

**SLEEP PROBLEMS AND DAYTIME CHALLENGING BEHAVIOUR IN
A CLINICAL SAMPLE OF CHILDREN WITH A MODERATE TO
SEVERE LEARNING DISABILITY AND/OR AUTISM. THE
RELATIONSHIP WITH MATERNAL STRESS.**

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**Submitted in part fulfilment towards the degree of Doctorate in Clinical
Psychology at the University of Edinburgh**

August 2004

DECLARATION

I declare that I am the sole author of this thesis and that the work contained herein is my own. This thesis, or any part of it, has not been submitted for any other degree or professional qualification.

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August 2004

ACKNOWLEDGEMENTS

During the preparation of this thesis I have become indebted to a number of people for their assistance:

Dr Sally Cheseldine and Dr Karen McKenzie for their supervision, helpful discussion and enthusiasm.

Dr Arthur Still for his statistical advice.

Mr Matthew Porter for all his support and encouragement.

Finally, I would like to thank the Learning Disability and Autism Service, Edinburgh, together with all the parents and schools who were involved in the study.

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ABSTRACT

Objective: The prevalence rates of sleep problems have previously been found to be significantly higher in children with a moderate to severe learning disability and/or autism in comparison to typically developing children (Richdale, Gavidia-Payne, Francis & Cotton, 2000). Further, the existence of a sleep problem has been found to be correlated with daytime challenging behaviour and maternal stress (Wiggs & Stores, 1996; Quine, 1991; Quine, 1992). To date, no study has investigated this relationship and prevalence rates specifically in a clinical population. In this study it was hypothesised that children who had been referred to a specialist learning disability and autism clinical service for complex psychological and behavioural difficulties and were, by definition, considered to have problems that have reached clinical significance, would have increased sleeping difficulties in comparison to children with the same degree of disability whose behaviour had not warranted referral. Further, this would have an impact on maternal stress in that stress levels would be again higher in the clinical group.

Design: A questionnaire method was used to analyse between group differences on measures of children's sleep, daytime challenging behaviour and maternal stress.

Method: Sixty-seven mothers of children with a moderate to severe learning disability and/or autism participated. Of these thirty-seven parents had a child who was currently being treated by the learning disability and autism service, and thirty had a child attending special education provision schools, whose behaviour had not warranted a current referral to a clinical service. Mothers were asked to complete

three questionnaires measuring children's sleep, daytime challenging behaviour and maternal stress.

Results: In comparison to the control group, mothers of children in the clinical group rated their children as having significantly more sleeping problems and daytime challenging behaviour. Further the mothers in the clinical group scored more highly on a measure of maternal stress. A correlation was found between all three variables in the clinical group; sleep and maternal stress were not correlated in the control group. Regression analysis suggested that children's sleep problems were the best predictor of maternal stress in the clinical group and daytime challenging behaviour was the best predictor of maternal stress in the control group. The results are discussed with reference to previous research findings and clinical implications. Consideration is also given to the methodological shortcomings of the current study and suggestions for future research are made.

CHAPTER ONE: INTRODUCTION

1.1 General Overview of Thesis

Sleep problems are known to be common in the general population at all ages (Partinen & Hublin, 2000), they are particularly prominent, but under researched, in children with a learning disability (Bartlett, Rooney & Spedding, 1985). Often, sleep problems have been found to be severe and persistent in children with a learning disability and, unfortunately, frequently not treated appropriately, if at all (Wiggs & Stores, 1996). Further, if persistent, sleep problems have been found to be correlated with both daytime challenging behaviour and maternal stress (Quine, 1991; Wiggs & Stores, 1996) in children with a learning disability.

To date, previous studies have taken the population of children with a learning disability as a whole, and, if a control group was used, compared the prevalence of sleep problems and daytime challenging behaviour with typically developing children (Richdale, Gavidia-Payne, Francis & Cotton 2000). Few have simultaneously researched the impact on maternal stress of these problems (Quine, 1991; 1992). More recently a small number of studies have begun to investigate sleep problems by aetiology of learning disability and degree of learning disability (Stores, 1993a). No study has made the distinction between a clinical population and a general population of children with a learning disability whose behaviour has not warranted referral to a specialist service. Such a distinction will be directly relevant for clinicians working with children with a learning disability.

This thesis will examine sleep problems and their relationship with daytime challenging behaviour and maternal stress in children with a moderate to severe learning disability and/or autism who have been referred to a specialist clinical service with children of the same ability (moderate to severe learning disability and/or autism) whose behaviour has not warranted a referral to such a service. A better understanding of how sleep problems, daytime challenging behaviour and maternal stress interact in a clinical population will have important clinical implications for the effective treatment and management of these difficulties.

The introduction to this thesis will review the relevant literature and develop a rationale for the study. This will be divided into three sections. Section One will provide definitions and contextual information. Section Two will provide relevant background information about sleep problems, challenging behaviour and parental stress in relation to children with a learning disability and/or autism. Section Three will outline the rationale for this study.

1.2 Section One: Definitions and Contextual Information

Section One will provide contextual information, which is pertinent to this thesis. This will include a definition of learning disability and information about the prevalence of learning disability in children together with a definition of challenging behaviour and information about the presentation and prevalence of challenging behaviour in children with a learning disability.

1.2.1 Definition of Learning Disability

There are international variations in the terminology used to describe learning disability. For example, terms such as 'intellectual disability' and 'mental retardation' are used in America. It should be noted, however, that the term 'learning disability' is the preferred option in the UK (British Psychological Society, 2000) and, therefore, will be the term employed throughout this thesis.

There are various classification systems that attempt to define and classify learning disability. As learning disability is socially constructed, what it means, how it is measured, and therefore, who counts as having a learning disability has varied both over time and internationally (Wright & Digby, 1996). This variance can be accounted for by differing ideological, political, economic and cultural factors (Fryers, 1993).

The main professional bodies which are most commonly consulted for classifications are: The American Association on Mental Retardation (2002); The World Health Organisation's 'International Classification of Diseases (10th edition)' (ICD-10) (1992); The American Psychiatric Association's 'Diagnostic and Statistical Manual for the Mental Disorders (4th edition)' (DSM-1V) (1994) and The Department of Health (1998). Despite differences in terminology and the wording in the various definitions, there are three core criteria for learning disability which have gained widespread acceptance across these professional boundaries within the UK and America. These are: evidence of significant impairment of intellectual functioning (IQ \leq 70); significant impairment of adaptive/ social functioning (in at least two of

the following; communication, self-care, home living, social/ interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure and health and safety) and an age of onset before the age of eighteen years. All three criteria must be met for a person to be considered to have a learning disability. The Scottish Executive's (2000) 'The Same as You?' review of services for needs for people with a learning disability additionally defines a learning disability in terms of the support needs that a person will have at various points over the course of their life.

The 2002 American Association of Mental Retardation (AAMR) classification system does not define levels of learning disability. However, the concept of different degrees of severity of learning disability is in almost universal usage. Despite the problems of psychometric testing with this population, these classifications are based on standardised IQ scores. It is, however, accepted that consideration should also be given to adaptive behaviour when making a judgement about level of learning disability (The British Psychological Society, 2000; Emerson, 1998). Within the clinical context, sub-classifications of *mild*, *moderate*, *severe* and *profound* 'mental retardation' are used by ICD-10 and DSM-IV. Whilst these systems do employ the same descriptive categories, the quoted IQ ranges do not correspond exactly. It should be noted that The British Psychological Society (2000) recommends that a two-category subdivision should be made into *significant* (IQ 55-69) and *severe* (IQ < 55) impairments of intelligence. They recommend that adaptive and social functioning should also be taken into consideration. There is obviously still much debate about the definition and classification of learning disability. This

thesis uses mild, moderate and severe to define sub-classifications of a learning disability as this usage is still the most widely used (The World Health Organisation, ICD-10, 1992; The American Psychiatric Association, DSM-IV, 1994) and recognised.

1.2.2 Prevalence of Learning Disability in Children

Most prevalence studies of learning disability are total population estimates, which combine both adults and children. Based on these studies, it is estimated that between 2-3% of children have a learning disability (Scott, 1994). Of this group, approximately 89% have a mild learning disability, 7 % have a moderate learning disability, 3 % have a severe learning disability and 1 % have a profound learning disability (Madle, 1990).

The number of people with a learning disability in the UK has increased over the last 35 years. Researchers estimate an increase of 1.2% a year between 1960 and 1995 of people with a severe learning disability, with a significant increase in those who are older (McGrother & Thorp, 1999). This means that the number of people with a severe learning disability has increased by 50% over the last 50 years. It is estimated that the number of people with a moderate learning disability has increased in much the same way (Scottish Executive, 2000). Hatton (1998) suggests the reason for this increase is due to improvements in health care in the past 20 years meaning that an increasing number of children with severe and complex disabilities are surviving through to adulthood.

1.2.3 Definition of Challenging Behaviour

Challenging behaviour refers to ‘culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities’ (Emerson, Cummings, Barrett, Hughes, McCool & Toogood, 1988. p.16).

There are three main important aspects of the above definition. First, is that challenging behaviours are defined by their impact. Consequently, the behaviours that fall under this definition range widely in their topography as do the psychological or biological processes which underlie them (Emerson, 1998). The second important aspect to highlight is that challenging behaviour is a social construction. That is, the behaviours transgress social rules. Whether behaviour is considered challenging or not will depend on the complex interaction between what the person is actually doing, the setting in which they do it and how the behaviour is interpreted or given meaning (Emerson, 1998). This is where the term ‘challenging behaviour’ differs from ‘problem behaviour’ as it moves the locus of the problem from the individual and onto the environment or setting in which it occurs. Third, the behaviours have wide-ranging personal and social consequences. Emerson (1998) noted that challenging behaviours may directly impair the health and/ or the quality of life of the person and those who live or care for him or her. He further points out that the ways in which the community, carers and services respond to people with challenging behaviours may prove significantly more detrimental than the immediate consequences of the actual behaviours themselves.

Between ten and fifteen percent of people who are supported by learning disability services show behaviours which are considered to cause a serious management problem (Emerson, 1998). The three most commonly identified forms of challenging behaviour are reported to be aggressive or destructive behaviour, self-injurious behaviour and stereotypical behaviour (Hastings & Remington, 1994).

1.2.4 Presentation and Prevalence of Challenging Behaviour in Children with a Learning Disability

There is much literature that suggests that children with a learning disability are more likely to engage in challenging behaviour than typically developing children (Dunlap, Robbins & Darrow, 1994; Einfeld & Tonge, 1996). In addition to difficulties such as tantrums and non-compliance which occur in the wider community, children with a learning disability can also engage in more serious activities such as self-injury or extensive property destruction (Chadwick, Piroth, Walker, Bernard & Taylor, 2000).

Personal pre-disposing factors for challenging behaviour have been found to include a greater degree of learning disability (Kiernan & Kiernan, 1994), few adaptive behaviours (Oliver 1991), more limited expressive language (Wing & Gould, 1979), co-morbid autism (Lainhart, 1999), co-morbid sensory and motor disabilities (Oliver, 1991) and the presence of particular syndromes such as Lesch-Nyhan (Dykens, Hodapp & Finucane, 2000), Smith-Magenis (Smith, Dykens & Greenberg, 1998) and

Prader-Willi (Dykens et al., 2000). Many of these predisposing factors limit the availability of alternative responses of equivalent efficiency through which the child can express the need to make social contact with carers or reduce the demands made by those caring for them (Oliver, 1995). Thus, the behaviours displayed become functionally adaptive.

Despite the recognised impact of problem behaviours as sources of further handicap, there is little information on actual prevalence figures of challenging behaviour among children with a learning disability (Einfield & Tonge, 1996). The rates that do exist in the literature vary from 22% (Kiernan & Kiernan, 1994) to 50% (Wilkin, 1979). Further, longitudinal studies of children with a learning disability who have challenging behaviours suggest that, once the behaviours are established, they often persist over time (Kollier, Richardson, Katz & McLaren, 1983; Carr, 1992).

Quine's (1986) study of two hundred five to eighteen year old children with a severe learning disability outlined the range of behaviours that are commonly presented. Twenty-nine percent of the children were described as 'attention seeking', 21% as overactive, 25% had temper tantrums, 21% were aggressive, 22% screamed, 18% wandered, 14% were destructive and 12% engaged in self-injurious behaviour.

1.2.5 Summary of Section One

It is estimated that 2-3% of children have a learning disability. Whilst prevalence rates for the proportion of these children who exhibit challenging behaviour are less clear, estimates range from 22% to 50%. Children with a learning disability have

been found to be more likely to engage in challenging behaviour than typically developing children. These behaviours may include aggression, stereotypy and self-injurious behaviour.

1.3 Section Two: Sleep, Parental Stress and Behaviour

The impact on parents of having a child with a learning disability can vary enormously. Many of the children have difficulties with sleep. This section will outline the difficulties that some children can have with sleep with reference to those who have a learning disability and/or autism, together with the impact that lack of sleep can have on both the child and his or her parents.

1.3.1 Prevalence and Definition of Sleep Problems

Sleep disturbance is a common problem, which affects both families bringing up children with a learning disability and those with typically developing children (Quine, 1991). Problems with sleep are common in young children. Up to 20% of two year old children and 14% of three year old children wake regularly during the night (Richman, Stevenson & Graham, 1975; Jenkins, Bax, & Hart, 1980). Further, Rutter, Tizard and Whitmore (1970) found in the Isle of Wight study that 20% of children at age ten to twelve years of age were still considered to have sleep problems by their parents.

It is important to distinguish between a sleep problem or complaint and the underlying cause of the problem, i.e., the sleep disorder (Stores & Wiggs, 2001).

This distinction is not often made in the literature. Stores and Wiggs (2001), outline three basic types of sleep problem. These are:

- Difficulty in getting to sleep or staying asleep
- Sleeping too much
- Disturbed episodes that interfere with sleep.

Each sleep problem can be caused by a variety of sleep disorders, of which over 80 are described in the International Classification of Sleep Disorders – Revised (ICSD-R) (American Sleep Disorder Association 1997).

Sleep disorders are defined by Stores and Wiggs (2001) as conditions or circumstances of a physical or psychological nature (or both combined) that cause a sleep disturbance or problem of one type or another. They are classified into two major categories: dyssomnias and parasomnias (Stores, 1999). Dyssomnias include a number of primary sleep disorders that cause either difficulty initiating or maintaining sleep (sleeplessness or insomnia), or excessive sleepiness during the day. Dyssomnias can be further classified as either intrinsic or extrinsic depending on the presumed origin of the disorder (Stores, 1999). Intrinsic disorders are presumed to arise from within the body. An example of this would be an individual experiencing seizures, sleep apnoea or involuntary limb movements that lead to frequent waking at night (Didden & Sigafos, 2001). Extrinsic disorders are those that can be attributed to external factors such as a sleeping environment that is an uncomfortable temperature, very noisy or light. Extrinsic disorders may also be related to a disrupted circadian sleep-wake cycle (Stores & Wiggs, 2001).

Parasomnias are abnormal events that interrupt sleep. Common types of parasomnias include teeth grinding, enuresis and nightmares. Parasomnias are further subdivided according to the phase of sleep with which they are associated. These are named 'arousal disorders', 'sleep-wake transition disorders' and 'parasomnias usually associated with REM (rapid eye movement) sleep (ICSD-R, American Sleep Disorder Association, 1997).

The difficulty with the ICSD-R is that it is adult in its orientation and consequently needs modification before it can be applied to children. Stores and Wiggs (2001) have highlighted the main ways in which children's sleep disorders differ from those of adults. First, they note that parenting factors or involvement feature prominently in the causation of many children's sleep disorders and in the way they can be treated. They further state that, in general, the effects of persistent sleep disturbance are more wide-ranging in children in comparison to adults as their intellectual and behaviour development can be affected by poor sleep. Another difference is that sleep disturbance is more likely to manifest itself in over activity and disturbed behaviour whilst the effect on an adult is more likely to be sleepiness and under activity. Finally, Stores and Wiggs (2001) state that generally, children's sleep disorders are very treatable.

1.3.2 Prevalence of Sleep Problems in Children with a Learning Disability

Relatively few studies have looked at sleep problems in children with a learning disability. Despite this, the evidence that does exist suggests that the prevalence of

these problems is particularly common in this group of children. In a study of 214 children with a learning disability, Bartlett, Rooney and Spedding (1985) found that 86% of children under the age of six years, 81% of children between the ages of six to eleven years and 77% of children aged twelve to sixteen years were reported to have sleep problems by their parents. Fifty-six percent were found to wake on average once per night, 53% were difficult to get to bed and 56% were difficult to settle. Further, Pahl and Quine (1984) studied two hundred children who were aged up to eighteen years. In this sample, it was found that 51% were described by their mothers as having settling difficulties and 67% as having night waking at least a 'few times a week'. Additionally Pahl and Quine (1984) reported similarly high prevalence rates of settling and night-waking difficulties to those found by Bartlett, Rooney and Spedding (1985). One difficulty with the above studies, however, is that they did not include a control group of typically developing children. Lack of control group is common among the current research in this area.

An exception to this is a recent study by Richdale, Gavidia-Payne, Francis and Cotton (2000) which compared the scores of fifty two children with a mild to profound learning disability with twenty five children who did not have a learning disability on several indices of sleep problems. More sleep problems were found in the group with a learning disability than the typically developing group: 57.7% and 16%, respectively.

Clements, Wing and Dunn (1986), however, reported somewhat lower prevalence rates. They found sleep problems in 34% of their sample of 155 children under the

age of 15 years. Of these, 13% had night waking, 13% experienced limited sleep duration, and 8% had both night waking and limited sleep duration. Wiggs and Stores (2001) suggest that the low rates found by this study may be a consequence of the somewhat 'eclectic nature' of their sample. The study included children with a learning disability *together* with those receiving special education who also displayed some behaviour found in early childhood psychosis. Further, settling difficulties were not considered in the Clements *et al.* (1986) study.

Piazza, Fisher and Kahng (1996) used a momentary time-sampling observational method to investigate the sleep of 51 young people who were between the ages of three and twenty-one years. Over a three week period, these individuals, who had been admitted to an inpatient unit for the treatment of daytime problem behaviour, were observed briefly at half-hour intervals to determine whether the person was asleep or awake. Individuals with developmental disabilities had less total sleep and more night time disruptive behaviour than their typically developing peers. Average duration of night waking was 48.3 minutes and, on average, these individuals required 69 minutes to fall asleep.

Wiggs and Stores (1996) noted that all preceding literature had looked at only settling, night waking and early waking as forms of sleep problems. In fact the majority of the literature in paediatric sleep research refers solely to these types of sleeping difficulties and is termed 'sleep problem'. Further, the definition of a 'sleep problem' appears to vary with each study. As previously discussed, the ICSD-R (1997) lists over eighty different disorders which can be used in the classification of

childhood sleep problems. The clinical features of the sleep of children with a learning disability are, therefore, under researched. Wiggs and Stores (1996) addressed this dearth in the literature in their study of 209 children with a severe learning disability aged between five and sixteen years. Questionnaire data from the children's parents revealed that all forms of sleep disturbance were represented (e.g. snoring 30%; co-sleeping, which is insistence in sleeping in a parents or siblings bed 20%; teeth grinding 15%; head banging 3%). Sleeplessness problems, however, predominated, with severe (i.e. occurring most nights or every night) settling, night-waking and/or early-waking problems in 44% of the sample.

The available literature suggests that these types of sleeplessness frequently coexist (Quine, 1992; Wiggs and Stores, 1996) and appear to be persistent in nature. Quine (1991) completed a three year longitudinal survey of 200 children with a severe learning disability who ranged from one to eighteen years of age. Sleep disorders were assessed initially, and the assessment was repeated three years later. At the initial assessment, 51% of the parents reported settling difficulties in the child, while 67% reported frequent night waking. Fifty percent to 75% of the children who exhibited sleep disorders when first assessed still showed these problems three years later. Specifically, 48% of those with settling problems still had such problems, as did 66% of the children with night-waking problems. In addition, 21% of children had developed sleep problems that were not present three years previously. Quine (1991) used The Behaviour Screening Questionnaire (BSQ) (Richman & Graham, 1971) to assess sleeping difficulties. This is a semi structured interview in which descriptions are obtained in twelve areas, one of which is sleep. Responses are rated

by the interviewer on a three point scale which indicates whether each behavioural item signifies 'no, or a trivial difficulty', 'a mild difficulty' or a 'marked difficulty'. This scale appears to be somewhat unsatisfactory for gaining detailed information about a sleeping difficulty. Additionally, relatively few questions are asked about each area of behaviour.

1.3.3 Prevalence of Sleep Problems in Children with Autism

Children with autism exhibit both deviance and delay in social development, communication and behaviour (American Psychiatric Association (APA) 1994). There are a number of secondary behavioural difficulties which frequently occur in children with autism, and among these is the presence of sleep problems.

In the literature, children with autism are frequently reported to display problematic sleep patterns which are often severe in nature (Stores & Wiggs, 1998; Richdale, 1999; Rapin, 1991). Around two thirds of children with autism exhibit sleep problems at any one time. For example, Hoshino, Watanabe, Yashima, Kaneko and Kumashiro (1984) found that, from a sample of 75 children with autism between the ages of three and fifteen years with a moderate to severe learning disability, 65% were found to have sleep problems. Taira, Takase and Sasaki (1998) found that 65.1% of children of 'pre-school to high school' age with autism had sleeping problems in a sample of 88.

Sleep problems in children with autism appear to be more prevalent in younger children (DeMeyer, 1979; Richdale & Prior, 1995), and are generally related to sleep

onset and maintenance. Sleep problems reported by various authors (DeMyer, 1979; Hoshino *et al.*, 1984; Clements *et al.*, 1986; Richdale & Prior, 1995; Patzold, Richdale & Tonge 1998; Taira *et al.*, 1998; Schreck & Mulick, 2000) include those of irregular sleep-wake patterns, problems with sleep onset, including long sleep latencies and problematic sleep routines, early morning wakening, poor general sleep, variable or late sleep onset and wake times, night waking, excessive co-sleeping with parents or siblings and an increased frequency of dyssomnias. For example, in a study by Patzold *et al.* (1998), sleep disorders were assessed in 38 children with autism and Asperger's syndrome, most of whom additionally had a learning disability. It was found that 63.2% and 76.3% had current and past sleep problems, respectively. Frequent night waking, restless sleep and 'bedtime problems' were reported in 23.3%, 72.2% and 32.8% of the cases respectively.

The limitations of the above research studies are that not all studies included comparison groups (DeMeyer, 1979; Taira *et al.*, 1998) and the sample size and the age of the children were variable.

There is less research on parasomnias in children with autism and what little does exist is contradictory. Richdale and Prior (1995) and Patzold *et al.* (1998) found that bad dreams, nightmares and sleep talking did not occur in children with autism any more frequently than in typically developing children. Contrary to this however, DeMeyer (1979) reported that night terrors were more common in children with autism. In a recent study, Schreck and Mulick (2000) reported that parasomnias were more frequent in autism than in other groups of children. In particular, parents

reported nightmares, environmental disturbances, disorientated awakening and apnoea to be problematic. The difficulty, however, in comparing these studies is the different age ranges of the children who participated in the research. For example, DeMeyer (1979) used children in 'early childhood' and Richdale and Prior (1995) used children between the ages of 2.7 and 19 years. Extrapolating general trends is, therefore, difficult and this area warrants further research.

1.3.4 Aetiological Factors

Various physical and psychosocial theories have been considered in the literature as possible predisposing factors of the development of sleep disturbance in children with a learning disability. One such factor is the physiological abnormalities associated with severe and extensive brain maldevelopment or damage. The evidence on the relation between level of learning disability and sleep disturbance is equivocal. Clements *et al.* (1986) and Richdale, Cotton and Hibbitt (1999) found no association between the presence or severity of sleep problems and level of learning disability. In contrast, Piazza *et al.* (1996) found a significant correlation between the amount of appropriate sleep and both IQ and expressive language scores. Similarly, Espie and Tweedie (1991) found that adults with a severe/profound learning disability spent twice as much time awake at night than did adults with a mild/moderate learning disability.

