Understanding and reducing sleep disorders in children with developmental delay

Summary of progress 2014 - 2018

The Cerebra Centre for Neurodevelopmental Disorders

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Why is the Sleep Project important for families?

Sleep is a universal phenomenon, influencing almost every human activity. We need good quality sleep in order to learn new information, pay attention to the world around us, and store memories effectively. Sleep influences our mood, how hungry or full we feel, as well as fundamental biological processes such as cell development. Given the wide-reaching impact of sleep, it is not surprising that poor sleep has a significant negative impact on people.

Unfortunately, short and disrupted sleep is common in children with neurodevelopmental disorders. Children with autism, intellectual disabilities and a variety of rare genetic syndromes are at greatest risk of experiencing the negative consequences of poor sleep. What's more, these children may already find learning new information, maintaining attention and regulating mood and behaviour very difficult; compromised sleep in these groups is therefore a huge concern.

Despite this great need, research on sleep in children with neurodevelopmental disorders is sadly lacking. *We know the least about sleep in the children for whom sleep is arguably most important.* The Sleep Project, conducted by the Cerebra Centre for Neurodevelopmental Disorders will change this. We lead cutting edge research to understand the different types and causes of sleep problems in children with neurodevelopmental disorders, identifying how poor sleep impacts on children and their families and trialling new interventions to reduce sleep problems more effectively.

What progress has the Sleep Project made since Cerebra began to support it?

Children taking part in the Actigraphy Research Study

Projects: We have completed five core components to date.

1. We have conducted a *large scale interview study*, speaking with fifty parents and carers of children with Angelman syndrome (a rare genetic syndrome associated with sleep problems) to identify their concerns and priorities in sleep.

2. We completed a *cross-syndrome sleep survey* with over 190 children with Angelman syndrome, Smith-Magenis syndrome, tuberous sclerosis complex and autism spectrum disorder. This provided robust evidence of syndrome specific sleep problems and unique pathways to sleep disturbance. We found that knowing the cause of a child's neurodevelopmental disorder is essential to ensure accurate understanding of their sleep problem.

3. We have completed the *largest direct study of sleep using Actigraphy in children with Angelman syndrome, Smith-Magenis syndrome and Autism Spectrum Disorder.* In this study over 100 children wore sleep trackers (Actigraphs) for a week, to provide direct evidence of their sleep-wake cycles. This resulted in the, largest, most robust international data on sleep patterns and the daytime impact of poor sleep in these rare groups.

4. We have collected *novel night-camera video data* on children in the Actigraphy study and are analysing these data to better understand what children do when they wake up. We will use our understanding of waking and settling behaviours to develop more tailored interventions for sleep.

Example of night-camera video data

5. Finally, we have conducted an *in-depth study of sleep and parental stress,* through collecting Actigraphy, self-report and bio-marker (cortisol) data from parents of children with neurodevelopmental disorder. This will enable us to quantify the impact of children's poor sleep upon parents and carers.

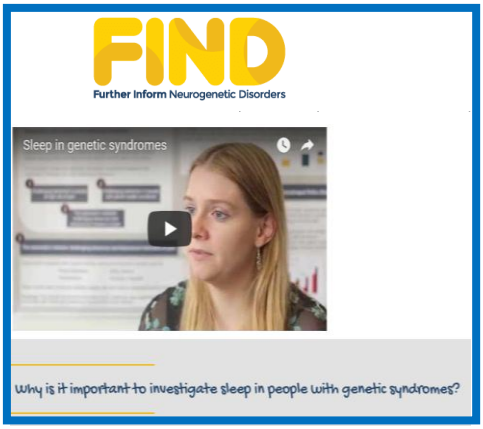
Families who have taken part in these studies have received detailed individualised feedback reports, and the results of these studies have been published or are in review at leading academic journals.

Public Knowledge: A key aim of the sleep project is to ensure that as we improve scientific understanding of sleep in children with neurodevelopmental disorders, we simultaneously share that information with families, clinicians and educators. Research traditionally takes 10 to 17 years to influence real world practice - that is an unacceptably long time. We are committed to reducing this lag. In addition to publishing our research in high-impact academic journals and speaking at scientific conferences, we provide regular talks on sleep to inform and update parents and professionals. These have included talks at schools, parent support conferences, national professional networking events and large public conferences such as *The Autism Show.*

In addition to this, we co-produced a Sleep Guide for parents, in partnership with Cerebra which is freely available via Cerebra's website.

Cerebra Sleep Guide

The guide explains how problems with sleep may develop, the specific nature of sleep problems in children with rare genetic syndromes, how to assess sleep problems, and how to intervene to improve sleep. Alongside the guide, we also co-produced brief Sleep Cards to be used by Cerebra's Sleep Service. These provide bite-size chunks of information on sleep interventions that the Cerebra Sleep Practitioners can give to families they are working with, to help parents and carers to implement evidence-based sleep interventions.



Jayne Trickett, Cerebra Funded Sleep PhD Student, talking about sleep on the FIND website

We have also launched new sleep content on our dissemination website: Further Inform Neurogenetic Disorders (FIND). The site has had over 14,000 page views since it was launched and continues to attract a high rate of hits. The sleep section on FIND contains accessible information on topics such as: current sleep knowledge, why it is important to investigate sleep in people with genetic syndromes, what interventions are available for sleep and the sleep research that we have been conducting.

Investing in People: The Sleep Project will increase expertise in Sleep Research in the UK. Through the first four years of the project, we have trained two PhD, seven Clinical Doctoral, three Masters and 10 Undergraduate students. The majority of these students are now working in either research or clinical psychology and therefore this investment in training has increased UK expertise in sleep problems in neurodevelopmental disorders.

What will be the longer term impact of the Sleep Project for families?

The long term goal of the Sleep Project is to improve sleep outcomes for children with neurodevelopmental disorders, ensuring that they have the same opportunities to thrive in life as their typically developing peers. With sustained funding, the Sleep Project will ensure that children with neurodevelopmental disorders have access to tailored assessments and timely interventions to ensure the best quantity and quality of sleep for them and their families.

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