘keeping an ear open’ approach was performed by those parents whose child with CP was in close proximity to them at night. The children all had severe CP and required parental assistance at night on a regular basis. These parents referred to being able to hear their child at night because of their close proximity and a trust in their ability to attach the correct meaning to their child’s vocalisations at night. Lack of proximity at night was the main reason given by parents for their use of technological monitoring via use of a baby monitor. All the children who had bedrooms located downstairs away from the rest of the family were ‘heard’ during the night via a baby monitor. These children had severe CP and woke every night in need of parental attendance. Two families used a combination of monitoring approaches, which included use of a baby monitor. This approach was based on traumatic experiences of their child having severe epileptic seizures at night.

11.6.1 Night-time monitoring and the downstairs bedroom: impact on parent sleep and child privacy

My research supports previous findings reporting that high levels of surveillance by adults are experienced by disabled children (Watson et al., 1999). My findings showed that parental surveillance in the home continues throughout the night, in line with Heaton et al. (2006) and Wright et al. (2006). The expected changing nature of parental monitoring through childhood is also
an important issue to consider in relation to children with CP. Night-time monitoring by parents of children with severe CP continues at high levels of intensity throughout their childhood and, as discussed, may actually increase if contextual factors change, for instance, the child with CP moves to a downstairs bedroom. Corker and Davis (2004) comment that disabled children are much more likely to be considered as needing protection from risk compared to non-disabled children. This in conjunction with the conceptualisation of sleep and the night-time as an inherently vulnerable and risky time (Williams, 2005) may go some way in explaining the continuing high levels of night-time surveillance of children with severe CP by parents and fits with the work of Watson et al. (1999). They reported high levels of adult surveillance of disabled children in settings that were highly structured such as at school. However, the researchers do not talk explicitly about levels of adult surveillance within the family home.

Past research has highlighted how parental night-time monitoring of disabled children has a direct negative impact on parents’ sleep. However, my research found that the degree of impact is dependent on the level and type of monitoring performed by parents which is primarily influenced by the proximity of the child’s bedroom to that of the parent/s, the severity of the child’s CP, additional health needs of the child and past experiences. Technological monitoring and combination monitoring were identified as the methods that had the greatest negative impact on parents’ sleep. The impact on parents’ sleep is not the only consequence of high levels of parental monitoring, especially technological monitoring, as there are potential implications too for the privacy afforded to children with CP.

For many of the parents in my research the night-time and sleep was constructed as a time of increased risk to the child with CP. Therefore, monitoring was a strategy in order to reduce this risk. For parents, specifically when the child’s bedroom was downstairs, away from the rest of the family and/or when the child had epilepsy, a practical solution in order to ‘hear’ the child (who regularly required parental assistance) as well as a responsibility for the safety of their child outweighed considerations about the impact on parents’
sleep. This highlights Lyon’s (2001) concept of ‘care and protection’ as an important consideration in the work on surveillance.

It is also useful to draw parallels with research on the care of elderly people with dementia. As discussed in Chapter 2, Arber and Venn (2011) describe six aspects of night-time care experienced by carers looking after their partners or older relatives with dementia or chronic illnesses at home. One of these aspects is the monitoring during the night by the carer if the person being cared for was considered vulnerable. A second relevant aspect to my own findings is the experiencing of ‘alert, light sleep’ because of the anticipation of being woken and needed to assist. This was applicable to all the families in my study that undertook, and was exacerbated by, technological monitoring but was particularly evident for the parents (the Hughes and the Gibsons) who undertook a combination of monitoring strategies because their child had epilepsy. A sense of unpredictability associated with the child’s epilepsy, as well as the monitoring equipment itself (for example, the SATs monitor alarm) led to a heightened state of alertness for parents during the night. However, for these two sets of parents this level of monitoring and the inevitable negative impact it had on their sleep was accepted because the risks and consequences of not doing it were too great.

For parents that monitored solely via a baby monitor (as opposed to combination monitoring) the location of the child’s bedroom was also an important aspect to consider in relation to the negative impact of monitoring on parent sleep. The main difference between parents that used ‘informal’ monitoring and those that used a baby monitor was the proximity between the child with CP and their parents at night. The children with CP of the parents that used baby monitors all had downstairs bedrooms whilst the rest of the family slept upstairs. As discussed in Chapter 10 the negative impact on parents sleep was greater for parents who used a baby monitor compared to those that informally monitored. These parents were disturbed because of the variety of noises emitted by the baby monitor and having to focus on distinguishing between the different noises in order to determine if it signalled that their child with CP needed attendance. There was also the expectation that
they would need to attend to their child with CP at some point during the night. The use of a baby monitor, because of lack of parent-child with CP proximity at night and the negative impact on the parents’ sleep must also be considered in conjunction with the findings, outlined in Chapter 9, that lack of proximity also led to parents waking more fully when physically attending to their child because they had to, for instance, turn on lights and negotiate stairs. Therefore, for parents of children with severe CP, who need parental attendance every night, a downstairs bedroom results in a substantial negative impact on parent sleep because of the physical distance that needs negotiating and because of the use of a technological monitoring device.

The use of a baby monitor also has the greatest potential impact on the privacy needs of children with severe CP. The consequences of night monitoring on the privacy needs of children with CP were not touched upon by the parents in my study. Instead the focus was on the care and protection of their child, as well as the logistics and practical considerations of being able to ‘hear’ their child who regularly needed assistance at night. Watson et al. (1999) report that a number of young people in their study highlighted the infringement of their privacy needs caused by adult surveillance. My study confirms that adult surveillance continues throughout the night and that when baby monitors are used this surveillance is at a constant and high level. As discussed in Section 11.5.1 the bedroom is an important space that children utilise in developing identity, autonomy and for attaining privacy. However, as discussed, this may not be applicable to children with severe CP, especially when their bedrooms are downstairs because they are often located in, and used, as household public spaces. The impact on the attainment of privacy may be further compounded because a downstairs bedroom (when the parents sleep upstairs) necessitates the use of a baby monitor. However, as discussed above the concepts of parental care, protection and responsibility need to be considered in relation to night-time monitoring. Parents and the children themselves (specifically those with additional health concerns) may construct the night as a time of risk and vulnerability for the child with CP. Therefore, for a number of parents the negative impact of night-time monitoring on their own sleep was outweighed by the need to care for, and protect, their child with CP.
Similarly, children with severe CP may draw comfort, reassurance and feelings of safety from being monitored by their parents during the night which may, in turn, outweigh their needs for privacy (McKintosh et al., 2010).

11.7 Co-sleeping

The practice of co-sleeping was engaged in by a small number of the families as discussed in Chapter 10. Co-sleeping in these cases refers to a parent sleeping (sharing sleep space) with their child with CP. My findings show how co-sleeping was adopted at specific times when, for instance a child became acutely ill or was having difficulty sleeping for a set period of time. Parents used co-sleeping as a safety practice to monitor their unwell child more closely and to be able to respond quickly if there was an illness related event. For others who used it at specific times of increased child wakefulness it was perceived as a way to protect family member’s sleep because response to the child’s wakefulness could be carried out more quickly thus reducing the disturbance to others caused by noise from the wakeful child. Therefore, for parents, co-sleeping was used as a way to reduce risk to the child at night at times that are perceived as unusually risky (i.e. times of acute illness) and also a practice to protect the sleep of the family. Both the families that practiced occasional co-sleeping with their child with CP usually undertook the informal or ‘keep an ear open’ approach to night-time monitoring. Therefore, co-sleeping at the specific times mentioned above highlights that these parents were flexible, in terms of night-time monitoring, when circumstances changed and warranted a different approach. This is in contrast to the findings related to parents who monitored their children with CP via a baby monitor and who were unable to change and adapt their method of monitoring at certain times, for example, when the child with CP was having a particularly wakeful night.

Co-sleeping has been found to be a common practice in families of children with disabilities (Jacquier and Newman, 2016). However, often in the research it is labelled as a sleep problem in itself (Robinson and Richdale, 2004) that negatively impacts on the co-sleeping parents’ own sleep. Jacquier and Newman (2016) comment that 70% of mothers in their study reported a negative impact of regular co-sleeping with their disabled child on their own
sleep quality. However, for the families in my study that practiced occasional co-
sleeping it was largely seen as a strategy that actually protected the sleep of
family members. Matt King (father) commented that by co-sleeping he was able
to respond to, and settle, his son, Brian, much more quickly which lessened the
impact on the sleep of Brian and Matt, as well as protecting the sleep of Vicky
(mother) who was often woken first by Brian when he vocalised his need for
assistance.

Perhaps for the families in my study co-sleeping was viewed in positive
terms because it was only practiced on a temporary or occasional basis. For
instance, Matt and Vicky King (parents) did voice their concerns about it
becoming a regular occurrence. This, in part, seemed to be influenced by their
perception and understanding of the Western cultural perspective that not only
labels co-sleeping as a sleep problem but also conceptualises it as a bad habit
and a potentially dangerous practice. As discussed in Chapter 10, in Western
culture historically, sleep has moved from the public domain to being an almost
entirely private affair. Child care experts recommend that babies are put to bed,
taught to self settle and that they sleep in their own beds in their own bedrooms
(Ben-Ari, 2008). Vicky King (mother) in particular seemed to be very aware of
these cultural norms despite co-sleeping being a useful occasional tool for her
family.

As with the other methods of parental night-time monitoring the impact
and the meaning of co-sleeping needs to be considered from the point of view
of the child with CP. Brian King (aged 13 years with severe CP) used the word
‘embarrassed’ when looking at photos of the futon placed next to his mattress
for his parents to co-sleep on. However, he also confirmed that his dad’s
presence at night was helpful to him. By using the word ‘embarrassed’ there is
an indication that Brian is aware of the Western cultural norms that promote
sleep as a private practice and that children should sleep independently of their
parents. However, because of his disability there must also be a recognition that
he needs, and will probably always need, help and assistance during the night.
In thinking about Brian, questions arise in relation to how age and gender affect
the practice of co-sleeping and the implications that it has for the privacy and
autonomy of the child with CP. Therefore, is there an age when co-sleeping no longer becomes an appropriate strategy or practice? Furthermore, does gender also become implicated? For instance, when the disabled child reaches a certain age should fathers not co-sleep with daughters nor mothers with sons? These are questions that warrant further research.

11.8 Conclusion

By exploring the concept of sleep from multiple family members’ perspectives an understanding has been gained of the complex and dynamic ways that sleep and the nightly lives of children and parents are organised, managed and practised as part of a family.

Of particular interest (both conceptually and methodologically) has been the way in which, by gaining multiple perspectives, the accounts of disabled children and their siblings can be compared and contrasted. Differences related to sleep were highlighted that existed because of the child's age and also because of the severity of the child’s CP. One of the main areas of difference concerned the sleep practices of children and the management of sleep, illustrated by a focus on the sleep ‘transition phases’ (Schwartz, 1970). The bedtime routine, especially, served as an important signifier of difference based on age and between children with severe CP and siblings/children with mild CP. As discussed, an increase in age led to an increase in autonomy, independence and choice at bedtime for older siblings and older children with mild CP, especially regarding control sleep timings. However, this was not evident for older children with severe CP, who had a total reliance on others (either parents or carers) to put them to bed and were physically unable to carry out tasks that were performed by older siblings/children with mild CP to delay sleep.

The bedtime routine was also important in drawing a focus to the concept of the family. It is a time laden with interactions, negotiations (for some), organisation and management and as such it can be identified as a ‘family practice’ (Morgan, 1996; 2011). Differences for families of children with severe CP were highlighted with a consideration of how the presence of a paid carer to manage the bedtime of the disabled child affects the notion of it being a ‘family
practice'. Whether the carer was perceived as one of the family depended, in part, on whose perspective was being considered but the length and quality of the relationship and the amount of familiarity that this enabled were also important factors.

The location and use of children's bedrooms and the differences between children with severe CP and siblings/children with mild CP emerged as one of the key findings of my research. The bedroom was identified as an important place that siblings and children with mild CP used to display identity and to attain privacy away from the rest of the family. However, this was not evident for children with severe CP, whose use of their bedroom was limited to sleep and personal care.

The location of the bedroom was also an important signifier of difference, in relation to the attainment of privacy. This was especially evident for children with severe CP who had downstairs bedrooms (when the rest of the family slept upstairs) and the potential implications this has on opportunities of privacy for the disabled child were highlighted. A negative impact on privacy may be due to a number of factors concerning downstairs bedrooms including their close proximity to public household spaces, their use by other family members and paid carers, and their use as storage areas for disability-related equipment. Because of the lack of proximity between parent-child bedrooms, a downstairs bedroom also necessitated the use of a baby monitor by parents at night to ‘hear’ their disabled child throughout the night. The downstairs bedroom has, therefore, been conceptualised as a ‘barrier to doing’ and a ‘barrier to being’ (Thomas, 1999) for children with severe CP which negatively impacts on their attainment of privacy and the development of their independence and identity (McKinney, 1998; Weigel-Garrey et al., 1998; Shmueli and Blecher-Prigat, 2010) which, in turn, may have long-lasting effects on their self-confidence and self-worth (Weigel-Garrey et al., 1998; Thomas, 1999; Reeve, 2004).

As mentioned above, a downstairs location of the bedroom of a child with severe CP, necessitated the use of a baby monitor at night by parents. Parental monitoring was necessary as all the children with severe CP woke regularly at night and required parental assistance. Monitoring via a baby
monitor impacted on the privacy of the child with severe CP because it was constant throughout the night. It also had a greater negative impact on parents’ sleep when compared to low level monitoring or the informal monitoring method. Parents who used a combination of monitoring methods (for instance, a baby monitor and a SATs monitor) did so because their child with CP had epilepsy. Monitoring via a combination of methods reassured the parents that they would be alerted in the event of their child having a seizure and, this gave them a sense of control. The impact, however, on the parents’ sleep was substantial but parents felt that this was outweighed by the reassurance, protection and control that combination monitoring allowed.

Co-sleeping was practiced by parents at specific times when their child with severe CP was unwell or when the child was having a particularly disturbed nights. Despite Western cultural connotations that co-sleeping is problematic, a bad habit and dangerous, the parents in my study regarded it as a strategy to be used to provide comfort to an unwell child and to protect the sleep of the whole family. The perception of co-sleeping as a helpful strategy, rather than as a problem, may be based, in part, on parents’ occasional and temporary practice of it.

This chapter has focussed on a number of the key findings from the research and considered them in relation to the existing literature. Sleep has been confirmed as social, interactional and relational through the analysis of its ‘meanings, methods, motives and management’ (Taylor, 1993) and it is embedded firmly within family life through a series of sleep-related family practices. However, sleep and, in particular, sleep practices are not the same for all children. Important differences, with reference to the meanings, organisation and management of sleep, have been highlighted dependent on age but, perhaps more significantly, between children with severe CP and siblings/children with mild CP. These differences may have significant implications, in terms of autonomy, independence and control for children with severe CP and on their opportunities to display identity and attain privacy within the family and household.
Chapter 12 - Conclusion

12.1 Introduction

This final chapter summarises the main conceptual findings of the research and highlights the contribution that it makes to existing literature within the sociology of sleep, childhood, disability and family. Reflections on the research will be discussed with reference to both the value and challenges that arose during the research process. The chapter will close with a discussion of the implications for relevant policy and practice and related recommendations for future research.

12.2 Summary and contribution of the research

Children with cerebral palsy (CP) account for the largest group of children with a physical disability in the UK. Evidence suggests that sleeplessness occurs commonly in children with CP (Newman et al., 2006), however, there has previously been very little in-depth research on the sleep of these children. Previous research on the sleep of children with CP, and disabled children in general, has relied on the viewpoints of parents, mainly mothers. This is the first study to directly seek the views of children with CP in relation to their sleep. By involving children with CP in the research, the study adds to the portfolio of research that seeks to bring together aspects of the ‘new’ sociology of childhood and the social model of disability. As discussed in Chapter 3, previous research such as the work of Watson et al. (1999) and Connors and Stalker (2003) has explored the everyday lives of disabled children, while my research contributes by providing insights now into the ‘every night’ lives of children with CP.