Okawa and Sasaki (1987) have described how the extent to which sleep physiology is disrupted depends on the extent of brain damage or dysfunction. They detail how extensive and severe brain damage, usually occurring in the perinatal period,

produces a state that they describe as 'acerebrate'. Those in this state show little response to external stimuli and have a highly irregular sleep-wake pattern. This is said by the authors to occur as a result of damage to the many integrated systems in the brain, including the brainstem ascending reticular formation which regulates wakefulness, the pontine and forebrain structures that regulate REM (rapid eye movement) and NREM (non rapid eye movement) sleep, and the suprachiasmatic nuclei and connections that control sleep-wake rhythms. This type of damage would result in individuals who are non-ambulant and profoundly intellectually impaired. Further, Okawa and Sasaki (1987) comment that it is difficult to physiologically distinguish awake and asleep states in these individuals.

It has further been hypothesised (e.g. Didden & Sigafos, 2001) that the production of the hormone melatonin is dampened in individuals with visual handicaps and in individuals with a learning disability. In the dark and at night, the pineal gland synthesizes and releases melatonin. The hypothalamic circadian clock, which is located in the suprachiasmatic nuclei (SCN), regulates the pattern of melatonin synthesis in humans. The SCN has been found to be a major sleep regulator. The light-dark cycle is the most powerful synchroniser known to entrain the endogenous circadian pacemaker on a 24-hour cycle (Hobson, 1989). Complicated changes occur in melatonin production during the course of childhood, with night-time levels peaking between one and three years of age. After this, the level declines, especially with the onset of puberty. Although research programmes on melatonin levels in children with a learning disability are very much still in their infancy, some evidence exists that melatonin production may be quantitatively different in specific aetiologies

of learning disability. For example, in relation to children with Smith-Magenis syndrome, De Leersnyder, Munnich, de Blois and Claustrat (2000) assessed 20 children between the ages of four and seventeen years using a combination of sleep questionnaires, interviews, sleep diaries and nocturnal actometry which included 24-hour monitoring of melatonin levels. A major finding of the study was that melatonin secretion was found to be 'abnormal' in that less was being produced. Pharmacological use of melatonin is a relatively new intervention used to treat sleep problems in children with a learning disability. The available literature on the area has reported mixed results. Jan, Espezel and Appleton (1994) found that melatonin was highly effective in establishing a normalised sleep-wake rhythm with 15 young children. In contrast, however, Camfield, Gordon, Dooley, and Camfield (1996) found no marked improvement in sleep disturbance for six children with developmental disabilities. Thus, whilst melatonin appears promising, it may not produce dramatic effects for all children.

The relationship between REM sleep and learning disability has received some attention in the literature (Stores, 1992). A relative deficiency or other abnormalities in REM sleep are thought to be factors in the cause of sleep problems in people who have a learning disability of various aetiologies. Feinberg, Braun and Shulman (1969) reported fewer and shorter REM sleep periods and fewer eye movements (known as 'low REM density') the lower the child's IQ level. REM sleep is thought to be particularly involved in information processing and other aspects of the learning process (Wiggs & Stores, 2001).

Research has also focused on sleep spindle activity as being different or abnormal in children with a learning disability. Sleep spindle activity is a feature of NREM, stage two sleep. In a healthy young adult, stage two sleep would be shown on an electroencephalogram (EEG) as consisting of slow wave EEG activity, followed by sleep spindles which are brief spindle-shaped bursts of EEG activity. Sleep spindles have been found to be absent, unusually diffusely distributed, high voltage and continuous (so called 'extreme spindles') or infrequent in children with a learning disability (Stores, 2001). There is evidence that these unusual features indicate abnormal brain development (Wiggs & Stores, 2001). Thus, the literature suggests that the sleep of individuals with a learning disability is qualitatively different to typically developing persons.

Wiggs and Stores (2001) suggest that children with less severely damaged brains, who still lack normal sensory appreciation of their environment together with a limited development of social relationships, may have abnormal sleep-wake patterns. They postulate that this may be a consequence of a combination of damage to basic brain structures and failure to register cues to day and night.

A psychosocial factor which may predispose children with a learning disability to the development of disturbed sleep has been proposed by Quine (1991). Teaching a child with a learning disability good sleep habits is more challenging than teaching a typically developing child. Quine (1991) suggests that possible reasons for this include problems of communication with the child. In her 1991 study, Quine found that 40% of children who were reported to have sleep problems were 'poor' at using

communication. Of those with no sleep problems, only 13% were 'poor' at using communication. In terms of understanding communication, 35% of those who had sleep problems were described as 'poor' at understanding communication, whilst only 9% of children who had no sleep problems were 'poor' in this category. Quine (1991) postulates that it seems likely that poor communication skills may result in frustration for both parent and child. For the parent, the inability to communicate with the child may make it much harder to initiate the training practices which might establish improved sleep routines.

An additional psychosocial factor which may contribute to the predisposition of this group to sleep problems is proposed by Wiggs and Stores (2001). They suggest that, out of compassion for their child and because of guilt feelings, parents may feel unable to impose discipline in the way that is usually needed to avoid bedtime problems and the child's overdependence on them when settling to sleep or on waking during the night. Further, parents of children with a learning disability may view sleep difficulties as an inevitable part of the child's basic condition. Unless educated otherwise, parents may well not realise that, with appropriate early intervention and advice, it may be possible to prevent or minimise such problems. It is possible to treat sleep problems effectively even when the sleep problem is severe, long standing and accompanied by challenging behaviour (Wiggs & Stores, 1998; Wiggs & Stores, 2001; Lancioni, O'Reilly & Basili, 1999), however, the task is made more difficult in children who are emotionally or behaviourally disturbed (Borthwick-Duffy, 1994).

A further predisposing factor is in relation to parenting. If the child's parents are demoralised or psychologically disturbed, or if disharmony exists in relation to their approach to the child's problems then this can hinder the treatment process. This, unfortunately, is not an uncommon difficulty in families with a child with a learning disability (Wiggs & Stores, 2001).

There are other factors which are thought to be associated with sleep problems. Age, medical conditions, genetic disorders, adaptive skills, visual handicaps or impairments and physical handicaps have all been associated with sleep problems in the literature (Didden, Korzilius, van Aperlo, van Overloop & de Vries, 2002). Quine (1991) and Clements *et al.* (1986) have shown that sleep problems are more common among children under the age of five years than in those who are older. Medical conditions such as seizure disorder and breathing related difficulties (e.g. obstructive sleep apnoea) have also been found to be related to sleep problems. The research on breathing difficulties has mainly identified this problem in individual's with Down syndrome (Marcus, Keens, Bautista, von Pechman & Davidson Ward, 1991; Stores, 1993a; Quine, 1991).

Relationships have been found between genetic disorders and sleep problems, suggesting that sleep problems may be a behavioural phenotype (Didden & Sigafos, 2001). Sleep problems have been found to be highly prevalent among children who have Angelman Syndrome (Clarke & Marston, 2000; Clayton-Smith, 1993), Prader-Willi syndrome (Richdale *et al.*, 1999), tuberous sclerosis (Bruni, Cortesi, Gianotti, Curatolo, 1995), Sanfillipo syndrome (Colville, Watters, Yule & Bax, 1996) and is

thought to be a major feature of Smith-Magenis syndrome (Smith, Dykens & Greenberg, 1998; Greenberg, Lewis, Potocki, Glaze, Parke, Killian, Murphy, Williamson & Brown, 1996). Finally, results from several studies have shown a relationship between sleep problems and daytime challenging behaviour (Quine, 1991; Wiggs & Stores, 1996; Richdale *et al.*, 1999).

1.3.5 Challenging Behaviour and its Association with Sleep Problems in Children with a Learning Disability.

Behavioural problems are common in children with a learning disability (Quine, 1986; Kiernan & Kiernan, 1994; Einfeld & Tonge 1996). Information on factors affecting the risk of behavioural problems in children with a learning disability is currently quite limited (Chadwick *et al.*, 2000) however, an improved understanding of the factors associated with the increased risk of these difficulties is potentially important in the development and evolution of appropriate intervention strategies (Murphy & Oliver, 1987; Oliver, 1995).

Studies with children have suggested that sleep problems are often associated with disturbed daytime behaviour. Certain forms of sleep problems may themselves be thought of as a behaviour difficulty, but whatever the nature of their cause, whether organic or psychological, it is probable that sleep problems compound any daytime difficulties and play a role in the maintenance or even the development of daytime behaviour problems (Wiggs & Stores, 1996).

The parents of children with sleep problems in Quine's (1991) study reported significantly more daytime management problems than the parents of children without sleep problems. Quine (1991) found that night-settling problems were found to be related to a large number of daytime behaviour problems namely management problems, hyperactivity, concentration, attention seeking, sexual problems with no social awareness, running away, inappropriate behaviour with strangers, interfering with other peoples' activities, being destructive, scattering objects, pica, swearing, embarrassing behaviours and being disruptive at school.

Quine (1991) further examined the association between night waking problems, and daytime behaviour problems. Again a large number of behaviours could be associated. These were encopresis, temper tantrums, moods, hyperactivity, concentration difficulties, problems with peers, attention-seeking, sucking objects, making noises, running away, stripping inappropriately, inappropriate behaviour with strangers, scattering objects, embarrassing behaviour, sexual problems with no social awareness, problems with social interaction, repetitive activities and delayed echolalia. Clements *et al.* (1986) additionally reported a strong association between night waking and self-injurious behaviour. Both short sleep duration and night waking appeared to be associated with tantrums and destructiveness in the day (Quine, 1991). The difficulty with the above findings is that all are from correlational studies. Consequently, as correlation does not imply causation, long lists of behaviours associated with disrupted sleep, such as that given by Quine, (1991) may in fact be caused by other factors.

Stores (1993b) conducted a questionnaire study of sleep disorders in children with Down syndrome which provided further evidence of associations between severe sleep problems and disturbed daytime behaviours, such as irritability, hyperactivity and stereotypies. Wiggs and Stores (1996) in their questionnaire survey of 209 children with a learning disability between the ages of five and sixteen years, reported that children with severe sleep problems showed significantly more irritability, lethargy, hyperactivity and stereotypic behaviour. Irritability, lethargy and hyperactivity have previously been associated with sleep loss (Guilleminault & Winkle, 1981; Horne, 1988). Wiggs and Stores (1996) additionally found that the children with learning disabilities who had sleep problems were more likely to have multiple daytime challenging behaviours than the group who did not experience sleep problems. The behaviours assessed were self-injury, aggression, screaming, temper tantrums, non-compliance and impulsivity. Again, this study was correlational.

Children's sleep problems are thought to affect their daytime behaviour in a number of ways. First, reduced or impaired sleep has been found to impair daytime functioning. This is because loss of slow wave sleep (stages 3 and 4 of non-rapid eye movement, NREM) has been seen to have adverse effects on behaviour and mood (Horne, 1988). Further, rapid eye movement sleep (REM), which has often been found to be impoverished in children with a learning disability (Stores, 1992), is thought to be associated with the learning process. Lack of sleep has been found to be a factor in behaviours that specifically interfere with learning such as non-compliance (Pritchard & Appleton, 1988), inattention to task (Stores, 1999),

depression (Bonnet, 2000) and previously mentioned behaviours such as aggression (Guilleminault, Winkle, Korobkin & Simmons, 1982).

Following on from this, any further reductions in sleep quality may hinder a child's ability to learn appropriate behaviour (Wiggs & Stores, 1996). Chronic sleep debt can decrease tolerance of difficult situations and lessen learning ability for both academic and social tasks (Horne, 1988). Individuals with a learning disability are clearly already compromised in these areas by virtue of their handicapping condition, and therefore, any additional factors must be assessed and treated in order to minimise the effect on the individual's ability to function to his or her full ability (Brylewski & Wiggs, 1999). A further factor is that the consequence of disrupted sleep is sleepiness the following day in both the parent and the child. Sleep deprived children have been found to have a tendency to manifest this in over activity rather than under activity as is found in adults (Guilleminault & Winkle, 1981). This is not conducive to the parent effectively managing the child's behaviour due to their own tiredness and the child having difficulty attending to learning new behaviours.

1.3.6 Challenging Behaviour and its Association with Sleep Problems in Children with Autism

In spite of the research relating sleep deprivation to people with a learning disability and inappropriate daytime behaviour, the influence of sleep problems for children with autism has been somewhat neglected in the literature. The limited research available suggests a few very general relationships between sleeping problems for children with autism and their daytime behaviour. These include increased rates of

over activity (Hoshino *et al.*, 1984), disruptive behaviour (Patzold *et al.*, 1998), communication difficulties (Segawa, Katoh, Katoh & Nomura, 1992) and difficulties with breaking routines (Segawa *et al.*, 1992) which are all problems that could significantly interfere with daytime learning.

A recent study by Schreck, Mulick and Smith (2004) sought to identify whether sleep problems may be a possible predictor of intensified symptoms of autism. It was found that the sleep problem which best predicted the overall diagnostic characteristics of autism (as made using the GARS Autism Quotient), was the reported number of hours per night the child slept. The fewer the hours slept, the more severe the reported symptoms of autism. The fewer the hours the child reportedly slept per night was also found to partially predict the severity of stereotypic behaviours and the difficulties with socially relating to other people in the environment.

In addition to the quantity of time slept, the quality of sleep for children with autism also predicted the severity of daytime behaviours relating to autism (Shreck *et al.*, 2004). Children who awakened screaming were found to be more likely to experience higher rates of stereotypy and to have more communication abnormalities. Children who reacted to uncomfortable sleeping environments were also found to be more likely to have communication problems and to have more general abnormalities in development that are commonly related to autism (e.g. rocking, regression in skills, delays in speech development etc.).

1.3.7 Parental Stress in Relation to Children with a Learning Disability

Parenting a child with a learning disability and other disabilities creates special difficulty for the parents (Cummings, Bayley & Rie, 1966; Rousey, Best, & Blatcher, 1992). In the last two decades, there has been growing interest in studying the well-being of parents caring for their children with developmental disabilities (Kwai-Sang & Li-Tsang, 1999).

Parents of children with a disability have been found to experience high levels of stress, often referred to in the literature as child-related stress or caretaker burden (Baker, Blacher, Kopp & Kraemer, 1997; Hodapp, Fidler & Smith, 1998). Studies of parental adaptation provide some evidence that parents of children with disabilities, in general, are additionally more likely than other parents to suffer from anxiety and depression (Philip & Duckworth, 1982). The severity of the child's disability is a possible source of stress for parents, in that children with a severe learning disability need more care and may put additional demands on their parents. In addition, children with a severe disability may be perceived by their parents as helpless and as sources of pessimism (Dyson, 1997).

Although all periods of a child's life may generate family stress, when the child has a disability (Wikler, Wasow & Hatfield, 1981), some of the changes associated with the child's age, needs and societal expectations make the school years uniquely challenging (Meyer, 1986). Family stress during this period can result from a number of sources. This may include a realisation for the parents of a greater discrepancy between the child's physical size and developmental capacity, visibility

of the disability and the comparison of their own child with other children who do not have a learning disability, especially where the child is included in mainstream classrooms. Similarly, the difficulty in securing babysitters or respite care providers, lack of information about coping with preadolescence problems and about managing the daily life and behaviour of children or adolescents with a disability can all be sources of stress (Fewell, 1986; Gallagher, Beckman & Cross, 1983; Meyer, 1986; Turnbull & Blacher-Dixon, 1980; Wikler, Wasow & Hatfield, 1981).

More recent research supports the above findings. Dyson (1997) found that parents of children with a disability experienced a disproportionately greater level of stress relating to their children than did those of children without disabilities. Stress was associated with aspects of family functioning. Those parents who evaluated their families as emphasising individual members' personal growth, as having organised routines, perception of social support from other members and a general positive family relationship, experienced lower stress. The relationship between parental stress, family functioning and social support found in the families of children with disabilities was not apparent for families of children without disabilities (Dyson, 1997).

It is a common perception that mothers experience greater stress than fathers when the family has a child with disabilities or chronic illness (Bristol, Gallagher & Schopler, 1988; Timko, Stovel & Moos, 1992). This assumption is understandable because more mothers traditionally have stayed at home, thus assuming a greater responsibility for overall child care (Lamb, 1986) and, in the past, mothers also

typically took on more child care than fathers when a child had special needs (Konstantareas & Homatidis, 1992). This, however, is obviously changing as more mothers are employed outside the home (Dyson, 1997).

Few investigators have examined the family experiences of fathers and mothers of school-age children with learning and physical disabilities. The results of those studies that have been published are conflicting. Cummings (1976) found that fathers experienced more stress and had fewer constructive outlets for their stress than did mothers. Others reported that fathers and mothers experience equal amounts of stress and similar levels of family functioning (Hagborg, 1989; Spaulding & Morgan, 1986; Dyson, 1997). Researchers have, however, also found lower levels of parental stress (Kazak & Marvin, 1984; Tavormina, Boll, Dunn, Luscomb & Taylor, 1981) and greater life satisfaction (Milgram & Atzil, 1988) in fathers than in mothers.

The presence of a child with a disability has been associated, not only with personal stress, but also with a lowering of parents' reported marital satisfaction and adjustment (Bristol, Gallagher & Schopler, 1988; Rousey, Best & Blatcher, 1992; Willoughby & Glidden, 1995). The increased demands of child care, the additional worries, and the physical and emotional fatigue all seem to have the potential for lowering dyadic adjustment and satisfaction (Bristol *et al.*, 1988). Trute (1990) clarifies the implications of the significant role of the parental subsystem on the family as a whole, stating that marital satisfaction is a strong predictor of positive family coping with stressors associated with family care of a child with a disability.

Several studies suggest that the presence of a productive marital subsystem positively impacts on the parents individually, their marriage, their family, and their ability to cope with the myriad details of the burden of caring for their child with a disability (Gavidia-Payne & Stoneman, 1997; Krauss, 1993). Baker, Landen and Kashima (1991) found, for example, that parents with low marital adjustment participating in a parent training programme were less likely to follow through on agreed-upon strategies. This has clear implications for carrying out clinical work with families.

The adaptation to having a child with a disability is now seen as an ongoing process throughout the child's life, rather than an event accomplished in the first months after diagnosis. Wikler, Wasow and Hatfield (1981) suggest that increased stress occurs at certain transition points, when there is a particular discrepancy between normative expectations and actual events. Such times are said to include diagnosis, the child starting school, adolescence and school leaving. Sloper and Turner (1993) conducted a study into risk and resistance factors in the adaption of parents of children with a severe disability. The study focused on families of children with severe motor disability at two key transition stages in the life cycle. These were the period of diagnosis of disability and the time when the child started school. Ninety-eight mothers completed self report questionnaires as did 72 fathers. Results indicated high levels of psychological distress, particularly for mothers. Personality factors, coping strategies, life events and socio-economic disadvantage were related to outcome for both parents. For mothers, greater physical disability and communication problems in the child were risk factors for poor coping and child gender and feeding problems showed significant associations with outcome.

There are also suggestions that the way parents are informed of the diagnosis is a vital factor in subsequent coping (Voysey, 1975), and there is considerable evidence of parental dissatisfaction with disclosure of diagnosis (Lynch & Staloch, 1988). Initially, when parents are informed that their child has a learning disability, a grief process is set in motion which includes the sub processes of shock, denial, emotional turmoil involving disappointment, anger and guilt, and acceptance (Carr, 1999). Several factors have been reported by parents to be particularly important when receiving such a diagnosis. These are the approachability of the clinician, the degree to which the clinician understands the parent's concerns', the sympathy of the clinician and the directness and clarity of communication (Quine & Rutter, 1994).

Further, a number of studies note parental dissatisfaction with help received in managing children with disabilities (O'Hagan, Sandys & Swanson, 1984) and stress associated with worry about where to obtain help and information (Baxter, 1987). The way in which parents seek or obtain help from formal or informal sources may be an important resource for adaptation, particularly at time of crisis, such as the diagnosis of disability in the child as previously mentioned. No research, however, has investigated the effect on parental stress when help or support is being received.

1.3.8 The Impact on Parental Stress of Caring for a Child with a Learning Disability and Challenging Behaviour.

One of the most significant stressors for family caregivers and support staff has been found to be related to the extent of behaviour problems exhibited by both children and adults with a learning disability (Hatton, Brown, Caine & Emerson 1995; Jenkins, Rose & Lovell, 1997; Quine & Pahl, 1989).

Child problem behaviours have been found to relate significantly to child-related parental stress in recent studies of specific genetic disorders, such as Smith-Magenis syndrome (Hodapp *et al.*, 1998) or Down syndrome (Stores, Stores, Fellows & Buckley, 1998), and also in studies of samples with mixed diagnoses (Stores *et al.*, 1998; Hauser-Cram, Warfield, Shronkoff & Kraus, 2001). In their study of three year old children, Baker, Blacher, Crnic & Edelbrock (2002) found that, when the influence of behaviour problems on parenting stress was accounted for, mental development explained no additional variance (Baker *et al.*, 2002).

Direction of effect in relation to parental stress and challenging behaviour is a question that has been unanswered in the literature. This is due to the fact that the majority of studies are correlational. Specific problem behaviours are viewed as part of the phenotype in some genetic disorders (for example, eating problems in Prader-Willi syndrome and self-injury in Lesch-Nyan syndrome) (Dykens *et al.*, 2000), and consequently are not likely to be caused by family factors.

Parental stress is one domain of risk that may be relevant to the emergence, or exacerbation, of behaviour problems (Crnic & Greenberg, 1987; Margalit, Shulman & Stuchiner, 1989). A highly stressed parent may engage in parenting behaviour which is less growth-promoting and may not be conducive to the resolution of the behaviour (Baker, McIntyre, Blacher, Crnic, Edelbrock & Low, 2003). There are, however, very few studies which have looked at the association between parenting stress and actual parenting behaviour (Deater-Deckard, 1998; Hastings, 2002). Studies have tended to focus on groups of children who do not have a learning disability such as parents of children with conduct problems (Deater-Deckard & Scarr, 1996) and high-risk situations such as when parents are suffering from depression (Downey & Coyne, 1990). The findings of these studies, therefore, have to be extrapolated to apply to the learning disability population.

More evidence exists, however, about the relationship between parent behaviour and the behaviour problems of children with a learning disability. Floyd and Phillippe (1993) conducted observations of family interactions and also asked both parents and teachers to complete a behaviour problems rating scale about the children. Associations were found between the children's behaviour problems, parents' behaviour management (that is the efforts they employed to direct and control the child's behaviour) and their use of coercive parenting behaviours. These associations were found to be independent of parenting attitudes, social support and depression (Floyd & Phillippe, 1993).

Challenging behaviour in children is often maintained by the way in which parents respond to behaviour (Carr, 1999). In particular, maladaptive patterns of parent-child interactions become established. The four main ones that have been identified are; inappropriate reinforcement of behaviour, coercive interaction, inconsistent discipline, and confused communication. These are described below.

The predominant approach to problem behaviour has been to view it as a product of operant conditioning. Operant conditioning theory, as proposed by Skinner (1953), states that behaviour is learned and maintained by positive and negative reinforcement. Parents often inadvertently reinforce problem behaviour simply by attending to it, and they conversely fail to reinforce more appropriate behaviour. The child, therefore, learns implicitly that displaying problem behaviour is an effective way of gaining a response from the parents.

Coercive interaction patterns are thought to be central to the maintenance of challenging behaviour in children (Patterson, 1982). Children with challenging behaviour become involved in escalating patterns of negative interaction with their parents. With such patterns, the child responds to parental criticism with increasingly aggressive or destructive behaviour. Eventually, parents withdraw from these exchanges to relieve both the stress of the situation for themselves and also their child (Carr, 1999). This experience of relief reinforces the behaviour of both the child and the parent. For the child, a high level of aggressive destructive behaviour is reinforced. For the parent, withdrawal from the child in the face of escalating

behaviour difficulties is reinforced. This process has been described as the 'negative reinforcement trap' by Wahler (1969).

A further way that parents may maintain challenging behaviour is via inconsistent parenting. Where the rules governing acceptable and unacceptable behaviour and the consequences associated with adherence to rules or rule violations are either unclear or clear but inconsistently enforced, problem maintaining parent-child interaction patterns may emerge (Kazdin, 1995). Children may refuse to comply with parental requests, because it is unclear to them what the consequences for compliance or defiance will be (Carr, 1999). In such situations, the child finds it difficult to internalise the rules for acceptable behaviour and so may continue to show problem behaviour (Webster-Stratton, 1985).

