

# **Research on sleep problems and psychological function in children with Down syndrome: implications for clinical practice and everyday care**

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### **Introduction**

With the financial support of the Portsmouth Down Syndrome Trust, based at the Sarah Duffen Centre in Portsmouth, research has been carried out in the last few years on the sleep problems of children with Down syndrome and the associations between these problems, learning, behaviour and family factors. The children studied were generally of school age and attending either mainstream or special schools. The research programme, which has involved a number of novel approaches to these neglected problems, has raised various issues which call for further investigation but the main findings already have implications for the care by both professionals and parents of children with Down syndrome. This account describes in general terms such findings and implications. Further details are available in the selected references provided.

### **Research findings**

#### **The occurrence of sleep problems**

Sleep problems are known to be very common in the general population at all ages, but they are particularly prominent in children with a learning disability, somewhat in relation to the degree of disability. Often they are more severe and persistent in children with a learning disability than in other children and, unfortunately, frequently not treated appropriately, if at all.

A basic finding in the Portsmouth research was confirmation of a high rate of severe sleep problems (as reported by parents) in the 91 children with Down syndrome studied and in children with other conditions characterised by learning disability (n=71). This rate was shown to be much greater in children with a learning disability in general compared with the non-learning disabled siblings of the children with Down syndrome (n=54) and children from the general population (n=71).

#### **Types of sleep problems**

Many childhood sleep problems (often of great concern to parents) take the form of reluctance or inability to go to sleep at night, or repeated night time wakings with distress and insistence on parents' attention. These problems were found to be very common in both of the groups of children with a learning disability, although somewhat less so in the children with Down syndrome. However, compared with the other groups, the children with Down syndrome were characterised by higher rates of parental reports of features which (especially in combination) raised the possibility that their children's breathing patterns were disturbed during sleep. These features were: loud snoring, gagging or choking sounds, interruption in breathing ('apnoeic episodes'), sleeping with the neck extended, mouth breathing and very restless sleep.

This distinctive profile is in keeping with the evidence that many children with Down syndrome are prone to obstruction of their upper airway during sleep caused by a number of possible anatomical factors. Some of these factors may be part of the child's basic condition, such as relatively small mouth and upper airway passages; others are less intrinsic such as enlarged tonsils and being overweight. Many children in the general population have upper airway obstruction (UAO), usually caused by enlarged tonsils and adenoids, but the rate is very much higher in children with Down syndrome. The importance of UAO is that it impairs

the quality of overnight sleep because of frequent arousals (usually without actual awakening) and this contributes to daytime learning and behaviour problems because of tiredness.

Other sleep problems shared by the children with Down syndrome with the other groups studied included sleep talking, teeth grinding and bedwetting. Nightmares, sleep walking and night terrors were not often reported by parents in any of the groups.

#### **Daytime behavioural disturbance and maternal stress levels**

High rates of daytime behavioural disturbance were also seen in the children with a learning disability, especially those with a learning disability other than Down syndrome, compared with the siblings of the children with Down syndrome and children from the general population. The same pattern was seen regarding maternal stress, which was often very high. These findings suggest that children with Down syndrome are generally less affected by daytime behaviour problems and their mothers less stressed when compared with children with other forms of learning disability. However, the heterogeneity of children with Down syndrome and their families needs to be acknowledged.

#### **Links between sleep problems, behavioural disturbance and maternal stress**

As in other children, disturbed behaviour and maternal stress may develop for a number of reasons in children with Down syndrome and it is very difficult to separate out individual associations or, indeed, to establish the direction of the association.

Overall, as predicted, sleep disturbance was generally linked with behavioural disturbance and maternal stress and also with excessive daytime sleepiness in the learning disabled groups.

Three different patterns of sleep disturbance in children with Down syndrome were suggested by factor analysis. Daytime behaviour problems and maternal stress were most prominent where the child's sleep showed evidence of disruption during the night (characterised by repeated waking and extreme restlessness). Sleep onset difficulties (i.e. getting the child to go to bed and/or settling to sleep) and features suggestive of UAO were less associated with daytime problems although, in all types of sleep disturbance, behavioural difficulties and maternal stress were significantly higher than in the children who were reported to sleep well.

#### **Other related studies**

The research programme included more circumscribed and exploratory studies concerning the assessment and significance of sleep related breathing problems in children with Down syndrome.

As snoring (or other noisy breathing at night) and restless sleep are both signs suggestive of UAO and therefore important to enquire about when taking the child's history, the accuracy of parents' ratings was assessed by comparing such ratings with objective measures of overnight sleep. These objective measures involved detailed analysis of overnight video/audio recordings of the child, and also body movements recorded by means of a small activity monitor attached to the child's wrist. In general, the correspondence between subjective and objective measures was satisfactory

suggesting that reliance on parental reports of these significant signs is usually justified.

A second study was concerned with how well certain factors predicted daytime psychological function. These factors were snoring (or other noisy breathing), restless sleep, total sleep time and repeated significant reductions in blood oxygen levels during sleep. These variables were chosen because they have been viewed as indices of sleep disruption of a type which might be expected to adversely affect daytime cognitive function and behaviour. A computerised version of the Continuous Performance Task (CPT) was used in an attempt to assess vigilance objectively and parents and teachers completed behaviour rating scales on the child. Each of these predictor variables showed a variety of associations with daytime behavioural disturbance but the inter-relationships were complicated. They are currently being considered further with a view to more detailed studies.

#### **Implications**

Certain recommendations about the assessment and care of children with Down syndrome are suggested by the above findings and those from related studies.

- 1) Sleep and its possible disorders should be assessed routinely, not only because of the immediate distress that a sleep problem can cause to the child and other family members, but also because the treatment of the sleep problem might have a beneficial effect on learning and behaviour.
- 2) This assessment needs to consist of a detailed account of sleep patterns and problems at the present time, and their development in relation to biological and psychosocial factors. Especially in the case of children with Down syndrome, enquiries are required about sleep disorders of 'behavioural' origin (usually responsive to competent behavioural treatment) and those caused by 'physical' factors (e.g. UAO) which call for a physical approach. Combinations of the two types of sleep problems may well occur.
- 3) The possible effects of persistent sleep problems on other members of the family (especially mothers) should be considered carefully. Distress, depression, poor parenting, marital problems and even worse consequences can result from long-standing sleep problems for which no effective help has been sought or provided.
- 4) Community and hospital services ought to be alert to the possibility of severe sleep disorders in children with Down syndrome. Appropriate psychological, physiological and other clinical investigations need to be available. Treatments appropriate to the individual case should be provided, as early in the child's development as possible.

#### **Further research**

The topic of sleep problems and their consequences in children with Down syndrome (or, for that matter, other children with psychological or physical problems) is seriously neglected in medical and other professional education. Not only does this adversely affect standards of clinical practice, it means that research has been very limited. Further investigation of this aspect of Down syndrome is much

needed. Aspects under consideration by our own group include the following:

- 1) the types of UAO in children with Down syndrome and their effects on psychological and also physical development (including growth and cardio-respiratory function),
- 2) screening procedures for UAO (including obstructive sleep apnoea syndrome), especially for use at an early age,
- 3) assessments of learning and behaviour (suitable for children with a learning disability) to provide insight into the deficits associated with sleep related breathing problems,
- 4) effective treatments for UAO, in the light of individual differences in the underlying cause,
- 5) in the case of 'behavioural' sleep problems, possible preventive measures by means of early parental instruction.

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