The findings of my research also build on previous work from the sociology of sleep (Williams et al. 2007; Moran-Ellis and Venn, 2007) and emphasise the social context of sleep and, in particular, highlights how sleep and the night-time is a time of activity and interaction for children and parents, thus supporting the notion of ‘doing’ sleep.
My research is the first to explore the conceptualisation of sleep from multiple family members’ perspectives from within the same family. By obtaining multiple family members’ perspectives this study embeds sleep within a family and relational context. Therefore, sleep is a lens through which to view family practices and ‘doing family’ in relation to the meanings, organisation and management of sleep in families with disabled children. Obtaining multiple family members’ viewpoints allowed for similarities and differences based on generation, age and disability standpoints within and across families to be better understood.

The inclusion of siblings and children with mild CP allowed comparisons to be made, in terms of sleep, with children with severe CP and age-dependent comparisons were also made. My research found that for older siblings/older children with mild CP their sleep practices facilitated the development of autonomy, independence and control and allowed for increasing (with age) periods of privacy within the family household. However, this did not occur for children with severe CP, irrespective of age.

These differences were clearly demonstrated by findings related to the practices, actions and interactions leading up to and following sleep. Older siblings and older children with mild CP in my research were beginning to assert independence, autonomy and control in relation to the organisation and management of their sleep, especially the timing of their sleep, during these sleep ‘transition phases’ (Shwartz, 1970). However, actions and interactions that signified autonomy and control were not evident for younger children or children with severe CP (irrespective of age).

Differences based on age and severity of CP, in terms of autonomy, independence and control were also evident in the findings related to the actors, artefacts and actions that children perceived as either helping or hindering their sleep. For instance, children reported that reasons for sleeplessness included physical and environmental factors such as being too hot or cold, thirsty or uncomfortable. Older siblings and older children with mild CP perceived these as minor disturbances that they could independently deal with to enable themselves to get back to sleep. However, younger children and children with
severe CP (younger and older) identified, and relied on, their mum and/or dad to attend to them in order for them to get back to sleep. Other artefacts, ‘agents’ and interactions were deemed as helpful by younger children and children with severe CP that provided comfort at night and aided sleep and included cuddly toys and nightlights. In contrast, older siblings and older children with mild CP discussed strategies and techniques they used to help themselves sleep which illustrated independence. The pet cat as an ‘agent’ that aided sleep was important for all the children (who had a pet cat), regardless of age and severity of CP. The pet cat, for children, was included in their definition of their family and highlights the relational context of sleep.

The meanings and definition of family were also explored with the conceptualisation of the bedtime routine as a ‘family practice’ (Morgan 1996, 2011). The social, interactional and relational context of the bedtime routine highlights not only ‘doing sleeping’ (Taylor, 1993) but also ‘doing family’ (Morgan, 1996; 2011). The fluidity and flexibility of the meaning of family is brought into focus through the lens of sleep. This was also highlighted by the discussion on the presence of paid carers during the disabled child’s bedtime routine and whether their presence negated the ‘family’ aspect of this ‘family practice’. For two of the mothers there was a widening of the definition of family to include their long-term paid carer, reflecting Smart’s (2007) personal life perspective and that a range of different personal relationships are significant to people and can be encompassed within the definition of ‘family’. However, the perception of paid carer’s as being part of the family was not shared by all, for instance Oliver Davis (child with severe CP). The inclusion of the paid carer in the definition of family depended on the length and quality of the relationship and the degree of familiarity that followed.

The presence of a paid carer at bedtime was also specific to children with severe CP, highlighting once again the differences evident between children with severe CP and siblings/children with mild CP. When the paid carer was not regarded as ‘part of the family’ there were implications for the privacy needs and privacy rights of the disabled child. Privacy, and the lack of it for children with severe CP was demonstrated most clearly by the findings related
to the use and location of their bedrooms, especially when comparisons were made with siblings and children with mild CP. The bedroom was conceptualised as a significant space for (some) children to form and display identity and autonomy and that enabled opportunities of privacy. However, this was not applicable to children with severe CP who, compared to siblings/children with mild CP, rarely used or spent time in their bedrooms except for the purpose of sleeping (or, for some, having their personal care needs met). The bedrooms of children with severe CP were often dominated by disability-related equipment such as ‘adapted’ or ‘hospital’ beds and hoists. This led to bedrooms feeling ‘clinical’ and the identity of the child and their ‘ownership’ of their bedroom was not as evident compared to the bedrooms of siblings/children with mild CP.

The lack of opportunity for periods of privacy was further compounded for 3 children with severe CP who had their bedrooms located downstairs when the rest of their family slept upstairs. Having a downstairs bedroom impacted negatively on the attainment of privacy for these children because of a number of intersecting factors including the close proximity to the public spaces of the household, the use of the downstairs bedroom by other members of the family and its use as a storage area for equipment and items related to the child’s disability. Furthermore, the downstairs location led to a decreased proximity between the disabled child’s bedroom and the parents’ bedroom at night. All the children with severe CP woke at night and required parental assistance, therefore, the lack of proximity necessitated the use of a baby monitor so parents could ‘hear’ their child at night. The constant use of a baby monitor throughout the night had implications for the privacy afforded children with severe CP. However, it is also recognised that for some children with CP the night-time may be perceived as a time of risk leading to worry and fear. Therefore, the knowledge that they are being monitored throughout the night by their parents may provide reassurance and comfort.

Questions are raised about whether the building of a downstairs bedroom for children with severe physical disabilities is a disability norm (and will be further discussed in Section 12.4). The impact that its location has on
the identity, autonomy and privacy needs of children with severe CP has led to a conceptualisation of the downstairs bedroom as a ‘barrier to doing’ and a ‘barrier to being’ (Thomas, 1999) as discussed in Chapter 11. As such it is proposed that the downstairs bedroom may have adverse implications for the development of independence, identity and self-esteem of children with severe CP (Weigel-Garrey et al., 1998; Thomas, 1999; Reeve, 2004).

For parents of children with severe CP, night time monitoring via a baby monitor was also found to have a negative impact on the parents’ sleep, especially in comparison to the impact on the sleep of parents who engaged in informal monitoring. Parents who used informal monitoring techniques were enabled to do so by the close proximity they had to their child with severe CP at night. Informal monitoring also allowed parents more flexibility when circumstances regarding their child with CP changed. For instance, when the child was unwell or when they were having particularly disturbed nights. At these times, two sets of parents discussed their engagement in co-sleeping with their disabled child. This was regarded as a useful temporary strategy by these parents in order to provide comfort to their child and/or to enable them to respond to and settle their child more quickly. The benefit of this practice was that it also protected the sleep of all family members as disturbances and disruptions caused by the sleeplessness of the child with CP were lessened.

Therefore, findings have emphasised the social and family context of sleep through an exploration of the everyday organisation and practice of sleep among children with CP and their families. This exploration, facilitated by obtaining multiple family members’ perspectives, has led to a number of important and significant differences being identified between younger and older children and between children with severe CP and siblings/children with mild CP. For older siblings and older children with mild CP sleep practices and the use and location of their bedrooms facilitate and influence the development of identity, autonomy, independence and control and allow for periods of privacy but this is not evident for younger children or children with severe CP. Parental night-time monitoring strategies also highlighted differences and have
significant implications for the attainment of privacy for children with severe CP monitored via a baby monitor.

The strengths of the research and its methodological approach will be discussed in the next section as will the challenges that transpired throughout the research process.

12.3 Research reflections: Strengths and limitations

As discussed above, obtaining multiple family member’s perspectives about the everyday and (every night) organisation and practice of sleep allowed for differences and similarities to be explored within family groups, between families, as well as, between differing standpoints of generation, age (i.e. younger and older children) and severity of CP. This approach is further supported with reference to the exploration of sleep. Williams et al. (2007) comment that an individual’s own sleep is difficult to self-report on so multiple perspectives (especially when exploring the social, interactional and relational context of sleep) are useful to build up the individual and family ‘story’ of sleep.

One of the aims of this research was to elicit the perspectives of children with CP with regards to their sleep. As discussed in Chapter 5, I experienced challenges when it came to the analysis and presentation of the data of the 5 children with CP who communicated in pre-dominantly non-verbal ways. I spent time and paid careful attention to how best to involve children with severe CP who communicated in non-verbal ways in my research. However, this did not prepare me for the difficulties I faced in the analysis of their data. Although valuable information was obtained directly from all the children with CP, the data of those who communicated in non-verbal ways could not be considered as truly qualitative or analysed as such. By definition, qualitative data provides in-depth and detailed accounts laden with emotion and meanings. Data obtained through the use of communication symbol systems or restricted to only ‘Yes’ and ‘No’ answers is limited, categorical and blunt and is not qualitative in the same way as the data obtained from verbal participants.

If my research had been based solely on the responses of children with severe CP who communicated in non-verbal ways my data, and analysis, would
have been very limited and my research methods not fit for purpose. Reflecting on the issues that I had at the analysis stage has led me to wonder if I should have developed and introduced specific aids to communication for the interviews, such as ‘Talking Mats’ (Murphy, 1998), with children with CP who communicated in non-verbal ways. Instead I relied on the children’s existing communication methods and systems during their interviews. However, I have examined how researchers using Talking Mats have analysed their resulting data and there is no clear evidence that it can be considered as truly qualitative data and analysed accordingly. Furthermore, the picture symbols used for the ‘Talking Mats’ method are selected by the researcher prior to the ‘interview’ so issues still arise about whether the participant’s choices, and thus their ‘views’ are truly represented or limited to the pre-determined choices they are given. Furthermore, I stand by my decision not to introduce a new communication system as to learn a new system would have been time consuming and potentially stressful for the children and parents and I was already concerned about taking up too much of the family’s time. How to analyse the data of participants using symbol-based systems or who can only respond ‘Yes’ and ‘No’ is an area that needs further consideration and research.

The inclusion of children with CP who communicated verbally, and who differed in terms of the severity of their CP, as well as the inclusion of siblings helped minimise some of the issues inherent in the analysis of the data of children who communicated in non-verbal ways. Through the identification of differences, as described above, and by obtaining multiple family member’s perspectives the data of the children (who communicated in non-verbal ways) was supplemented and ‘filled out’ and an understanding of the meanings of sleep for these children and how it is practiced, organised and managed was achieved.

I adopted a qualitative approach and conducted semi-structured interviews with children with CP, their siblings and their parents. Supplementing this approach, and in line with child-focused methodology and research involving disabled children (as discussed in Chapter 4), was the use of task-based methods which involved the children taking photographs and all
participants completing a 2 week sleep diary, a one-off sleep questionnaire and wearing an Actiwatch for 2 weeks. The information collected via these activities was used to facilitate, and prompt, discussion in the semi-structured interviews. For me, and from a child-focussed perspective, the photographs were particularly valuable in facilitating discussion with the children. They allowed a greater depth to be explored by anchoring discussions to what was significant in children’s lives in relation to sleep-related practices. The photographs also drew focus to the topic of the bedroom which emerged as an important theme, specifically in highlighting differences between children with severe CP and those without and in the consideration of displays of identity and the privacy needs of children. Overall, I feel that qualitative interviews (supplemented by the other methods) were the most appropriate method for exploring the organisation and practice of sleep and for exploring how it is embedded in a social and family context.

Recruitment of participants was a slow and, at times, frustrating process. As discussed in detail in Chapter 4, I relied on an ‘opt-in’ approach whereby, through posters and leaflets, families were asked to contact me for further study information. In this way I had no initial direct contact with children and families to introduce the study and gauge their potential interest. By relying on posters and leaflets to garner interest it was also unclear if children with severe CP were able to access the details of the study. I was dependent on parents and other adult ‘gatekeepers’ to pass on information and discuss the study with children with CP. Another reason why recruitment was slow may have been because families with disabled children are busy families. Often parents and children are juggling numerous clinical and care-related appointments with attending school, going to work, periods of illness etc. By asking families to contact me to obtain further information I was adding another task or job to an already busy schedule which may have led to reluctance on the part of families to make further enquiries. With hindsight I feel that I could have increased the speed and uptake, in terms of recruitment, if I had been able to have some initial direct contact with families. This would not necessarily have negated an ‘opt-in’ or ethical approach as I could have introduced the study to families in person (for instance, being present in reception areas of clinical centres, such
as where I work or by attending events run by local support and family groups) and given them the relevant information sheets to take home. Families could have then ‘opted-in’ by contacting me or I could have offered to contact them at a convenient time, with their permission.

Another issue to consider in relation to sample recruitment is the lack of diversity, in terms of socio-economic and ethnic background, of the families that took part in the study. All the families that took part were from white British and middle class backgrounds. They all lived in either 3 or 4 bedroom houses and all the children (apart from Stanley and Alex Edwards) had their own bedrooms. Furthermore, apart from Greg Jackson (who lived with his mother and step father) all the children lived with both their parents. Williams (2005) highlights how the social context of sleep is likely to differ according to the material circumstances and socio-economic status of different families. Williams et al. (2007) discuss that children feel discontent and violations of their privacy when having to share bedrooms, which was particularly relevant for those children that had to either temporarily or permanently share bedroom space with step-siblings. Williams et al. (2007) postulate that children’s sleeping arrangements are ‘indexical of shifting family forms’ (para. 3.9).

Furthermore, another key issue is to what extent my ‘opt-in’ sample represented all families/parents of children with CP. The sample I recruited may only primarily represent families, with disabled children, that are ‘successfully’ managing and negotiating sleep and everyday (and every night) family life. The recruitment process and ‘opt-in’ method may omit families who are less successful, chaotic and in-crisis, and who are not managing well with the realities and demands of caring for their disabled child at home.

Therefore, it is recognised that my own research is limited in terms of the diversity of the sample of families that took part. Any future research needs to consider this and aim for recruitment of families from more diverse backgrounds. A slightly altered recruitment strategy, as outlined above, whereby researchers approach families and there is not total reliance on families contacting the researcher to express interest may aid recruitment of families from wider and more diverse backgrounds.
12.4 Implications for policy and practice and recommendations for future research

My research highlights four key implications for policy and practice for professionals working in health and social care. Related to the discussion of these are recommendations for future research.

A first implication relates to converting the ground floor of the family home to create a bedroom for children with severe CP, which seemed to be the preferred option for Local Authorities (where the research was based). This was carried out in order to address issues related to parents being able to move their growing, and increasingly heavy, disabled children to and from their bedrooms. Future research needs to explore this further and ascertain if this is a common nationwide practice.

My research highlighted how a downstairs bedroom (when the rest of the family have bedrooms upstairs) has implications for both the child with CP and for parents. For children with CP there are potential negative consequences to their well-being through experiencing segregation from the rest of the family at night and being unable to access large areas of their own home (upstairs) as well potential feelings of difference and loneliness. Furthermore, the downstairs bedrooms of the child with CP often led straight from public spaces of the ground floor and, therefore, there was a risk that the child's bedroom also became perceived and used as an extension of public space by others in the household. This may have a negative impact on the attainment of privacy and the development of autonomy, independence and control for disabled children. For parents there was a negative impact on their own sleep when their child with CP had a downstairs bedroom. Firstly, parents who had to regularly attend to their disabled child at night reported that they felt they woke more fully compared to when their child had had an upstairs bedroom. The reasons given included, due to the decreased proximity, parents having to switch on lights, negotiate stairs and getting cold when they attended to their child with CP at night. An adverse impact on parents sleep was also attributed to the type of night-time monitoring parents undertook because of the decreased proximity
caused by their child with CP having a downstairs bedroom. Monitoring via a ‘baby monitor’ was used by all the parents who slept upstairs and had a child with CP who slept downstairs. Parents reported being woken by every sound and movement picked up by the ‘baby monitor’ which then led to a more awake and alert state as they deciphered whether the noise was an indication that their disabled child needed attending to or not. This high level of technological monitoring also has implications for the privacy of the child with CP and may be especially problematic for older and teenage disabled children. However, it is recognised that parental night-time monitoring needs to be considered within a context of care and protection and that it potentially provides comfort and reassurance to disabled children. Therefore, if the creation and use of downstairs bedrooms is common for children with physical disabilities, further research is needed, with disabled children and their parents, to understand more fully the potential implications (both negative and positive).