Challenging behaviour can additionally be maintained by confused communication patterns (Jacob, 1987; Dadds, 1995). These are characterised by poor parental listening and by giving unclear and indirect messages to the child. Forehand and McMahon (1981) found that parents of children without challenging behaviour tend to use more alpha commands (i.e. clear, specific and direct commands that are given one at a time and are followed by a five second delay for compliance). Parents of children who display challenging behaviour tend to use more beta commands (i.e. vaguely worded chains of instructions, often delivered as questions and frequently followed by a rationalisation). Unclear parent-child communication can lead to the child having no clear boundaries within which to behave, which in turn maintains and exacerbates challenging behaviour.

Together with the above parenting factors, children who have a learning disability have additional deficits in their comprehension and communication skills which may further complicate the process of establishing adaptive parenting strategies (Quine, 1991). As communication development is often delayed, children are typically not able to learn problem solving skills and negotiation strategies and therefore in response to these deficits, they implicitly learn to use their challenging behaviour functionally (Carr, 1999). For example, a common behavioural pattern that may maintain self-injurious behaviour has been described by Oliver (1995). Oliver asserts that it may equally be applied to aggressive behaviour. This is outlined below.

A period of social isolation leads the child to a state of heightened need for social contact, and challenging behaviour occurs. In response to this, the carer provides social contact until the child's need for contact is satiated. When the child's need for contact ceases, it is more likely that the child will engage in challenging behaviour again, since giving attention leads the adult ultimately to experience relief when the challenging behaviour ceases. This makes the behaviour less stressful for the parent in the short term. This more functional approach to understanding difficult behaviour has increasingly overtaken the operant conditioning explanation (Lovett, 1996).

1.3.9 The Impact on Parental Stress of Caring for a Child with a Learning Disability and Sleep Problems.

As outlined previously, studies indicate that children with a learning disability are at high risk from sleep disorders which are often persistent. The findings also suggest that sleep problems are associated with disturbed behaviour in the daytime and additionally, with family stress. This was detailed in the reports by Quine and Pahl (1989) and Clements *et al.* (1986). Quine and Pahl found that parents of children with sleep problems were significantly more likely to report that their child was difficult to manage, could not be left unsupervised and was difficult to keep occupied and safe.

The effect of children's sleep problems on parental stress is not well documented in the literature concerning people who have a learning disability. Quine (1991; 1992) is arguably the author who has most thoroughly investigated the effects of disrupted sleep on parents. In her 1991 study, 32% of the parents reported that they rarely got enough sleep themselves. In particular, mothers of children with sleep problems showed significantly higher scores on maternal stress and irritability, extra demands on time and energy and reduced social life compared with mothers of children without sleep problems. Furthermore, it was found that severe sleep problems are related to increased levels of maternal stress, decreased family functioning, increased levels of maternal irritability and use of punishment, and negative feelings towards the child (Quine, 1992).

The difficulty with the above studies, however, is that the measures used to ascertain both parental stress and sleep problems are somewhat unsatisfactory. As previously mentioned, in order to ascertain presence and levels of sleep problems, two items from the Behaviour Screening Questionnaire (BSQ, Richman & Graham, 1971) were used. This is not a scale that is designed specifically to look at sleep problems and, therefore, does not yield useful, detailed information on this area. Quine (1991) used this measure of sleep problems on which to base the study. Additionally, the BSQ was originally designed for use on three year old children however was used in the Quine (1991) study with participants aged 0 to 18. Further, the measure used to assess parental stress was The Malaise Inventory. This is a binary-choice questionnaire and, therefore, again does not yield a great deal of detailed information about the nature of the mother's stress. In relation to enquiring about children's sleep, it is now established that settling, night waking and early waking are not the only forms of sleep problems experienced by children and, therefore, for completeness, research must now concentrate on the occurrence of other features of sleep. It would be useful to further Quine's (1991) study in this way.

1.3.10 Summary of Section Two

Research has shown that sleep problems are common in children with a learning disability and/or autism. The majority of studies, however, have tended to solely concentrate on settling, night-waking and early waking difficulties. Further research is needed that outlines more detailed features of sleep. It has been suggested that the impact on the child and his or her parent, or parents, is perhaps far reaching.

Disturbed sleep has been associated with daytime challenging behaviour and in some studies, it has been suggested that it has a further, detrimental effect on parental stress. The evidence for this, however, is not well documented. There are various methodological difficulties with the existing studies in this area. These will be outlined in section three. Further, no research exists on how the inter-relationships between sleep, daytime challenging behaviour and the impact on the main caregivers experience of stress exist in a clinical population.

1.4 Section Three: Thesis Rationale

It would seem that there is a gap in the current literature regarding the prevalence of an inter-relationship between sleep problems, daytime challenging behaviour and maternal stress in a *clinical population*. There is a necessity for such a study as the knowledge gained could have an impact on current clinical practice by leading to improved psychological services. Given the finding that mothers and fathers may experience stress differently (Dyson, 1997), this thesis will focus on maternal stress. Mothers are most often the dominant caregivers (Konstantareas & Homatidis, 1992), therefore, spending the most time with the child. Previous studies have used the more general term 'parental stress', however, in reality have focused more on the stress of the female caregiver (Quine, 1991; 1992).

The present study will differ from previous research in that it will use well researched and established measures of sleep and maternal stress and focus on investigating outcomes for a clinical population. This will ensure that any

information gained will have immediate relevance for clinical practice whilst furthering knowledge about prevalence of sleep problems in children with a learning disability and/or autism in general. Section three will outline the importance of research in this area, flaws that exist in some of the current research, together with research aims and hypotheses of this thesis.

1.4.1 The Importance of Research into Sleep Problems in Children with a Learning Disability

Stores and Wiggs (2001) note that the issue of sleep disturbance creates a ‘curious paradox’ (p. 3). They highlight that there is ample evidence that, at all ages, sleep disturbance is known to be very common in the general population and, if persistent, can cause much personal, educational, occupational and other social disadvantage and sometimes even adverse physical effects with a huge overall cost to the national economy (National Commission on Sleep Disorders Research, 1994).

Stores and Wiggs, (2001) suggest that the paradox exists because the subject of sleep and its disorders usually features very little in medical and other professional healthcare teaching and training despite the documented impact that it can have on individuals and family members (Stores & Crawford, 1998). Stores and Crawford (1998) found that British medical students receive an average of only five minutes of formal teaching on the topic out of their typical five year course and they found no further evidence that this shortcoming was addressed at postgraduate level. It was highlighted that this was the case even in specialities where sleep problems can be

expected to be commonly encountered (e.g. paediatric medicine). Further studies into the training of nurses and clinical psychologists have highlighted that they too receive little or no training in this area (Wiggs & Stores R, 1996).

1.4.2 Limitations of Previous Studies

In considering the general trends from studies on sleep patterns, several limitations and methodological issues should be highlighted as a number of problems arise in interpreting and comparing findings from these past studies. First, factors such as age, gender distribution and method of recruitment of the sample are all relevant to the study of sleep problems, but these aspects have either not been reported or have varied between studies. For example, De Meyer (1979) stated that the age range of those included in his study were those in 'early childhood'. Richdale and Prior (1995) included young persons up to the age of 19 years whilst Herring, Epstein, Elroy, Iancu and Zelnik (1999) included children up to the age of 12 years.

Further, different studies often use different criteria or cut-off points to define a sleep disorder. This makes comparison across studies difficult. For example, in defining early morning waking, Wiggs and Stores (1996) used a 5am cut-off, whereas Brylewski and Wiggs (1998) used 6am. Piazza *et al.* (1996), in contrast, define early waking as a period in which the individual is awake for at least one hour and during which the individual does not re-initiate sleep before scheduled wake-up time. The same problem can be found in some studies in relation to their definition of problem

behaviour. Some studies have used arbitrary cut-offs to define problem behaviour rather than viewing disturbed behaviour as a continuum (Cuskelly & Dadds, 1992).

Further, interpretation of the literature can be difficult because of the low response rate (percentage of returned questionnaires) in most studies. While, this obviously limits the generality of the conclusions, it is a perpetual problem in carrying out research (Oppenheim, 1992).

Despite these methodological limitations, the emerging database clearly indicates that sleep disorder is a major problem for many individuals with a learning disability and/ or autism. Good evidence is also emerging on the more specific types of sleep disorders that are common in this population, however, this has not fully been researched with studies tending to focus solely on settling, night-waking and early waking difficulties.

All previous research has separately investigated sleep problems, daytime challenging behaviour and maternal stress in isolation or, more typically, with a pairing of sleep problems and challenging behaviour. Few studies (other than Quine, 1991) have investigated all three difficulties in the same sample. For methodological reasons detailed above, it is difficult to generalise between studies because of the variations in the samples used. It would, therefore, be useful to have further research to investigate the three aforementioned problems in the same sample whilst using a control group.

As was outlined previously, no research can be found on the prevalence of sleep problems, daytime challenging behaviour and the relationship with maternal stress specifically in a clinical population. It may, therefore, be that if high prevalence rates of sleep disorder and challenging behaviour are identified in a clinical population, a question should be raised about whether sleep problems or challenging behaviour should be treated first.

It would seem therefore that a study into sleep disorders, challenging behaviour and the impact on parental stress in a clinical population would be a useful and relevant study.

1.5 Research Aims and Hypotheses

1.5.1 Aims

The main aim of this study was to conduct a preliminary account of the sleep and challenging behaviour of children with a moderate to severe learning disability and/or autism in a clinical population. A secondary aim is to investigate the impact that these problems have on maternal stress and, the final aim is to look at the inter-relationships between all three variables.

1.5.2 Hypotheses

- 1. The prevalence of sleep problems reported by mothers in all children surveyed with a learning disability and/or autism will be between 44% and 86%** in accordance with previous literature (Bartlett, 1985; Quine, 1991; Wiggs & Stores, 1996). This has been shown to be higher than is found in typically developing children.
- 2. A correlation between sleep problems, challenging behaviour and maternal stress will exist for all children surveyed with a learning disability and/or autism.** This is in line with research cited previously.
- 3. There will be a higher correlation between sleep problems, challenging behaviour and maternal stress in the clinical group in comparison with the control group.** This is hypothesised because if children are referred to a clinical service for reasons that their behaviour has reached 'clinical significance' then according to the research in this area, (Wiggs & Stores, 1996; Quine, 1991) which asserts that there is a high correlation between sleeping difficulties and behaviour, sleeping difficulties should be more highly correlated with their behaviour, than for children whose behaviour has not warranted referral.

4. **The incidence of sleep problems will be higher in the clinical group in comparison to the control group.** Following on from hypothesis three, sleep problems have been found in the literature to be correlated with challenging behaviour. As the behaviour of the children referred to the clinical service has been deemed by professionals to have reached 'clinical significance', sleep problems should be more prevalent in the clinical group. This is in line with previous research (Wiggs & Stores, 1996; Quine, 1991).

5. **The incidence of challenging behaviour will be higher in the clinical group in comparison to the control group.** This is in agreement with previous research by Quine (1991) that has demonstrated that children with sleep problems exhibit more frequent and challenging behaviour. As the majority of referrals to the Learning Disability and Autism Service (clinical group) are for complex behavioural problems, the incidence of challenging behaviour should be higher in the clinical group whose behaviour is said to have reached 'clinical significance'.

6. **The incidence of maternal stress will be higher in the clinical group in comparison to the control group.** This will be in accordance with research conducted by Quine (1991) who found that in particular, maternal stress was more frequently reported in those who had children with increased sleep problems.

CHAPTER TWO: METHODOLOGY

This section will outline the methodology used in the thesis. The study design will be reported followed by details of a pilot study that was carried out. Further, the procedures, participants, measures and statistical analyses used in the main study will be detailed.

2.1 Design

A parental report questionnaire method was used to analyse prevalence rates and inter-relationships between sleep problems, challenging behaviour and maternal stress in children with a moderate to severe learning disability and/or autism, attending a specialist learning disability and autism service. The study used a between subjects design to compare this group with children with a moderate to severe learning disability and/or autism attending three specialist provision schools in Lothian.

A pilot study was carried out prior to the main study. The central aim of this was to investigate how long it would take the participants to complete the questionnaire, whether any of the questions were difficult to understand, whether the instructions were clear and whether the questionnaire would yield the appropriate information to answer the research questions.

2.2 Pilot Study

2.2.1 Pilot Study – Procedure

Pilot study participants were recruited through friends and work colleagues of the researcher. Each participant received a questionnaire pack including a letter explaining the pilot study (see Appendix 1), a demographics questionnaire (see Appendix 2), three further questionnaires (The Child's Sleep Habits Questionnaire, The Aberrant Behaviour Checklist –Community and The Parental Stress Index – Short Form) and a pre-paid reply envelope (see Appendices 3, 4 and 5 respectively). Twenty-five questionnaires were distributed, seventeen (68%) of which were returned.

2.2.2 Pilot Study - Participants

The participants in the pilot study were 18 mothers of children whose mean age was 7 years (range 0 – 13 years, standard deviation (S.D.) 4.38). None of the mothers had a child with a learning disability or a child on the autistic spectrum and no child was currently receiving any medication or treatment for behavioural or sleep problems. Participants reported that their child slept for a mean of 10.1 hours (range 8-12 hours, S.D. 1.26).

2.2.3 Pilot Study – Measures

Participants were asked to fill out a total of four questionnaires. This included a short demographic questionnaire, The Child's Sleep Habits Questionnaire, The Aberrant Behaviour Checklist –Community and The Parental Stress Index – Short Form. Finally, the participants were asked to fill out a pilot study questionnaire (see Appendix 6) which asked about the length of time it took to fill in the previous four questionnaires, whether the instructions and questions were easy to understand and they were provided with a space to add further comments. The three main measures will be outlined below.

2.2.4 Child's Sleep Habits Questionnaire (CSHQ) (Owens, Spirito & McGuinn, 2000). This is a parent-report sleep screening survey specifically designed for school-aged children. The CSHQ includes thirty-three items relating to a number of key sleep domains that encompass the major presenting clinical sleep complaints in this age-group. The design of the CSHQ is based on common clinical symptom presentations of the most prevalent paediatric International Classification of Sleep Disorders diagnoses (ICSD-R, American Sleep Disorder Association, 1997). There are eight subscales: bedtime resistance (six items); sleep onset delay (one item), sleep duration (three items); sleep anxiety (four items); night wakings (three items); parasomnias (seven items); sleep disordered breathing (three items) and daytime sleepiness (eight items).

The parent is asked to recall sleep behaviours occurring over a 'typical' recent week. Items are rated on a three-point scale: 'usually' if the sleep behaviour occurred five

to seven times per week; 'sometimes' for two to four times per week; and 'rarely' for zero to once per week. Some items are reversed in order to make a higher score consistently indicative of more disturbed sleep.

The CSHQ is intended by the authors (Owens *et al.*, 2000) to be used primarily as a screening tool. The sleep domains reflected in seven of the CSHQ subscales have been found to parallel symptom constellations associated with ICSD-R (American Sleep Disorder Association, 1997) classifications. These are Dyssomnias – Intrinsic and Extrinsic Sleep Disorders, including Sleep Onset Association Disorder, Limit Setting Sleep Disorders, Adjustment Sleep Disorder and Inadequate Sleep Hygiene; Circadian Rhythm Sleep Disorders, including Delayed Sleep-Phase Syndrome, (CSHQ Subscales, bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, and night wakings); Parasomnias and Obstructive Sleep Apnoea (CSHQ Subscale, sleep disordered breathing). Owens *et al.* (2000) note that the daytime sleepiness subscale reflects the daytime consequences common to many of the above disorders.

The CSHQ has been found (Owens *et al.*, 2000) to have yielded a sensitivity of .80 and specificity of .72. Test-retest reliability has been found to be acceptable (range .62 to .79) (Owens *et al.*, 2000). As the CSHQ is a relatively new publication, few studies in this area have utilised the scale. Honomichl, Goodlin-Jones, Burnham, Gaylor & Anders (2002) however utilised the CSHQ in their study of sleep patterns in children with pervasive developmental disorders. Further, Wiggs (Wiggs, L., November, 2003, personal correspondence) recommended the use of the scale in the

present study because it yields more detailed information about specific sleep problems and a total cut-off score can be used. Owens et al. (2000) suggest that a cut-off score of 41 may be used with the CSHQ to signify that an individual has a sleep problem.

2.2.5 Aberrant Behaviour Checklist - Community (ABC-C) (Aman, Singh, Stewart & Field, 1985a) was initially designed to measure common behaviour problems in children and adults with a learning disability residing in institutional care. It consists of 58 items that are rated on a Likert 4-point scale of 0 (not a problem at all), 1 (a problem to a slight degree), 2 (moderately serious), 3 (severe). The psychometric properties of the ABC are well established, with good reliability and validity consistently being reported (Aman, Singh, Stewart & Singh, 1985b).

This measure has been shown to have satisfactory test-retest reliability and inter-rater reliability (Aman *et al.*, 1985b). The scale has been validated against other measures including direct observation of behaviour (Aman *et al.*, 1985b). These characteristics and the factor structure have been confirmed in further studies in the USA (Aman & Singh, 1986) and the UK (Newton & Sturmey, 1988). The ABC has also been used with populations of children and its factor structure has held up (Freund & Reiss, 1991; Rojahn & Helsel, 1991). Factor analysis yields five factors: irritability, aggression and crying (fifteen items), lethargy, social withdrawal (sixteen items), stereotypic behaviour (seven items), hyperactivity, non-compliance (sixteen items), and inappropriate speech (four items).

The present study uses the later version of the ABC which has been more recently produced (Aman & Singh, 1994) and is named the Aberrant Behaviour Checklist – Community. As the name suggests, this has been devised for use in the community. The difference between the ABC and the ABC-C is a revision of the wording of both the checklist's instructions and of individual items. For example, the original version referred to the person being rated as 'the resident' and was changed to 'the client'. In item one, the wording was changed from 'excessively active on the ward' to 'excessively active at home, school, work or elsewhere'.

Marshburn and Aman (1992) conducted a large scale factor analytic study of the ABC-C in special education schools in the USA. Teachers rated a total of 666 randomly-selected children on the instrument. Factor analysis resulted in a four-factor solution that closely paralleled the first four factors of the original ABC, with congruence coefficients ranging from .87 to .96. Coefficient alpha ranged from .76 to .96 (median = .90) across subscales. Marshburn and Aman (1992) concluded that the results were sufficiently close for the original scoring method to be used unaltered with community samples of school children.

Although no formal cut-off scores exist for the total and subscale scores of the ABC-C, Aman and Singh (1994) suggest that a score could be regarded as extreme or clinically significant when the person's subscale score exceeds the 85th percentile for his or her normative group. This study used the teacher ratings of children in special education placements that are given as normative data in the ABC-C manual (Aman & Singh, 1994).

In the literature on sleep problems and their relation to challenging behaviour, the ABC-C is commonly used as a measure of behaviour (e.g. Didden, Korzilius, van Aperlo, van Overloop & de Vries, 2002; Chadwick *et al.*, 2000; Wiggs & Stores, 1996).

2.2.6 The Parent Stress Index - Short Form (PSI-SF) (Abidin, 1990) the PSI- SF is a direct derivative of the Parenting Stress Index full length test and is designed to be completed in under ten minutes (Abidin, 1990). The tool consists of thirty six items and parents are asked to respond using a five point scale of SA (strongly agree), A (agree), NS (not sure), D (disagree), or SD (strongly disagree).

The PSI-SF yields subscale scores related to a parental distress subscale (PD), parent-child dysfunctional interaction subscale (P-CDI), a difficult child (DF) subscale and gives a total stress score. The PSI- SF additionally includes a Defensive Responding scale which assesses the extent to which the respondent approaches the questionnaire with a strong bias to present the most favourable impression of himself or herself and to minimise indications of problems or stress in the parent-child relationship.

The parental distress (PD) subscale determines the distress a parent is experiencing in his or her role as a parent as a function of personal factors that are directly related to parenting (Bendall, Stone & Field, 1989). The component stressors associated with the PS subscale are impaired sense of parenting competence, stresses associated with the restrictions placed on other life roles, conflict with the child's other parent,

lack of social support, and presence of depression, which is a known correlate of dysfunctional parenting (Abidin, 1990)

The parent-child dysfunctional interaction (P-CDI) subscale focuses on the parent's perception that his or her child does not meet the parent's expectations, and whether the interactions with his or her child are not reinforcing to him or her as a parent. Those scoring highly in this subscale are said by Abidin, (1990) to feel rejected by their child, and may feel disappointed and alienated by the child. Additionally, high scores may indicate that the parent-child bond is either threatened or has never adequately been established (Abidin, 1990).

The difficult child subscale (DC) focuses on some of the basic behavioural characteristics of children that make them either easy or difficult to manage. These characteristics are often rooted in the temperament of the child, but they may also include learned patterns of defiant, noncompliant and demanding behaviour (Webster-Stratton, 1988; Abidin, 1990).

The total stress score is designed to provide an indication of the overall level of parenting stress an individual is experiencing. The total score does not include stresses associated with other life role and life events, thus giving an indication purely of the stress level experienced within the role as a parent. The score reflects the stresses reported in the areas of personal parental distress, stresses derived from the parent's interaction with the child and stresses that result from the child's behavioural characteristics (Abidin, 1990). Parents who obtain a total stress score

above a raw score of 90 (90th percentile) are said to be experiencing clinically significant levels of stress.

Correlation analysis (Abidin, 1990), indicates that the total stress score of the full-length PSI and the total stress score of the PSI- SF have a correlation of .94.

The PSI- short form has been used in studies with parents who have a child with a disability. For example, Button, Pianta & Marvin (2001) used the tool in a study investigating maternal stress in families raising young children with cerebral palsy and Smith, Oliver & Innocenti (2001) used the assessment tool in their study of parenting stress in families of children with multiple disabilities. In terms of use with parents who have a child with a learning disability, a study by Ong, Chandran & Peng (1999) used the PSI-SF. As previously mentioned, studies which have included measures of parental stress in this area are few but have tended to use the Malaise Inventory (Rutter *et al.*, 1970). This is a twenty-four item binary choice questionnaire and therefore does not yield as detailed information as the PSI- SF.

2.2.7 Demographic Information

A short demographic questionnaire was devised principally to gain information about the child about whom the questionnaires were being completed. The instructions stated that if the participant had more than one child, then they should answer in relation to their eldest child provided they were under the age of sixteen years. The only question asked about the participant themselves was an enquiry about that person's relationship with the child (i.e. mother, father, grandparent, guardian). A

covering letter asked that the person who filled in the information for the study be the person who spends the most time in a caring role for the child.

In relation to the child, the participants were asked to indicate their age and gender together with details of any medication currently being prescribed (specifically asking about Melatonin as this is often prescribed to children with sleeping problems and is taken to aid sleep). In relation to diagnoses, it was asked if the child had an autistic spectrum disorder and/or a learning disability. Further, it was asked if the child was currently receiving any treatment for sleep disturbance or behavioural difficulties. Finally, participants were asked how many hours the child had slept the previous night.

2.2.8 Pilot Study Questionnaire

Pilot study participants were asked questions in relation to the questionnaire, including how long it took them to complete the questionnaire and whether they found any of the questions difficult to understand or offensive. Space was also provided for the participants to make any additional comments about the questionnaires.

2.2.9 Pilot Study – Results

The average length of time taken to complete the questionnaire was 17.6 minutes (range 5 – 35 minutes, SD = 8.31). No participant found the wording of any question offensive or difficult to understand. As a result of the pilot, no change was made to structure of the actual questionnaires. The only change made was relatively minor. Despite the covering letter explaining that the study was anonymous and that no personal details should be given, some participants did write the name and age of the child about whom they were responding. As the questionnaires being used in the study are published for clinical use, there are some questions that ask for demographic information. These questions were scored out before being sent out for the main study. The researcher was, further, satisfied that the questionnaires yielded the appropriate information to answer the research questions.

