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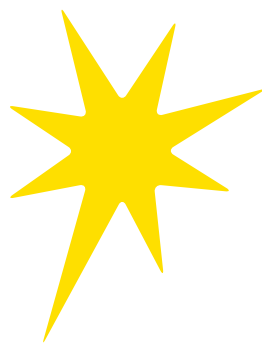
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Research Summary

Behavioural interventions for
sleep problems in people with an
intellectual disability: Do they work?



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Thank you.

Behavioural interventions for sleep problems in people with an intellectual disability: Do they work?

This is a summary of a recently published academic paper (link below). The summary was prepared by the research team (Lee Priday, Christopher Byrne and Vaso Totsika) and was reviewed by Dawn Cavanagh from CEREBRA.

Key findings

- We identified all studies that examined whether behavioural interventions improve sleep in children and adults with intellectual disabilities.
- Seven studies were included in this review with a total of 1 69 people with intellectual disability.
- The evidence from all studies suggested that behavioural interventions lead to large improvements: sleep problems showed an improvement of about 53% compared to before the start of the intervention.
- In particular, behavioural interventions improved both **sleep initiation** problems (falling asleep) and **sleep maintenance** problems (staying asleep).
- The evidence at the moment shows that some of the improvements are maintained over a longer time: co-sleeping (sleeping in parents' bed), falling asleep independently, and the time it takes to fall asleep. Other sleep problems, such as falling asleep in own bed and night waking, improved a lot after the intervention but improvements did not remain at high levels over a longer period, suggesting these problems require longer or repeated behavioural interventions.

About the research team:

The research team are Lee Priday, Christopher Byrne and Vaso Totsika. This review took place when Lee Priday and Christopher Byrne were doing their clinical psychology doctoral training at the **North Wales Clinical Psychology Programme** (NWCPP). Vaso Totsika was at the time working at the NWCPP, supporting clinical psychology trainees on conducting research.

The topic, or research question, came about as all three research team members' shared an interest in understanding what could make a difference to the lives of people with an intellectual disability. (The term intellectual disability is what in the UK is known as learning disability or learning difficulties; the term intellectual disability is used world-wide.) Sleep problems were identified as one of the least well studied problems in the lives of people with an intellectual disability; an issue that has implications for the health and well-being of those who experience them, but also for the well-being of those who support them, parents and staff carers.

The team set out to find out in a systematic way whether behavioural interventions could improve sleep problems.

What is a behavioural intervention?

Behavioural interventions are a set of processes that aim to change socially significant behaviour through changes in the environment in which this behaviour takes place. Behavioural interventions are based on the science of applied behaviour analysis. Below, we provide some examples of behavioural interventions (i.e., changes in the environment) to promote sleep.

Why behavioural interventions?

When we looked at what was known about effective interventions for sleep problems with people with intellectual disability, we realised that all the systematic evidence up until that point related to the role of medication and in particular melatonin. We decided that this was not very informative or helpful for three reasons: (a) melatonin is not licensed for prescribing for sleep problems in all countries; (b) behavioural interventions are offered in clinical practice to people with intellectual disability and we need to know what the overall evidence is telling us; (c) sleep problems are a complex issue, and likely to benefit from a variety of approaches.

What was the process?

We systematically searched the literature to find studies that examined whether behavioural interventions (when delivered on their own) work to improve sleep problems (this process is known as systematic review).

We found 7 studies that had done this. They included a total of 169 people with intellectual disability. Six of the studies focused on children with intellectual disability (starting from the age of 1), and involved training parents to deliver behavioural interventions. Two of the studies included adults with intellectual disabilities (aged up to 66 years-old).

We pooled all the data from these studies into a single number so as to understand whether behavioural interventions work for sleep problems (this process is known as meta-analysis).

- Four studies were group studies: i.e., offered a similar behavioural intervention across a group of people with intellectual disability.
- Three studies tailored behavioural interventions and evaluations around the individual child or adult (these studies are called single case experimental studies).

What are behavioural interventions for sleep problems?