There was no evidence that the child with CP was consulted when plans were made to build, and move them into, a downstairs bedroom. Given the potential negative implications for the child this seems like a major oversight. Often plans are made and implemented by a team of professionals, including occupational therapists and social workers, who will already know the child and their family and, therefore, be in a position to talk to and consult the child. Parents may also need to be more fully consulted and involved when plans are being drawn up for a downstairs bedroom. Aileen Edwards (mother) clearly felt that her concerns were not being listened to but felt that she had been given little choice and that she had to ‘compromise’. Moving to a downstairs bedroom is a potentially significant and emotive transition for children and parents and, as outlined, can have negative implications in terms of well being and sleep, therefore, professionals need to be more aware of these issues and be prepared to have open and consultative discussions with the whole family.

A second implication for policy and practice concerns the need for health and social care professionals to assess and enquire about the sleep of children with severe CP, their parents and their siblings on a consistent and regular basis. Wiggs (2007) comments that research shows that many parents of
disabled children are not surprised that their child has sleeplessness issues and that they view ‘the problem as an inevitable part of the child’s underlying condition for which they often do not seek help’ (para 3.5). This may be of particular relevance when sleeplessness is caused (and perceived as being caused) by predominantly physical problems. This was confirmed by parents in my research, for instance, when Nicola Davis (mother) commented that her son’s sleeplessness and need for night-time assistance occurred purely because of his physical disability that prevented him from being able to have a drink or adjust his own bedding. If parents perceive sleeplessness as an inevitable consequence of their child’s disability then it may be the case that clinicians and professionals also see it as such, which may lead to a failure to enquire about sleep and a lack of discussion about possible support for families, if they require it. It must be noted that often sleeplessness attributed to physical problems may also entail an element of behavioural based issues, often relating to the initiation and maintenance of sleep and linked to parental management (McDaid and Sloper, 2008). Therefore, full screening and assessment regarding sleep is required to determine the reasons for sleeplessness and to determine and implement suitable interventions and/or support strategies (Stores and Wiggs, 2001). Assessment must take account of how sleep is embedded in family life and practices. Therefore, consultation should involve all family members.

A third implication for policy and practice and future research concerns support offered to families. As discussed in Chapter 7, a number of the families in the study accessed and used the direct payments scheme to employ carers to help with their disabled child within the home. Only one family used the scheme to employ a carer for overnight care (one night every other week). Access to, and allocation of, respite care within and outside of the family home seemed to vary greatly between the families and seemed to depend, in part, on where the families lived. Three families used a hospice for respite care away from the home and this, from general discussion, seemed to be highly valued by the families. It allowed the families to be together but because the child with CP was looked after, and attended to, during the night by hospice staff it meant that parents (and siblings) had undisturbed nights. However, these services did not
appear to be offered or available to all the families. Further research on the use of both paid carers within the home and also on respite services for disabled children and their families is required. This needs to explore the inconsistencies in the provision of care and also needs to take account of families’ preferences for types of respite care within and outside of the home. This is important to explore using multiple family member’s perspectives as it may be that opinions will differ between the disabled child, the parents and the siblings, as discussed in Chapters 7 and 11.

A fourth implication for practice and area of potential future research concerns the privacy needs, and perception of these needs, of disabled children. My research highlighted, through the exploration of sleep, that opportunities for privacy within the household are rare for children with severe CP. This was examined specifically through comparison with the experiences of siblings and older children with mild CP regarding the location and use of bedrooms. A potential adverse impact on privacy was also highlighted by the discussion of parental monitoring and surveillance of children with severe CP at night. However, parents in my research made little reference to their children’s need for privacy and there was no evidence that opportunities for privacy for children with severe CP were facilitated by parents (apart from the King family). This is in contrast to Weigel-Garrey et al. (1998) who found that parents of disabled children in the USA were aware and supportive of the privacy needs for their disabled children and actively facilitated opportunities for it to be attained. Further research is needed to establish the perceptions of parents, in terms of their disabled children’s privacy needs, in conjunction with obtaining the views of disabled children themselves.

This section has highlighted the implications of my research with regard to policy and practice within health and social care in Southeast England. These implications are linked to the practice of building, and thus re-locating physically disabled children to, a downstairs bedroom when they become too heavy for parents to lift them upstairs. Screening and enquiry by professionals about the sleep of children with CP, their parents and siblings must be conducted consistently and regularly in order for families to receive help and
support that they require or to simply have an opportunity to talk about sleep. Families must not feel that sleeplessness is simply ‘part and parcel’ of having a child with severe CP. There is variation and inconsistency in the access parents have to services such as direct payments for paid carers and hospice/respite care which could potentially offer support to families struggling with the adverse impacts of child sleeplessness. Further research in relation to these implications is recommended as is future research to explore parental, and child, perceptions of the privacy needs of disabled children.

12.5 Concluding reflections

This study has found, through the exploration of sleep, important and significant differences between children and between families. By including siblings and children with differing degrees of severity of CP, and through the exploration of the management and organisation of their sleep and sleep practices, disabled childhoods and family life has been found to be different for children with severe CP.

Sleep practices and the location of sleep influence and facilitate displays of identity, development of independence and autonomy, and allow for periods of privacy for some children. However, this does not extend to younger children or children with severe CP (irrespective of age). Children with severe CP wake regularly every night and require parental help. An understanding has been obtained about how the organisation of sleep (including sleep location) and sleep practices affect the impact of sleeplessness for parents, the disabled child and their siblings.

This study has provided insight into, and understanding of, the sleep of children with cerebral palsy, their siblings and their parents. By obtaining multiple family member’s perspectives, which included the views of the disabled child themselves, a novel exploration of sleep has been achieved which has highlighted the social context of sleep and presented the night-time as a time of action and interactions embedded within the family and related family practices.
Appendices
Appendix 1.1 Recruitment poster with tear off tags

Are you:
A young person, aged between 6 and 15 years, with cerebral palsy?

Or
A parent/carer of a young person, aged between 6 and 15 years, with cerebral palsy?

If the answer is **YES**, I would like to invite you and your family to take part in my research project which aims to find out more about the sleep of young people with cerebral palsy and the sleep of their families.

If you and your family are interested in taking part please contact me, **Jessica Underhill**, for more information at:

XXXXXXXX, XXXXXXXXXXX, XXXXXXXXXXXXXXXXXXX

Tel: XXXXXXXXXXX ext. XXXX

E-mail: xxxxxxxxxxxxxxxxxxxxxxx

Alternatively, tear off and fill out one of the slips below, pop it in the box at reception and I will contact you with more information.
Appendix 1.2 Recruitment poster

Are you:

A young person, aged between 6 and 15 years, with cerebral palsy?

Or

A parent/carer of a young person, aged between 6 and 15 years, with cerebral palsy?

If the answer is YES, I would like to invite you and your family to take part in my research project which aims to find out more about the sleep of young people with cerebral palsy and the sleep of their families.

If you and your family are interested in taking part please contact me, Jessica Underhill, for more information at:

Research Fellow, Research Department,
XXXXXXXXXXXXXXXXXX,
XXXXXXXXXX,
XXXXXXXXX, XXXXXXX.

Tel: XXXXXXXXXXXX ext. XXXX
E-mail: XXXXXXXXXXXXXXXXXXXXX
Appendix 1.3 Recruitment leaflet

Are you:

A young person, aged between 6 and 15 years, with cerebral palsy?

Or

A parent/carer of a young person, aged between 6 and 15 years, with cerebral palsy?

If the answer is YES, I would like to invite you and your family to take part in my research project which aims to find out more about the sleep of young people with cerebral palsy and the sleep of their families.

If you and your family are interested in taking part please fill out the tear off slip below and send it back to me in the freepost envelope provided.

Many thanks,
Jessica Underhill, Research Fellow
XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
Tel: XXXXXXXXXXX ext. XXXX
E-mail: XXXXXXXXXXXXXXXXXXXXXXX

I would like more information about Jessica’s sleep project.

Name:
Telephone No:
E-mail:

I would prefer Jessica to contact me by:

☐ Telephone (preferred time: )
☐ E-mail
Appendix 2.1: Information sheet for child with CP – written format

Information Sheet for Children with Cerebral Palsy

STUDY TITLE: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Hello,

My name is Jessica and I am doing some research to find out about the experience of sleep for children with cerebral palsy and their families. I would like to invite you and your family to take part in my research. Before you decide if you want to take part or not, I want to tell you why the research is being done and what you would be asked to do. Here are some questions you might want to ask about the research, together with my answers. Please read this information carefully. Talk about it with your family and friends if you want to. I will be contacting your family in about a week’s time, but if you have any questions you would like to ask please contact me or ask someone in your family to contact me. My contact details are below.

Thank you for reading this,

Signed ____________________________________________

Jessica Underhill
Research Fellow
Research Department,
XXXXXXXXXXXXXXXXXXXXXXXXX,
XXXXXXXXXXXXXXXXXX,
XXXXXXXXXXXXXXX,
XXXXXXXXXXXX,
XXXXXXXX,
Tel: XXXXXXXXXXXXX ext. XXXX
Email: XXXXXXXXXXXXXXXXXXXXX

331
What is research?

People carry out research when they want to find out more about something and want to find answers to a question.

What is your research about?

I am studying at the University of Surrey for something called a PhD and this research is part of my studies. My research is about finding out more about the sleep of young people with cerebral palsy and the sleep of their families. At the moment there is no research that has done this even though it is very important for us to sleep. When I find more out I am going to write a booklet about sleep for young people with cerebral palsy and their families.

Why me?

You have been invited to take part because:

- You are a young person with cerebral palsy.
- You are between 6 and 15 years old.
- Your mum and/or dad have said they would like to take part in the research with you.

I will also be inviting your mum and/or dad and, if you have them, your brothers and/or sisters to take part. Altogether, up to 20 families will be taking part in the research.

Do I have to take part?

No, it is up to you to decide if you want to take part. You can change your mind and stop taking part at any time without giving a reason.

What will happen to me if I take part?

If you decide to take part you will be asked to do the following:

- Answer a short questionnaire about your sleep. You can ask someone to help you do this if you want.
- Wear a special watch on your wrist called an Actiwatch-L for 2 weeks. This is very similar to an ordinary watch (see picture below). This machine records when you are asleep and when you are awake.
- Spend some time (probably around 10 minutes) each day doing a sleep diary for 2 weeks and saying how you’ve slept and how you feel. You can choose to write a sleep diary (using pen and paper or the computer), or you can do an ‘audio’ sleep diary by talking into a tape recorder, or you can use your communication system and a friend or someone in your family can write down what you say.
- Take some photographs of your bedroom and about your sleep with a disposable camera that I will give you. You can decide what you want to take photos of. If you need help to use the camera you can ask a friend or someone in your family to help.
- Have a tape and/or video recorded interview with me. This will last about 45 minutes.
All of this will be done at your house.

**What will the interview be like?**

I will ask you to tell me about yourself, your sleep and the sleep of your family. We will have a look at, and talk about, your questionnaire, your sleep diary, your Actiwatch information and your photographs.

If it is ok with you I would like to tape record and maybe video record the interview so I don’t have to write too many notes.

I would like to interview you on your own because I am interested in what you think. But if you don’t want to be interviewed on your own that is OK. You can choose a friend or someone from your family to sit in the room with you.

**Who will know what I say or write?**

I won’t tell anyone in your family or your friends what you tell me in the interview and I won’t show them your questionnaire, sleep diary, Actiwatch results or photographs. The only time that I might have to break this promise is if I think you or someone else might be at risk of being hurt. If you want to tell or show someone what you’ve done that is OK.

I would like to publish what I find out in books, journals and magazines. This might include writing down some of the things that you have told me but you will be given a different name, which you can choose, so that no one knows that it is you that said it. I will let you know what I find out.

**What if I don’t want to do the research anymore?**

You can stop taking part in the research at any time and you don’t have to tell me why. If you want to stop just tell your mum or dad and they can let me know. If you want to stop don’t worry as no one will be cross.

**Has anyone checked that the research is ok to do?**

Before any research is allowed to happen it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research has been checked by the XXXXXXX XXXXX West Research Ethics Committee.
I want to take part. What should I do now?

You can let your parent/s know if you want to take part. I will be contacting them in about 1 week and they can tell me then.

Thank you for reading this. Please contact me or ask someone in your family to contact me if you have any questions.

Jessica Underhill,

Tel: XXXXXXXXXXXX ext.XXX Email:XXXXXXXXXXXXXXXXXXXXXXXXX
Symbol Information Sheet for Children with Cerebral Palsy

STUDY TITLE: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Hello,

My name is Jessica and I am doing some research to find out about the experience of sleep for young people with cerebral palsy and their families. I would like you and your family to take part in my research. Before you decide if you want to take part, I want to tell you why the research is being done and what you would be asked to do. Here are some questions you might want to ask about the research, together with my answers. Please read this information carefully. Talk about it with your family and friends if you want to.

If you have any questions please contact me or ask someone in your family to contact me.

My contact details are below.
What is research?

People carry out research when they want to find out more about something and want to find answers to a question.

What is your research about?

I am studying at the University of Surrey for something called a PhD and this research is part of my studies. My research is about finding out more about the sleep of young people with cerebral palsy and the sleep of their families. At the moment there is no research that has done this even though it is very important for us to sleep. When I find more out I am going to write a booklet about sleep for young people with cerebral palsy and their families.

Why me?

You have been invited to take part because:

- You are a young person with cerebral palsy.
- You are between 6 and 15 years old.
• Your parents have said they would like to take part in the research with you.

I will be asking your mum and/or dad and, if you have them, your brothers and/or sisters to take part. Altogether, up to 20 families will be taking part in the research.

Do I have to take part?

No, it is up to you to decide if you want to take part. You can change your mind and stop taking part at any time without giving a reason.

What will happen to me if I take part?

If you decide to take part you will be asked to do the following:

• Answer a short questionnaire about your sleep. You can ask someone to help you do this if you want.

• Wear a special watch on your wrist called an Actiwatch-L for 2 weeks. This is very similar to an ordinary watch and looks like this:
It records when you are asleep and when you are awake.

- Spend some time (probably around 10 minutes) each day doing a sleep diary for 2 weeks and saying how you've slept and how you feel. You can choose to write a sleep diary (using pen and paper or the computer), or you can do an 'audio' sleep diary by talking into a tape recorder, or you can use your communication system and a friend or someone in your family can write down what you say.

- Take some photographs of your bedroom and about your sleep with a disposable camera that I will give you. You can decide what you want to take photos of. If you need help to use the camera you can ask a friend or someone in your family to help.

- Have a tape and/or video recorded interview with me. This will last about 45 minutes.

All of this will be done at your house.
What will the interview be like?

I will ask you to tell me about yourself, your sleep and the sleep of your family.

We will have a look at, and talk about, your questionnaire, your sleep diary, your Actiwatch information and your photographs.

If it is ok with you I would like to tape record and maybe video record the interview so I don’t have to write too many notes.

I would like to interview you on your own because I am interested in what you think. But if you don’t want to be interviewed on your own that is OK. You can choose a friend or someone from your family to sit in the room with you.

Who will know what I say or write?

I won’t tell anyone what you tell me. The only time I might have to break this promise is if I think you or someone else might be at risk of being hurt.
If you want to tell or show someone what you’ve done that is OK.

I would like to publish what I find out in books, journals and magazines. This might include writing down some of the things that you have told me but you will be given a different name, which you can choose, so that no one knows that it is you that said it. I will let you know what I find out.

What if I don’t want to do the research anymore?

You can stop taking part in the research at any time and you don’t have to tell me why.

If you want to stop don’t worry as no one will be cross.

Has anyone checked that the research is ok to do?

Before any research is allowed to happen it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research has been checked by the Brighton West Research Ethics Committee.
**I want to take part. What should I do now?**

You can let your parent/s know if you want to take part. I will be contacting them in about 1 week and they can tell me then.

Thank you for reading this. Please contact me or ask someone in your family to contact me if you have any questions.