2.3 Main Study

2.4 Procedure

2.4.1 Recruitment of Parents of Children with a Moderate to Severe Learning Disability Currently Referred to the Learning Disability and Autism Service (Clinical Group)

The researcher received permission to carry out the research from the Lothian NHS Research Ethics Committee and Lothian NHS Trust's Research and Development Committee (see appendix 7). Ethical principles are concerned with protecting the

rights, dignity, and welfare of research participants. There were several ethical issues to be considered in relation to the current study. Firstly, was the issue of informed consent. The researcher made every effort to give full and detailed information about the study via an information letter which was included in the questionnaire pack. Further, contact details were given of both the researcher and her two supervisors in order that any potential participant could seek further information or clarification. One parent, with an interest in children's sleep problems, took this opportunity to contact the researcher. Parents were able to freely choose whether or not they wished to take part in the study and implied consent by completing their questionnaire and returning it. The issue of confidentiality for participants was also respected. The study invited only anonymous responses.

Finally, a major ethical consideration for any researcher is the avoidance of harm, psychological or otherwise, of any participant. The current research was questionnaire based and a pilot study was used in an attempt to identify any questions that a parent may find intrusive or offensive. None were identified.

The clinical group of parents were recruited via identification by the Patient Information Management System (the hospital's patient database) that their child was currently receiving treatment from the Learning Disability and Autism Service. This team is part of the Child and Adolescent Mental Health Service (CAMHS) and provides community based psychiatric and clinical psychology input to children up to the age of sixteen years. It typically accepts referrals for children with a moderate

to severe learning disability and/or autism with complex psychological and behavioural problems.

A questionnaire pack was sent to the parents. This included a letter explaining the study and inviting parents to participate (see Appendix 8), a demographics questionnaire, three further questionnaires (The Child's Sleep Habits Questionnaire, The Aberrant Behaviour Checklist – Community and The Parental Stress Index – Short Form) and a pre-paid reply envelope. All questionnaires were the same as those used in the pilot study, excluding the pilot study questionnaire. Participants' consent was implied by their return of the completed questionnaires. The covering letter outlined that the most appropriate person to participate in the study would be the person who spends the most time in a caring role for the child or young person.

The researcher was aware of the names and addresses of those families who were invited to participate as part of the clinical group. No other details, however, were known and at no time was the researcher required to look at case notes of potential participants other than for unrelated, routine, clinical work. The returned questionnaires were anonymous and the researcher was unaware of who had, or had not, filled out and returned their questionnaire.

After a period of six weeks, a further letter was sent out to all those asked to participate in the clinical group thanking those who participated and reminding those who had not filled in the questionnaires to complete and return them if they wished

to participate (see Appendix 10). Again, the researcher had no knowledge of who had, and had not, decided to participate in the research study.

2.4.2 Recruitment of Parents of Children with a Moderate to Severe Learning

Disability and/or Autism Attending Schools in the Lothian Area (Control Group)

The researcher received permission from the City of Edinburgh Council, Education Department to carry out the study in three schools for children with a learning disability and/ or autism. The three schools were selected because the children on their roll have a moderate to severe learning disability. One of the schools additionally has a high population of children who have autism. This meant that, as far as is possible in an anonymous study, both the clinical and control sample were matched.

A questionnaire pack was sent to the parents via the school. Class teachers put a pack into each child's school bag. In this way, the parents were contacted without the researcher having any access to the names or addresses of any parent/ caregiver or child. The pack included a letter explaining the study and inviting parents to participate (see Appendix 9), a demographics questionnaire, three further questionnaires (The Child's Sleep Habits Questionnaire, The Aberrant Behaviour Checklist –Community and The Parental Stress Index- Short Form) and a pre-paid reply envelope. Participants implied consent to take part in the study by the return of the questionnaire.

After a period of six weeks, a further letter was distributed to all parents in the same way as above. This thanked those who participated and reminded those who had not filled in the questionnaires to complete and return them if they wished to participate (see Appendix 10). Again, the researcher had no knowledge of who had, or had not, decided to participate in the research study.

It was possible that a small number of caregivers may have received the questionnaire pack and invitation to participate in the study twice. This could potentially have happened if a child had been referred to the Learning Disability and Autism Service and coincidentally attended one of the schools from which parents were recruited for the control group. This was unavoidable as the researcher had no personal details or names of any potential participant in the control group. To address this problem, the questionnaire packs were sent out to the clinical group a week in advance of the control group. Additionally, on the information sheet for the clinical group, it stated that this duplication may potentially occur and asked that they dispose of any further questionnaires they may receive.

2.4.3 Inclusion and Exclusion Criteria

For the clinical group, the inclusion criterion was that all questionnaires completed by the main caregiver of children with a moderate to severe learning disability and/or autism currently being seen by the Learning Disability and Autism Service within CAMHS, Edinburgh would initially be included in the study. The exclusion criteria for this group were any caregiver of a person who is over the age of 16 years; the

caregivers of children who have a *mild* learning disability and those persons who were not the main caregiver (that is, they are not the person who spends the most time caring for the child). This criterion was filled in retrospectively on analysis of the demographic questionnaire which asked about this information. On analysis, all questionnaires completed by persons other than the child's mother were additionally excluded in order that *maternal* stress could be investigated.

For the control group, the inclusion criterion was that all questionnaires completed by caregivers of children attending the selected schools for children with a moderate to severe learning disability would initially be included in the study. The exclusion criteria for this group were any caregiver of a child with a mild learning disability; any caregiver whose child had been referred to the Learning Disability and Autism Service within CAMHS; caregivers of children who are over the age of 16 years and those persons who were not the main caregiver (that is, they were not the person who spends the most time caring for the child). This criterion was filled in retrospectively by analysing the demographic questionnaire which asked about this information. On analysis, all questionnaires completed by persons other than the child's mother were additionally excluded in order that *maternal* stress could be investigated.

2.5 Participants

2.5.1 Response Rate

A large number of questionnaires were distributed relative to the number of participants required to reach statistical power for the study. This was to account for the low response rate expected from postal questionnaires (Oppenheim, 1992). A

total of 288 questionnaires (189 via three schools for children with a learning disability and 99 via parents of children currently being seen by the learning disability and autism service) were distributed.

A total of 76 (26.4%) questionnaires were returned overall. Of the 76 questionnaires returned, 41 were from parents of children attending the learning disability and autism service. There was, therefore, a response rate of 41.4% for the clinical group. Thirty-five questionnaires were returned from parents of children attending one of three schools for children with a learning disability in Lothian. The response rate for the control group was 18.5%. A total of 9 returned questionnaires could not be included in the study. Of these, 7 were excluded as a result of a failure by the participant to fill in all three questionnaires and 2 were excluded as they were filled in by persons other than the child's mother or female guardian. This left a total of 37 participants in the clinical group and 30 participants in the control group.

2.6 Measures

The main study utilised the same measures that were used in the pilot study. These were, The Child Sleep Habits Questionnaire, The Aberrant Behaviour Checklist – Community and The Parental Stress Index – Short Form. As with the pilot study, respondents were additionally asked to fill in a demographics questionnaire.

2.7 Statistical Analysis

All analyses were carried out using version ten of the Statistical Package for the Social Sciences (SPSS-10) using Mann Whitney tests, Pearson (r) correlations, partial correlations, multivariate analysis of variance and multiple regression.

Both parametric and non-parametric statistical analyses were used. Parametric tests make the assumption that the data is measured on an interval or ratio scale, the sample data are drawn from a normally distributed population and that there is homogeneity of variance. Non-parametric tests do not make such assumptions.

The study assumed a large effect size as previous studies (Wiggs & Stores, 1996; Bartlett *et al*, 1985) found large effect sizes occur as a result of sleep problems. In order to assume a large effect size with a power of 0.8, alpha level of 0.05, on any of the variables tested, an N of 28 was needed as the minimum number of participants in each group for correlations (clinical group and control group). This corresponds to Cohen's estimate based on what he refers to as a large effect size (Cohen, 1992).

CHAPTER THREE: RESULTS

Demographic information about the participants' children will be presented. Further, descriptive statistics will be given in relation to sleep problems, daytime challenging behaviour and maternal stress. The results will then be presented for each hypothesis in the order presented in the introduction to this thesis. All analyses were one-tailed unless otherwise stated.

3.1 Demographic Information

All participants were the mother of the child about whom they were responding, with the exception of one participant in the control group who was a female guardian.

Demographic information was collected about the participant's child. The average age of the children in the clinical group was 9.9 years (range 3-16 years, S.D. = 3.48) and 12.0 years in the control group (range 5-16 years, S.D. = 3.26). There was a significant difference ($t = 2.578$, $df = 65$, $p \leq 0.05$, two-tailed) between the ages of the children in each group. In the clinical group, 8 (21.6%) children were aged 0-6 years, 13 (35.1%) were aged 7-11 years and 16 (43.2%) were aged 12 – 16 years. In the control group, 4 (13.3%) of children were in the 0 – 6 years age bracket, 6 (20%) were aged 7 – 11 years and 20 (66.7%) were aged from 12 to 16 years.

In the clinical group, 29 (78.6%) of the children were male and 8 (21.6%) were female. In the control group, 21 (70 %) of the children were male and 9 (30 %) were female.

With regards to use of Melatonin for inducing sleep, 13 (35.1%) children in the clinical group had been prescribed the medication compared to 7 (23.3%) in control group. No children in either group were reported to be receiving any other type of intervention for sleep problems. In terms of diagnosis, 18 (48.6%) of children in the clinical group had an autistic spectrum disorder. This figure was 15 (50%) children in the control group. Of the clinical, group 2 (5.4%) of children did not have a learning disability and were on the autistic spectrum, whilst 4 (13.3%) of those children making up the control group had no learning disability but were on the autistic spectrum. Information was gathered about the causes of learning disability in the groups where known. The results of this are detailed in Table 1.

Table 1: Cause of Learning Disability by Group.

Cause of Learning Disability	Clinical Group n=37		Control Group n=30	
	Count	Percentage	Count	Percentage
Unknown Cause	17	45.9%	10	33.3%
Prolonged epileptic seizures	4	10.8%	0	0%
Premature	2	5.4%	0	0%
L.D. related to autism	4	10.8%	7	23.3%
Microcephaly	1	2.7%	0	0%
Cerebella ataxia	1	2.7%	0	0%
No learning Disability (ASD only)	2	5.4%	4	13.3%
Chromosome disorder	4	10.8%	1	3.3%
Head Injury	1	2.7%	0	0%
Acute Encephalopathy	0	0%	1	3.3%
West Syndrome	1	2.7%	0	0%
Cerebral Haemorrhage	0	0%	1	3.3%
Wolf Hirschhorn Syndrome	0	0%	1	3.3%
Fragile X Syndrome	0	0%	1	3.3%
Autonomic Seizures	0	0%	1	3.3%
Birth Asphyxia	0	0%	1	3.3%
Rett Syndrome	0	0%	1	3.3%
M.E.L.A.S. (stroke in womb)	0	0%	1	3.3%

The causes of learning disability in the clinical sample can be grouped into five broad categories; unknown (45.9%); autism (10.8%); related to epilepsy (10.8%); chromosome disorder (10.8%) and other known diagnosis (16.2%). The same groupings for the control group are; unknown (33.3%); autism (23.3%); related to epilepsy (3.3%); chromosome disorder (3.3%) and other known diagnosis (26.6%).

3.2 Descriptive Statistics

3.2.1 Sleep Disturbance

One child (2.7% of the sample) in the clinical group was reported to have no sleep problems at all and scored the minimum possible on the CSHQ. The number of children in the control sample who scored the minimum on the CSHQ was three (10%). The demographic questionnaire asked how many hours the child had slept the night prior to the day of filling in the questionnaires. The mean number of hours was 8.05 (S.D.= 1.96, range = 3 – 12 hours) in the clinical group and 8.14 hours (S.D. = 8.14, range = 2 – 11.5 hours) in the control group. There was not a significant difference between the number of hours the child had slept the previous night for each group ($U = 534.000$, $Z = -0.267$, $p = 0.789$).

The CSHQ enquires about the usual time that the child is put to bed, the usual time the child wakes and the average duration of night waking in minutes. In the clinical group, the mean bedtime was 8.52 pm (S.D. = 1.23, range = 7pm to 12am). In the control group, the mean bedtime was 9.10 pm (S.D. = 1.01, range = 7.30 pm to 11pm.). There was no significant difference between group bedtimes ($U = 453.000$, $Z = -1.308$, $p = 0.095$).

In the clinical group, the mean time that the child woke in the morning was 6.34 a.m. (S.D. = 1.04, range = 3 am – 8 am.). In the control group, the mean wake time was 6.43 a.m. (S.D. = 1.04, range = 5 am - 8 am.). There was no significant difference between the waking times of the two groups ($U = 497.500$, $Z = -0.731$, $p = 0.232$).

The mean number of minutes that the clinical sample were awake at night was 51.03 minutes (S.D. = 63.3, range= 0 minutes – 240 minutes. $N = 34$ (91.9% of group)). The control group were found to have a mean night waking time of 49. 48 minutes (S.D. = 72.1, range = 0 – 240 minutes. $N = 29$ (96.7% of the sample)). With regard to night waking, many parents added a note to the effect that this time varied considerably each night. Some parents felt they were unable to give an estimate of night waking in minutes. This is the reason for the reduced number in each group. There was no significant difference between the clinical and control group in the number of minutes they spent awake at night ($U = 408.000$, $N^1 = 34$, $N^2 = 29$, $Z = -1.187$, $p = 0.117$).

In accordance with previous literature (Wiggs & Stores, 1996), the sleep features that children were reported by their mothers to be showing are presented in the following tables. This information is presented in tabular format and gives the sleep features which make up each subscale of the CSHQ. Figures, together with percentages (in brackets), of children who were reported to show each particular sleep feature are presented for each group. The numbers of children who are experiencing the sleep feature five or more nights per week are given, followed by the overall number of

children who are showing the same sleep feature two to seven nights per week. The second figure gives a more inclusive illustration of the frequency that the children in each group are showing a sleep feature.

Table 2 outlines the sleep features which make up the Bedtime Resistance scale of the CSHQ. The frequency with which children were reported by their mothers to be showing these is expressed as a whole number and a percentage (in brackets).

Table 2: Bedtime Resistance Subscale items (CSHQ). Frequency of occurrence by group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	+ 5 nights per week	2-7 nights per week	+ 5 nights per week	2-7 nights per week
Item from Bedtime Resistance Scale	No. (%)	No. (%)	No. (%)	No. (%)
Does not go to bed at same time every night	5 (13.5%)	9 (24.3%)	3 (10.0%)	8 (26.6%)
Does not fall asleep in own bed	10 (27.0%)	11 (29.7%)	1 (3.3%)	4 (13.3%)
Falls asleep in others bed (e.g. parents bed)	4 (10.8%)	10 (27.0%)	1 (3.3%)	3 (10.0%)
Needs parent in room to sleep	6 (16.6%)	10 (27.0%)	3 (10.0%)	9 (30.0%)
Struggles at bedtime	7 (18.9%)	18 (48.6%)	1 (3.3%)	8 (26.6%)
Afraid of sleeping alone	4 (10.8%)	5 (13.5%)	1 (3.3%)	1 (3.3%)

The two features of the above scale which appear to be more distinctive in the clinical group are, 'does not fall asleep in own bed' and 'struggles at bedtime'. These two features were found to be significantly higher in the clinical group ($U = 449.500$, $Z = -1.831$, $p < 0.05$) and ($U = 414.000$, $Z = -2.053$, $p < 0.05$) respectively.

Table 3 presents information from the sleep onset delay subscale of the CSHQ.

Table 3: Sleep Onset Delay Subscale item (CSHQ). Frequency of Occurrence by Group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>
Item from Sleep Onset Delay Scale	No. (%)	No. (%)	No. (%)	No. (%)
Takes more than 20 minutes to fall asleep.	13 (35.1%)	27 (72.9%)	7 (23.3%)	19 (63.3%)

Taking in excess of twenty minutes to fall asleep was reported to be a common problem by parents with the majority of children from both groups displaying this sleep feature between two to seven nights per week.

Table 4 presents information about the occurrence of sleep features from the sleep duration subscale of the CSHQ.

Table 4: Sleep Duration Subscale items (CSHQ). Frequency of Occurrence by Group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>
Item from Sleep Duration Scale	No. (%)	No. (%)	No. (%)	No. (%)
Sleeps too little	11 (29.7%)	28 (75.6%)	3 (10%)	15 (50%)
Does not sleep the right amount	11 (29.7%)	25 (67.5%)	7 (23.3%)	12 (40%)
Does not sleep the same amount each day	4 (10.8%)	16 (43.2%)	7 (23.3%)	10 (33.3%)

Three quarters (75.6%) of the clinical group reported that their child slept too little between two and seven nights per week. This was a problem in half (50%) of the control group.

Table 5 presents information from the sleep anxiety subscale of the CSHQ.

Table 5: Sleep Anxiety Subscale Items (CSHQ). Frequency of Occurrence by Group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>
Item from Sleep Anxiety Scale	No. (%)	No. (%)	No. (%)	No. (%)
Needs parent in room to sleep	6 (16.2%)	10 (27.0%)	3 (10%)	9 (30%)
Afraid of sleeping in the dark	5 (13.5%)	6 (16.2%)	3 (10%)	5 (16.6%)
Afraid of sleeping alone	4 (10.8%)	5 (13.5%)	1 (3.3%)	1 (3.3%)
Trouble sleeping away	9 (24.3%)	17 (45.9%)	7 (23.3%)	14 (46.6%)

The biggest sleep anxiety was reported to be ‘Trouble sleeping away’. This question refers to sleeping away from home and was a problem ‘sometimes’ to ‘usually’ in just under half the clinical group (45.9%) and just under half (46.6%) the control group. It is acknowledged that the reply ‘two to seven nights per week’ does not fit as a response to this question. The parents were given a choice of replying ‘rarely’, ‘sometimes’ and ‘usually’. As previously stated (see methodology), these responses correspond to the number of nights a sleep feature occurs. In response to the ‘trouble sleeping away’ question, respondents used the verbal label. It was not possible to clearly state this response on the above table.

Table 6 gives information from the night wakings subscale of the CSHQ.

Table 6: Night Wakings Subscale Items (CSHQ). Frequency of Occurrence by Group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>
Item from Night Wakings scale	No. (%)	No. (%)	No. (%)	No. (%)
Moves to others bed in night	3 (8.1%)	12 (32.4%)	4 (13.3%)	6 (20%)
Awakens once during the night	11(29.7%)	29 (78.3%)	7 (23.3%)	15 (50%)
Awakens more than once per night	10 (27%)	20 (54.0%)	4 (13.3%)	9 (30%)

A feature of the clinical group appears to be the greater number of children who wake more than once per night in comparison to the control group. This difference was found to be significant ($U = 366.000, Z = - 2.308, p < 0.05$).

Table 7 gives information from the parasomnias subscale of the CSHQ.

Table 7: Parasomnias Subscale Items (CSHQ). Frequency of Occurrence by Group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>
Item from Parasomnias Scale	No. (%)	No. (%)	No. (%)	No. (%)
Wets the bed at night	7 (18.9%)	11 (29.7%)	4 (13.3%)	8 (26.6%)
Talks during sleep	5 (13.5%)	17 (45.9%)	1 (3.3%)	8 (26.6%)
Restless and moves a lot	15 (40.5%)	29 (78.3%)	6 (20%)	18 (60%)
Sleep walks	0 (0%)	1 (2.7%)	0 (0%)	1 (3.3%)
Grinds teeth during sleep	4 (10.8%)	12 (32.4%)	2 (6.6%)	6 (20%)
Awakes, screaming, sweating	2 (5.4%)	8 (21.6%)	0 (0%)	5 (16.6%)
Alarmed by scary dream	0 (0%)	10 (27.0%)	0 (0%)	4 (13.3%)

Over three quarters (78.3%) of the clinical sample were reported to be restless sleepers. This was additionally the most common sleep feature from the parasomnias subscale in the control group.

Table 8 presents information from the sleep disordered breathing scale of the CSHQ.

Table 8: Sleep disordered Breathing Subscale Items (CSHQ). Frequency of Occurrence by Group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>	<i>+ 5 nights per week</i>	<i>2-7 nights per week</i>
Item from Sleep Disordered Breathing Scale	No. (%)	No. (%)	No. (%)	No. (%)
Snores loudly	4 (10.8%)	14 (37.8%)	2 (6.6%)	9 (30%)
Stops breathing	3 (8.1%)	5 (13.5%)	0 (0%)	2 (6.6%)
Snorts and Gasps	2 (5.4%)	7 (18.9%)	0 (0%)	5 (16.6%)

Snoring was found to be a sleep feature present in over a third of the clinical sample.

Finally, Table 9 presents information from the daytime sleepiness subscale of the CSHQ.

Table 9: Daytime Sleepiness Subscale Items (CSHQ). Frequency of Occurrence by Group.

	CLINICAL GROUP n=37		CONTROL GROUP n=30	
	<i>+ 5 nights/days per week</i>	<i>2-7 nights/days per week</i>	<i>+ 5 nights/days per week</i>	<i>2-7 nights/days per week</i>
Item from Daytime Sleepiness Scale	No. (%)	No. (%)	No. (%)	No. (%)
Does not wake by self	7 (18.9%)	8 (21.6%)	2 (6.6%)	7 (23.3%)
Wakes up in negative mood	7 (18.9%)	25 (67.5%)	3 (10%)	10 (33.3%)
Others must wake child	11 (29.7%)	20 (54.0%)	5 (16.6%)	12 (40%)
Hard time getting out of bed	4 (10.8%)	6 (16.2%)	3 (10%)	6 (20%)
Takes long time to become alert	5 (13.5%)	13 (35.1%)	3 (10%)	8 (26.6%)
Seems tired	8 (21.6%)	26 (70.2%)	1 (3.3%)	14 (46.6%)
Tired watching T.V.	3 (8.1%)	10 (27.0%)	5 (16.6%)	7 (23.3%)
Tired riding in car	7 (18.9%)	11 (29.7%)	2 (6.6%)	6 (20%)

Just over seventy percent of the clinical group reported that their child seemed tired during the day (two to seven days of the week). This was reported to be a problem in just under half (46.6%) of the control group and was found to be a significant difference ($U = 381.000$, $Z = -2.403$, $p < 0.05$) between the two groups.

The most frequently reported sleep features, or problems, across both groups were restless sleeping, awakening once per night, sleeping too little and taking in excess of twenty minutes to fall asleep and trouble sleeping away from home.

3.2.2 Daytime Challenging Behaviour

The mean total of the ABC-C in the clinical group was 65.65 (range = 6 – 132, S.D. = 30.875). The mean total in the control group was 44.40 (range = 1 -126, S.D. = 31.791). Table 10 gives the number and percentage of children who scored above the 85th percentile for each subscale together with the total score. This cut-off indicates that the scores should be considered to be clinically significant (Aman & Singh, 1994).

Table 10: Number and Percentage of Children with a Score above the 85th Percentile for each ABC-C Subscale

ABC-C Subscale	Clinical Group n=37		Control Group n=30	
	Count	Percentage	Count	Percentage
Irritability	22	59.4%	8	26.4%
Lethargy	13	35.1%	8	26.6%
Stereotypy	20	54.1%	14	46.6%
Hyperactivity	13	35.1%	7	23.3%
Inappropriate Speech	25	67.6%	8	26.6%
Total ABC Score	16	43.2%	7	23.3%

It can be seen from Table 10 that the clinical group had a higher number of children scoring above the 85th percentile for each subscale in comparison to the control

group. The clinical group reported that the most problematic behaviour was inappropriate speech whilst the control group reported that stereotypy was the set of behaviours most typically seen.

3.2.3 Maternal Stress

Of the 37 mothers in the clinical group, 35 (94.6%) were found to have a clinically significant score (90 or above) and 2 (5.4%) were found to be scoring below this cut-off. In the control group, 18 (60%) of the mothers questioned were experiencing clinically significant levels of stress, whilst 12 (40%) scored below the cut-off. This was found to be a significant difference between the two groups ($U = 363.000$, $Z = - 3.437$, $p < 0.01$).

The Defensive Responding score was not included in the final analysis. As highlighted earlier (see methodology), this scale assesses the extent to which the respondent approaches the questionnaire with a strong bias to present the most favourable impression of himself or herself and to minimise indications of problems or stress in the parent-child relationship. Scores of ten or below on this scale indicate that this may be happening. In the clinical group, no respondents scored ten or below on the defensive responding subscale. Four people (13.3%) in the control group did, however, score ten or below.