Some examples of behavioural interventions from these studies:

A big focus of behavioural interventions is around establishing a bed time routine: how to set up the environment to encourage good sleep habits; how to use signals to indicate it is time for sleep (sleep routine), what is a good sleep routine; what type of activities are helpful or not helpful for signaling sleep; what type of activities during the rest of the day help a good night's sleep; what to do about daytime naps.

Another big focus of behavioural interventions is how other people should respond when the person with intellectual disability is showing behaviours that are incompatible with sleeping (i.e., getting up from bed, waking up, playing up): behavioural interventions train parents or carers to respond to such behaviours in a way that encourages sleep.

Are there any improvements in sleep after behavioural interventions?

We looked at the different types of studies (group and individual) separately but in a parallel way.

Both types of evaluations suggested that there are **large improvements in sleep problems overall** after behavioural intervention. One of the metrics we used indicated that sleep problems improved by **53%** after the intervention.

We then examined whether there is a difference depending on the type of sleep problem or the type of data collected.

Sleep problems relate to three phases: sleep initiation (falling asleep), sleep maintenance (staying asleep) and rising. The studies we included had only looked at the first two phases. Pulling the data together suggested that both **sleep initiation** and **sleep maintenance** problems benefitted significantly from behavioural interventions. One of the metrics we used suggested that improvements in these phases was at 50% to 56% over baseline problems, for initiation and maintenance, respectively.

Improvements are significant whether the data are collected by parents filling in diaries or through more objective methods (e.g., actigraphy monitor which is a monitor worn by participants to record their sleep pattern). However, parents tend to report larger gains, whereas actigraphy records show more modest gains.

Do the improvements maintain over a longer period?

The answer to this question is **'it depends'**. The two types of studies (group and individual studies) gave a different answer to this question. Group studies suggested that improvements are not only maintained, they are actually strengthened over time (about **3 months** after the intervention). Individual studies (single case experimental studies) suggested that maintenance is more variable, and it probably depends on the exact type of problem.

It appears that improvements were more likely to maintain for problems of **co-sleeping** (sleeping with parents), **falling asleep independently**, and **the time it takes to fall asleep**. These three types of problems showed improvements of between 50% to 100% at follow up. However, problems of **falling asleep in own bed** and **night wakings**, even though they improved significantly after the intervention, their improvement longer-term was more variable (i.e., for some people gains maintained or increased whereas for others they decreased). This could suggest that these types of problems might need longer or repeated behavioural intervention to ensure that improvements are maintained over a longer period of time.

Overall conclusions of the review

- The data so far suggest behavioural interventions work well to improve sleep problems in children and adults with intellectual disability.
- The quality of the studies we included was adequate (except for one that was of good quality). Taking into account the study quality, we can conclude that behavioural interventions are **a promising evidence-based practice**.
- What would it take to conclude that behavioural interventions are an established evidence-based practice? More studies are needed, and more studies of stronger quality.
- We need to repeat this review when we have more studies.

Where can I find this study?

The study was accepted for publication by an academic journal entitled 'Journal of Intellectual Disability Research' after being independently reviewed by two experts who were not part of the research team. The study can be found here:

<http://onlinelibrary.wiley.com/doi/10.1111/jir.12265/abstract>

For further details or any questions please contact any of the research team; we would be happy to discuss this study

And some concluding comments about the study from the researchers

Lee is now a practicing clinical psychologist in a low secure forensic unit, whereas Chris is planning to practice within the area of neuropsychology. This study helped them to start thinking about how the findings of different studies can be combined, in order to provide summary data that can be used to inform clinical practice. The review highlights the benefits of non-pharmacological interventions for a variety of sleep difficulties. Vaso Totsika is a researcher in learning disabilities and autism, currently working as an Associate Professor at University College London. She believes the study is very important because it provided the first systematic synthesis of behavioural interventions for sleep problems, but also because it used, for the first time in this field, evidence that came from two different types of studies (group and single case experimental studies). She believes that we need to draw on all good quality evidence we have available in research so as to address parents' and practitioners' urgent questions, and come up with answers about what works and what doesn't.

The findings of this report are those of the author, not necessarily those of Cerebra.

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