

## Sleep problems in children and young people with neurodevelopmental disorders

### A Cerebra funded research programme

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Many parents of children and young people with the most complex needs will say that their child has a sleep problem. All too often this is assumed to be part and parcel of a learning disability or autism with the assumption that nothing can be done. Our experience as clinicians and researchers was that sleep problems were common but neglected and that poor sleep might be related to both daytime behaviour in children and parental wellbeing.



*Dr. Caroline Richards led the programme of sleep research*

In some syndromes poor sleep is a major problem and so these syndromes were a very good starting point to try to understand the different causes of sleep problems and their impact. With all this in mind, Dr. Caroline Richards (Lecturer in Neurodevelopmental Disorders at the University of Birmingham) led a programme of research to identify parents' priorities in this area, work out how to assess the most severe sleep problems in children with complex needs and describe the possible causes of poor sleep.

Two Cerebra funded PhD students, Jayne Trickett and Georgie Ager, worked on sleep in Tuberous Sclerosis Complex, autism, Angelman and Smith-Magenis syndromes. The results showed that difficulties getting off to sleep were common in autism, short and variable sleep was the norm in Angelman syndrome and night-time waking and

daytime sleepiness were common in Smith-Magenis syndrome. This means different groups have different types of sleep problems.

Georgie Ager went on to code hundreds of hours of night-time video and found that unusual leg movements seemed to occur just before waking in Angelman syndrome. This might indicate pain or an unusual type of seizure. Either way the next step in assessment and intervention is clear, to identify and treat co-occurring physical health problems to improve sleep. The assessment procedures developed in these studies have now been made available in the Cerebra Sleep Guide so clinicians and researchers can identify possible causes of poor sleep in children with the most complex needs.



*Grace wore an actigraph on her ankle so that researchers could record movement at night*

Other work by Dr. Andy Surtees, Dr. Emma Clarkson and Jayne Trickett has shown that poor sleep affects daytime behaviour. Remarkably, only a short break in night-time sleep in Smith-Magenis syndrome significantly increases the chance of challenging behaviour the next day. This is

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important for clinicians to know as a sleep intervention may help challenging behaviour. In related work, Dr. Stacey Bissell has been working closely with the Smith-Magenis Foundation to provide advice on safe sleeping given the common night-time waking.

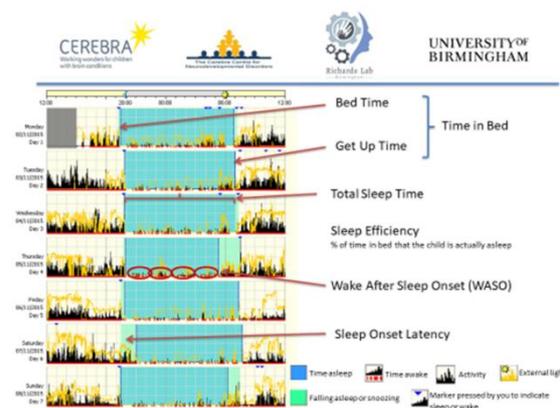


*The sleep team attend a Smith-Magenis conference to give out information and invite people to take part in research.*

Parents of children with Angelman syndrome were most concerned about the impact of loss of sleep on their ability to work and support their family. Dr. Mary Heald found that stress in parents was not related to overall lack of sleep, as we had thought it might be, but to unpredictable sleep in their children. This discovery fitted with Jayne Trickett's finding that there was significant variability night to night in sleep in Angelman syndrome. The goal of intervention for this group then might not be more sleep overall but reducing the number of poor nights. Parent priorities were humbling to us. Perhaps the most modest request we heard was from the parent of a child who only slept for 3 to 4 hours a night. They asked for one extra hour of sleep in the morning.

This programme of research has been very productive and there are clear implications.

Helping to make sleep more predictable and consolidated, identifying breathing problems, pain and seizures as a cause of night-time waking, describing the relationship between sleep and daytime behaviour more accurately, and seeking that one extra hour of sleep a night are all achievable goals. These challenges will be met by the research conducted by the Cerebra Network for Neurodevelopmental Disorders.



*This is a record of one child's sleep from the analysis of the actigraph data*

#### Examples of publications:

Surtees, A., Oliver, C., Jones, C. A., Evans, D. and Richards, C. (2018). Shorter duration and poorer quality sleep in people with intellectual disabilities: A meta-analysis. *Sleep Medicine Reviews*, **40**, 135-150.

Trickett, J., Oliver, C., Heald, M., Denyer, H., Surtees, A., Clarkson, Gringras, P. and Richards, C. (2019). Multi-method assessment of sleep in children with Angelman syndrome: A case-controlled study. *Frontiers in Psychiatry*. **10**, 874.