3.3 Results of Hypotheses

Results will be presented for each hypothesis, in the order in which they were presented in the introduction.

3.3.1 Hypothesis 1: The prevalence of sleep problems reported by mothers in all children surveyed with a learning disability and/or autism will be between 44% and 86%.

Both the clinical group and the control group scores were combined when analysing the data. Problems were defined as severe if they occurred five or more nights per week. In relation to severe night waking, 18 (26.8%) of those surveyed reported that their child woke once during the night. Fourteen (20.8%) participants reported that their child woke more than once per night, in excess of five nights per week.

In terms of severe settling difficulties, 20 (29.8%) of the group surveyed reported that it took in excess of twenty minutes for their child to fall asleep at night.

Early morning waking was defined as waking at 5am or before. A total of nine (13.4%) children and their families reported that this was the usual time that their child woke. This group of children had an average age of 12.6 years (range = 5 – 15 years, S.D. = 3.177).

Using the cut-off score of 41, it was found that 54 (80.6%) participants reported that their child had a significant sleep problem according to their total score on the CSHQ. In respect of this, hypothesis one was accepted.

3.3.2 Hypothesis 2: A correlation between sleep problems, challenging behaviour and maternal stress will exist for all children surveyed with a learning disability and/or autism.

The total scores of the CSHQ, the ABC-C and the PSI-SF were examined visually and for the degree of kurtosis and skewness to determine whether parametric tests were appropriate. The distributions were tested for normality, and a departure from normality in the ABC-C total was removed with a square root transform. Two outliers remained, one in the clinical group of the ABC-C total, the other in the control of the PSI-SF total score. Parametric tests were carried out with and without the outliers present. Both groups were combined for this analysis.

Using Pearson's r , parametric test of correlation, it was found that there was a significant positive correlation between children's sleep and maternal stress ($r = 0.529$, $n = 65$, $p < 0.01$), a significant positive correlation between children's sleep and daytime challenging behaviour ($r = 0.539$, $n = 65$, $p < 0.01$) and a significant positive correlation between daytime challenging behaviour and maternal stress ($r = 0.525$, $n = 65$, $p < 0.01$). When the above analysis was carried out with the outliers included, the results of the analysis did not differ, with all correlations reaching the same level of significance. Hypothesis two was, therefore, accepted. Further analysis

of correlations was later carried out using a test of multiple regression. The results of this can be found on page 90.

3.3.3 Hypothesis 3: There will be a higher correlation between sleep problems, challenging behaviour and maternal stress in the clinical group in comparison with the control group.

Analysis was carried out to investigate whether there was a higher correlation in the clinical group between sleep, daytime challenging behaviour and maternal stress in comparison with the control group. As before, the total scores of the CSHQ, the ABC-C and the PSI-SF were examined visually and for the degree of kurtosis and skewness to determine whether parametric tests were appropriate. The distributions were tested for normality, and a departure from normality in the ABC-C total was removed with a square root transform. Two outliers remained, one in the clinical group of the ABC-C total, the other in the control of the PSI-SF total score. To investigate the relationship between the three variables, Pearson's r parametric tests of correlation were carried out using the total scores from the CSHQ, the PSI-SF and the ABC-C (square root transformed data). Tests were carried out with and without the outliers present.

In the clinical group, it was found that there was a significant positive correlation between children's sleep and parental stress ($r = 0.575$, $n = 36$, $p \leq 0.01$), a significant positive correlation between children's sleep and behaviour ($r = 0.536$, $n = 36$, $p < 0.01$) and a significant positive correlation between behaviour and maternal

stress ($r = 0.362$, $n = 36$, $p < 0.05$). When the above analysis was carried out with the outliers included, the results of the analysis did not differ, with all correlations reaching the same level of significance. The only exception was that of the correlation between behaviour and maternal stress, which reached significance at the $p < 0.01$ level rather than the $p < 0.05$ level achieved when the analysis was run with the outlier excluded.

In the control group, it was found that there was no significant correlation between children's sleep and maternal stress ($r = 0.197$, $n = 29$, $p = 0.152$). There was however a significant positive correlation between children's sleep and daytime challenging behaviour ($r = 0.323$, $n = 29$, $p < 0.05$) and a significant positive correlation between daytime challenging behaviour and maternal stress ($r = 0.428$, $n = 29$, $p < 0.01$). The correlation between daytime challenging behaviour and maternal stress was higher than that found in the clinical group. As with the clinical group, the analysis was also run with the outliers included. This had the effect of producing a significant correlation between children's sleep and maternal stress at the $p < 0.05$ level. Additionally, the correlation found between behaviour and maternal stress together with children's sleep and behaviour was stronger with significance reaching the $p < 0.01$ level.

The difference between the correlations for both groups with respect to children's sleep and maternal stress was in the predicted direction but not significantly higher in the clinical group ($Z=1.52$, $p > 0.05$). The same was true for the correlations between

children's sleep and daytime challenging behaviour ($Z= 1.04, p>0.05$) and daytime challenging behaviour and maternal stress ($Z=0.49, p>0.05$).

On the basis that the correlation between daytime challenging behaviour and maternal stress was found to be higher in the control group in comparison to the clinical group, hypothesis three was rejected and the null hypothesis was retained. Further, the remaining correlations were not found to be significantly higher in the clinical group.

Whilst correlation does not imply causation, previous studies (Wiggs & Stores, 1996; Bartlett *et al.*, 1985; Quine, 1991) have speculated that it is children's disturbed sleep which has a negative effect on both daytime challenging behaviour and maternal stress and may therefore account for the correlation between the two. In order to see whether there was a correlation between daytime challenging behaviour and maternal stress, independently of sleep, a partial correlation was carried out for the data given by the clinical group. This enabled children's sleep to be held constant, or partialled out of the correlation. In the clinical group, a partial correlation revealed that there was no significant positive correlation between children's daytime challenging behaviour and maternal stress when sleep was excluded ($r = 0.0778, n = 36, d.f. = 33, p = 0.328$).

Although not a primary aim of this thesis, exploratory analysis was carried out in order to assess whether the age of the child was correlated with sleep problems, daytime challenging behaviour and maternal stress. Although age was probably not

normally distributed, Pearson's parametric tests of correlation were carried out as parametric tests are generally considered to be robust (Clark-Carter, 1997) and were thought to be the most flexible and powerful for this study. Again, the transformed data were used with outliers removed. It was found that age was not correlated with either sleep ($r = 0.185$, $n = 36$, $p = 0.140$, two-tailed), daytime challenging behaviour ($r = 0.033$, $n=36$, $p = 0.425$, two-tailed) or maternal stress ($r = 0.161$, $n = 36$, $p = 0.174$, two-tailed) in the clinical group. In the control group it was found that a higher age was significantly correlated with sleep disturbance ($r = 0.368$, $n = 29$, $p < 0.05$, two-tailed) with sleep problems increasing with the age of the child. No significant correlation was found between age and either maternal stress ($r = 0.201$, $n = 29$, $p = 0.296$, two-tailed) or daytime challenging behaviour ($r = 0.063$, $n = 29$, $p = 0.746$, two-tailed). The results of this analysis did not differ when the tests were rerun with the outliers included. There was, however, evidence from the scatter plots that the relationship between age and the three main variables was not, in fact, wholly linear. To examine this further, age was split into groups (i.e. 0-6 years, 7 – 11 years and 12-16 years). Raw mean scores for the three variables (children' sleep, daytime challenging behaviour and maternal stress) are presented.

In the clinical group, the mean total CSHQ score was found to be highest (Mean = 56.38, S.D. = 9.48) in the 0-6 years age category, falling for the 7-11 years age group (Mean = 49.46, S.D. = 7.61) and rising again in the 12-16 age group (Mean = 51.56, S.D. = 9.19). The pattern in the control group was found to be different in that the mean CSHQ score rose with the age of the child. The youngest age group (0-6 years) had the lowest mean score of the CSHQ (Mean = 39.75, S.D. = 1.71) and the eldest

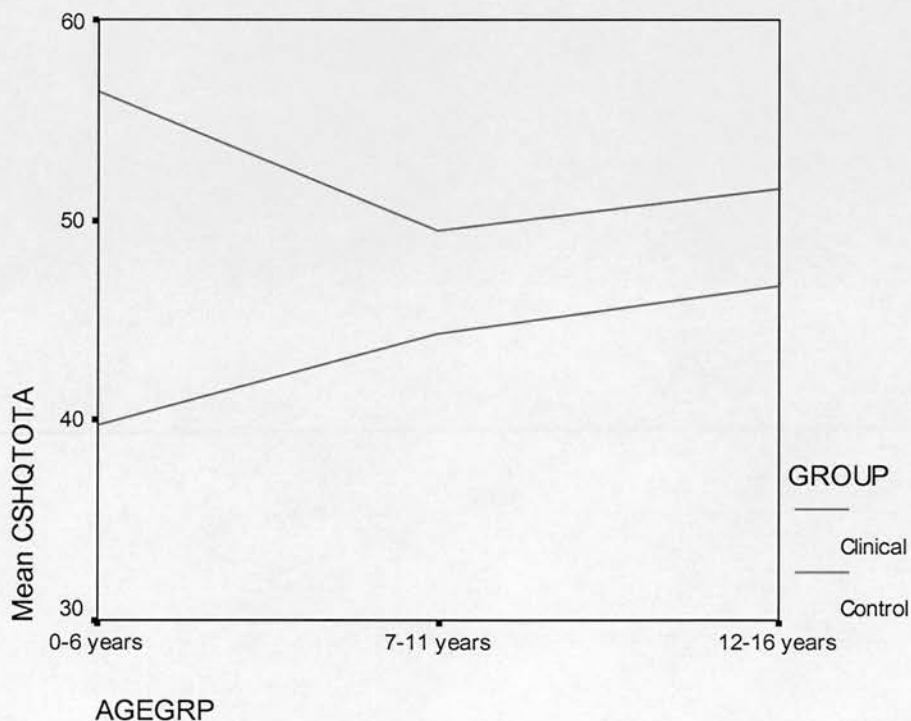
age group (12 -16 years) had the highest mean CSHQ score. The mean CSHQ total scores and standard deviations by age group and experimental group are summarised in Table 11.

Table 11: Means and Standard Deviations of CSHQ Total Scores by Group and Age Group.

Age Group	Clinical Group		Control Group	
	Mean & S.D.	No. in group	Mean & S.D.	No. in group
0-6 years	56.38 ± 9.48	8	39.75 ± 1.71	4
7-11 years	49.46 ± 7.61	13	44.33 ± 7.68	6
12-16 years	51.56 ± 9.19	16	46.70 ± 8.27	20

Figure 1 illustrates the mean total scores on the CSHQ by age group and experimental group.

Figure 1: Mean total CSHQ score by age group and experimental group.



In the clinical group, the mean total of the ABC-C was found to be highest in the 0 -6 year age group. Behaviour appeared to be less challenging in the 7 – 11 year age group. The opposite, however, was found to be the case with the control group. The 0

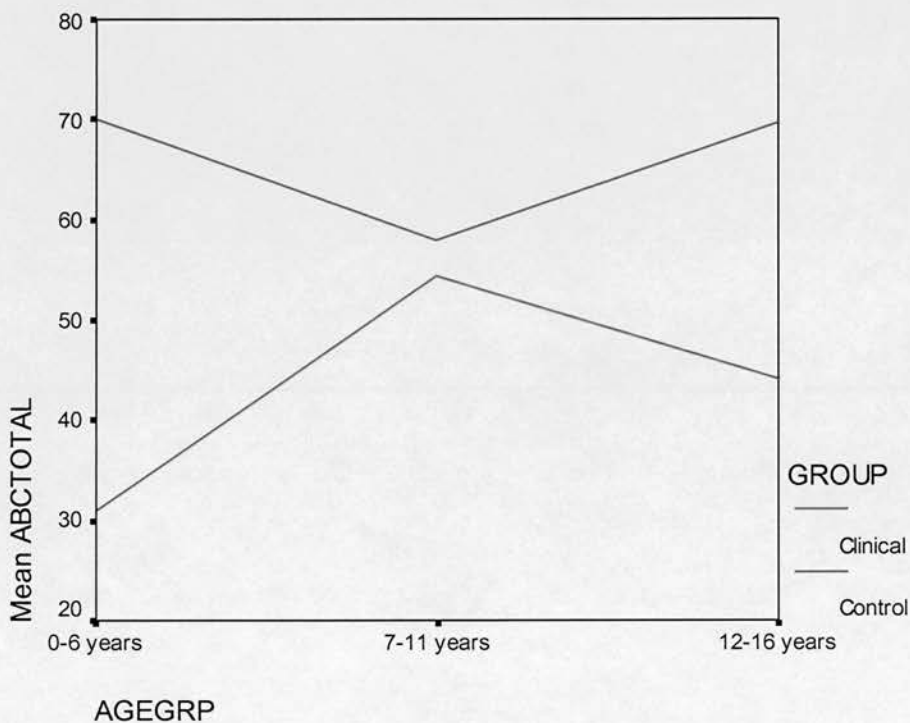
-6 year age group were reported to have the least challenging behaviour, with the 7 – 11 year old age group having the highest scores on the ABC –C. Table 12 gives the means and standard deviations for each age group by experimental group.

Table 12: Means and Standard Deviations of ABC-C Total Score by Group and Age Group.

Age Group	Clinical Group		Control Group	
	Mean & S.D.	No. in group	Mean & S.D.	No. in group
0-6 years	70.00 ± 17.30	8	31.00 ± 32.73	4
7-11 years	58.00 ± 27.61	13	54.33 ± 21.02	6
12-16 years	69.69 ± 38.21	16	44.10 ± 34.47	20

Figure 2 graphically illustrates the mean total score of the ABC-C by age group and experimental group.

Figure 2: Mean total ABC-C score by age group and experimental group.



It was found that maternal stress levels appeared to be the highest for those who had children in the 12 -16 years age group in the clinical group and those who had

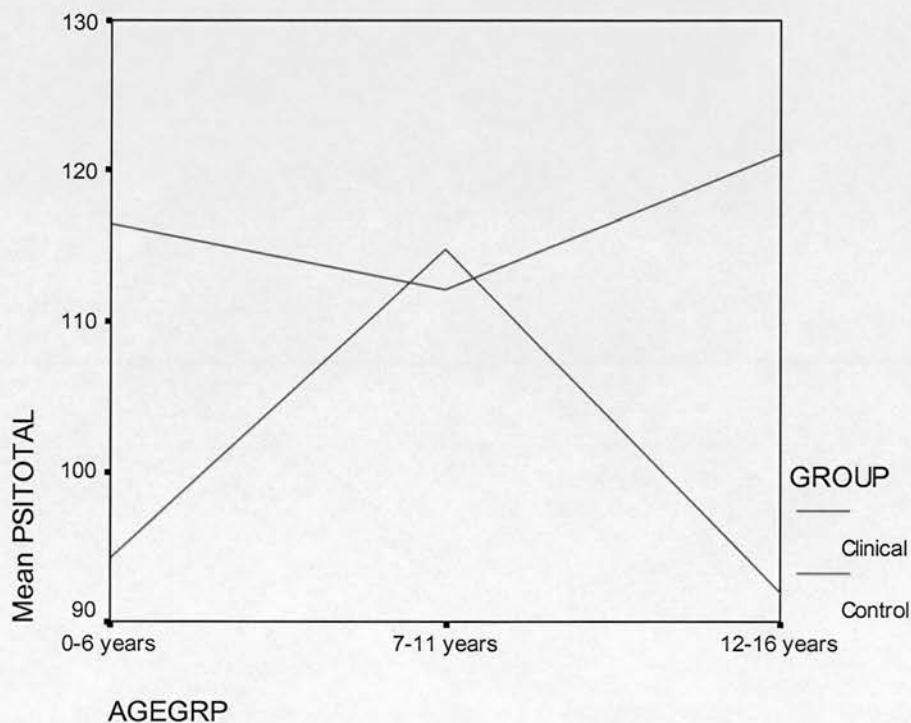
children in the 7 – 11 years age group in the control group. The mean maternal stress scores and standard deviations by age group and experimental group are given in Table 13.

Table 13: Means and Standard Deviations of PSI-SF Total Score by Group and Age Group.

Age Group	Clinical Group		Control Group	
	Mean & S.D.	No. in group	Mean & S.D.	No. in group
0-6 years	116.50 ± 14.23	8	94.25 ± 12.63	4
7-11 years	112.15 ± 15.98	13	114.83 ± 9.88	6
12-16 years	121.13 ± 24.71	16	91.90 ± 29.49	20

The mean total PSI-SF score is graphically illustrated by age group and experimental group in Figure 3.

Figure 3: Mean total PSI-SF score by age group and experimental group.



In order to examine whether there was a significant difference between the clinical group and control group when mean scores for the three variables were plotted

against age group, a multivariate analysis of variance (MANOVA) was carried out. This looked at the effects of interaction between age group and experimental group and the relationship between the three dependent variables (children's sleep, daytime challenging behaviour and maternal stress). Analysis was carried out, as for the correlations above, using the transformed data from the ABC-C. Two remaining outliers were removed: one from the clinical group of the ABC-C total and the other from the control group of the PSI-SF total score. The effects of interaction between the experimental groups and age groups were not significant for children's sleep ($F_{(2, 59)} = 1.881, p = 0.161$) or daytime challenging behaviour ($F_{(2,59)} = 2.497, p = 0.091$), but was found to be significant for maternal stress ($F_{(2, 59)} = 4.840, p < 0.05$). A significant difference was found between the two groups when the dependent variables were combined. Table 14 summarises these results.

Table 14: MANOVA Combined Dependent Variable of CSHQ, ABC-C and PSI-SF. Summary of Results.

MANOVA TEST	VALUE	F VALUE	D.F.	SIGNIFICANCE
Pillai's Trace	0.256	2.842	6, 116	0.013
Wilks' Lambda	0.757	2.840	6, 114	0.013
Hotelling's Trace	0.304	2.836	6, 112	0.013
Roy's Largest Root	0.227	4.393	3, 58	0.007

All results were significant at the $p < 0.05$ level.

A stepwise multiple regression was carried out to examine factors associated with maternal stress. Children's sleep, daytime challenging behaviour and age were entered into the model for both the clinical and control groups. A significant model emerged for both the clinical ($F_{1, 34} = 16.80, p < 0.01, \text{adjusted R square} = 0.311$) and the control group ($F_{1, 27} = 6.05, p < 0.05, \text{adjusted R square} = 0.183$). Children's

sleep problems ($[\beta] = 0.574, t = 4.09, p < 0.01$) emerged as the only predictor of maternal stress in the clinical group. In the control group, daytime challenging behaviour was the only significant predictor ($[\beta] = 0.428, t = 2.46, p < 0.05$). When analysis was carried out with the outliers included, the results were similar, reaching the same level of significance.

3.3.4 Hypothesis 4: The incidence of sleep problems will be higher in the clinical group in comparison to the control group.

Mann-Whitney tests were used to investigate whether the scores for the individual subscales, together with total score, were significantly higher in the clinical group in comparison to the control group. Non-parametric tests were used due to the finding that the individual sub-scales of the CSHQ were positively skewed with outliers. Means, standard deviations and trimmed means (to allow for the outliers and the skew in the data), are presented for each subscale of the CSHQ in Table 15.

Table 15: Means, Standard Deviations and Trimmed Means of Subscales of the CSHQ.

CSHQ Subscale	Clinical Group n=37		Control Group n=30	
	Mean & S.D.	Trimmed Mean	Mean & S.D.	Trimmed Mean
Bedtime resistance	8.68 ± 3.24	8.39	7.43 ± 2.04	7.15
Sleep-onset delay	2.08 ± 0.79	2.09	1.87 ± 0.77	1.85
Sleep duration	5.68 ± 1.70	5.64	4.80 ± 2.07	4.69
Sleep anxiety	5.68 ± 1.79	5.53	5.33 ± 1.78	5.13
Night waking	5.30 ± 1.53	5.27	4.50 ± 1.57	4.44
Parasomnias	10.2 ± 2.03	10.21	9.10 ± 2.28	8.91
Sleep-disordered breathing	3.95 ± 1.49	3.72	3.60 ± 0.89	3.52
Daytime Sleepiness	12.6 ± 3.25	12.4	11.13 ± 2.80	10.96
Total sleep disturbance	51.8 ± 9.19	51.80	45.3 ± 7.81	44.94

It can be seen from Table 15 that the mean scores for each subscale are higher in the clinical group in comparison to the control group.

When comparing the scores of the subscales between the two groups, a significant difference was found on the sleep duration sub-scale ($U = 407.000$, $Z = -1.906$, $p < 0.05$), the night waking subscale ($U = 389.000$, $Z = -2.136$, $p < 0.05$), the parasomnias subscale ($U = 355.000$, $Z = -2.55$, $p < 0.01$) and the daytime sleepiness subscale ($U = 406.000$, $Z = -1.891$, $p < 0.05$) with the clinical group scoring higher than the control group on these scales, indicating greater sleep disturbance.

On the subscales of the CSHQ, no significant difference was found between the clinical and control groups in the bedtime resistance subscale ($U = 463.000$, $Z = -1.20$, $p = 0.115$), the sleep-onset delay subscale ($U = 472.500$, $Z = -1.11$, $p = 0.134$), the sleep anxiety subscale ($U = 488.500$, $Z = -0.874$, $p = 0.191$) or the sleep-disordered breathing subscale ($U = 494.500$, $Z = -0.852$, $p = 0.197$). Overall, the total score of the CSHQ was found to be significantly higher in the clinical group ($U=324.500$, $Z= -2.909$, $p < 0.01$) than the control group. Hypothesis four was therefore accepted.

When using the cut-off score of 41, it was found that 34 (91.9%) of the clinical group had a sleep problem in comparison to 20 (66.7%) of the control group. This was a significant difference ($U = 415.000$, $Z = -2.577$, $p < 0.01$). When this was broken down by age, 100% of the under six years age group had a score above the cut-off, 92.3% of the seven to eleven year olds had a score above the cut-off and 87.5% of

twelve to sixteen year olds scored above this level in the clinical group. This score was 25%, 66.6% and 75% for each respective age category in the control group

As an exploratory analysis, when the total score of the CSHQ was compared for those children in the clinical group who were currently being prescribed melatonin for disturbed sleep, it was found that there was no significant difference ($U = 122.500$, $Z = -1.067$, $p = 0.291$, two-tailed) between the two scores. A significant difference was however found in the control group with the children who were being prescribed melatonin being reported to suffer from more disrupted sleep ($U = 30.500$, $Z = -2.458$, $p < 0.01$, two-tailed). Further, it was found that there was no difference in the total sleep problems reported in children who were reported to have an autistic spectrum disorder in both the clinical ($U = 154.000$, $Z = 344.000$, $p = 0.605$, two-tailed) and control groups ($U = 104.500$, $Z = -0.333$, $p = 0.739$, two-tailed).

3.3.5 Hypothesis 5: The incidence of challenging behaviour will be higher in the clinical group in comparison to the control group.

The individual subtests of the ABC-C were tested for normality. As not all the subtests had an acceptable degree of skewness and kurtosis, Mann Whitney tests were used again to compare scores. As above, mean scores are presented for interest.

Table 16 shows the means and standard deviations of the subscales of the ABC-C.

Table 16: Means, Standard Deviations and Trimmed Means of the Subscales of the ABC-C.

ABC-C Subscale	Clinical Group n=37		Control Group n=30	
	Mean & S.D.	Trimmed Mean	Mean & S.D.	Trimmed Mean
Irritability	19.8 ± 9.72	19.83	12.0 ± 11.0	11.19
Lethargy	12.1 ± 8.85	11.54	9.17 ± 9.12	8.24
Stereotypy	6.86 ± 5.61	6.57	5.13 ± 5.05	4.74
Hyperactivity	21.7 ± 11.1	21.53	15.8 ± 10.7	15.72
Inappropriate Speech	5.11 ± 3.35	5.01	2.30 ± 2.98	2.02
Total ABC Score	65.6 ± 30.8	65.02	44.4 ± 31.7	42.09

The clinical group had a higher mean score on all subscales in comparison to the control group.