Jessica Underhill, Research Fellow

Tel: XXXXXXXXXXXXXXXXXX

Email: XXXXXXXXXXXXXXXXXX
Appendix 2.3: Information sheet – Child with CP, audio script as recorded on a CD

Audio Information for Children with Cerebral Palsy

STUDY TITLE: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Hello,

My name is Jessica Underhill and I am doing some research to find out about the experience of sleep for children with cerebral palsy and their families. I would like to invite you and your family to take part in my research. Before you decide if you want to take part or not, I want to tell you why the research is being done and what you would be asked to do. Here are some questions you might want to ask about the research, together with my answers. Please listen to this information carefully and it might be a good idea to listen to it more than once. Talk about it with your family and friends if you want to. I will be contacting your family in about a week’s time, but if you have any questions you would like to ask please contact me or ask someone in your family to contact me. My telephone number is XXXXXXXXXX and my extension is XXXX. My e-mail address is XXXXXXXXXXXXXXXXXXXXXXXX

Thank you for listening.
The first question is:

**What is research?**

My answer is that people carry out research when they want to find out more about something and want to find answers to a question.

The second question is:

**What is Jessica’s research about?**

At the moment I am studying at the University of Surrey for something called a PhD and this research is part of my studies. My research is about finding out more about the sleep of young people with cerebral palsy and the sleep of their families. At the moment there is no research that has done this even though it is very important for us to sleep. When I find out more I am going to write a booklet about sleep for young people with cerebral palsy and their families.

You might also like to ask me:

**Why are you asking me to take part?**

You have been invited to take part because:

- You are a young person with cerebral palsy.
- You are between 6 and 15 years old.
- Your mum and/or dad have said they would like to take part in the research with you.

As well as your mum and dad I will also be inviting, if you have them, your brothers and sisters to take part. Altogether, up to 20 families will be taking part in the research.

Another question is:

**Do I have to take part?**

No, it is up to you to decide if you want to take part. You can change your mind and stop taking part at any time without giving a reason.

You might also want to know:

**What will happen to me if I take part?**

Well, if you decide to take part you will be asked to:

- Answer a short questionnaire about your sleep. You can ask someone to help you do this if you want.
- And you will wear a special watch on your wrist called an Actiwatch-L for 2 weeks. This is very similar to an ordinary watch. I have sent a picture of one with this tape/CD that you can look at. This machine records when you are asleep and when you are awake.
- You will also spend some time (probably around 10 minutes) each day doing a sleep diary for 2 weeks and saying how you’ve slept and how you feel. You can
choose to write a sleep diary using pen and paper or your computer, or you can do an ‘audio’ sleep diary by talking into a tape recorder, or you can use your communication system and a friend or someone in your family can write down what you say.

- I would also like you to take some photographs of your bedroom and about your sleep with a disposable camera that I will give you. You can decide what you want to take photos of. If you need help to use the camera you can ask a friend or someone in your family to help.
- Lastly, you will have a tape or video recorded interview with me. This will last about 45 minutes.

All of this will be done at your house.

**What will the interview be like?**

During the interview I will ask you to tell me about yourself, your sleep and the sleep of your family. We will have a look at, and talk about, your questionnaire, your sleep diary, your Actiwatch information and your photographs.

If it is ok with you I would like to tape record and maybe video record the interview so I don’t have to write too many notes.

I would like to interview you on your own because I am interested in what you think. But if you don’t want to be interviewed on your own that is OK. You can choose a friend or someone from your family to sit in the room with you.

Another question you might have is:

**Who will know what I say or write?**

My answer is that I won’t tell anyone in your family or your friends what you tell me in the interview and I won’t show them your questionnaire, sleep diary, actiwatch results or photographs. The only time I might break my promise on this is if I think you or someone else might be at risk of being hurt, If you want to tell or show someone what you’ve done that is OK.

I would like to publish what I find out in books, journals and magazines. This might include writing down some of the things that you have told me but you will be given a different name, which you can choose, so that no one knows that it is you that said it. I will let you know what I find out.

You might want to ask:

**What if I don’t want to do the research anymore?**

You can stop taking part in the research at any time and you don’t have to tell me why. If you want to stop just tell your mum or dad and they can let me know. If you want to stop don’t worry as no one will be cross.

An important question is:

**Has anyone checked that the research is ok to do?**
Well, before any research is allowed to happen it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research has been checked by the XXXXXXXX XXXX Research Ethics Committee.

The last question you might want to ask is:

*I want to take part. What should I do now?*

You can let one of your parents know if you want to take part. I will be contacting them in about 1 week and they can tell me then.

Thank you for listening to this. Please contact me or ask someone in your family to contact me if you have any more questions and I hope to see you soon.

Goodbye.
STUDY TITLE: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Hello,

My name is Jessica and I am doing some research to find out about the experience of sleep for children with cerebral palsy and their families. I would like to invite you and your family to take part in my research. Before you decide if you want to take part or not, I want to tell you why the research is being done and what it will involve for you and your family. Please take time to read the following information carefully and discuss it with your family and friends if you wish. I will be contacting your family in about a week’s time, but in the meantime if you have any questions you would like to ask please do contact me or ask someone in your family to contact me. My contact details are below.

Thank you for reading this,

Signed __________________________________________

Jessica Underhill

Research Fellow
Research Department,
XXXXXXXXXXXXXXXXXXXXX,
XXXXXXXXXXXXXXX,
XXXXXXXXXXXX,
XXXXXXXXX,
XXXXXXXX,
XXXXXXXX.

Tel: Xxxxxxxxxxxx ext. XXXX

Email: XXXXXXXXXXXXXXXXXXXXXXXXXXXXX
What is the research about?

I am carrying out this research as part of completing my PhD at the University of Surrey. I want to do this research to understand more about the sleep of young people with cerebral palsy and the sleep of their families. At the moment there is no research that has done this even though sleep is really important for all us. With the information I get from the research I want to write a booklet about sleep for young people with cerebral palsy and their families.

Why me?

You have been invited to take part because:

- You are the brother or sister of a young person with cerebral palsy.
- You are over 6 years old.
- Your brother or sister with cerebral palsy and your mum and/or dad have said they might like to take part in the research.

Altogether, up to 20 families will be taking part in the research.

Do I have to take part?

No, it is up to you to decide if you want to take part. If you decide to take part I will ask you to sign a form which shows that you understand what the research is about and what you have to do and that you want to take part. You can change your mind and stop taking part at any time without giving a reason.

What will happen to me if I take part?

If you decide to take part you will be asked to do the following:

- Fill out a short questionnaire about your sleep. You can ask someone to help you do this if you want.
- Wear an Actiwatch-L (see picture below) day and night for 2 weeks. This is very similar to wearing an extra watch. The Actiwatch-L has a crystal in it which monitors your movement levels. From this it records when you are asleep and when you are awake.
- Spend some time (probably around 10 minutes) each day completing a sleep diary for 2 weeks. This will involve describing your sleep from the night before. You can choose to do a written sleep diary (i.e. using pen and paper or the computer) or an ‘audio’ sleep diary using a Dictaphone that I will provide you with.
- Take some photographs of your bedroom and about your sleep with a disposable camera that I will give you. You can decide what you want to take photos of.
- Have a tape-recorded interview on your own, lasting about 1 hour.
You can do all of this at home.

**What type of questions will I be asked in the interview?**

The questions will depend on the topics you mention and things you want to talk about. I will ask you to talk in general about your opinions and experiences concerning your sleep and the sleep of your family. We will have a look at, and talk about, your questionnaire, your sleep diary, your Actiwatch information and your photographs.

I am asking to interview you on your own because I am interested in your views. But if you are uncomfortable about being interviewed alone, you can be interviewed with a brother, sister, friend or parent sitting in the room with you.

**What will happen to the information I provide?**

Everything you say or write, your Actiwatch data and your photographs will remain strictly confidential except where the information gathered indicates that you or others are at risk of significant harm.

None of this will be repeated or shown to your parents or to your brothers and sisters. The interview tapes, questionnaire, sleep diary, Actiwatch data and photographs will be coded with a number, and your name will not be used at any stage.

The results from this study may be used for publication but your name will not be used. I will write a report outlining the results which I can send to you and your family or, if you want, I can come and see you to tell you about the results. This report will be about all the results, not just about your family, and I will not use your name in it.

**What happens if I decide to stop?**

You are free to stop taking part in the research at any time and you do not have to give a reason. Information and data from people who have stopped taking part will only be used if they agree.

**Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This research has been checked by the XXXXXXXX XXXX Research Ethics Committee.
**I’m interested in taking part. What should I do now?**

You can let your mum or dad know if you are interested in taking part. I will be contacting your family in about 1 week and they can tell me then. If you and your family are interested in taking part in the research I will arrange to come and see you and your family. At this meeting we will go through this information again and you can ask me any questions about the research.

Thank you for reading this. Please contact me or ask someone in your family to contact me if you have any questions.

Jessica Underhill,

Tel: XXXXXXXXXXX ext.XXXX

Email:XXXXXXXXXXXXXXXXXXXXXXXXXX
Appendix 2.5: Information sheet – Younger siblings

Information Sheet for Siblings

STUDY TITLE: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Hello,

My name is Jessica and I am doing some research to find out about the experience of sleep for children with cerebral palsy and their families. I would like to invite you and your family to take part in my research. Before you decide if you want to take part or not, I want to tell you why the research is being done and what you would be asked to do. Here are some questions you might want to ask about the research, together with my answers. Please read this information carefully. Talk about it with your family and friends if you want to. I will be contacting your family in about a week’s time, but if you have any questions you would like to ask please contact me or ask someone in your family to contact me. My contact details are below.

Thank you for reading this,

Signed ________________________________

Jessica Underhill

Research Fellow,
Research Department,
XXXXXXXXXXXXXXXXXXXXXXXX,
XXXXXXXXXXXXXXXXX,
XXXXXXXXXXXXX,
XXXXXXXXXXXX,
XXXXXXXX,
XXXXXX.

Tel: XXXXXXXXXXX ext. XXXX
Email: XXXXXXXXXXXXXXXXXXXXXXXX

350
What is research?

People carry out research when they want to find out more about something or to try and find answers to a question.

What is your research about?

At the moment I am studying at the University of Surrey for something called a PhD and this research is part of my studies. I want to do my research to find out more about the sleep of young people with cerebral palsy and the sleep of their families. At the moment there is no research that has done this even though it is very important for us to sleep. When I find more out I am going to write a booklet about sleep for young people with cerebral palsy and their families.

Why me?

You have been invited to take part because:

- You are the brother or sister of a young person with cerebral palsy.
- You are over 6 years old.
- Your brother or sister with cerebral palsy and your mum and/or dad have said they might like to take part in the research.

Altogether, up to 20 families will be taking part in the research.

Do I have to take part?

No, it is up to you to decide if you want to take part. You can change your mind and stop taking part at any time without giving a reason.

What will happen to me if I take part?

If you decide to take part you will be asked to do the following:

- Answer a short questionnaire about your sleep. You can ask someone to help you do this if you want.
- Wear a special watch on your wrist called an Actiwatch-L for 2 weeks. This is very similar to an ordinary watch (see picture below). This machine records when you are asleep and when you are awake.
- Spend some time (probably around 10 minutes) each day doing a sleep diary for 2 weeks. This will involve writing or saying how you’ve slept and how you feel. You can choose to write a sleep diary (using pen and paper or the computer) or an ‘audio’ sleep diary by talking into a tape recorder.
- Take some photographs of your bedroom and about your sleep with a disposable camera that I will give you. You can decide what you want to take photos of.
- Have a tape-recorded interview on your own. This will last about 45 minutes.
I will come and see you at your house so that all of this can be done there.

**What will the interview be like?**

I will ask you to talk about yourself, your sleep and the sleep of your family. We will have a look at, and talk about, your questionnaire, your sleep diary, your Actiwatch information and your photographs.

If it is ok with you I would like to tape record the interview so I don’t have to write too many notes.

I would like to interview you on your own because I am interested in what you think. But if you don’t want to be interviewed on your own that is OK. You can choose a friend or someone from your family to sit in the room with you.

**Who will know what I say or write?**

I won’t tell anyone in your family or your friends what you tell me in the interview and I won’t show them your questionnaire, sleep diary, Actiwatch results or photographs. The only time that I might have to break this promise is if I think that you or someone else might be at risk of being hurt. If you want to tell or show someone what you’ve said, written or your photographs that is fine.

I would like to publish what I find out in books, journals and magazines. This might include writing down some of the things that you have told me but you will be given a different name so that no one knows that it is you that said it. I will let you know what I find out.

**What if I don’t want to do the research anymore?**

You can stop taking part in the research at any time and you don't have to tell me why. If you want to stop just tell your mum or dad and they can let me know. Don’t worry as no one will be cross if you want to stop.

**Has anyone checked that the research is ok to do?**

Before any research is allowed to happen it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research has been checked by the XXXXXXX XXXX Research Ethics Committee.
I want to take part. What should I do now?

You can let your parent/s know if you want to take part. I will be contacting them in about 1 week and they can tell me then.

Thank you for reading this. Please contact me or ask someone in your family to contact me if you have any questions.

Jessica Underhill,

Tel: XXXXXXXX ext.XXX

Email:XXXXXXXXXXXXXXXXXXXXX
STUDY TITLE: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Hello,

Thank you for your interest in my research about the experience of sleep for children and young people with cerebral palsy and their families. I would like to invite you and your family to take part in the research. Before you decide if you want to take part or not, I want to tell you why the research is being done and what it will involve for you and your family. Please take time to read the following information carefully and discuss it with others if you wish. I will be contacting you again in about a week’s time, but in the meantime if you have any questions you would like to ask please do contact me, Jessica Underhill.

Thank you for reading this,

Signed ____________________________________________

Jessica Underhill

Research Fellow
Research Department,
XXXXXXXXXXXXXXXXXXXXXX,
XXXXXXXXXXXXXXXXXX,
XXXXXXXXXXXXXXX,
XXXXXXXXXXXXXX,
XXXXXXXXXX.

Tel: XXXXXXXXXXXXXX ext. XXXX
Email: XXXXXXXXXXXXXXXXXXXXXXXXXXXXX
What is the purpose of the study?

I am carrying out this research as part of completing my PhD at the University of Surrey. The main aim of the research is to obtain an in-depth understanding of the sleep of young people with cerebral palsy and the sleep of their families. Sleep is a necessary yet often overlooked element of daily life and occupies about a third of our life in total. Despite this there is little research exploring the experience of sleep for people. Specifically, there are very few research studies on the sleep of children with disabilities, with only a couple of studies focusing on children with cerebral palsy. This existing research has often focused only on children’s sleep problems and has relied on questionnaires and sleep diaries being completed by parents.

By using a number of different ways to gather information about the experience of sleep (rather than just sleep problems) and by involving different family members, including the young person themselves, I hope to gain a much more in-depth understanding of the experience of sleep for the whole family. With the information gained from the research I aim to develop a resource about sleep for young people with cerebral palsy and their families.

Why me?

You have been invited to take part because:

- You are the parent of a child with cerebral palsy who is between 6 and 15 years old.
- Your child, with cerebral palsy, has expressed an interest in taking part in the research.
- Your child with cerebral palsy lives with you at the family home for the majority of the week.

Your spouse/partner and your other children (if over the age of 6 years) are also invited to take part.

For a family group to be included in the research there must be at least one child with cerebral palsy and one parent wanting to take part in the research.

Altogether, up to 20 family groups will be taking part in the research.

Do I have to take part?

It is entirely up to you to decide whether or not you want to take part. If you choose to take part I will arrange to come and see you and the other members of your family who are interested in taking part. At this meeting we will have the opportunity to go through this information sheet again and you can ask me any questions about the research. You will also be asked to sign a ‘consent form’ to show you have agreed to take part. If you then decide to take part, you are still free to withdraw from the research at any time, without giving a reason.
What will happen to me if I take part?

If you agree to take part you will be asked to participate in the following:

- Completion of a short questionnaire about your general sleep quality.
- Daily data collection for 2 weeks involving:
  - Wearing an Actiwatch-L (see picture below) to monitor your activity and light exposure for the whole 2 week period. This is not intrusive, and very similar to wearing an extra watch outside your sleeves.
  - Spending time (probably around 10 minutes) each day completing a sleep diary. You can choose to complete a written sleep diary (i.e. using pen and paper or the computer) or you can complete an ‘audio’ sleep diary using a Dictaphone that I will provide you with.
- A tape-recorded interview on your own, lasting between 1 to 1.5 hours. This will be arranged for 1-3 weeks after the 2 week daily data collection period.

