

## NOCTURNAL DIFFICULTIES IN A POPULATION OF MENTALLY HANDICAPPED CHILDREN

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*Increasingly, parents elect to keep their mentally handicapped children at home, frequently at some cost to themselves and their other children. Professional attention is focusing on many of the pervasive, chronic problems burdening families in these circumstances; problems such as habit, behaviour, eating, bowel and bladder disorders, hyperactivity, learning difficulties and obsessional states. So far, little interest has been shown in sleep patterns, or, taking a broader view, nocturnal problems.*

Sleep problems are known to be common, and have been studied extensively in normal children (Richman 1981; Guilleminault and Anders 1976). Links between perinatal damage and sleep disorders have been postulated (Burton Jones 1978; Richman 1981), suggesting that the mentally handicapped might be particularly vulnerable. References in the literature to handicapped children with sleep disturbances are scanty. The sensitive survey carried out by Tizard and Grad (1961), though dealing with a wide range of problems faced by families with a mentally handicapped child, failed to comment on nocturnal problems. Wing (1975) listed *sleepless nights* as one of the factors that correlated with requests for residential care. Hewett (1970) in her study of cerebral palsied children, found that 20% had difficulties in getting off to sleep, 10% woke frequently and 53% woke sometimes. She commented, "To have regularly disturbed sleep is very hard for parents to bear, and can in some instances make a crucial difference to their ability to care for the children at home".

Clinical experience with mentally handicapped children and their families in Southampton led us to a similar conclusion, and a decision was taken to set up a workshop to help families in the Southampton District. A questionnaire was designed to locate families with night problems (which often remain undisclosed at ordinary medical appointments) and to obtain a measure of need. Following a pilot study outside the District, the questionnaire was sent to the parents of all severely subnormal children on the District Handicap Register. The Register includes all severely subnormal children of school age, (16 and under) and those pre-school children so far assessed. The response was good, and after telephone calls, home visits and further letters, 214 properly completed schedules were received from the Register population of 236, a 90.6% response.

### THE QUESTIONNAIRE

Parents were required to answer between twenty two and sixty questions, depending on the presence or absence of nocturnal difficulties. The term "difficulty" is highly subjective, but relevant in a survey concerned with the way parents feel about their children. The questionnaire took about ten minutes to complete. Parents were asked about difficulties in the previous seven days only. This seven day limitation was felt to be so important that reminders to consider only the past seven days were built into the questionnaire at five different points.

The following areas were covered by questions:

Problems with preparing for bed

Problems with settling to sleep

Problems with waking (frequency, duration, and pattern)

1) General Hospital, Southampton.  
2) Odstock Hospital, Salisbury

- Morning routines
- Use of comforters
- Medication
- Sleeping arrangements
- Attitude of neighbours
- Whether help required
- Social data
- Family data

## FINDINGS

### Nocturnal Difficulties of Any Kind

171 (80%) of parents indicated that they had one or more difficulties. Recordings of 1—4 specific difficulties were graded "mild", and 5—10 "severe". Using these criteria, 120 (56%) had "mild" problems and 49 (23%) "severe".

### Age

Maturation is known to be associated with the stabilisation of sleep patterns. As a child grows older, these synchronise better with the family and social environment (Guilleminault and Anders 1976). Several studies have found that in normal children, sleep disorders diminish with age (Richman 1981). Our data (Table 1) suggested that mentally handicapped children are slower at growing out of sleeping difficulties.

**Table 1**

Nocturnal Difficulties by Age

<i>Under 6</i>	<i>6—Under 11</i>	<i>11—16+</i>
183 (86%)	172 (81%)	165 (77%)

### Social Class

Nothing significant emerged from the data.

### Residential Establishments

Caretakers experienced nocturnal difficulties with only 16 (47%) of the thirty four children living in residential establishments (hostels, hospitals, children's homes or boarding school) and in only one case could these be classified as "severe". Children in residential care might be expected to be more of a problem and less manageable than those at home, and it seems likely that this finding is due to the fact that residential establishments have staff specifically employed on night duty, who do not therefore experience disturbed nights as a problem in the same way as parents who expect to sleep at night.

### Getting the Child to Bed

Preparing a child for bed in Western societies is often a highly ritualised, anxiety-reducing operation. In a study of normal children (Roberts and Schoelkopf 1951), 90% of 2 year olds had bedtime rituals, 33% very elaborate ones. Our survey revealed that handicapped children have similar routines — an unsurprising finding as it is well known that most handicapped children like “sameness” in their lives. There are difficulties at this stage of the proceedings with 114 (53%) of the children, 106 (49%) coming into the “mild” category and 8 (4%) “severe”.

### Getting the Child to Sleep

As parents know, even when the child is in bed, the settling phase can be protracted and complicated. 120 (56%) of the parents reported difficulties at this stage but only 3 (1.4%) came into the “severe” category. The picture is set out in Table 2.

**Table 2**

Crying and being miserable in bed	32%
Calling out to parents	22%
Getting out of bed (but remaining in room)	35%
Getting out of bed (joining parents)	1%
Getting out of bed and disturbing other children	27%
Restless behaviour such as rocking and head-banging.	1%
Other undesirable behaviour	1%

### The Child Waking

56.5% of the parents faced broken nights. We obtained information about the average number of wakings per night and the average resettling times (Tables 3 and 4).