A Mann-Whitney test revealed that the clinical group scored significantly higher than the control group on the Irritability sub-scale ($U = 316.500$, $Z = -3.009$, $p < 0.01$), the lethargy subscale ($U = 412.500$, $Z = -1.800$, $p < 0.05$), the hyperactivity subscale ($U = 396.500$, $Z = -1.999$, $p < 0.05$) and the Inappropriate Speech subscale ($U = 284.000$, $Z = -3.468$, $p < 0.01$). Significance was not reached on the stereotypy subscale ($U = 456.000$, $Z = -1.254$, $p = 0.105$). Overall, the clinical group scored significantly higher on the total score of the questionnaire than the control group ($U = 333.000$, $Z = -2.800$, $p < 0.01$). Hypothesis five was accepted.

3.3.6 Hypothesis 6: The incidence of maternal stress will be higher in the clinical group in comparison to the control group.

The data were examined for normality. The data for the individual subtests could not be said to be normally distributed. Non-parametric tests of analysis were used.

Table 17 shows the means, standard deviations and trimmed means (to account for outliers) of the subscales of the CSHQ.

Table 17: Means, Standard Deviations and Trimmed Means of the Subscales of the PSI-SF.

PSI Subscale	Clinical Group n=37		Control Group n=30	
	Mean & S.D.	Trimmed Mean	Mean & S.D.	Trimmed Mean
Defensive Responding	22.9 ± 5.19	23.10	18.0 ± 6.39	17.91
Parental Distress	37.6 ± 8.85	37.89	29.5 ± 10.8	29.19
Parent-Child Dysfunctional Interaction	34.5 ± 8.51	34.19	30.0 ± 6.97	29.44
Difficult Child	44.7 ± 7.19	44.82	37.0 ± 11.9	37.20
Total Score	116.9 ± 19.8	116.58	96.8 ± 26.2	96.09

All subscale means were higher in the clinical group in comparison to the control group.

A significant difference was found between the clinical group and the control group on all subscales of the PSI-SF: the parental distress subscale ($U = 302.500$, $Z = -3.187$, $p < 0.01$), the parent-child dysfunctional interaction subscale ($U = 373.000$, $Z = -2.298$, $p < 0.01$), difficult child ($U = 333.500$, $Z = -2.795$, $p < 0.01$) and on the overall total score ($U = 297.500$, $Z = -3.248$, $p < 0.01$), with the clinical group scoring higher than the control group on all scales. Hypothesis six was accepted.

3.4 Summary of Results

- The majority of mothers in both groups reported that their child had at least one sleep problem.
- A correlation was found between sleep problems, daytime challenging behaviour and maternal stress for all children surveyed.

- A correlation was found between sleep problems, daytime challenging behaviour and maternal stress in the clinical group, however, a partial correlation suggested that the relationship between behaviour and maternal stress was found to be an effect of children's sleep.
- A correlation, in the control group, was found between children's sleep and daytime challenging behaviour, and maternal stress and daytime challenging behaviour in the control group. No correlation, in this group, was found between children's sleep and maternal stress.
- The correlation between maternal stress and daytime challenging behaviour was found to be higher in the control group in comparison to the clinical group. This was not, however, found to be a significant difference.
- Regression analysis suggested that maternal stress was best predicted by children's sleep problems in the clinical group and best predicted by daytime challenging behaviour in the control group.
- In general, the clinical group reported that children's sleep problems, daytime challenging behaviour and maternal stress were most problematic between the ages of 0 – 6 years, were less problematic between the ages of 7 – 11 years and elevated again for the 12 – 16 years age group. Conversely, it was found that sleep problems, daytime challenging behaviour and maternal stress were highest, or most problematic, between the ages of seven and eleven years in the control group.
- In general, the incidence of reported sleep problems was higher in the clinical group as compared to the control group. Sleep duration, night waking,

parasomnias, daytime sleepiness and CSHQ total score were found to be significantly higher in the clinical group in comparison to the control group.

- In general, the incidence of reported daytime challenging behaviour was found to be higher in the clinical group. In particular, daytime irritability, lethargy, hyperactivity, inappropriate speech and ABC-C total score were found to be significantly higher in the clinical group in comparison to the control group.
- The clinical group were found to experience more maternal stress, a greater parent-child dysfunctional interaction, more likely to perceive their child as difficult and have an overall higher score than the control group.

CHAPTER FOUR: DISCUSSION

The main aim of this study was to conduct an investigation into the sleep and daytime challenging behaviour of children with a moderate to severe learning disability and/or autism in a clinical population. A secondary aim was to study the impact that these problems have on maternal stress and a final aim was to look at the inter-relationships among all three variables. Previous researchers (Wiggs & Stores, 1996; Quine, 1991) have found that incidence rates of sleep problems are significantly higher in children with a learning disability and autism in comparison to typically developing children. Further, the existence of sleep problems has been found to be correlated with daytime challenging behaviour and maternal stress (Quine, 1991; 1992). Previous studies had not investigated this relationship in a clinical population (Wiggs & Stores, 1996; Quine, 1991; Bartlett *et al.*, 1985). Given that children who have been referred to a specialist learning disability and autism clinical service for complex psychological and behavioural difficulties are, by definition, considered to have problems that have reached clinical significance, it was proposed that all three variables, but sleep in particular, would in fact be more problematic in this group than children with the same degree of disability whose behaviour had not warranted referral.

The research findings of this thesis suggest that sleep problems, daytime challenging behaviour and maternal stress are all correlated in the clinical group and the prevalence rates of each variable are higher in comparison to the control group of children with the same degree of learning disability who have not been referred to a

clinical service. These findings will be discussed with reference to the previous literature. Methodological issues pertaining to the current study will be considered together with the clinical implications of the research findings. Finally, suggestions will be made for future research in the area.

4.1 Discussion of Results

4.1.1 Results Relating to Sleep Problems

The results of the present thesis corroborate the results of other epidemiological studies (Wiggs & Stores, 1996; Quine, 1991; Bartlett *et al.*, 1985) which have found that parent-reported sleep problems are common among children with a learning disability and/or autism and suggest that milder or undesirable sleep related phenomena may regularly and frequently affect most children in this population.

Almost all children (97.3% in the clinical sample and 90% of the control sample) were reported to exhibit at least one type of sleep problem or mild sleep problem. This is comparable to a previous finding by Didden *et al.* (2002) who noted that 99.4% of the sample he used were reported to display at least one type of sleep problem. The wide range of frequent sleep disturbances which affected the whole sample is a finding which needs further study and explanation. Most of the features are common in children and many have no adverse effects (Wiggs & Stores, 1996), although some can be distressing for the parents to watch and the child to experience (Clare & Hibel, 1993). This may especially be the case if the parents are not familiar

with children's sleep disturbances and how best to cope with them. Wiggs and Stores (1996) suggest that such high prevalence rates indicate the need to increase awareness amongst parents who will, as predicted from the literature, be likely to encounter some form of sleep disturbance in their child due to the child having a learning disability.

Using the cut-off score of the CSHQ, it was found that, when the scores from both groups were considered, 80.6% of children with a learning disability and/or autism in this sample had a total score indicative of a significant sleep problem. As predicted, this figure was significantly higher for the clinical group (91.9%) in comparison to the control group (66.7%). In terms of age when both groups were combined, 75% of children under the age of six years, 84.2% of children between seven and eleven and 80.5% of children between twelve and sixteen were found to have a sleep problem using this criterion. These figures are broadly comparable to those found by Bartlett *et al.* (1985), who found evidence of sleep problems in 86%, 81% and 77% of children in each respective age group but much higher than that of Wiggs and Stores (1996) who found that, overall, 44% of the children in their sample suffered from significant or severe sleep problems. This may be a reflection of the fact that a different measurement of sleep was used in the each of the different studies, including the present one.

Previous studies (e.g. Wiggs & Stores, 1996; Didden *et al.*, 2002), in recent times, have used criteria developed by Richman and Graham (1971) to define sleep problems. These criteria are not necessarily used by every study on sleep in the area,

however, they are most commonly used where the authors have utilised the Simonds and Parraga (1982) questionnaire as this is based on the Richman and Graham (1971) criteria. Here, settling problems and night-waking were defined as severe if they occurred on three or more nights per week. As the present thesis used the CSHQ, slightly different criteria were used, due to the different questions being asked in the standardised questionnaire. Settling problems and night waking were defined as a severe problem if they occurred on five or more nights per week. This resulted in narrower criteria which a sleep feature had to meet before it was considered to be a severe problem. Despite this, the results of the present study are broadly similar to that of Wiggs and Stores (1996) who found that the percentage of children with a learning disability suffering from settling difficulties, night-waking and early waking was 19%, 22% and 11% respectively. The present study found that, when the groups were merged, the settling difficulties, night-waking and early waking occurred in 29.8%, 26.8% and 13.4% of cases respectively. The increased prevalence of settling difficulties found in the present study are most likely due to Wiggs and Stores (1996) having defined this as a problem if the child took more than one hour to fall asleep, whereas, here, this was defined as taking more than twenty minutes but occurring five or more nights per week. The advantage of using the CSHQ in the present study was that a range of sleep problems were looked at, rather than simply the above three. This is reflected in the higher overall prevalence rate compared to that found by Wiggs and Stores (1996).

The most troubling sleep features in the clinical group were reported to be the child not falling asleep in his or her own bed, taking in excess of twenty minutes to fall

asleep, sleeping too little or not the right amount as judged by the mother, night waking, restless sleeping and trouble sleeping away from home. The most commonly reported sleep features reported in the control group were taking in excess of twenty minutes to fall asleep, not sleeping the right amount as judged by the mother, not sleeping the same amount every night, night waking and trouble sleeping away from home. The fact that both groups reported that trouble sleeping away from home may indicate that this is an important sleep feature. It may have implications for the family going away for a holiday or short break, or may be a factor in families being reluctant to seek overnight respite services. Whilst no literature appears to exist on this specific sleep feature, the impact of this problem on the child and family warrants further investigation.

Participants in both groups reported, where relevant, that the only treatment for sleep problems they were currently receiving was pharmacological intervention in the form of prescription of melatonin. The children who were reported as being on a regular dose of melatonin were not found to have significantly different total sleep problem scores from those who were not being prescribed the medication. These results should be considered with caution due to the small numbers of children in each group being prescribed the medication. Further, as the study was questionnaire based, no information was known about whether other strategies were in place, for example good sleep hygiene and a consistent bedtime routine, to complement any effectiveness. Behavioural treatments should be used in conjunction with pharmacological intervention if a family should choose to use this method (Stores & Wiggs, 2001). The available literature on the area has reported mixed results.

Zhdanova (2000) notes that melatonin has yet to be shown to deserve the sometimes enthusiastic claims made for it as a treatment for various sleep disorders and its effectiveness needs to be much better researched.

The high prevalence of sleep problems in each group additionally highlights the fact that families can vary in the extent to which they cope with their child's disturbed sleep. Some may not seek help at all. Only a minority of families in each group reported receiving input specifically for sleep problems and, as stated, this was based on pharmacological intervention only (i.e. the prescription of melatonin). The reason for families not seeking help may be for a number of reasons. At times, this may be due to a belief that the problems are inevitable and cannot be changed. This can occur in some children with a learning disability with particularly severe sleep problems (Wiggs & Stores, 1998) and may be the reason why families in the clinical sample appear to seek intervention for daytime challenging behaviour in favour of treating sleep problems. In other cases, the family's general way of life may be so disorganised that no effort is made to improve matters (Stores & Wiggs, 2001). In these circumstances, there may be a good argument in favour of tactful intervention in an attempt to treat the sleep disturbance because of its harmful effects on the child and possibly on the family as a whole (Stores & Wiggs, 2001). An additional difficulty is that families not in contact with services may be only too aware of their child's sleep problems, but may be unsure about where to seek help. There are few specialised regional services that take referrals specifically for sleep problems. A clinical implication of this is that given that much evidence exists about the prevalence of sleep problems in this population, parents should be alerted from an

early stage, perhaps by their health visitor, that their child may be vulnerable to such problems, and given basic information on good sleep hygiene and sources of potential help in the first instance.

4.1.2 Results Relating to Age and Sleep Problems

It was found that when both groups were combined, age had no correlation with sleep problems. In relation to age and sleep problems, the results of previous studies have been equivocal. Shreck and Mulick (2000) found that age was not significantly related to measures of sleep quantity and sleep quality in children with a learning disability and/or autism. This corroborates the results found in this study for the clinical sample. Conversely, however, Bartlett *et al.* (1985) reported that sleep problems decreased slightly as the age of the child increased.

Exploratory analysis of the pattern of sleep problems by age category serves to further cloud this picture. In the clinical sample, sleep problems were found to peak between the ages of 0-6 years, fall between the ages of 7-11 years before becoming more problematic again in the 12 – 16 year age category. In the control sample, sleep problems increased with age of child. These findings are exploratory and should, therefore, be treated with caution due to the small numbers of children in each age category. The pattern is difficult to explain in terms of previous research but may be a function of the fact that a high prevalence of sleep problems were reported overall and that the group was, therefore, unrepresentative of the general population of children with a learning disability as a whole. The pattern of sleep disturbance found

in both groups does however add to findings in the literature (Quine, 1992; Wiggs & Stores, 1996) that sleep problems appear to be persistent in nature.

4.1.3 Results Relating to Daytime Challenging Behaviour

As predicted, the present study revealed a higher prevalence of daytime challenging behaviour within a sample of children with a learning disability referred to specialist clinical service in comparison to the control group which included children whose behaviour had not warranted referral. This result on its own is not surprising given that the majority of children in the clinical group are referred to the service for behavioural problems. A significantly higher score was achieved by the clinical group on all subscales of the ABC -C other than the stereotypy subscale. The stereotypy subscale includes items such as meaningless recurring body movements, stereotyped repetitive movements and rocking of the head or body. Around half of each group were reported to display significant levels of this behaviour. Stereotypy has been shown by Brylewski & Wiggs (1998), in a study of adults with a learning disability, to be one of three behaviours found to most common in people with sleep problems and has been found be correlated with the severity of the learning disability (Berkson, 1983). As both groups were found to have a high prevalence of sleep problems and those included in the study were known to have a moderate to severe learning disability this could be a possible reason why this was a commonly reported behaviour and, therefore, not significantly higher in either group.

4.1.4 Results Relating to Age and Daytime Challenging Behaviour

No overall correlation between age and daytime challenging behaviour was found in the present study, however, when age was collapsed into categories and plotted against the total mean score of the ABC-C there was evidence that the relationship between the two variables was not linear. In the clinical group, daytime challenging behaviour was found to be highest in the 0-6 year age group, falling for the 7 -11 year group and rising again 12 to 16 year olds. In the control group, daytime challenging behaviour was found to worsen between the ages of 7-11 years . Whilst the above findings are of interest, it is noted that these findings are exploratory and should be viewed with caution due to the small numbers of children in each age category.

Very few studies have examined either the development or the course of challenging behaviour over time. The limited evidence which is available, however, suggests that severely challenging behaviour may develop in early childhood and be extremely persistent over time (Emerson, 2001; Kiernan, Reeves, Hatton, Alborz, Emerson, Mason, Swarbrick & Mason, 1997). Generally, the most extreme challenging behaviour is thought to increase markedly around the age of 15 years before diminishing around the age of 35 years (Emerson, 1998). In the clinical group in this study, there was a suggestion that daytime challenging behaviour was increasing from the age of seven years, however, the prevalence of daytime challenging behaviour started to reduce from this age in the control group. This finding is difficult to explain though it is likely to be a reflection of the small sample size. It is also possible, however, that a general trend of challenging behaviour increasing with

age may have been less apparent because of the low mean age of the group and/or because the population studied represented a skewed sample of younger children with more severe behaviour problems. Further research on the development and course of challenging behaviour is needed.

4.1.5 Results Relating to Maternal Stress

The majority of the mothers (94.6%) in the clinical group were found to be suffering from clinically significant levels of stress. As predicted, mothers in the clinical group reported higher levels of stress in comparison to the control group. Although slightly lower in the control group (60%), the number of mothers experiencing clinically significant levels of stress in the control group was still high. The higher prevalence of clinically significant stress in the clinical group may be the reflection of the fact that sleep problems and daytime challenging behaviour were additionally high in this group. The consequences of this for parenting can be very serious. Stress can make individuals feel tired, irritable and depressed, making them less able to carry out complicated intervention programmes (Quine, 1992). Furthermore, when explaining the challenges faced in dealing with their children, parents often report significant stress to be the main factor that hinders progress (Turnbull & Ruef, 1996). This has a particularly serious implication for treatment of those children in the clinical group whose behaviour had warranted referral to a specialist service but whose mothers reported the highest stress levels. Baker *et al.* (1991) found in their study that while teaching or training parents to use strategies to manage their child's behaviour had good social validity and increased parental skill acquisition, families with characteristics such as stress and poor marital adjustment made the fewest gains.

Other authors have reported similar results (Dadds, Schwartz & Saunders, 1987; Webster-Stratton, 1985). This present study highlights that any functional analysis of a child's referred problems should include a full assessment of stress levels experienced by the main carer of the child as this may identify possible challenges to successful treatment.

4.1.6 Results Relating to Age and Maternal Stress

When age of child was split into categories and plotted against maternal stress, it was found that maternal stress, in the clinical group, was at its lowest for children in the 7-11 year age category. Conversely, maternal stress peaked for those mothers who had children within this same age group in the control group. This finding should again be treated as purely exploratory due to the small numbers in each age category. It is, however, unclear from the literature why this finding, if valid, may have arisen. Whilst, this finding could purely be an artefact of the sample used, it may be a useful avenue for future research. The present study did not enquire about other factors which may have affected the mother's stress levels. For example, whether the child's father was present, marital relationship, how many other siblings the child had or whether respite was used. It would be important for future research to collect this information to gain more of an understanding about patterns of maternal stress and their causes.

4.1.7 Results Relating to Correlations between Sleep Problems, Daytime

Challenging Behaviour and Maternal Stress.

Overall, a correlation was found to exist between sleep problems, daytime challenging behaviour and maternal stress. This is consistent with previous findings by Quine (1991; 1992). When the clinical group was separated from the control group for analysis, it was found that a correlation between all three variables still existed. As a partial correlation then revealed that there was no significant relationship in the clinical group between daytime challenging behaviour and maternal stress in the absence of the effect of disturbed sleep it is suggested that it is the effect of children's sleep problems which accounts for the association between behaviour and maternal stress in this sample. Whilst correlation does not imply causation, this finding highlights the importance of identifying and treating sleep problems as early as possible. The consequence for parenting as a result of children's sleep problems can be very serious. Quine (1992) has described mothers of children with a learning disability and severe sleep problems as more irritable and concerned about their own health, less affectionate towards their children and more likely to use physical punishment than mothers of similarly disabled children without sleep problems. It has also been suggested that marital discord and separation, and even physical abuse of children, can result from children's sleep problems (Chavin & Tinson, 1980). Successful treatment of the sleep disorder can improve parental functioning and well-being (Wolfson, Lacks & Futterman, 1992; Minde, Faucon & Falkner, 1994).

In the control group, there was no association between children's sleep and maternal stress, however, a correlation was found when the outlier was included in the analysis. Possible reasons for this were explored. The outlier was a male, aged 14 years, who was on the autistic spectrum and had an associated learning disability. His scores on all three measures were comparably very high to the rest of the control group, he had been prescribed melatonin and had slept for only four hours the night before the questionnaire was completed. It was speculated that an unusually disturbed night prior to completing the questionnaires may have negatively influenced reporting by his mother. This highlights one of the difficulties with using questionnaires as there is no opportunity to gain information about other possible contributing factors or checking information to control for biases in answers. Another possible reason for his high score may be that the information given was a true reflection of his typical behaviour and sleeping pattern and whilst his behaviour and poor sleeping has perhaps reached clinical significance, no referral to a professional clinical service for intervention had been made. His scores would not be considered to be unusually high in the context of the clinical sample. This serves to underline the importance of identifying sleep problems and daytime challenging behaviour as early as possible.

Further implications of the finding that no correlation existed between maternal stress and sleep problems in the control group were considered. It was hypothesised from the literature that those children in the control group would be broadly matched to children in the Quine (1991; 1992) studies as their behaviour had not warranted referral and they represented a general population of children with a moderate to

severe learning disability. On this basis, it was hypothesised, that in line with Quine's findings, increased maternal stress would be associated with a higher prevalence of sleep problems in the control group. Given, that children in the clinical group displayed behaviour that had reached clinical significance, and as suggested in previous literature (Wiggs & Stores, 1996; Quine, 1991) sleep and daytime challenging behaviour are correlated and further have an effect on maternal stress, maternal stress and sleep should also be correlated in the clinical group but more strongly. It is therefore speculated that there is a possibility that Quine's studies (1991, 1992) may have used samples of children which have included individuals whose sleep problems have been unrepresentatively high. Quine (1991; 1992) does not give a great deal of information on the children who were included in her study other than that 96 children with a degree of 'identified sleep problems' were selected from a sample of 166 children with a moderate to severe learning disability. It is possible, therefore, that this sample included children whose behaviour may additionally have already reached clinical significance and warranted referral to a service, thus, causing the sample to be biased by a few extreme cases. This highlights the need for future studies in this area to assess separately those children from a clinical sample, from those from the general population of children with a learning disability, in order that the findings can be properly applied to each group appropriately.

The effect of children's sleep on maternal stress is not well documented in the literature on children with a learning disability. Much of the experimental and clinical evidence that exists is on the effects of persistent sleep loss or disruption, and

comes from sleep deprivation studies. The potential seriousness of the cognitive effects can be judged from adult studies showing the influence of sleep deprivation on memory, attention and visuospatial abilities, verbal abilities, sustained attention and creative thinking (Horne, 1988; Pilcher & Huffcutt, 1996). The general effects of sleep deprivation on mood in adults has been found to be irritability, aggression and depressed mood (Pilcher & Huffcutt, 1996). The exact ways or mechanisms by which sleep deprivation leads to feelings of stress are an area that is under-researched and warrants further investigation, particularly in light of further evidence provided by this thesis of an association between these two variables in the clinical group.

The finding that daytime challenging behaviour was the best predictor of maternal stress in the control group and that the two variables were more highly correlated in comparison to the clinical group is perhaps a consequence of the lower prevalence of sleep problems reported in this group. Had there been a higher prevalence of sleep problems in the control group, then this may have proved more troublesome for the parents. Direction of effect in relation to parental stress and daytime challenging behaviour is a question that has been unanswered in the literature, and that this study additionally cannot comment on. Possible ways in which parental stress may be relevant to the emergence, or exacerbation, of behaviour problems were outlined in the introduction. Research has suggested that a highly stressed parent may engage in parenting behaviour which is less growth-promoting and may not be conducive to the resolution of the behaviour (Baker *et al.*, 2003). Few studies, however, have specifically looked at the association between parenting stress and actual parenting behaviour in detail (Hastings, 2002) and have, instead, tended to focus on the effect

of parenting behaviour regardless of how this parenting behaviour may have been manifested. The main ways in which daytime challenging behaviour in children is maintained by parents is thought to include such maladaptive patterns of parent-child interactions as inappropriate reinforcement of behaviour, coercive interaction, inconsistent discipline and confused communication. Given that stress can make people feel irritable, tired and depressed (Quine, 1991) it would be difficult to imagine that these factors would not influence parenting behaviour.

The lower correlation found between daytime challenging behaviour and maternal stress in the clinical group, despite higher levels of actual daytime challenging behaviour, may additionally be indicative of the fact that the clinical group were receiving treatment for behavioural problems. Maternal stress appeared to be more closely related to the presence of sleep problems for the clinical group. It is speculated that the support from a clinical service for behavioural problems may reduce the stress on the parent in relation to these particular difficulties. This warrants further research.

The different relationships between sleep problems, daytime challenging behaviour and maternal stress found for the clinical group as compared with the control group, which are outlined above, were further supported by a multiple regression analysis. Children's sleep problems were found to be the best predictor of maternal stress in the clinical group whilst daytime challenging behaviour was found to be the best predictor of maternal stress in the control group. Regardless of the cause of maternal

stress, the high levels in both groups are concerning and as previously highlighted, can have serious effects on parenting.