Source: Cambridge Neurotechnology

In total, you will be involved in the research for 3-6 weeks. None of this will require you to attend XXXXXXXX XXXXXXXX XXXXXXXX or a hospital and all of it can be conducted in your own home. Apart from being involved in the data collection listed above, there are no restrictions on your normal routine or lifestyle. There will be no medical benefit or medical risk from participating in this research.

The enclosed information sheets and/or audio information for your spouse/partner and children tell them what they will be asked to do if they agree to take part in the research. This is identical to what will be asked of you except your children will be asked to take photographs of aspects of their bedrooms and bedtime routines with a provided disposable camera.

What type of questions will I be asked in the interview?

The interview should feel a little like a conversation. The interview is designed to be free flowing and the type of questions asked will, to some extent, depend on how the interview develops. I will ask you to talk in general about your opinions and experiences concerning your sleep and the sleep of your family. We will have a look at, and discuss, your data collected during the 2 week period of daily data collection. I will also ask you for some background and general information, for example, about your day and night-time routines, hobbies, family activities and outings, relationships within your family, work schedules and general health.

What will happen to the information I provide?

Everything you say or write and the Actiwatch data will remain strictly confidential except where the information gathered indicates that you or others are at risk of
significant harm. Nothing you say or write will be repeated or shown to your spouse/partner or your children.

The interview tapes, questionnaire, sleep diary and the Actiwatch data will be coded with a number, and your name will not be disclosed at any stage.

The results from this study may be used for publication but your name will not be used and the data will be kept strictly anonymous.

**Will I be compensated for my time?**

As a thank you for your time and effort your family will be given a £50 ‘High Street’ gift voucher.

**What happens if I decide to stop?**

You are free to withdraw from the study at any time and you do not have to give a reason for your withdrawal. Information and data from participants who have withdrawn from the study will only be used if this is expressly permitted.

Your family can continue to take part in the research if your child with cerebral palsy and one other parent (i.e. your spouse/partner) wish to continue. If your child with cerebral palsy, or if the one and only parent taking part, decides to withdraw the whole family will be withdrawn from the research.

**What will happen to the results of the research?**

The results from the research may be used in publications. I also aim to write a report outlining the results. I would like to send this report to you or if preferred I would be happy to come and see you and your family to tell you about the results.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This research has been reviewed and given favourable opinion by the XXXXXXX XXXX Research Ethics Committee.

**I'm interested in taking part. What should I do now?**

I will be contacting you in about 1 week. If you and your child with cerebral palsy are interested in taking part in the research I will arrange to come and see you, your child and, if they are also interested in taking part, your spouse/partner and your other children. At this meeting we will go through this information again and you can ask me any questions concerning the research.

Thank you for taking the time to read this information. If you would like any further information before making a decision, please contact me.

Jessica Underhill,

Tel: XXXXXXXXXXXX ext.XXXX, Email: XXXXXXXXXXXXXXXXXXXXXXXXXXXX
Appendix 3: NHS Research Ethics Approval Letter

22 July 2008

Miss Jessica Underhill
Research Fellow
South Downs Health NHS Trust
Chailey Heritage Clinical Services
Beggars Wood Road
North Chailey, East Sussex
BN8 4JN

Dear Miss Underhill

Full title of study: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

REC reference number: 08/H1111/39

Thank you for your letter of 04 July 2008, responding to the Committee’s request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements.
Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdfrum.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<tr>
<td>Application</td>
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<tr>
<td>Investigator CV</td>
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<td>Protocol</td>
<td>5</td>
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<td>Covering Letter</td>
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<tr>
<td>Interview Schedules/Topic Guides</td>
<td>4</td>
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<tr>
<td>Interview Schedules/Topic Guides</td>
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<td>28 April 2008</td>
</tr>
<tr>
<td>Questionnaire: Chailey sleep questionnaire</td>
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<tr>
<td>Questionnaire: Children's sleep habits questionnaire</td>
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<tr>
<td>Questionnaire: Pittsburgh sleep quality index</td>
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<tr>
<td>Advertisement</td>
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<td>Participant Information Sheet: Younger sibling information sheet</td>
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<td>Participant Information Sheet: Older Sibling Information Sheet</td>
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<td>Participant Information Sheet: Index Child Information Sheet - audio version</td>
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<td>Participant Information Sheet: Index Child Information Sheet - symbolic version</td>
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<td>Participant Information Sheet: Parent Information Sheet</td>
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<tr>
<td>Participant Consent Form: Child and young person consent form</td>
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<td>23 June 2008</td>
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<tr>
<td>Participant Consent Form: Index Child symbol consent form - audio</td>
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<td>Participant Consent Form: Index Child symbol consent form</td>
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<tr>
<td>Participant Consent Form: Parent consent form</td>
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<tr>
<td>Participant Consent Form: Adult Consent form</td>
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<tr>
<td>Participant Consent Form: Index Child Symbol consent form - audio version</td>
<td>4</td>
<td>28 April 2008</td>
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<tr>
<td>Response to Request for Further Information</td>
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<td>04 July 2008</td>
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<td>Statement of Indemnity arrangements</td>
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<td>24 July 2007</td>
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<td>Background Information Sheet</td>
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<td>23 June 2008</td>
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<td>covering letter to families</td>
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<td>23 June 2008</td>
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<td>Supervisor's CV</td>
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<tr>
<td>Email re: NHS indemnity</td>
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<td>03 July 2003</td>
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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.
After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review.

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

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

Yours sincerely

Dr. Andrew Nayagam  
Chair

Email: charlotte.graham@bhc.pct.nhs.uk

Enclosures: *After ethical review – guidance for researchers’ SL-AR2 for other studies

Copy to: Miss Aimee Cox  
R&D office for NHS care organisation at lead site
Appendix 4: University of Surrey Ethics committee approval letter

Jessica Underhill  
Sociology  
FAHS  

05 August 2008  

Dear Jessica  

Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families  
FC/2008/62/FAHS Fast-Track  

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.  

Date of confirmation of ethical opinion: 6 August 2008  

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:  

<table>
<thead>
<tr>
<th>Document</th>
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<tr>
<td>Summary of project</td>
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</tr>
<tr>
<td>Detailed protocol</td>
<td>6 Aug 08</td>
</tr>
<tr>
<td>Information sheet</td>
<td>6 Aug 08</td>
</tr>
<tr>
<td>Consent form</td>
<td>6 Aug 08</td>
</tr>
<tr>
<td>Questionnaire/Interview schedule</td>
<td>6 Aug 08</td>
</tr>
<tr>
<td>Standard letter</td>
<td>6 Aug 08</td>
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<tr>
<td>Protocol submission proforma</td>
<td>6 Aug 08</td>
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<tr>
<td>CRB</td>
<td>6 Aug 08</td>
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<tr>
<td>Insurance cover/indemnity</td>
<td>6 Aug 08</td>
</tr>
<tr>
<td>NHS Bright West REC confirmation of favourable opinion</td>
<td>6 Aug 08</td>
</tr>
</tbody>
</table>

This opinion is given on the understanding that you will comply with the University’s Ethical Guidelines for Teaching and Research.  

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons.  

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.  

Please inform me when the research has been completed.  

Yours sincerely  

Aimee Cox (Miss)  
Secretary, University Ethics Committee  
Registry  

cc: Professor T Desombre, Chairman, Ethics Committee
Appendix 5: NHS Research Governance approval letter

Ms. Jessica Underhill
Research Fellow
Chailey Heritage
Beggars Wood Road
North Chailey
Near Lewes
BN8 4JN

Dear Ms. Underhill,

RAMC ID: 1095/SOUD/2008
TITLE: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Thank you for your application to the Research Approval and Monitoring Committee (RAMC) for approval for this study.

A sub-committee of the RAMC have considered this study. The documents considered were as follows:

- NHS REC form parts A and B (unsigned and dated 06/05/08)
- NHS Site Specific Information form (signed and dated 08/07/08)
- Protocol (version 5, dated June 2008)
- Recruitment poster (version 4, dated 20/04/08)
- Recruitment leaflet: home/school books (version 5, dated 23/06/08)
- Families Covering letter (version 5, dated 23/06/08)
- Background Information form (version 5, dated 23/06/08)
- Parent Information Sheet (version 5, dated 23/06/08)
- Index Child Information Sheet – written (version 5, dated 23/06/08)
- Index Child Information Sheet – symbol (version 5, dated 23/06/08)
- Index Child Audio Script Information (version 5, dated 23/06/08)
- Older Sibling Information Sheet (version 5, dated 23/06/08)
- Younger Sibling Information Sheet (version 5, dated 23/06/08)
- Adult Consent Form – parents and siblings over 16 years (version 5, dated 23/06/08)
- Parent Consent Form (version 5, dated 23/06/08)
- Index Child Symbol Consent Form (version 5, dated 23/06/08)
- Index Child Symbol Consent Form – audio version (version 5, dated 23/06/08)
- Child and Young Person Consent Form – written for index children and younger siblings (version 5, dated 23/06/08)
- Pittsburgh Sleep Quality Index Questionnaire – parents and siblings over 16 years (version 4, dated 28/04/08)
- Children’s Sleep Habit Questionnaire – parent with siblings under 16 years (version 4, dated 28/04/08)
- Chailey Sleep Questionnaire – parent with young person with CP (version 4, dated 28/04/08)
- Actwatch-L Instruction Sheet and Log (version 4, dated 28/04/08)
- Sleep Diary Instruction Sheet (version 4, dated 28/04/08)
- Camera Instruction Sheet (version 4, dated 28/04/08)
- Parent Individual Qualitative Interview – topic guide (version 4, dated 28/04/08)
- Sibling Individual Qualitative Interview – topic guide (version 4, dated 28/04/08)
- CV for Jessica Underhill (signed and dated 03/07/08)
- Letter from University of Surrey confirming indemnity (signed and dated November 2007)
- Brighton West REC approval letter (signed and dated 22/07/06)
- E-mail from Jessica Underhill with clarifications (received 31/07/08)
- E-mail from Lorraine Southby, South Downs Health NHS Trust, agreeing management authorisation (received 13/08/08)
- E-mail from Jessica Underhill with management authorisations from Pauline Shute and Janet Jones at Worthing and Southlands Hospitals NHS Trust (received 18/08/03)

I am pleased to tell you that the study was approved, and so may proceed. This approval is valid in the following organisations:
- South Downs Health NHS Trust
- Worthing and Southlands Hospitals NHS Trust
- West Sussex ICPCT
- East Sussex Downs and Weald PCT

Your RAMC approval is valid providing you comply with the conditions set out below:
1. You commence your research within one year of the date of this letter. If you do not begin your work within this time, you will be required to resubmit your application to the committee.
2. You notify the RAMC by contacting me, should you deviate or make changes to the RAMC approved documents.
3. You alert the RAMC by contacting me, if significant developments occur as the study progresses, whether in relation to the safety of individuals or to scientific direction.
4. You complete and return the standard annual self-report study monitoring form when requested to do so at the end of each financial year. Failure to do this will result in the suspension of RAMC approval.
5. You comply fully with the Department of Health Research Governance Framework, and in particular that you ensure that you are aware of and fully discharge your responsibilities in respect to Data Protection, Health and Safety, financial probity, ethics and scientific quality. You should refer in particular to Sections 3.5 and 3.6 of the Research Governance Framework.
6. You ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice, Data Protection Act and Human Rights Act. Unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Please contact the Consortium Office if you wish this approval to be extended to cover other Consortium Organisations; such an extension will usually be agreed on the same day. We also have reciprocal arrangements for recognition of Research Governance approval with some other NHS Organisations; such an extension can usually be arranged within ten working days.

Good luck with your work.

Yours sincerely,

Mrs Helen Vaughan
Senior Research Governance Officer
Appendix 6.1: Interview Topic Guide – Children with CP

Introduction:

- Tape recording interview (and video recording if applicable) if consent given and why (i.e. so I don’t have to concentrate on taking notes and so I can have an exact record of what is said). I will transcribe the recording.
- The participant can stop the interview at any time. How will you tell me or show me if you want to stop. Role play stopping the interview.
- Confidentiality – not repeated to anyone. But if they want to talk to friends and family that is OK.
- Purpose of research. There are no right or wrong answers; I’m interested in what you have to say. Interview is designed to be flexible, so don’t wait for me to ask questions, just say what seems relevant at the time.
- Tell me if you don’t understand what I’ve asked or if you don’t want to tell me something. Role play how they will do this. Reassure that I won’t be cross or mind at all.

‘Ice-breaker’:

- Tell me a little about you. What do you like doing in your free time? Interests? Hobbies? Treats?

Sleep and You:

I am interested in obtaining an in-depth understanding of the sleep of young people with cerebral palsy so I will firstly ask you to tell me in a general way about your sleep.

Additionally, the following topics, if not covered, will be raised:

- Tell me about your usual routine leading up to bedtime and on waking up. What do you do (bath, read, brush teeth, snack, hot drink, medicines). Times of getting ready for bed, going to bed, going to sleep, waking up? Changes with weekdays/weekends?
- Do you like sleeping? Do you ever wake up and think I’ve had a really good sleep? Why is that? What helps/stops that?
- Looking at your sleep diary and Actiwatch information. I will go through and describe what the Actiwatch data means. On which nights did you feel you slept well and not so well? Can you remember why and what happened on the nights you didn’t sleep so well?
- Is not sleeping well linked to…
  - stress/worry (about what?)
  - physical factors (i.e. pain, discomfort),
  - needing toilet or needing changing,
  - night-time feed,
  - do other family members disturb them,
  - or other factors.
  - What happens when you can’t sleep, wake up in the night or wake early in the morning (i.e. do you wake anyone else up? Do they help you and if so how?)
- How does it feel when you don’t sleep well?
- How does this affect you during the day? i.e at school, mood, concentration, out of school activities?
• If you don’t sleep well how does it affect your relationship with your parents, siblings, friends?
• Sleeping environment - Thank you for taking these photographs of your bedroom can you tell me about each of them (ask young person to write on back of each photo their descriptions). Discuss further aspects of their bedroom referring to the photographs where necessary:
  - layout,
  - favourite things,
  - worst things,
  - bedroom sharing,
  - If applicable, what about siblings bedroom. How does their bedroom differ?

Sleep and the Family:

• Do any members of your family have trouble sleeping? If yes, why do you think this is?
• How do you think this affects them?
• Can you tell me about some things you do as a family?
  - Family activities
  - Holidays
  - Nights out
  - (If young person or someone else in family has disturbed sleep) Does not sleeping well affect doing any of these activities?
• Do mum and/or dad go out in the evenings? If yes, who looks after you? What is that like?
• Do you ever spend nights away from home e.g. respite, grandparents, friends.
• How do you sleep when away from home? Do you like it?
• Do you have friends to stay the night at your home? Yes – do you like it? No – why not?

Coping strategies:

• When you don’t sleep well what do you do or what have you tried in the past to make it better?
• Who helps you, or has given you help in the past, to sleep better?
• If other children with CP are finding it hard to sleep what advice would you give to help them?

Finally to close the interview I will ask the young person if they have anything else they would like to add about their sleep or the sleep of their family. Why did they decide to participate in the research and how have they found the experience of participating.
Appendix 6.2: Interview Topic Guide – Siblings

Introduction:

- Tape recording interview (and video recording if applicable) if consent given and why (i.e. so I don’t have to concentrate on taking notes and so I can have an exact record of what is said). I will transcribe the recording.
- The participant can stop the interview at any time. How will you tell me or show me if you want to stop. Role play stopping the interview.
- Confidentiality – not repeated to anyone. But if they want to talk to friends and family that is OK.
- Purpose of research. There are no right or wrong answers; I’m interested in what you have to say. Interview is designed to be flexible, so don’t wait for me to ask questions, just say what seems relevant at the time.
- Tell me if you don’t understand what I’ve asked or if you don’t want to tell me something. Role play how they will do this. Reassure that I won’t be cross or mind at all.