**Table 3**  
Reported Wakings per Night

<i>Number of Children</i>	<i>Number of Wakings</i>
93	None
57	1
39	2
18	3
5	4
2	5

**Table 4**  
Reported Re-Settling Times

<i>Number of Children</i>	<i>Time to Settle (minutes)</i>
68	0—15
22	16—30
9	31—45
12	45—60
10	60+

### **Changing Beds**

17.3% of the children went into the parents' bed and 7.5% of parents went into the child's bed. There were many variations. Stays in the inappropriate bed were sometimes short, sometimes night long. Sometimes there were secondary movements, e.g. when a big child came into the parental bed, one parent might go to the child's bed, either for peace, or through lack of bed space.

### **Morning Difficulties**

Parents described various problems. The commonest were noisiness, wandering about and disturbing other members of the family, and failure to co-operate over getting up and dressing. 43 (20%) produced difficulties at this end of the night. 4 (2%) coming into the "severe" category.

### **Impact on Siblings**

24 children were without siblings. 23 (96%) of these had difficulties, in nine cases "severe". Difficulties decreased steadily as the number of siblings rose. In the "more than 4 siblings" group, only 4 children out of 6 (66%) had difficulties. If children with artificially high numbers of siblings are included — the residentially placed children already described — the trend persists.

### **Medication**

15% of the children were on anticonvulsants. The incidence of difficulties (85%) did not differ significantly from the group as a whole. 12% were on other drugs, including hypnotics, antihistamines, antitussives and muscle relaxants, and of this group, which contained several children with concomitant physical handicaps, 24 out of 25 (96%) had difficulties.

### **Comforters**

Under half of the survey children (95 out of 214) habitually had comforters. Those with comforters had proportionately more difficulties (87% as against 74% of the comforterless).

### **Neighbours**

13% admitted worrying about neighbours at night time. 5% indicated they had had complaints.

## **DISCUSSION**

In the last quarter century the stressful consequences of having a handicapped child have been recognised (Rutter *et al.*, 1970; Satterwhite, 1978; Travis, 1976; Haggerty *et al.*, 1975). The findings in this survey delineate one particular area of family stress, and may be of practical value since clinical experience suggests that therapeutic intervention can reduce nocturnal stress and thus improve the quality of family life for an important part of the twenty four hour cycle.

Forty five families wanted help, over a fifth of all the families in the survey. Most were already in touch with general practitioners, teachers, health visitors, school doctors and paediatricians. So why had they not asked for help earlier? Comments suggest there were several reasons. They had other problems with which to trouble professionals. Some had asked for help and were offered sedatives which did not help, and in some instances made matters worse. Several parents observed that they had not thought their nocturnal

struggles relevant — professionals seldom asked routine questions about that part of the day. An interesting finding was that a number of parents with difficulties did not perceive themselves as having real problems. Out of the 52 families found to have "severe" difficulties, 28 turned down the offer of help. Some of these families had severe problems by any standards.

*Example.*

Kenneth is a 12 year old mentally handicapped boy. He has a vocabulary of three or four words. His motor co-ordination is poor and whilst he can walk he prefers crawling. He attends a day school for the severely handicapped. He lives with his father in a council flat. The father is unemployed and has a disability pension. Kenneth's mother couldn't cope and left years ago. The father's life is determined by Kenneth's needs. Survey questions about "bed time" seem meaningless to him. He waits until Kenneth shows signs of wanting to go to bed — then they both go together. Kenneth is untrained in a toilet sense — the father deals with wetting and soiling as the occasion demands. Shopping is done when Kenneth is at school. Apart from an odd half hour in the pub midday, the father lives an isolated life. He complained about his lot to the survey team but showed no interest in changing things.

These families with pronounced symbiotic features manifest a style of parenting described by MacKeith (1973) as "lavishly caring". He considered that this was a pathological state of affairs, a reaction formation against feelings of revulsion and rejection. Whilst we encountered strong ambivalent feelings in these parents we had no reason to attribute the pathological over involvement to "reaction formation". Whatever the underlying mechanisms are, these parents lead unusual and frequently stress-ridden lives.

The tendency for nocturnal difficulties to diminish as family size increased may be attributable to a number of factors. Only children in normal populations frequently have unduly anxious parents. Unhandicapped siblings may create nocturnal "norms" which help orientate parents. Siblings from an early age come to share in the caretaking, diluting parental responsibility and obsessive vigilance. The dramatic excess of problems in family-based over institute-based children is strong evidence of the importance of relationships and emotional factors in the aetiology of nocturnal problems.

## CONCLUSION

This survey suggests that families with severely subnormal children are subject to considerable nocturnal stress. In character, the difficulties described by these parents are essentially similar to those affecting families with normal children. In the case of normal children intervention can reduce difficulties and alleviate stress. Now that many severely subnormal children are remaining with their families it behoves doctors, psychologists and others to offer help. We ourselves have set up a workshop service for the forty five families who responded to our offer of assistance. This stage of the project is well advanced and will be the subject of a further report.

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