The relationship found between sleep problems and daytime challenging behaviour in both the clinical group and the control group supports previous research (Quine, 1991, Wiggs & Stores, 1996; Guilleminault & Winkle, 1981; Horne, 1988). The nocturnal demands placed on mothers of children with sleep problems appear to be compounded by the increase in daytime demands; the worse the sleep problem, the more likely that the child was to have daytime challenging behaviour which was severe and taking many forms. It is not possible to say, from the present study, whether the sleep problems are causal or maintaining factors of the daytime challenging behaviour, or whether the sleep problems are yet another manifestation of challenging behaviour. Wiggs and Stores (1996) suggest that the answer lies somewhere between the two explanations. Only detailed longitudinal studies would provide a clear answer to the temporal development of these problems. There is, however, some evidence which suggests that sleep problems may at least be contributing to current problem behaviour. Previous limited research has shown an improvement in the behaviour of children (with and without a learning disability) following behavioural intervention for sleep problems (Quine, 1993; Minde *et al.*, 1994). It is also of importance that poor outcome of the sleep problem is not associated with the presence of behaviour problems at initial presentation (Wier & Dinnick, 1988). This provides hope for those children referred to clinical services because of their behaviour. It would therefore seem that intervention for sleep

problems may be helpful in reducing challenging behaviour and that challenging behaviour may not preclude the resolution of the sleep problem.

4.1.8 Results Relating to Age, Sleep problems, Daytime Challenging Behaviour and Maternal Stress

A multivariate analysis of variance suggested that when sleep problems, daytime challenging behaviour and maternal stress were combined as one variable, the general pattern that problems seem to peak at age 7 – 11 years in the clinical group and conversely appeared to dip at the same age band for the control group was significantly different between the two groups. This unexpected finding is difficult to explain based on previous literature and, again, may simply be an artefact of the sample used. This finding does, however, warrant further research. As outlined previously, this study did not collect detailed information about family circumstances. This is likely to be important in understanding more about the relationship between sleep, daytime challenging behaviour and maternal stress in relation to age of the child. For example, it could be speculated that the reason for the pattern found in the groups may be related to the presence of other siblings. Perhaps, in relation to the clinical group, the problems that the child experiences are so stressful for the mother that the decision is taken to have no more children. This then reduces stress and makes mothers less likely to rate other problems as severe as the child reaches the ages of 7-11 years. In contrast, for the control group, the problems that the child has are of a lower level in comparison to those in the clinical group. They are, therefore, perhaps more likely to go onto have other children which

raises stress levels with the increased burden of care, particularly between the ages of 7-11 years, and makes mothers more likely to rate problems as troublesome at this age. More detailed research on this finding is necessary.

4.2 Methodological Issues

4.2.1 Methodological Strengths

The current study had several methodological strengths. First, a pilot study was carried out which enabled the researcher to check that participants found the questions asked unambiguous, inoffensive and easy to understand. In addition, the pilot study was used to gain an estimation of the average length of time it took to fill in all questionnaires. Three questionnaires were included in the study plus a short demographics questionnaire. It was essential to check that filling in this number of questionnaires was not overly time consuming and that an estimation of the time involved in participating could be given so as to maximise the response rate.

Related to this, an advantage of the present study was that despite looking at three variables, only three, relatively brief questionnaires were used. Some studies have used in excess of this number, for example, Quine (1992), who used five measures and asked parents to keep a diary for two weeks. This creates an additional burden for a group of people who are already known to suffer from increased stress levels (Hodapp *et al.*, 1998).

An additional strength was the quality of the questionnaires used. The study used the CSHQ, the ABC-C and the PSI-SF questionnaires all of which have been shown to have good reliability and validity with unambiguous scoring (Owens *et al.*, 2000; Aman & Singh, 1994; Abidin, 1990). In relation to measures of sleep, previous studies (e.g. Wiggs & Stores, 1996; Didden *et al.*, 2002) have most commonly utilised a sleep questionnaire originally developed by Simonds and Parraga (1982) and later modified by Wiggs and Stores (1996). The modified sleep questionnaire consists of five parts. The main body of the questionnaire utilises a five-point scale for participants to respond about their child's sleep. The scale was: (1) never; (2) less than once per month; (3) between two and four times per month; (4) several times per week; or (5) nightly. The researcher's impression was that the fourth choice, 'several times per week', was ambiguous and could lead to participants interpreting the actual number of nights per week differently. Further, there appears to be a large jump between the participant having to respond on the basis of a sleep feature occurring 'between two and four times per month' to 'several times per week' with no in-between choice. Arguably, few researchers would be interested in a sleep feature that occurred either 'between two and four times per month' or 'less than once per month'. For this reason, the present study opted to refrain from using the Simonds and Parraga (1982) questionnaire, despite it being a widely used measure in the area, in favour of the CSHQ (Owens *et al.*, 2000).

The CSHQ yields a total score, focuses on sleep features that occur in the timescale of a week and gives clear choices to the participant as to the definition, in terms of number of nights, of the points on the scale (i.e. rarely, sometimes or usually). Other

studies have utilised other, somewhat unsatisfactory measures of sleep. For example, Quine (1992) used one sub-scale of the Behaviour Screening Questionnaire (Richman & Graham, 1971) together with a scale devised for the purpose of the study to measure maternal responsiveness to sleep problems (The Maternal Responsiveness Scale, Quine & Wade, 1991). This does not yield such detailed information as the CSHQ provides.

Those studies which have investigated maternal or parental stress in relation to sleep problems have additionally used varying ways of measuring this stress. For example, Quine (1992) and Cunningham, Sloper, Rangelcroft, Knussen, Lennings, Dixon and Reeves (1986) utilised 'The Malaise Inventory' (Rutter, Tizard & Whitmore, 1970). This scale is, however, a 24 item binary choice questionnaire which does not yield such detailed information as the PSI-SF. The information gained with this method can be narrow. An additional difficulty with using a binary choice questionnaire is that participants can feel constrained by the response system and may feel that their response does not fit into either of the two categories given (Coolican, 1994). The PSI-SF is a widely used measure for assessing stress in parents of children with a learning disability (e.g. Ong *et al.*, 1999; Rimmerman, Turkel & Crossman, 2003) and has been found to have good validity and reliability (Abidin, 1995).

In order to measure daytime challenging behaviour, this study used the ABC-C (Aman & Singh, 1994). This scale was considered particularly appropriate for the present study since items were derived from identified problem behaviours in a group of people with a moderate through to profound learning disability and has been

used successfully with both adults and children (Aman & Singh, 1994). It appears to be more psychometrically sound than other behaviour scales used with children with a learning disability such as the Adaptive Behaviour Scale (Nihira, Foster, Shellhaas & Leland, 1974) and those derived from the general population (e.g. the Achenbach Scales; Achenbach & Edelbrock, 1978). The ABC-C has been widely used by other studies in the relevant literature on sleep and behaviour problems (e.g. Wiggs & Stores, 1996; Didden *et al.*, 2002).

No other study has looked at the incidence of sleep problems in a clinical population of children with a moderate to severe learning disability. This study has immediate clinical relevance to clinicians working with this population. Further, few studies have investigated the relationship between sleep, behaviour and maternal stress in one study. This is with the exception of Quine (1991; 1992), although again, not with a clinical population.

4.2.2 Methodological Difficulties

The results of this study and their interpretations should be considered in the context of potential limitations or methodological difficulties.

Several well-documented disadvantages associated with postal questionnaires (Oppenheim, 1992) may have affected the results in the current study. One such example is that postal questionnaires generally yield low response rates (26.4% in the current study) which consequently could mean that the sample was unrepresentative of children with a moderate to severe learning disability and/or autism. It is possible

that the respondents consisted of the families where children had the most troublesome sleep since the questionnaires might have appeared most interesting and relevant to these families although this does not explain the differences found between groups. Similarly, however, there is a possibility that the converse may be true where the respondents consisted of the families where children and mothers, although scoring highly on measures of sleep, behaviour and maternal stress, were not representative of the population because those with higher levels of stress and children with poorer sleep and behaviour were unable to find the time to respond to the questionnaire or had stress levels which were too high to enable them to participate. Again, however, the high prevalence rate suggests this may not be the case. It was not possible to enquire about non-responders since the individual names of the children were not known to the researcher for reasons of confidentiality. Attempts were made to address this methodological weakness. Primarily, a large number of questionnaires were distributed to account for the expected low response rate. Further, the covering letter accompanying the questionnaire stressed the importance of information gathered from children both with and without sleep problems.

Further difficulties which can arise when using a postal questionnaire method are that it is unsuitable for participants of poor literacy and there is no opportunity for the researcher to correct misunderstandings. This study attempted to alleviate the effects of the above by providing contact details on the information letter so that participants could seek clarification of the questions. In addition, a pilot study was carried out principally to check that participants found the questions unambiguous, inoffensive

and easy to understand. It is acknowledged however, that there is a possibility that some participants may have been unable to respond because of poor literacy or not having English as a first language.

All children in the study were assumed to have a moderate to severe learning disability. A limitation of the study could be said to be the fact that no formal test of intellectual functioning was carried out to ascertain this. In addition, children who were on the autistic spectrum who were not reported to have a learning disability were included in the study. The reason for inclusion of children who had an autistic spectrum disorder with no learning disability was a deliberate attempt to reflect a true clinical sample. To exclude these children would have further affected the extent to which the finding could be generalised due to the fact that the group would not have been representative of the young people who are referred to a clinical service.

No formal test of intellectual functioning was undertaken for a number of reasons. First, the study was designed to be anonymous and the researcher did not have access to the names of the children in the control group. Further, the difficulties of accurately assessing intellectual functioning with a psychometric test for children with a learning disability have been well documented (Hatton, 1998, p. 27). Few tests of IQ have been standardised for use with a population of people with a learning disability, particularly for people who have a moderate to severe learning disability. The researcher assumed level of functioning (moderate to severe learning disability) on the grounds that the clinical service used in the study will only accept referrals from children with a moderate to severe learning disability (and/or autism) with

children with a mild learning disability being seen by another part of the service. The schools chosen for inclusion in the study were additionally known only to accept children with a moderate to severe learning disability. This is with the exception of one school used who predominantly accept children with autism. The schools were selected with the intention that the two groups would be matched for ability.

A further limitation of the research was that factors such as family makeup were not included. For example, asking for further information regarding the presence of the child's father, marital adjustment, number of siblings and the use of resources to find a deprivation score for each family would have yielded greater information and depth to the study, particularly in relation to maternal stress. Asking for further information, however, especially that which is more sensitive in nature, would have meant that the study would not have allowed for an anonymous response and may additionally have had a negative effect on the response rate.

4.2.3 The Use of Parametric Statistics

The current thesis uses a number of parametric statistical tests. Parametric tests make the assumption that the data are measured on an interval scale or ratio scale, the sample data are drawn from a normally distributed population and that there is homogeneity of variance for each condition. Bradley (1968) has been one of the strongest proponents of the opinion that violations of parametric test assumptions may cause that test to be less powerful than a corresponding nonparametric test and concludes that it is, therefore, inappropriate to use a parametric test in the absence of all three assumptions being met. Given that this thesis has, for some statistical

analysis, used parametric tests with ordinal level data, it is acknowledged that it is possible that these results could be considered to be invalid.

There has however been much controversy about the use of parametric tests when any of the three basic assumptions are violated. Many authors (e.g. Howell, 2002; Rasmussen, 1987; Cramer, 1998; Coolican, 1994) who argue in favour of using parametric tests when violations occur do not deny that nonparametric tests are more liberal in the assumptions they require. They argue, however, that the assumptions normally cited as being required of parametric tests are overly restrictive in practice and that the parametric tests are remarkably unaffected by violations of assumptions. Howell (2002) further emphasises the robustness of the parametric test to violations of their assumptions and the loss of power incurred by the use of the equivalent nonparametric tests. In addition, it has been argued that parametric tests can be used with ordinal data, as the tests are applied to the numbers themselves rather than what they relate to (Cramer, 1998). A definitive stance on the above debate does not, presently, appear to exist. This thesis, therefore, used parametric tests in some instances throughout the analysis as they were considered to be the most powerful and flexible for the study.

4.3 Implications for Clinical Practice

The findings of this study have a number of clinical implications for working with both the mothers of children with a learning disability and the child themselves. The advantage of the present study was that it used a clinical population. All other studies in this area are from a general population of children with a learning disability.

Clinicians have, therefore, previously had to apply the available information to the group of children who had been referred to their service. This study is therefore clinically useful.

The high incidence rate of sleep problems reported in both groups of children in this study may have implications for staff training. Stores & Crawford (1998) highlighted that British medical students receive an average of only five minutes of formal teaching on sleep problems or disorders. Stores R (1996) found clinical psychologists and nursing staff additionally receive little or no training in this area. In the clinical group, a correlation was found between sleep problems, daytime challenging behaviour and maternal stress. In order to treat individuals with a learning disability effectively it would seem essential that staff working with this population, particularly those referred to a clinical service, should be aware of the correlation between these variables. This implies that training courses for all professions should devote some time to raising awareness of sleep difficulties and ways of treating them.

The finding that despite the high prevalence of sleep problems, few families were receiving any input regarding their child's difficulties other than pharmacological intervention, would seem to suggest there is a need to develop informed professional services to provide accurate diagnosis and effective treatment of sleep problems. Stores (2001) envisages such a service operating at three levels. The first would be at a primary care level for the relatively straightforward sleep problems such as settling and night-waking. These problems are already treated effectively by some health

visitors or general-practice-based psychologists. At a secondary level, he suggests that community or hospital paediatric services for more difficult diagnostic or treatment problems should be put into place with clinical psychologists working closely with child psychiatrists. The third level would be the development of specialised sleep disorder services, at a regional level, for diagnostic or treatment purposes where attempts at the primary or secondary levels have not been adequate. Stores (2001) adds that for such a system to operate effectively, teaching and training of all personnel involved at these three levels need to improve dramatically.

Raising awareness of sleep problems is particularly important in light of the finding in this study, in agreement with others (e.g. Quine, 1991; 1992), that sleep problems are associated with daytime challenging behaviour which both additionally have an association with maternal stress. This is important as parents of children with a learning disability who are under increased stress may engage in different parenting behaviours (Hastings, 2002) as certain parenting behaviours (e.g. a coercive style) may be linked to higher levels of challenging behaviours via reinforcement processes (Patterson, 1982). The clinical implication of this is that clinicians interested in changing parent behaviour with a view to remediating children's behaviour problems could include parental stress reduction as an element in their treatment plans. Reducing parental stress may have an indirect beneficial effect on the child's behaviour by improving the quality of parenting behaviour (Hastings, 2002). Similarly, as a correlation exists between children's behaviour problems and maternal stress, improving parents' behaviour management skills may help to reduce children's behaviour problems, which should improve parental well-being. Hastings

(2002) suggests that cognitive-behavioural interventions aimed at parental appraisal processes (e.g. coping, self-efficacy and parental beliefs) may enable parents to manage better the stresses of significant behaviour problems in their child. Hastings and Taunt (2002) noted that something as straightforward as encouraging parents to recognise the positive dimensions of life with their child may be of benefit in helping to reduce the impact of child-related stressors on parental well being. It would seem, however, that children's sleep problems may have to be treated concurrently as parents who are suffering from disrupted sleep may simply be too tired to either actively engage in treatment for themselves or implement treatment strategies suggested for their children.

4.4 Implications for Future Research

The present study found that overall levels of maternal stress were significantly higher in the clinical group in comparison to the control group. Whilst this finding supported the hypothesis and was interpreted as indicating that a high level of maternal stress may be a by-product of the fact that children's sleep difficulties and challenging behaviour are, by definition, expected to be more severe in the clinical group, this finding warrants further investigation. This is because a paradox is created by the fact that the clinical group were all receiving regular input from a specialist clinical service yet this support did not appear, in this study, to have a reducing effect on maternal stress. The only indication that treatment may have had an effect on maternal stress was the finding that the correlation between maternal stress and daytime challenging behaviour was lower in the clinical group in

comparison to the control group. This, however, was in the context of the behavioural problems being higher in the clinical group as is therefore suggestive of the fact that it is sleep problems which cause the clinical group more stress.

In order to fully investigate the effect of treatment on children's sleep, daytime challenging behaviour and, in particular, maternal stress, future research could be designed around a longitudinal study which assessed all three variables at various points of treatment e.g. at initial assessment, mid-treatment and post-treatment. Any study focusing on this issue would further have take care to control for factors such as frequency of treatment sessions and individual qualities and personality of therapist.

Future studies may consider assessing sleep and daytime challenging behaviour separately in those whose behaviour has warranted referral to a clinical service from those whose behaviour has not been deemed to have reached clinical significance and, therefore, not warranted referral to a specialist service. The findings of this study suggest that this distinction is important if research outcomes are to be generalised to children in a general learning disability population.

Future work with larger samples might be able to examine the sleep problems experienced by children with different causes of a learning disability. The numbers of children with the different diagnoses, or causes, or learning disability were too small for any comparison in this study. Future studies might more usefully focus on the problems of children with specific syndromes or disabilities as the problems and experiences of children and their parents are likely to be different.

In addition, further research focusing on the efficacy of treatments, both behavioural and pharmacological, for the resolution of sleep problems would be helpful in addressing a seemingly common problem for families of children with a learning disability.

4.5 Conclusion

This thesis sought to investigate the relationship between sleep problems, daytime challenging behaviour and maternal stress in a clinical population of children with a moderate to severe learning disability. It was found that the prevalence of children's sleep problems, daytime challenging behaviour and maternal stress were all higher in children who had been referred to a specialist clinical service for intervention with complex behavioural and psychological difficulties. This was in comparison to children of the same level of ability whose behaviour had not warranted referral.

In line with previous research (Quine, 1991), a correlation between children's sleep problems, daytime challenging behaviour and maternal stress was found in the clinical group. No significant correlation between children's sleep and maternal stress was found in the control group. Regression analysis suggested that the best predictor of maternal stress in the clinical group was children's sleep problems and the best predictor of maternal stress in the clinical group was daytime challenging behaviour. The finding that there was no correlation between children's sleep and maternal stress in the control group, which was intended to be representative of a general population of children with a learning disability, is suggestive of the

possibility that previous studies in this area (e.g. Quine, 1992) may have inadvertently skewed their sample in favour of extreme cases of problematic behaviour by including children whose difficulties had reached clinical significance. This finding warrants further research and future studies may consider separately assessing sleep and daytime challenging behaviour in those whose behaviour has warranted referral to a clinical service from those whose behaviour has not been deemed to have reached clinical significance and, therefore, not warranted referral to a specialist service. The findings of this study suggest that this distinction is important if research outcomes are to be generalised to children in a general learning disability population.

Overall, age was not found to be correlated with children's sleep problems, daytime challenging behaviour or maternal stress. This, together with the high prevalence of sleep problems found in both the clinical and control group suggests that, in agreement with other studies (Quine, 1992; Wiggs & Stores, 1996), sleep problems may be particularly persistent in this population. There was, however, evidence that the relationship with age and children's sleep problems, daytime challenging behaviour and maternal stress was not in fact linear, when age was collapsed into categories. This area warrants further research.

This study highlights further the correlation between sleep problems and daytime challenging behaviour. Further research on the treatment of sleep problems is needed to further elucidate the connections between sleep problems and behaviour. Of particular interest would be the extent to which effective treatment of sleep problems

in children reduces concurrent and later emerging challenging behaviour. This is particularly important for the effective treatment of individuals who are referred to clinical services for intervention with challenging behaviour. In addition, it is important for further clinical investigations to assess the degree to which sleep problems in children provide a source of major stress in parents. The high levels of maternal stress reported in the present study are of particular concern. Identifying the extent to which sleep problems disrupt parenting and parental well being may be an important consideration in promoting the child's adjustment and in explaining treatment outcomes.

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APPENDIX 1

Pilot study participant letter

APPENDIX 1

**Learning Disability & Autism Service
Child and Family Mental Health Service
Royal Hospital for Sick Children
3 Rillbank Terrace
Edinburgh EH9 1LL**

Tel: 0131 662 2202

(30th January 2004)

Dear parent,

As part of my clinical psychology training I have to undertake a research thesis. I am carrying out a study into children's sleep problems and the effect that this has on their behaviour and wellbeing of their family. I am writing to invite you to take part in the *preliminary pilot study* for this project as I am interested about your experience and views on this subject. In addition I am keen to gain feedback on the questionnaires that I have chosen to use for the purpose of this research.

Your participation in this pilot study is voluntary. If you decide to take part, all I ask is that you as *the main caregiver of the child* (the relation who spends the most time with him or her) take approximately 15-20 minutes of your time to ***fill out the attached questionnaires and return it to me using the pre-paid envelope provided by Friday, 27th February.*** You do not have to write your name or your child's name on the questionnaire and I will be the only person who sees it. If you have more than one child, please fill the questionnaire out in relation to your *eldest* child provided he/she is under the age of 16 years.

If you do not want to take part in the study then you do not have to do anything, just dispose of the questionnaires.

What are the benefits of taking part?

Whilst the pilot study includes parents from the general population, the main study of the thesis will be looking at sleep, behavioural problems and parental stress specifically in a clinical population of children with moderate to severe learning disabilities. I hope that the information from the main study will help us to improve psychological treatments for children who are referred to learning disability services.

By participating in the pilot study *your feedback* will allow me to ascertain whether the questionnaires are suitable for use in the main study together with providing basic data such as length of time to fill out the questionnaires and acceptability to parents.

Who can you get in touch with if you need more information about the pilot study?

If you need more information about the pilot study, please do not hesitate to contact me at the above address or telephone number.

Alternatively you can talk in confidence to either of my supervisors. They can be contacted at the following numbers:

Dr Sally Cheseldine
Consultant Clinical Psychologist
CFMHS
Tel: 0131 6622210

Dr Karen McKenzie
Clinical Psychologist
University of Edinburgh
Tel: 0131 537 6102

I hope you decide to take part. Thank you for your time and help.

Yours sincerely

Eleanor Chalmers
Trainee Clinical Psychologist

APPENDIX 2

Demographic questionnaire

APPENDIX 2

Please fill in the following information. All information given is **confidential**.

- Child's Gender (Please Tick): Male
 Female
- Child's age (in years and months): _____
- Your relationship to child (please tick): Mother
 Father
 Other (please specify):

- Is your child currently being prescribed Melatonin? (please tick):
 Yes - If yes, please state dose if known: _____
 No
- Is your child prescribed any other medications? (If yes, please state below)

- Does your child have an autistic spectrum disorder?
 Yes
 No
- If your child has a learning disability, please state cause if known:

- Is your child currently receiving any help or treatments, e.g. medicine, nursing advice or help from 'Sleep Scotland', for the following (please tick) :
 - Sleep disturbance
 - Behavioural difficulties
 - Neither of the above

If yes to any of the above, please state what help you are currently receiving:

- How many hours did your child sleep for last night? _____

Thank you for your time

APPENDIX 3

The Child's Sleep Habits Questionnaire

APPENDIX 3

Child's Sleep Habits (Preschool and School-Aged)

Coding

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. Also, please indicate whether or not the sleep habit is a problem by circling "Yes," "No," or "Not applicable (N/A)".

Bedtime

Write in child's bedtime: _____

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
1) Child goes to bed at the same time at night (R)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
2) Child falls asleep within 20 minutes after going to bed (R)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
3) Child falls asleep alone in own bed (R)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
4) Child falls asleep in parent's or sibling's bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
5) Child needs parent in the room to fall asleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
6) Child struggles at bedtime (cries, refuses to stay in bed, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
7) Child is afraid of sleeping in the dark	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
8) Child is afraid of sleeping alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A

Sleep Behavior

Child's usual amount of sleep each day: _____ hours and _____ minutes
(combining nighttime sleep and naps)

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
9) Child sleeps too little	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
10) Child sleeps the right amount (R)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
11) Child sleeps about the same amount each day (R)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
12) Child wets the bed at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
13) Child talks during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
14) Child is restless and moves a lot during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
15) Child sleepwalks during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
16) Child moves to someone else's bed during the night (parent, brother, sister, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
17) Child grinds teeth during sleep (your dentist may have told you this)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
18) Child snores loudly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A

Sleep Behavior (continued)

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
19) Child seems to stop breathing during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
20) Child snorts and/or gasps during sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
21) Child has trouble sleeping away from home (visiting relatives, vacation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
22) Child awakens during night screaming, sweating, and inconsolable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
23) Child awakens alarmed by a frightening dream	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A

Waking During the Night

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
24) Child awakes once during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
25) Child awakes more than once during the night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A

Write the number of minutes a night waking usually lasts: _____

Morning Waking/Daytime Sleepiness

Write in the time of day child usually wakes in the morning: _____

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
26) Child wakes up by him/herself (R)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
27) Child wakes up in negative mood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
28) Adults or siblings wake up child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
29) Child has difficulty getting out of bed in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
30) Child takes a long time to become alert in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A
31) Child seems tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Yes	No	N/A

Child has appeared very sleepy or fallen asleep during the following (check all that apply):

	1 Not Sleepy	2 Very Sleepy	3 Falls Asleep
32) Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33) Riding in car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX 4

The Aberrant Behaviour Checklist - Community

APPENDIX 4

ABERRANT BEHAVIOR CHECKLIST

INSTRUCTIONS

The ABC-Community rating scale is designed to be used with clients living in the community. Please note that the term *client* is used throughout to refer to the person being rated. This may be a child of school age, an adolescent, or an adult.