‘Ice-breaker’

- Tell me a little about you. What do you like doing in your free time? Interests? Hobbies? Treats?

Sleep and You:

I am interested in obtaining an in-depth understanding of the sleep of siblings of young people with cerebral palsy so I will firstly ask you to tell me in a general way about your sleep.

Additionally, the following topics, if not covered, will be raised:

- Tell me about your usual routine leading up to bedtime and on waking up. What do you do (bath, read, brush teeth, snack, hot drink). Times of getting ready for bed, going to bed, going to sleep, waking up? Changes with weekdays/weekends?
- Do you like sleeping? Do you ever wake up and think I’ve had a really good sleep? Why is that? What helps/stops that?
- Looking at your sleep diary and Actiwatch information. (I will go through and describe what the actiwatch data means). On which nights did you feel you slept well and not so well? Can you remember why and what happened on the nights you didn’t sleep so well?
- Is not sleeping well linked to…
  - stress/worry (about what, is it linked to worry about sibling with CP and if so why?)
  - physical factors (i.e. pain, discomfort),
  - needing toilet,
  - do other family members disturb them (is it sibling with CP who disturbs them? If so do they or parents attend to them),
  - or other factors.
- What happens when you can’t sleep, wake up in the night or wake early in the morning (i.e. do you wake anyone else up? Do they help you and if so how?)
- How does it feel when you don’t sleep well?
- How does this affect you during the day? i.e. at school, mood, concentration, out of school activities? For older siblings, employment issues?
• If you don’t sleep well how does it affect your relationship with your parents, siblings, friends?
• Sleeping environment - Thank you for taking these photographs of your bedroom can you tell me about each of them (ask young person to write on back of each photo their descriptions). Discuss further aspects of their bedroom referring to the photographs where necessary:
  - layout
  - favourite things,
  - worst things,
  - bedroom sharing.
  - What about your sibling’s (with CP) bedroom. How does their bedroom differ?

Sleep and the Family:

• Do any members of your family have trouble sleeping? If yes, why do you think this is?
• How do you think this affects them?
• Can you tell me about some things you do as a family?
  - Family activities
  - Holidays
  - Nights out
  - (If young person or someone else in family has disturbed sleep) Does not sleeping well affect doing any of these activities?
• Do mum and/or dad go out in the evenings? If yes, who looks after you? What is that like? For older siblings – are you expected to baby sit? How do you find this?
• Do you ever spend nights away from home e.g. school trips, grandparents, friends.
• How do you sleep when away from home? Do you like it?
• Do you have friends to stay the night at your home? Yes – do you like it? No – why not?
• Does your sibling with CP spend nights away from home?
  - If yes, where and when?
  - How does your sleep differ or change when they are spending nights away and how do you think they sleep when away from home?

Coping strategies:

• When you don’t sleep well what do you do or what have you tried to make it better?
• Who helps you or has given you help to sleep better?
• If your sibling with CP has trouble sleeping or has in the past what have they or your parent/s tried to make them sleep better? What worked and what didn’t work?
• What advice would you give to other young people who have difficulty sleeping?

Finally to close the interview I will ask them if they have anything else they would like to add about their sleep or the sleep of their family. Why did they decide to participate in the research and how have they found the experience of participating.
Appendix 6.3: Interview Topic Guide – Parents

Introduction:

- Tape recording interview if consent given and why (i.e. so I don’t have to concentrate on taking notes and so I can have an exact record of what is said). I will transcribe the recording.
- The participant can stop the interview at any time.
- Confidentiality – not repeated to anyone.
- Purpose of research. There are no right or wrong answers; I’m interested in what you have to say. Interview is designed to be flexible, so don’t wait for me to ask questions, just say what seems relevant at the time.

Sleep and You:

I am interested in obtaining an in-depth understanding of the sleep of parents of young people with cerebral palsy so I will firstly ask you to tell me in a general way about your sleep.

Additionally, the following topics, if not covered, will be raised:

- Describe your usual bedtime routine and your sleep pattern. Weekdays and Weekends.
- Sleeping environment (i.e. layout of bedroom, sharing of bed, lighting, temperature etc.)
- How would you define a good night’s sleep?
- How would you define a poor night’s sleep?
- Looking at your sleep diary and Actiwatch data which nights were ‘good’ and which ‘poor’?
- Were the two weeks when you were completing the sleep diary and wearing the Actiwatch typical weeks? If not, why not?
- What are the reasons for your poor sleep? (relate back to PSQI questionnaire, sleep diaries and Actiwatch data)
  - Child with CP has disturbed sleep? Why? Do they need parent to attend – e.g. to turn them, to toilet them, need night-time feed or night-time medication, or to comfort.
  - Other children have disturbed sleep? Why? Do they need parent to attend?
  - Partner/Spouse has disturbed sleep? Why?
  - Stress/worry? About what? Linked to child with CP or about other factors.
  - Physical factors – own poor health or that of other family members, pain, getting up to toilet etc.
  - Other factors contributing to poor sleep.
- How does a poor night’s sleep make you feel?
- How does poor sleep impact on you in the day – employment, household tasks, mood, and concentration?
- How does poor sleep affect your relationships with your partner/spouse, your children?
Sleep and the Family:

- As a family how well do you think you sleep? Are all family members getting enough sleep?
- If not, who and why? How do you think their poor sleep impacts on them?
- How does this affect your family?
  - Daytime activities
  - Family holidays
  - Nights out as a family
  - Nights out for parent/s only – difficulties getting babysitters, too tired to go out etc.
- Does your child with CP spend nights away from home?
  - If yes, where and when?
  - How does your sleep differ or change when they are spending nights away and how do you think they sleep when away from home?

Coping strategies:

I am interested in the coping strategies tried and used by parents to:

i). Deal with their own disturbed sleep (i.e. where it is not necessarily linked to their child’s sleep disturbance)

ii). If applicable, deal with their child’s disturbed sleep which in turn is disturbing their own sleep.

- Sleep medications i) for yourself ii). For your child.
- Strategies for dealing with difficulty getting to sleep i) for yourself ii). for your child
- Strategies for coping with waking in the night i) for yourself ii). for your child
- Strategies for coping with early morning waking i) for yourself ii). for your child
- Daytime napping i) for yourself ii). for your child
- Use of respite care
- Where have you gone to for help i) for yourself ii). for your child (e.g. doctor)?
- Did you get the help you needed i) for yourself ii) for your child?
- What help was given?
- Knowing what you do now what advice would you give to other families?

Finally to close the interview I will ask them if they have anything else they would like to add about their sleep or the sleep of their family. Why did they decide to participate in the research and how have they found the experience of participating.
Dear Parent/ Carer and <child's name>

Research Title - Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Thank you for your interest in my research about the experience of sleep for children and young people with cerebral palsy and their families. Further to our telephone conversation I enclose more information about the research. As discussed I have included a parents information sheet for you and <spouse/partner name if approp.> and an information sheet/CD <delete as appropriate> for <index child's name> as well as an information sheet for <sibling name/s if approp.>.

Please take time to read or listen to the information carefully and discuss it with each other, friends or other family members if you wish.

Please fill out the enclosed background information form and send this back to me in the envelope provided.
I will be contacting you again in about a week’s time, but in the meantime if any of you have any questions please contact me

With best wishes,

Yours Sincerely

Jessica Underhill

Research Fellow,

XXXXXXXXXXXXXXXXXXXXXXXXXXXXX
Appendix 8: Background Information Form

Family Background Information Form

If your family is interested in participating in the research, please complete the following form with details about all family members interested in taking part. Please send it back to me in the envelope provided.

Completing this form does not commit you to participating, and nor does it show your consent to participate in the research. The information given here will be treated in the strictest confidence in accordance with the Data Protection Act 1998.

Information about 1st parent:

Title:  
Name:  
Female/Male (delete as appropriate)

Age:

Information about 2nd parent (if applicable, i.e. they are interested in taking part in the research):

Title:  
Name:  
Female/Male (delete as appropriate)

Age:

Information about your child with cerebral palsy:

Name:  
Female / Male (delete as appropriate)

Age:
Information about other children (if applicable, i.e. they live at home and are interested in taking part in the research):

<table>
<thead>
<tr>
<th>Child’s Name</th>
<th>Age</th>
<th>Female / Male</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Contact Information:

Home address:

E-mail address (if any):

Home telephone number:

Mobile telephone number (if any):

When would be the most convenient time for me to telephone you?

Thank you very much for taking the time to fill in this form. Please send it back to me in the provided envelope. I will contact you in about one week’s time to discuss your family’s participation in the research. If you or any of your family has any questions in the meantime, please do not hesitate to contact me:

Jessica Underhill,
Tel: XXXXXXXXXXXX ext.XXXX
E-mail: XXXXXXXXXXXXXXXXXXXXXXXXXXX

373
Appendix 9.1: Consent form for child with CP and siblings, written format

Consent Form for Children and Young People

Research Title: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Researcher: Jessica Underhill

Please read, or listen to, the following questions and circle the answer you agree with (either Yes or No):

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have you read, or listened to, the information about the research?</td>
<td></td>
</tr>
<tr>
<td>2. Has Jessica explained the research to you?</td>
<td></td>
</tr>
<tr>
<td>3. Do you understand what the research is about?</td>
<td></td>
</tr>
<tr>
<td>4. Do you understand what you have to do if you take part in the research?</td>
<td></td>
</tr>
<tr>
<td>5. Do you understand that your interview will be tape &amp;/or video recorded?</td>
<td></td>
</tr>
<tr>
<td>6. Do you understand that some of what you say in the interview and some of the photographs you take will be used by Jessica to tell people what she has found out?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>7. Have you asked all the questions you want?</td>
<td></td>
</tr>
</tbody>
</table>
8. Has Jessica answered your questions in a way you understand?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
</table>

9. Do you understand it's OK to stop taking part at any time?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
</table>

10. Are you happy to take part?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
</table>

If **any** answers are 'no' or you don’t want to take part, **don’t write your name!**

If you **do** want to take part, you can write your name below and Jessica will write her name too. Jessica will give you a copy of this form for you to keep.

Your name:_________________________________  Date:_____________

Your signature:__________________________________

Jessica’s name:_____________________________  Date:______________

Jessica’s signature:  _____________________________
Appendix 9.2: Consent form for child with CP, symbol format

Consent Form for Young People with Cerebral Palsy

Research Title: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Researcher: Jessica Underhill

Please read, or listen to, the questions and circle the answer you agree with

(either yes or no):
1. Have you read, or listened to, the information about the research?  
   ![Yes / No]

2. Has Jessica explained the research to you?  
   ![Yes / No]

3. Do you understand what the research is about?  
   ![Yes / No]

4. Do you understand what you have to do if you take part in the research?  
   ![Yes / No]

5. Do you understand that your interview will be tape &/or video recorded?  
   ![Yes / No]
6. Do you understand that some of what you say in the interview and some of the photographs you take will be used by Jessica to tell people what she has found out?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Yes" /></td>
</tr>
</tbody>
</table>

7. Have you asked all the questions you want?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Yes" /></td>
</tr>
</tbody>
</table>

8. Has Jessica answered your questions in a way you understand?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Yes" /></td>
</tr>
</tbody>
</table>

9. Do you understand it’s OK to stop taking part at any time?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Yes" /></td>
</tr>
</tbody>
</table>

10. Are you happy to take part in the research?  

<table>
<thead>
<tr>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Yes" /></td>
</tr>
</tbody>
</table>
If any answers are 'no' or you don’t want to take part, don’t write your name!

If you do want to take part, you can write your name below and Jessica will write her name too. Jessica will give you a copy of this form for you to keep.

Your name: _______________________________ Date: __________

Your signature: _______________________________ 

Jessica’s name: _______________________________ Date: __________

Jessica’s signature: _______________________________
Appendix 9.3: Consent form for child with CP, audio/video recording

Consent Form for Young People with Cerebral Palsy

Research Title: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Researcher: Jessica Underhill

The following questions will be shown and read out to you and you can communicate to me the answers you agree with (either Yes or No). If it’s ok with you this will be videotaped and/or audio taped so that I can have a record of your answers.
1. Have you had read to you, or listened to, the information about the research?  
   ![Yes / No]

2. Has Jessica explained the research to you?  
   ![Yes / No]

3. Do you understand what the research is about?  
   ![Yes / No]

4. Do you understand what you have to do if you take part in the research?  
   ![Yes / No]

5. Do you understand that your interview will be tape &/or video recorded?  
   ![Yes / No]
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Do you understand that some of what you say in the interview and some</td>
<td></td>
</tr>
<tr>
<td>of the photographs you take will be used by Jessica to tell people what</td>
<td></td>
</tr>
<tr>
<td>she has found out?</td>
<td></td>
</tr>
<tr>
<td>7. Have you asked all the questions you want?</td>
<td></td>
</tr>
<tr>
<td>8. Has Jessica answered your questions in a way you understand?</td>
<td></td>
</tr>
<tr>
<td>9. Do you understand it's OK to stop taking part at any time?</td>
<td></td>
</tr>
</tbody>
</table>
10. Are you happy to take part in the research?  Yes / No

If your answers are all yes, and you do want to take part in the research Jessica will write her name below. You can keep a copy of this form.

A copy of the videotape and/or the audiotape will be kept by Jessica in a safe place.

Jessica's name: ___________________________  Date: ____________

Jessica's signature: ________________________

Appendix 9.4: Consent form, adult for own participation

Adult Consent Form (for Parents and Siblings over 16 years).

Research Title: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Chief Investigator: Jessica Underhill

Please read the following statements and initial the corresponding box if you AGREE with the statement.

1. I confirm that I have read and understand the information sheet dated provided for the above titled research.

2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

4. I understand that the interview will be audio taped and that quotes from the interviews will be used in the dissemination of the study findings.
5. I agree to take part in the above study.

If you have initialled all the boxes and you would like to take part in the research please sign your name below. A copy of this form will be given to you to keep.

___________________  _____________________  ___________
Name                 Signature             Date

___________________  _____________________  ___________
Name of Researcher   Signature             Date
Appendix 9.5: Consent form, parental for child’s participation

Parent Consent Form

Research Title: Exploring and Understanding the Experience of Sleep for Children and Young People with Cerebral Palsy and their Families.

Chief Investigator: Jessica Underhill

One parent/carer should complete the following for each of their children (under the age of 16 years) wanting to take part in the research. Please read the following statements and initial the corresponding box if you AGREE with the statement.

1. I confirm that I have read and understand the information sheet for the above titled research.

2. My child and I have had the opportunity to ask the researcher questions and we have had these answered satisfactorily.

3. I understand what the research will involve for my child.

4. I understand that the interviews with my child will be audio and/or video taped and that quotes from my child and photographs that my child has taken will be used in the dissemination of the research findings.
5. I agree to my child being invited to take part in the above research and, if my child agrees to take part, I consent to their participation.

6. I understand that my child's participation is voluntary and that this consent can be withdrawn at any time without giving a reason.

If you have initialled all the boxes and you consent to your child taking part in the research please sign your name below. A copy of this form will be given to you to keep.

____________________________
Child's Name

______________________________
Name of Parent

______________________________
Parent signature

______________________________
Date

______________________________
Name of Researcher

______________________________
Researcher signature

______________________________
Date
Appendix 10.1: Sleep diary instruction sheet

Two week sleep diary:

During the two weeks that you are wearing the Actiwatch-L please record your thoughts about your sleep every day soon after you wake up.

You can choose how you would like to complete this ‘sleep diary’. You can complete a written sleep diary by either using a pen and notepad or your home computer. Or you can complete an ‘audio’ sleep diary by speaking into a tape recorder (which I will provide you with). Or you can use your own communication system and ask a friend, someone in your family or me to write down what you communicate. You are also welcome to add to your sleep diary at any time during the day, but please remember to note down what the time is and what day it is when you start.