Please rate this client's behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the appropriate number:

- 0 = not at all a problem
- 1 = the behavior is a problem but slight in degree
- 2 = the problem is moderately serious
- 3 = the problem is severe in degree

When judging this client's behavior, please keep the following points in mind:

- (a) Take relative *frequency* into account for each behavior specified. For example if the client averages more temper outbursts than most other clients you know or most others in his/her class, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.
- (b) If you have access to this information, consider the experiences of other care providers with this client. If the client has problems with others but not with you, try to take the whole picture into account.
- (c) Try to consider whether a given behavior interferes with his/her *development, functioning, or relationships*. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item—your first reaction is usually the right one.

1. Excessively active at home, school, work, or elsewhere	0	1	2	3
2. Injures self on purpose	0	1	2	3
3. Listless, sluggish, inactive	0	1	2	3
4. Aggressive to other children or adults (verbally or physically)	0	1	2	3
5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums/outbursts	0	1	2	3
<hr/>				
11. Stereotyped behavior; abnormal, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable and whiny	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizarre in behavior	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3
20. Fixed facial expression; lacks emotional responsiveness	0	1	2	3

21. Disturbs others	0	1	2	3
22. Repetitive speech	0	1	2	3
23. Does nothing but sit and watch others	0	1	2	3
24. Uncooperative	0	1	2	3
25. Depressed mood	0	1	2	3
26. Resists any form of physical contact	0	1	2	3
27. Moves or rolls head back and forth repetitively	0	1	2	3
28. Does not pay attention to instructions	0	1	2	3
29. Demands must be met immediately	0	1	2	3
30. Isolates himself/herself from other children or adults	0	1	2	3
<hr/>				
31. Disrupts group activities	0	1	2	3
32. Sits or stands in one position for a long time	0	1	2	3
33. Talks to self loudly	0	1	2	3
34. Cries over minor annoyances and hurts	0	1	2	3
35. Repetitive hand, body, or head movements	0	1	2	3
36. Mood changes quickly	0	1	2	3
37. Unresponsive to structured activities (does not react)	0	1	2	3
38. Does not stay in seat (e.g., during lesson or training periods, meals, etc.)	0	1	2	3
39. Will not sit still for any length of time	0	1	2	3
40. Is difficult to reach, contact, or get through to	0	1	2	3
<hr/>				
41. Cries and screams inappropriately	0	1	2	3
42. Prefers to be alone	0	1	2	3
43. Does not try to communicate by words or gestures	0	1	2	3
44. Easily distractible	0	1	2	3
45. Waves or shakes the extremities repeatedly	0	1	2	3
46. Repeats a word or phrase over and over	0	1	2	3
47. Stamps feet or bangs objects or slams doors	0	1	2	3
48. Constantly runs or jumps around the room	0	1	2	3
49. Rocks body back and forth repeatedly	0	1	2	3
50. Deliberately hurts himself/herself	0	1	2	3
<hr/>				
51. Pays no attention when spoken to	0	1	2	3
52. Does physical violence to self	0	1	2	3
53. Inactive, never moves spontaneously	0	1	2	3
54. Tends to be excessively active	0	1	2	3
55. Responds negatively to affection	0	1	2	3
56. Deliberately ignores directions	0	1	2	3
57. Has temper outbursts or tantrums when he/she does not get own way	0	1	2	3
58. Shows few social reactions to others	0	1	2	3

APPENDIX 5

The Parent Stress Index – Short Form

Instructions

This questionnaire contains 36 statements. Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response that best represents your opinion.

Circle the SA if you strongly agree with the statement.

Circle the A if you agree with the statement.

Circle the NS if you are not sure.

Circle the D if you disagree with the statement.

Circle the SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA **(A)** NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. **YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.**

Circle only one response for each statement, and respond to all statements. **DO NOT ERASE!** If you need to change an answer, make an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies. SA A NS ~~(D)~~ **(SD)**

Before responding to the statements, write your name, gender, date of birth, ethnic group, marital status, child's name, child's gender, child's date of birth, and today's date in the spaces at the top of the questionnaire.

SA = Strongly Agree

A = Agree

NS = Not Sure

D = Disagree

SD = Strongly Disagree

- | | | | | | |
|---|-----|-----|-----|-----|----|
| 1. I often have the feeling that I cannot handle things very well. | SA | A | NS | D | S |
| 2. I find myself giving up more of my life to meet my children's needs than I ever expected. | SA | A | NS | D | S |
| 3. I feel trapped by my responsibilities as a parent. | SA | A | NS | D | S |
| 4. Since having this child, I have been unable to do new and different things. | SA | A | NS | D | S |
| 5. Since having a child, I feel that I am almost never able to do things that I like to do. | SA | A | NS | D | S |
| 6. I am unhappy with the last purchase of clothing I made for myself. | SA | A | NS | D | S |
| 7. There are quite a few things that bother me about my life. | SA | A | NS | D | S |
| 8. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend). | SA | A | NS | D | S |
| 9. I feel alone and without friends. | SA | A | NS | D | S |
| 10. When I go to a party, I usually expect not to enjoy myself. | SA | A | NS | D | S |
| 11. I am not as interested in people as I used to be. | SA | A | NS | D | S |
| 12. I don't enjoy things as I used to. | SA | A | NS | D | S |
| 13. My child rarely does things for me that make me feel good. | SA | A | NS | D | S |
| 14. Most times I feel that my child does not like me and does not want to be close to me. | SA | A | NS | D | S |
| 15. My child smiles at me much less than I expected. | SA | A | NS | D | S |
| 16. When I do things for my child, I get the feeling that my efforts are not appreciated very much. | SA | A | NS | D | S |
| 17. When playing, my child doesn't often giggle or laugh. | SA | A | NS | D | S |
| 18. My child doesn't seem to learn as quickly as most children. | SA | A | NS | D | S |
| 19. My child doesn't seem to smile as much as most children. | SA | A | NS | D | S |
| 20. My child is not able to do as much as I expected. | SA | A | NS | D | S |
| 21. It takes a long time and it is very hard for my child to get used to new things. | SA | A | NS | D | S |
| For the next statement, choose your response from the choices "1" to "5" below. | | | | | |
| 22. I feel that I am: | 1 | 2 | 3 | 4 | 5 |
| 1. not very good at being a parent | | | | | |
| 2. a person who has some trouble being a parent | | | | | |
| 3. an average parent | | | | | |
| 4. a better than average parent | | | | | |
| 5. a very good parent | | | | | |
| 23. I expected to have closer and warmer feelings for my child than I do and this bothers me. | SA | A | NS | D | S |
| 24. Sometimes my child does things that bother me just to be mean. | SA | A | NS | D | S |
| 25. My child seems to cry or fuss more often than most children. | SA | A | NS | D | S |
| 26. My child generally wakes up in a bad mood. | SA | A | NS | D | S |
| 27. I feel that my child is very moody and easily upset. | SA | A | NS | D | S |
| 28. My child does a few things which bother me a great deal. | SA | A | NS | D | S |
| 29. My child reacts very strongly when something happens that my child doesn't like. | SA | A | NS | D | S |
| 30. My child gets upset easily over the smallest thing. | SA | A | NS | D | S |
| 31. My child's sleeping or eating schedule was much harder to establish than I expected. | SA | A | NS | D | S |
| For the next statement, choose your response from the choices "1" to "5" below. | | | | | |
| 32. I have found that getting my child to do something or stop doing something is: | 1 | 2 | 3 | 4 | 5 |
| 1. much harder than I expected | | | | | |
| 2. somewhat harder than I expected | | | | | |
| 3. about as hard as I expected | | | | | |
| 4. somewhat easier than I expected | | | | | |
| 5. much easier than I expected | | | | | |
| For the next statement, choose your response from the choices "10+" to "1-3." | | | | | |
| 33. Think carefully and count the number of things which your child does that bother you.
For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. | 10+ | 8-9 | 6-7 | 4-5 | 1- |
| 34. There are some things my child does that really bother me a lot. | SA | A | NS | D | SI |
| 35. My child turned out to be more of a problem than I had expected. | SA | A | NS | D | SI |
| 36. My child makes more demands on me than most children. | SA | A | NS | D | SI |

APPENDIX 6

Pilot study questionnaire

APPENDIX 6

Pilot Study Questionnaire

Thank you for taking the time to fill out the preceding questionnaires. I would appreciate any feedback you have on them.

1. In total, how long did it take you to fill out the questionnaires (excluding this one)? _____ minutes

2. Did you find any of the instructions or questions difficult to understand or confusing? Yes

No

If yes, please state the number(s) of the question(s) and the name of the questionnaire below. Please also state why it was confusing.

3. Did you find any question in any way offensive? Yes

No

If yes, please state the number(s) of the question(s) and the name of the questionnaire below.

4. In the space provided below, please give any additional comments that you may have concerning the questionnaires/ study.

Thank you for all your time and help

APPENDIX 7

Letter from Lothian NHS Research Ethics Committee

Lothian NHS Board

Lothian Research Ethics Committee
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9346
www.nhsllothian.scot.nhs.uk



Miss Eleanor Chalmers
(2F1) 2 Alva Street
West End
Edinburgh
EH2 4QG

Date 13 February 2004
Your Ref
Our Ref LREC/2003/7/46

Enquiries to Stephanie Butler
Extension 89050
Direct Line 0131 536 9050
Email stephanie.butler@lhb.scot.nhs.uk
US IRB No.: IRB00001462

Dear Miss Chalmers,

PARENTAL PERCEPTIONS OF SLEEP PROBLEMS AND DAYTIME CHALLENGING BEHAVIOUR IN CHILDREN WITH SEVERE LEARNING DISABILITIES IN A CLINICAL POPULATION. THE IMPACT ON MATERNAL STRESS.

Thank you for submitting the above research proposal for ethical review. The Primary Care/Public & Mental Health Research Ethics Committee of the Lothian Research Ethics Committee has reviewed this proposed research and has given it a favourable ethical opinion. An official Certificate of Ethical Opinion outlining the conditions of this opinion is enclosed together with a list of members present at the meeting. Please note that the LREC reference number LREC/2003/7/46 **must** be quoted on all correspondence. Correspondence received without the LREC reference number will be returned.

Under the terms of the Scottish Executive Health Department Research Governance Framework for Health and Community Care this opinion has been notified to the Research & Development Office of the relevant NHS Trust(s) where the research is intended to take place. It is the NHS Trust(s) from whom you must obtain management approval before any work on the proposed research can proceed.

Details of the Lothian Research Ethics Committee and its documentation can be found on http://www.nhsllothian.scot.nhs.uk/nhs_lothian/about_lothian_health/lrec/index.html

Yours sincerely

Stephanie Butler
Committee Administrator



Headquarters
Deaconess House 148 Pleasance Edinburgh EH8 9RS

Chair Brian Cavanagh
Chief Executive James Barbour O.B.E.

Lothian NHS Board is the common name of Lothian Health Board

LOTHIAN RESEARCH ETHICS COMMITTEE

CERTIFICATE OF ETHICAL OPINION

LREC Reference Number: LREC/2003/7/46

Title: Parental perceptions of sleep problems and daytime challenging behaviour in children with severe learning disabilities in a clinical population. The impact on maternal stress.

Researcher: Miss Eleanor Chalmers

The Primary Care/Public & Mental Health Research Ethics Committee of the Lothian Research Ethics Committee (the Committee) reviewed this proposed research and is of the opinion that it is ethical and appropriate to be carried out in the Lothian Area. This opinion encompasses all aspects of the application including the Patient/Subject Information Sheet and all other accompanying documentation provided.

The LREC application form, protocol, subject information sheet, information on compensation arrangements, payments to researchers and the provision of expenses to subjects (where appropriate) were reviewed and approved and the members of the Committee present at the meeting are shown on the attached *Membership List*.

This opinion is issued subject to the following conditions and is invalid if they are not followed:

- You must obtain appropriate management approval from the relevant NHS Trust(s) before starting the proposed research. It is the NHS Trust(s) that ultimately decide whether or not this research should go ahead taking account of the advice of the Local Research Ethics Committee.
- You must notify the Sub-Committee and the relevant NHS Trust(s), in advance, of any significant proposed deviation from the original protocol or application form and obtain approval for any such amendments using the *Amendment Approval Request Form*.
- You must submit reports to the Sub-Committee and the NHS Trust(s) once the study is underway if there are any unusual or unexpected results which raise questions about the safety of the research.
- You must report annually on successes, or difficulties, in recruiting subjects in order to provide useful feedback on perceptions of the study among patients and volunteers using the *Progress Report Form*.
- Where the study is terminated prematurely you must report within fifteen days indicating the reasons for early termination.
- You must submit a final report within three months of the completion of the study using the *Progress Report Form*.
- This opinion does not cover the inclusions of adults with incapacity in any study. Such opinion can only be given by the Multi-Centre Research Ethics Committee for Scotland.

Peter Reith
Secretary
Lothian Research Ethics Committee

Stephanie Butler
Administrator
Primary Care/Public & Mental Health
Research Ethics Committee

13 February 2004

LOTHIAN RESEARCH ETHICS COMMITTEE

Members of the Primary Care/Public & Mental Health Committee present at the Meeting held on 11th February 2004:

Mr N Grier(Chairman)	(Lay Member)	
Professor D Blackwood	(Consultant Psychiatrist)	(Expert Member)
Dr A Richardson	(Consultant Psychologist)	(Expert Member)
Dr M S Wilson(GP Representative)	(Expert Member)	
Mr M Brown (Consultant Nurse)	(Expert Member)	
Dr J M Duncan (Consultant Psychiatrist)	(Expert Member)	
Dr D Morrison (Consultant Psychiatrist)	(Expert Member)	
Ms E Munro	(Lay Member)	
Mr R Beasley	(Lay Member)	

Lothian Primary Care NHS Trust

Lrec 2003/7/46
Our Ref: JEW/AMH/03/093
Enquiries to: Jackie Warburton
Ext. No: 0131 537 9522
Date: 28 January 2004

Headquarters
St Roque
Astley Ainslie Hospital
133 Grange Loan
Edinburgh EH9 2HL
Telephone 0131 537 9000
Reception 0131 537 9525
Fax 0131 537 9500
www.show.scot.nhs.uk/lpct/



Miss Eleanor Chalmers
Trainee Clinical Psychologist
(2F1) 2 Alva Street
EDINBURGH
EH2 4QG

Dear Miss Chalmers

Research Proposal: Sleep problems and daytime challenging behaviour in children with severe learning disabilities. The impact on maternal stress

I refer to your recent application to Lothian Primary Care NHS Trust. This has now been considered by the Trust's Research and Development Committee and I would like to confirm that the Lothian Primary Care NHS Trust approves your proposal subject to the written approval of the Research Ethics Sub-Committee being obtained prior to commencement of the study.

A condition of this approval is that you advise me, in advance, of any significant proposed deviation from the original protocol including significant changes to the dates when this research will be active.

I would like to remind you that research must be conducted in accordance with the research governance framework and I enclose a copy of the responsibilities of the Principal Investigator extracted from the framework. One of the conditions of the framework is that any researchers who have access to patients, patient data or records and who are not employed by the NHS must have an honorary NHS contract. If you need to arrange this please contact the Trust Research Manager.

Details of your research will be forwarded to the National Research Register in about six months time. Therefore, if for any reason this research does not go ahead I would be grateful if you could advise me.

With best wishes.

Yours sincerely

cc Stephanie Butler, Simon Fawcett

Headquarters
St Roque, Astley Ainslie Hospital, 133 Grange Loan, Edinburgh EH9 2HL

Chairman Garth Morrison CBE
Chief Executive Murray Duncanson

APPENDIX 8

Main study participant information letter
(for parents recruited via the Learning Disability & Autism Service)

APPENDIX 8

**Child and Family Mental Health Service
Learning Disability and Autism Service
3 Rillbank Terrace
Edinburgh EH9 1LL**

Tel: 0131 662 2202

Fax: 0131 662 2229

19th March 2004

Dear parent/ guardian,

I am aware that your child presently has contact with the learning disability and autism service. I would appreciate it if you could spare a few moments to read this letter.

Who am I?

I am a trainee clinical psychologist attached to The University of Edinburgh. I work alongside Dr Sally Cheseldine (Consultant Clinical Psychologist) and Dr Duncan Manders (Consultant Psychiatrist) at the learning disability and autism service. As you will be aware, this service is part of the Child and Adolescent Mental Health Service, based at the Royal Hospital for Sick Children. My job is to provide psychological input to children with learning disabilities and/or autism and their families.

Why am I writing to you?

I am carrying out a study into children's sleep problems and the effect that this has on their behaviour and wellbeing of their family. I am writing to invite you to take part in this study as I am interested in your experience and views on this subject. Even if your child does not experience these difficulties, it is important that information is gathered about children both with and without sleep problems.

Your participation in this study is voluntary. Although I would be very grateful if you agreed to take part, you do not have to. If you do take part, all I ask is that you, as *the main caregiver of the child* (the relation who spends the most time with him or her) take 15-20 minutes of your time to ***fill out the attached questionnaires and return them to me using the pre-paid envelope provided, by 20th of April 2004.*** You do not have to write your name, or your child's name, on the questionnaires and I will be the only person who sees them. As the process is completely anonymous, nobody will know whether or not you took part in the study.

If you do not want to take part in the study then you do not have to do anything, just dispose of the questionnaires. This will not, in any way, influence your child's access to psychology services now or at any time in the future. If you do take part in the

study but later want to withdraw your questionnaire, you can do so at any time and this will again not influence your child's access to psychology services in the future.

Who else has been asked to take part in the study?

I am asking all parents/ guardians who currently have contact with the service to take part. The study does not require me to look through any of your child's medical notes at any time and I do not have any information about you or your family other than your name and address.

In addition, all parents/ guardians of children with learning disabilities and/ or autism attending three schools in Lothian will be invited to participate. It is therefore possible that some parents/ guardians may receive an additional questionnaire pack through their child's school within the next few weeks. I would ask you to *complete this questionnaire and dispose of any further copy* you may receive through school. Unfortunately this is unavoidable due to the fact that the study is anonymous. Consequently, I do not know which school your child attends and cannot prevent some parents being sent an extra copy.

What are the benefits of taking part?

I hope that the information from this study will help us to improve psychological treatments for children with sleep and behaviour problems that are difficult to manage. In addition, it will help us to understand how children's problems can affect their families.

Who can you get in touch with if you need more information about the study?

If you need more information about the study, please do not hesitate to contact me at the above address or telephone number.

Alternatively you can talk in confidence to either of my supervisors. They can be contacted on the following numbers:

Dr Sally Cheseldine
Consultant Clinical Psychologist
CAMHS
Tel: 0131 662 2210

Dr Karen McKenzie
Consultant Clinical Psychologist
University of Edinburgh
Tel: 0131 537 6102

I hope you decide to take part. Thank you for your time and help.

Yours sincerely

Eleanor Chalmers
Trainee Clinical Psychologist in supervision with
Dr Sally Cheseldine, Consultant Clinical Psychologist

APPENDIX 9

**Main study participant information letter
(for parents recruited via schools)**

APPENDIX 9

**Learning Disability & Autism Service
Child and Family Mental Health Service
Royal Hospital for Sick Children
3 Rillbank Terrace
Edinburgh EH9 1LL**

**Tel: 0131 662 2202
Fax: 0131 662 2229**

30th March 2004

Dear parent/guardian,

Your child will have brought this letter home from school. I would appreciate it if you could spare a few moments to read this letter.

Who am I?

I am a trainee clinical psychologist attached to The University of Edinburgh. I work at the Child and Adolescent Mental Health Service at the Royal Hospital for Sick Children, Edinburgh. My job is to provide psychological input to children with a learning disability and/or autism and their families. I work alongside Dr Sally Cheseldine (Consultant Clinical Psychologist) and Dr Duncan Manders (Consultant Psychiatrist).

Why am I writing to you?

I am carrying out a study into children's sleep problems and the effect that this has on their behaviour and wellbeing of their family. I am writing to invite you to take part in this study as I am interested in your experience and views on this subject. Even if your child does not experience these difficulties, it is important that information is gathered about children both with and without sleep problems.

Your participation in this study is voluntary. Although I would be very grateful if you agreed to take part, you do not have to. If you do take part, all I ask is that you as *the main caregiver of the child* (the relation who spends the most time with him or her) to take 20 minutes of your time to **fill out the attached questionnaires and return it to me using the pre-paid envelope provided by Monday 3rd May 2004**. You do not have to write your name or your child's name on the questionnaires and I will be the only person who sees them. Your child's school will not know whether or not you took part in the study. Non-participation will not affect your child's schooling in any way.

If you do not want to take part in the study then you do not have to do anything, just dispose of the questionnaires. This will not negatively influence your child's access to psychology services if this is needed in the future. If you do take part in the study but later want to withdraw your questionnaire, you can do so at any time and this will not influence your child's access to psychology services in the future.

Who else has been asked to take part in the study?

I am asking the parents of children in three schools to take part in the study. I decided to send the questionnaire through your child's school to protect your privacy. I do not have, and never will have, any information about you or your family.

What are the benefits of taking part?

I hope that the information from this study will help us to improve psychological treatments for children with sleep and behaviour problems that are difficult to manage. In addition, it will help us to understand how children's problems can affect their families.

Who can you get in touch with if you need more information about the study?

If you need more information about the study, please do not hesitate to contact me at the above address or telephone number. Also, the head teacher at your child's school knows about this study and you may wish to talk to him/her about it.

Alternatively you can talk in confidence to either of my supervisors. They can be contacted at the following numbers:

Dr Sally Cheseldine
Consultant Clinical Psychologist
CAMHS
Tel: 0131 662 2210

Dr Karen McKenzie
Consultant Clinical Psychologist
University of Edinburgh
Tel: 0131 537 6102

I hope you decide to take part. Thank you for your time and help.

Yours sincerely

Eleanor Chalmers
Trainee Clinical Psychologist in supervision with
Dr Sally Cheseldine, Consultant Clinical Psychologist

APPENDIX 10

Thank you letter for participants

APPENDIX 10

**Child and Family Mental Health Service
Learning Disability and Autism Service
3 Rillbank Terrace
Edinburgh EH9 1LL**

**Tel: 0131 662 2202
Fax: 0131 662 2229**

20th April 2004

Dear parent/guardian,

You may remember that a few weeks ago I sent you a questionnaire about sleep problems in children with learning disabilities and/or autism.

I wanted to write to you to thank all those who decided to participate in the study. By filling out the questionnaires and returning them, you have helped to provide us with knowledge about sleep problems in children and the effect that this can have on their behaviour and well-being of their family. This information is helpful in enabling us to recognise and treat these problems more effectively.

If anybody has not yet had the time to fill out a questionnaire but wishes to do so, then there is still opportunity to return this to us. The final date to return questionnaires is 1st May 2004. Participation is entirely voluntary and the process is confidential. You do not have to write your name, or your child's name, on the questionnaire.

As the process is completely anonymous, nobody knows who has and has not chosen to take part in the study. Your decision to participate does not in any way affect current or future treatments for your child.

Thank you again for your time. If you have any questions about this research, please do not hesitate to contact me at the above number.

Yours sincerely,

Eleanor Chalmers
Trainee Clinical Psychologist in supervision with
Dr Sally Cheseldine, Consultant Clinical Psychologist.