Please record a summary each morning about your sleep for the night before. Please remember to include the day, date and time. You can decide exactly what you want to write or say about your nights’ sleep but to give you some ideas you might like to think about:

- The time you went to bed and why you went to bed at that time,
- Did you sleep alone? Was there anyone else (including pets) in the bed or room?
- Was it easy or difficult for you to get to sleep? Why was this?
- How did you sleep?
- Did you wake up during the night? When? Why?
- What time did you wake up this morning? Why did you wake up at that time?
- Was there anything unusual about your sleep that night?
- Anything else you can think of?
Appendix 10.2: Photography instruction sheet for children

Photography and the disposable camera:

During the two weeks that you are wearing the Actiwatch-L and completing your sleep diary please use the disposable camera that I have given you to take photos of things related to your sleep. For instance you could take photos of your bedroom or of the things that help you sleep or the things that stop you from sleeping. You can choose what you want to take your sleep photos of but to give you some ideas you might like to think about:

- The best and worst parts of your bedroom
- Your favourite toy or objects in your bedroom
- People or pets you share your bedroom with
- The things that help you to sleep
- The things that stop you from sleeping or that wake you up.

You could also ask other family members if you can take photos of their bedrooms and of things related to their sleep. But please ask their permission first.

If you need help to use the camera you can ask a friend, someone in your family or me to help.
Appendix 10.3: Actiwatch instruction sheet

Details about Actiwatch-L:

You have been asked to wear the Actiwatch-L outside your sleeves on your wrist for two weeks. The Actiwatch-L records your movements, and will give an indication about the length and nature of your daily activities and sleep. The Actiwatch-L also records light intensity for the environment where you are, so it is very important that your sleeves do not cover the Actiwatch-L.

The Actiwatch-L is not waterproof, so please remove it and put it somewhere safe and dry while you wash, shower or swim etc. Please record below when and for how long you removed the Actiwatch-L each day, and don’t forget to put it back on once you are dry.

**Actiwatch-L Log**

Please note when, for how long, and why you took off your Actiwatch-L between 00.00 and 23.59.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time when you took off your Actiwatch-L</th>
<th>Time when you put your Actiwatch-L back on</th>
<th>Reason for removing your Actiwatch-L</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 11.1: Sleep Questionnaire – PSQI, for parents and siblings >16 years

Pittsburgh Sleep Quality Index questionnaire

Instructions:

The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all the questions.

During the past month, when have you usually gone to bed at night?

Usual bed time:

During the past month, how long (in minutes) has it usually take you to fall asleep each night?

Number of minutes:

During the past month, when have you usually got up in the morning?

Usual getting up time:

During the past month, how many hours of actual sleep did you get at night? (This may be different from the number of hours spent in bed.)

Hours of sleep per night:

For each of the remaining questions, please tick the one best response. Please answer all questions.

During the past month, how often have you had trouble sleeping because you…..

a) Cannot get to sleep within 30 minutes

Not during the past month_____ Less than once a week_____ Once or twice a week_____ Three or more times a week_____
b) Wake up in the middle of the night or early morning

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

c) Have to get up to use the bathroom

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

d) Cannot breathe comfortably

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

e) Cough or snore loudly

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

f) Feel too cold

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

g) Feel too hot

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

h) Had bad dreams

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>
i) Have pain
Not during the past month_____           once a week_____            a week_____               times a week_____
Less than                          Once or twice              Three or more

Questions j, k and l are for parents only. Siblings, please ignore and go to question m.

j) Attend to your child’s health needs
Not during the past month_____           once a week_____            a week_____               times a week_____
Less than                          Once or twice              Three or more

k) Experience stress related to your child’s health
Not during the past month_____           once a week_____            a week_____               times a week_____
Less than                          Once or twice              Three or more

l) Experience stress not related to your child’s health
Not during the past month_____           once a week_____            a week_____               times a week_____
Less than                          Once or twice              Three or more

m) Other reason(s), please describe
........................................................................................................................................

How often during the past month have you had trouble sleeping because of this?
Not during the past month_____           once a week_____            a week_____               times a week_____
Less than                          Once or twice              Three or more

6) During the past month, how would you rate your sleep quality overall?
    Very good________________
    Fairly good______________
    Fairly bad_______________
    Very bad________________
7) During the past month, how often have you taken medicine (prescribed or “over the counter”) to help you sleep?

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

8) During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

During the past month, how much of a problem has it been for you to show enthusiasm to get things done?

- No problem at all
- Only a very slight problem
- Somewhat of a problem
- A very big problem

10) Do you have a bed partner or roommate?

- No bed partner or roommate?
- Partner/roommate in other room
- Partner in same room, but not same bed
- Partner in same bed

If you have a roommate or bed partner, ask him/her how often in the past month you have had...

a) Loud snoring

<table>
<thead>
<tr>
<th></th>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>
b) Long pauses between breaths while asleep

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

c) Legs twitching or jerking while you sleep

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

d) Episodes of disorientation or confusion during sleep?

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>

e) Other restlessness while you sleep; please describe

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

<table>
<thead>
<tr>
<th>Not during the past month</th>
<th>Less than once a week</th>
<th>Once or twice a week</th>
<th>Three or more times a week</th>
</tr>
</thead>
</table>
Appendix 11.2: Sleep Questionnaire – Children’s Sleep Habits Questionnaire (CSHQ), for siblings

Child’s Name:______________________ Child’s Date of Birth:________________
Child’s Age:________

Date Form Completed:___________ Who filled out the form? Mum or Dad (please circle)

Children’s Sleep Habits Questionnaire (CSHQ)

The following statements are about your child’s sleep habits and possible difficulties with sleep. Think about the past week in your child’s life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week. Answer USUALLY if something occurs 5 or more times in a week; answer SOMETIMES if it occurs 2-4 times in a week; answer RARELY if something occurs never or 1 time during a week.

Bedtime

Write in child’s bedtime: week nights______________ weekends______________

<table>
<thead>
<tr>
<th>Item</th>
<th>Usually (5-7)</th>
<th>Sometimes (2-4)</th>
<th>Rarely (0-1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child goes to bed at the same time at night</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Child falls asleep within 20 minutes after going to bed</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Child falls asleep alone in own bed</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Child falls asleep in parent’s or sibling’s bed</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Child falls asleep with rocking or rhythmic movements</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Child needs special object to fall asleep (doll, special blanket, etc.)</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
Child needs parent in the room to fall asleep □ □ □

Child is ready to go to bed at bedtime □ □ □

Child resists going to bed at bedtime □ □ □

Child struggles at bedtime (cries, refuses to stay in bed etc.) □ □ □

Child is afraid of sleeping in the dark □ □ □

Child is afraid of sleeping alone □ □ □

**Sleep Behaviour**

Child’s usual amount of sleep each day: week days ___________ hours and ___________ minutes.

(combining nighttime sleep and naps) weekends ___________ hours and ___________ minutes.

<table>
<thead>
<tr>
<th></th>
<th>Usually (5-7)</th>
<th>Sometimes (2-4)</th>
<th>Rarely (0-1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child sleeps too little</td>
<td>□ □ □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child sleeps too much</td>
<td>□ □ □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child sleeps the right amount</td>
<td>□ □ □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child sleeps about the same amount each day</td>
<td>□ □ □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child wets the bed at night</td>
<td>□ □ □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child talks during sleep</td>
<td>□ □ □</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Child is restless and moves a lot during sleep
Child sleepwalks during the night
Child moves to someone else’s bed during the night (parent, brother, sister, etc.)
Child reports body pains during sleep. Is so, where?
Child grinds teeth during sleep (your dentist may have told you this)
Child snores loudly
Child seems to stop breathing during sleep
Child snorts and/or gasps during sleep
Child has trouble sleeping away from home (visiting relatives, friends, holidays)
Child complains about problems sleeping
Child awakens during night screaming, sweating and inconsolable
Child awakens alarmed by a frightening dream
### Waking During the Night

<table>
<thead>
<tr>
<th></th>
<th>Usually (5-7)</th>
<th>Sometimes (2-4)</th>
<th>Rarely (0-1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child awakes once during the night</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child awakes more than once during the night</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child returns to sleep without help after waking</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Write in the number of minutes a night that waking usually lasts: __________

### Morning Waking

<table>
<thead>
<tr>
<th></th>
<th>Usually (5-7)</th>
<th>Sometimes (2-4)</th>
<th>Rarely (0-1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child wakes up by him/herself</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child wakes up with alarm clock</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child wakes up in negative mood</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Adults or siblings wake up child</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child has difficulty getting out of bed in the morning</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child takes a long time to become alert in the morning</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Child wakes up very early in the morning</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Child has a good appetite in the morning

Daytime Sleepiness

<table>
<thead>
<tr>
<th></th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(5-7)</td>
<td>(2-4)</td>
<td>(0-1)</td>
</tr>
</tbody>
</table>

Child naps during the day

Child suddenly falls asleep in the middle of active behaviour

Child seems tired

During the past week, your child has appeared very sleepy or fallen asleep during the following (check all that apply):

<table>
<thead>
<tr>
<th>Activity</th>
<th>Very Sleepy</th>
<th>Falls Asleep</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Play alone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Playing with others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Watching TV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Riding in a car</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating meals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going to the bathroom</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 11.3: Sleep Questionnaire – Chailey Sleep Questionnaire for children with CP

Chailey Sleep Questionnaire for Children with Cerebral Palsy.

How to use the questionnaire:

This questionnaire should be used in consultation with a parent/carer and for children with cerebral palsy. The questionnaire should take about 30 min to complete. It is recommended that a one week sleep diary be completed in conjunction with the questionnaire to provide further details.

The Clinical Profile Section should highlight areas impacting on sleep and should be brought to the attention of the child’s paediatrician. The Sleep Profile Section should highlight problem areas which can then be addressed. Standard references on management of sleep problems are listed at the back.

◼ Where this symbol is shown, and if this problem usually occurs, it should be brought to the attention of the child’s paediatrician.
BACKGROUND INFORMATION

Child’s Name: ____________________________  Today’s Date: ____________________________

Date of Birth: ____________________________  Gender:  Male ☐  Female ☐

Home Address: ____________________________  Tel: ____________________________

Name of School and Class Teacher: ____________________________

Is the school:
- Mainstream ☐
- Special ☐
- Dual placement ☐

G.P Name & Address: ____________________________

Paediatrician Name & Address: ____________________________

Purpose of questionnaire analysis:
- Clarify sleep disturbance and aid management ☐
- Identify medical problems impacting on sleep ☐
- Risk assessment tool before prescribing sleep system ☐
- Repeat questionnaire to monitor progress ☐
- Research purpose ☐
- Other………………………………………………………………………………… ☐
Clinical Profile

GENERAL

1. Primary Diagnosis:

2. GMFCS Level:

3. Details of recent surgery (last six months):

4. Details of recent hospitalisation (last six months):

5. Current Medication and Doses:

6. Details of recent medication changes (last six months):

7. Communication Difficulties & use of alternative or augmentative communication systems:
### NIGHT-TIME CARE:

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Does your child need medication during the night?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes:</strong></td>
<td></td>
</tr>
<tr>
<td>8a. Please detail:</td>
<td></td>
</tr>
<tr>
<td>8b. How is the medicine administered?</td>
<td>Orally / Rectally / gastrostomy / other route</td>
</tr>
<tr>
<td>8c. How often, per week, is the medicine given during the night? Please detail:</td>
<td></td>
</tr>
<tr>
<td>9. Does your child need a feed during the night?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes:</strong></td>
<td></td>
</tr>
<tr>
<td>9a. How is the feed given?</td>
<td>Tube / Gastrostomy / Other</td>
</tr>
<tr>
<td>9b. Does this wake your child?</td>
<td>Yes / No / Sometimes</td>
</tr>
<tr>
<td>10. Does your child require any other night time care?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes, please detail:</strong></td>
<td></td>
</tr>
</tbody>
</table>

### SENSORY IMPAIRMENTS:

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Does your child have problems with his/her vision?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes, please detail:</strong></td>
<td></td>
</tr>
</tbody>
</table>
12. Does your child have a hearing problem?  
   If Yes, please detail:  
   | Yes / No |

**ORTHOPAEDIC PROBLEMS:**  

13. Does your child have orthopaedic problems?  
   If Yes:  
   13a. Please detail:  
   | Yes / No |

   13b. Do these problems cause pain during the night?  
   If Yes, please detail:  
   | Yes / No / Sometimes |

**SPINAL CURVATURE (Scoliosis/Kyphosis):**  

14. Does your child have Scoliosis/Kyphosis?  
   If Yes:  
   14a. Grade the degree of Scoliosis/Kyphosis?  
   | Mild / Moderate / Severe |

   14b. Is the Scoliosis getting worse?  
   | Yes / No |

   14c. Is spinal surgery planned / or has it occurred?  
   If so, when:  
   | Yes / No |
14d. Does your child wear a spinal jacket? | Yes / No

14e. Does your child sleep in a spinal jacket? | Yes / No

**BREATHING PROBLEMS:**

15. Has your child had a chest infection in the last 6 months? | Yes / No

If **Yes**:

15a. How many chest infections has your child had in the last 6 months? | 1 / 2-5 / 6+

15b. How many of these required antibiotics? | None / Some / All of them

15c. How many required hospitalisation? | None / Some / All of them

16. Is your child’s breathing disturbed during sleep? | Yes / No / Sometimes

17. Does your child snore? | Yes / No / Sometimes

18. Does your child’s breathing stop and start during sleep? | Yes / No / Sometimes

19. Does your child have shallow breathing during sleep? | Yes / No / Sometimes

20. Does your child struggle for breaths during the night? | Yes / No / Sometimes

21. Is your child’s breathing at night interrupted with snorts and gasps? | Yes / No / Sometimes
<table>
<thead>
<tr>
<th>22. Does your child gag or choke during the night?</th>
<th>Yes / No / Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td>23. Is your child’s breathing poorer in certain sleep positions?</td>
<td>Yes / No / Sometimes</td>
</tr>
<tr>
<td>If <strong>Yes</strong>, what positions?</td>
<td></td>
</tr>
<tr>
<td>24. Does your child have recurrent ear/throat infections?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>25. Have your child’s tonsils/adenoids been removed?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If <strong>Yes</strong>, please detail:</td>
<td></td>
</tr>
<tr>
<td>26. Does your child find it difficult to recover from a cold?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>27. Does your child find it difficult to cough?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>NUTRITION &amp; FEEDING RELATED PROBLEMS:</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>28. Does your child have difficulties with chewing/swallowing?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes, please detail:</td>
<td></td>
</tr>
<tr>
<td>29. Does your child have problems with feeding?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes:</td>
<td></td>
</tr>
<tr>
<td>29a. Is your child fed by nasogastric /gastrostomy feeds alone?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>29b. Is your child fed by combination of tube and oral?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>If Yes, please detail:</td>
<td></td>
</tr>
<tr>
<td>30. Does your child experience vomiting/regurgitation during:</td>
<td></td>
</tr>
<tr>
<td>- daytime.</td>
<td>Yes / No</td>
</tr>
<tr>
<td>- night time.</td>
<td>Yes / No</td>
</tr>
<tr>
<td>31. Is there a risk of aspiration?</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>Please detail:</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Option</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>32. Does your child experience periods of constipation?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes:</strong></td>
<td></td>
</tr>
<tr>
<td>32a. Does this cause discomfort at night?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>SEIZURES/FITS &amp; NEUROLOGICAL:</strong></td>
<td></td>
</tr>
<tr>
<td>33. Has your child ever had a seizure or fit?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes:</strong></td>
<td></td>
</tr>
<tr>
<td>33a. How many seizures/fits has your child had in the last 6 months?</td>
<td>None / 1-5 / 6-10 / 11-20 / Daily</td>
</tr>
<tr>
<td>33b. What time of the day/night do the convulsions/fits usually occur?</td>
<td>Early morning / afternoon / evening / night time</td>
</tr>
<tr>
<td>Please detail:</td>
<td></td>
</tr>
<tr>
<td>33c. How long do the convulsions/fits last?</td>
<td>Seconds / less than 15 minutes / 15 minutes +</td>
</tr>
<tr>
<td>33d. How many different medications are needed to control the convulsions/fits?</td>
<td>None / 1 drug / 2 drugs / 3 drugs / more than 3 drugs</td>
</tr>
<tr>
<td>33e. What are the name of the drugs?</td>
<td>Please detail:</td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>34. Does your child indicate that they suffer from headaches?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>35. Does your child seem to have headaches in the mornings?</td>
<td>Yes / No</td>
</tr>
<tr>
<td>36. Does your child have a cerebral shunt?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes:</strong></td>
<td></td>
</tr>
<tr>
<td>36a. Has the cerebral shunt caused any problems in the last 6 months?</td>
<td>Yes / No</td>
</tr>
<tr>
<td><strong>If Yes, please detail:</strong></td>
<td></td>
</tr>
</tbody>
</table>
Sleep Profile

GENERAL:

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

2. What time in the morning does your child usually wake up on:
   Schooldays
   Weekends/school holidays

3. What time does your child usually get up or is aided to get up on:
   Schooldays
   Weekends/school holidays

4. Does your child have a set bedtime routine? Yes / No
   If Yes, please detail:

5. What is your child’s favourite sleeping position?

6. Does your child take daytime naps? Yes / No
   If Yes:
   How many naps a day does your child take?
   How long (approximately) does your child nap for?
7. Does your child regularly spend nights away from home?   Yes / No

If Yes, please detail where and when and if your child sleeps better when
at home, when away or the same.

8. Does your child use posture management equipment?   Yes / No

If Yes, please detail:

If your child uses a sleep system/lying support:

8a. What brand does your child use:

8b. How often does your child sleep in the sleep system/lying support?
(i.e. how many nights per week):

8c. For how long each night does your child sleep in the sleep system/lying support?

8d. Does your child sleep better or worse in the sleep system/lying support?

8e. If the sleep system/lying support is no longer used by your child what were the
reasons for discontinuing its use?

Please detail:
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Does your child go to bed at the <strong>same time</strong> each night?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>10. Once in bed does your child fall asleep within <strong>20 minutes</strong>?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>10a. If <strong>not</strong>, how long is it before s/he falls asleep?</td>
<td>20-30mins / 30-45mins / 45mins+</td>
</tr>
<tr>
<td>11. Does your child fall asleep alone in their <strong>own</strong> bed?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>12. Does your child fall asleep alone in their <strong>parent's</strong> bed?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>13. Does your child fall asleep alone at night in <strong>other</strong> places? e.g. sofa, wheelchair</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>14. How many children sleep in the <strong>same bedroom</strong> as your child?</td>
<td>0 / 1 / 2 / 3+</td>
</tr>
<tr>
<td>15. Does your child need a <strong>parent</strong> with them in order to fall asleep?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>16. Does your child need <strong>medication</strong> to help them fall asleep/stay asleep?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>If Yes, please detail type and dose:</td>
<td></td>
</tr>
<tr>
<td>17. Is your child <strong>reluctant</strong> to go to bed at bedtime? e.g. refuses to stay in bed, cries etc.</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
</tbody>
</table>
| NIGHT-TIME BEHAVIOUR | Usually = 5-7 nights per week  
|                     | Sometimes = 2-4 nights per week  
|                     | Rarely = 0-1 night/s per week |

18. Does your child **wake** during the night?  
   **If Yes:**  
   18a. How many times a night does your child wake?  
   Usually / Sometimes / Rarely  
   1-3 times / 4-6 / 7+  
   18b. How long, on average, are the waking periods?  
   0-10 mins / 11-30 / 30+  
   18c. Do you **attend** to your child when they wake during the night?  
   Usually / Sometimes / Rarely  

19. Does your child **cry** when they wake during the night?  
   Usually / Sometimes / Rarely  

20. Does your child wake during the night **sweating, screaming and distressed**?  
   Usually / Sometimes / Rarely  

21. Does your child move, or are they moved, to **someone else’s bed** when they wake up during the night?  
   Usually / Sometimes / Rarely  
   Please detail who’s bed:  

22. Is your child **restless** and **moves** a lot during the night?  
   Usually / Sometimes / Rarely  

23. Does your child **talk or vocalise** whilst asleep?  
   Usually / Sometimes / Rarely  

24. Does your child **grind their teeth** whilst asleep?  
   Usually / Sometimes / Rarely  

25. Does your child **bang their head or rock back and forth** whilst falling asleep or when asleep?  
   Usually / Sometimes / Rarely
<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. Does your child <strong>wet the bed</strong> during the night?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>or</td>
<td></td>
</tr>
<tr>
<td>If your child wears nappies/pads are they <strong>wet</strong> and/or <strong>soiled</strong> in the morning?</td>
<td></td>
</tr>
<tr>
<td>27. Does your child wake during the night in <strong>pain</strong>?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>If <strong>Yes</strong>, please detail:</td>
<td></td>
</tr>
<tr>
<td>28. Can your child <strong>change his/her position</strong> at night?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>29. Do you or another need to <strong>change your child’s position</strong> during the night?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>30. Do you think your child sleeps <strong>too little</strong>?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>31. Do you think your child sleeps <strong>too much</strong>?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>32. Is your child <strong>drowsy</strong> and takes a lot of time to become <strong>alert</strong> in the <strong>morning</strong>?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
<tr>
<td>33. Does your child seem <strong>tired</strong> to you in the <strong>morning</strong>?</td>
<td>Usually / Sometimes / Rarely</td>
</tr>
</tbody>
</table>
Appendix 12.1 Example of Actogram of child with severe CP
Appendix 12.2 Example of Actogram of parent (father)
Appendix 12.3 Example of Actogram of parent (mother)
Appendix 13: Extract of interview with Libby Cooper (child with severe CP, 12 years old)

Interview with Libby Cooper, 12 years old. The interview took place in the family home in the dining area of the kitchen and was conducted over 2 separate visits. Libby is non-verbal and uses a range of methods to communicate. She has an established ‘yes’ response which is a higher pitched vocalisation and movement of her eyes and head upwards to the left. Her response for ‘No’ is sometimes more ambiguous. Sometimes she verbally responds with a clear ‘No’, other times a lower pitched vocalisation and movement of her eyes and head downwards to the right means ‘No’ and sometimes no response is interpreted as meaning ‘No’. Libby also uses a picture symbol book system. The system is based on the structuring of ‘20 questions’, requiring a ‘yes’ or ‘no’ response. The vocabulary is organised into Categories, which are then subdivided into ‘Topics’ and then ‘Key Words’. To aid recognition of the Categories, the system is colour coded. For Libby to use this system she relies on a facilitator to read her out her category, topic and keyword choices. The facilitator allows enough time after each choice for Libby to indicate ‘Yes’ or ‘no’ using her established responses as detailed above. A carer comes to the family home 2 evenings a week to be with Libby to do such activities as arts and crafts, reading etc and it was decided with Libby’s agreement that the carer – Sally (who also works with Libby at school so knows her well) would act as facilitator. This was checked and re-checked with Libby and she was happy with this arrangement.

Interviewer ...I just wondered, using the words in your book, if you could tell me what it feels like when you feel tired. Shall we have a look?

Sally Do you think we should look in feelings [category]

Libby [Vocalisation and head movement upwards indicative of Libby’s Yes].

Sally Down feelings?

Libby [Vocalisation and head movement upwards indicative of Libby’s Yes].

Sally Ok. You got ‘sad’...‘don’t like’...‘bad’...‘worried’...
Libby [Vocalisation and head movement upwards indicative of Libby’s Yes].

Sally

Worried?

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

OK, you’ve got ‘upset’...‘cross’...

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

OK, I’ve seen you...‘bored’...‘hungry’...‘thirsty’...‘tired’...

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

I’ve got ‘scared’...

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

‘Fed up’...‘puzzled’... ‘homesick’...‘lazy’...‘lonely’...

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

‘Jealous’...

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

Are you saying yes to all of these?

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

Right ok, try to think of the ones about how you feel when you haven’t had a very good night’s sleep. OK...‘temper’... ‘Angry’... ‘Embarrassed’...

L [Vocalisation and head movement upwards indicative of Libby’s Yes].
S Do you want the word embarrassed?

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

S Are you sure?

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

S ‘Confused’...

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

S Are you saying yes to all of them now?

L No [clear verbal response]

S OK, that’s fine. ‘Annoyed’...

L [vocalisation]

S Do you want the word annoyed?

L [Vocalisation and head movement upwards indicative of L’s Yes].

S OK...and ‘nightmare’ and ‘dream’...

L [No response]

Interviewer OK so Libby that’s a lot of words. So when you haven’t had a good night’s sleep these are the words you’ve chosen for how you feel, you’ve chosen ‘worried’, ‘cross’, ‘tired’, ‘scared’, ‘lonely’, ‘jealous’, ‘embarrassed’ ‘confused’ and ‘annoyed’. Is that right?

L [Vocalisation and head movement upwards indicative of Libby’s Yes].

Interviewer OK, thank you Libby.

(Libby Cooper, 12 years old, severe CP)
Appendix 14 Gross Motor Function Classification System (GMFCS) descriptors

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

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**GMFCS Level I**
Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

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**GMFCS Level II**
Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

---

**GMFCS Level III**
Children walk using a handheld mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

---

**GMFCS Level IV**
Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

---

**GMFCS Level V**
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.
GMFCS E & R between 12th and 18th birthday: Descriptors and illustrations

**GMFCS Level I**
Youth walk at home, school, outdoors and in the community. Youths are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.

**GMFCS Level II**
Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.

**GMFCS Level III**
Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.

**GMFCS Level IV**
Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.

**GMFCS Level V**
Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.
Appendix 15 Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

Purpose
The purpose of the CFCS is to classify the everyday communication performance of an individual with cerebral palsy into one of five levels. The CFCS focuses on activity and participation levels as described in the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF).

User Instructions
A parent, caregiver, and/or a professional who is familiar with the person’s communication selects the level of communication performance. Adults and adolescents with cerebral palsy may also classify their communication performance. The overall effectiveness of the communication performance should be based on how they usually take part in everyday situations requiring communication, rather than their best capacity. These everyday situations may occur in home, school, and the community.

Some communication may be difficult to classify if performance falls across more than one level. In those cases, choose the level that most closely describes the person’s usual performance in the most settings. Do not consider the individual’s perceived capacity, cognition, and/or motivation when selecting a level.

Definitions
Communication occurs when a sender transmits a message and a receiver understands the message. An effective communicator independently alternates as a sender and a receiver regardless of the demands of a conversation, including settings (e.g., community, school, work, home), conversational partners, and topics.

All methods of communication performance are considered in determining the CFCS level. These include the use of speech, gestures, behaviors, eye gaze, facial expressions, and augmentative and alternative communication (AAC). AAC systems include (but are not limited to) manual sign, pictures, communication boards, communication books, and talking devices — often called voice output communication aids (VOCAs) or speech generating devices (SGDs).

Effective senders and receivers shift quickly and easily between transmitting and understanding messages. To clarify or repair misunderstandings, the effective sender and receiver may use or request strategies such as repeating, rephrasing, simplifying, and/or expanding the message. To speed up communication exchanges, especially when using AAC, an effective sender may appropriately decide to use less grammatically correct messages by leaving out or shortening words with familiar communication partners.

A comfortable pace of communication refers to how quickly and easily the person can understand and convey messages. A comfortable pace occurs with few communication breakdowns and little wait time between communication turns.

Unfamiliar conversational partners are strangers or acquaintances who only occasionally communicate with the person. Familiar conversational partners such as relatives, caregivers, and friends may be able to communicate more effectively with the person because of previous knowledge and personal experiences.
Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

Clarifications

- Determining the CFCS level does not require testing, nor does it replace standardized communication assessments. The CFCS is not a test.
- The CFCS groups people by the effectiveness of current communication performance. It does not explain any underlying reasons for the degree of effectiveness such as cognitive, motivational, physical, speech, hearing, and/or language problems.
- The CFCS does not rate the person’s potential for improvement.
- The CFCS may be useful in research and service delivery, when classifying communication effectiveness is important. Examples include:
  1) describing functional communication performance using a common language among professionals and laypersons,
  2) recognizing the use of all effective methods of communication including AAC,
  3) comparing how different communication environments, partners, and/or communication tasks might affect the level chosen,
  4) choosing goals to improve the person’s communication effectiveness.

* See page 3 for a description of the five levels.
* See page 4 for a chart to help distinguish between levels.
* Frequently-asked questions can be found on the CFCS website: http://cfcs.us

Communication Methods

Regardless of the number of communication methods used, only 1 CFCS level is assigned for the overall communication performance.

The box below is provided to list all the communication methods used.

The following methods of communication are used by this individual:
(Please check all that apply)

- Speech
- Sounds (such as an “aaaaah” to get a partner’s attention)
- Eye gaze, facial expressions, gesturing, and/or pointing (e.g., with a body part, stick, laser)
- Manual signs
- Communication book, boards, and/or pictures
- Voice output device or a speech-generating device
- Other

Reference for CFCS Development:
Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

I. Effective Sender and Receiver with unfamiliar and familiar partners.
   The person independently alternates between sender and receiver roles with most people in most environments. The communication occurs easily and at a comfortable pace with both unfamiliar and familiar conversational partners. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

II. Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.
   The person independently alternates between sender and receiver roles with most people in most environments, but the conversational pace is slow and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstandings are often repaired and do not interfere with the eventual effectiveness of the person's communication with both unfamiliar and familiar partners.

III. Effective Sender and Receiver with familiar partners.
   The person alternates between sender and receiver roles with familiar (but not unfamiliar) conversational partners in most environments. Communication is not consistently effective with most unfamiliar partners, but is usually effective with familiar partners.

IV. Inconsistent Sender and/or Receiver with familiar partners.
   The person does not consistently alternate sender and receiver roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is sometimes effective with familiar partners.

V. Seldom Effective Sender and Receiver even with familiar partners.
   The person is limited as both a sender and receiver. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is seldom effective even with familiar partners.

Key
P: Person with CP
U: Unfamiliar Partner
F: Familiar Partner
Effective
Less effective

The difference between Levels I and II is the pace of the conversation. In Level I, the person communicates at a comfortable pace with little or no delay in order to understand, compose a message, or repair a misunderstanding. In Level II, the person needs extra time at least occasionally.

The differences between Levels II and III concern pace and the type of conversational partners. In Level II, the person is an effective sender and receiver with all conversational partners, but pace is an issue. In Level III, the person is consistently effective with familiar conversational partners, but not with most unfamiliar partners.

The difference between Levels III and IV is how consistently the person alternates between sender and receiver roles with familiar partners. In Level III, the person is generally able to communicate with familiar partners as a sender and as a receiver. In Level IV, the person does not communicate with familiar partners consistently. This difficulty may be in sending and/or receiving.

The difference between Levels IV and V is the degree of difficulty that the person has when communicating with familiar partners. In Level IV, the person has some success as an effective sender and/or an effective receiver with familiar partners. In Level V, the person is rarely able to communicate effectively even with familiar partners.
CFCS Level Identification Chart

Does the person consistently and effectively alternate sender and receiver roles with familiar partners?

YES

Is the person an effective sender AND/OR a receiver at least some of the time?

YES

Level II
Effective, but slower-paced Sender and/or Receiver with unfamiliar and familiar partners

NO

Level III
Effective Sender AND Effective Receiver with familiar partners

NO

Level IV
Inconsistent Sender and/or Receiver with familiar partners

NO

Level V
Seldom Effective Sender and Receiver with familiar partners

Does the person consistently and effectively communicate with unfamiliar partners?

YES

Does the person usually maintain a comfortable conversational pace with communication partners?

YES

Level I
Effective Sender and Receiver with unfamiliar and familiar partners

NO

Level II
Effective, but slower-paced Sender and/or Receiver with unfamiliar and familiar partners
Appendix 16 Classification of CP sub types

Classification tree for sub-types of Cerebral Palsy

- Is there persisting increased muscle tone in one or more limbs?
  - Y: Are both sides of the body involved?
    - Y: Spastic Bilateral
    - N: Spastic Unilateral
  - N: Non-classifiable

- Is the tone varying?
  - Y: Reduced activity - tone tends to be increased
    - Dystonic CP
  - N: Increased activity - tone tends to be decreased
    - Chorea-Athetotic CP
  - N: Ataxic CP
  - N: Non-classifiable

Bibliography


McIntosh, I., Punch, S., Dorrer, N. and Emond, R. (2010) “You don’t have to be watched to make your toast”: Surveillance and food practices within residential care for young people’, Surveillance and Society 7(3): 287–300.


