Autism and Sleep: The Sleep Scotland Model - a cognitive behavioural intervention approach to sleep problems

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Abstract

Severe sleep disorders are more common in children with additional support needs, with the sleep problem often continuing for years and having damaging consequences for the mental and physical health of the entire family. Sleep Scotland is a charity which trains sleep counsellors to support these families using a cognitive behavioural intervention model, addressing non-sleeping as a form of learned behaviour which can also be unlearned. The charity provides support to families who have children and young people with additional support needs and sleep problems, and has more recently extended its service to teenagers in mainstream schools. This article describes the origins of Sleep Scotland, considers why sleep is such a major difficulty for people with autism spectrum disorder, and presents the intervention model used by our counsellors. This model is illustrated using a case study.

Keywords: sleep problems, additional support needs, autism spectrum disorder, cognitive behavioural strategies

Introduction

Sleep Scotland is a charity that provides support to families who have children and young people with additional support needs and sleep problems; it has recently extended its service to teenagers and vulnerable children. The origins of the charity are highly personal and go back to 1998: at this time my middle son, Andrew, who is on the autistic spectrum with severe learning difficulties, was experiencing sleep difficulties, and sleeping only in fragments.

Having a child who doesn't sleep makes you part of a secret club you only find out about when you join it, and would prefer not to be a part of. When everyone else is switching their lights off and going to sleep, you are switching yours on. The final confirmation that this was a widespread problem with an unmet need for support came when Andrew's teacher said that in her twenty-five years of special education she had yet to meet a pupil who didn't have some kind of sleeping disorder.

Research revealed some startling facts. Whilst sleep is just as essential as adequate nutrition, children and young people with additional support needs often have serious sleep problems. Although the impact of sleep deprivation is vast, sleep problems feature very little in medical or healthcare professional teaching.

Using my psychology background and intensive research, I formulated a sleep programme for Andrew based on cognitive and behavioural techniques. By sticking to consistent routines and reinforcing positive behaviour, I found that Andrew's sleep pattern improved dramatically. Fast forward fifteen years and Andrew is now a happy and strong twenty-five year old with no sleep problems, and I am the CEO of Sleep Scotland.

At present Sleep Scotland has 253 sleep counsellors practising in Scotland and has provided an intensive sleep programme to 2710 children. The charity trains sleep counsellors to work face to face with families, and provide them with a tailor-made sleep programme and ongoing support to help them improve their child's sleep.

In 2011 Sleep Scotland also launched Sound Sleep, an educational initiative for secondary schools to raise awareness of the importance of sleep for health and wellbeing. This project was developed as

a response to the common complaint made to Sleep Scotland staff of young people 'turning night into day'. Research offers a dismal picture of our young people's current quality and quantity of sleep. Sound Sleep provides professionals with a one day 'Train the Trainer' course and teaching pack, enabling them to help teenagers implement positive sleep habits into their routines.

Our sleep counselling research and practice has underlined the need that exists for Sleep Scotland's service. Not only are severe sleep disorders more common in children with additional support needs but the sleep problems can continue for years. Moreover, when a child with additional support needs is suffering from a sleep disorder, carers and siblings also often suffer from sleep deprivation – a major source of stress for families. The quality of parental care within the family can be reduced, and the development of the child and their siblings can be affected. Family members may experience physical and mental health problems: severe sleep deprivation has been linked to obesity, heart disease and mental health difficulties. The strain often leads families to decide on residential care for their child.

Sleep Difficulties in Children and Young People with Autism Spectrum Disorder

56-83% of people with autism spectrum disorder experience some kind of sleep difficulty (1). These include problems with settling, anxiety, overactivity, poor concept of time, rigid behaviour and obsessive behaviour. So why are children on the autistic spectrum more likely to have sleep problems?

While sometimes there is a physical basis for their sleep problem, generally it is connected to their communication difficulties, hyperactivity, and poor cognitive skills, as well as bedtime routines not being established and parents unwittingly reinforcing their behaviour of not sleeping.

It is difficult for children on the autistic spectrum to appreciate other people's expectations of them. It is also a challenge for them to understand the impact of their behaviour on others. These two fundamental interactions of daily living have a significant impact on sleep.

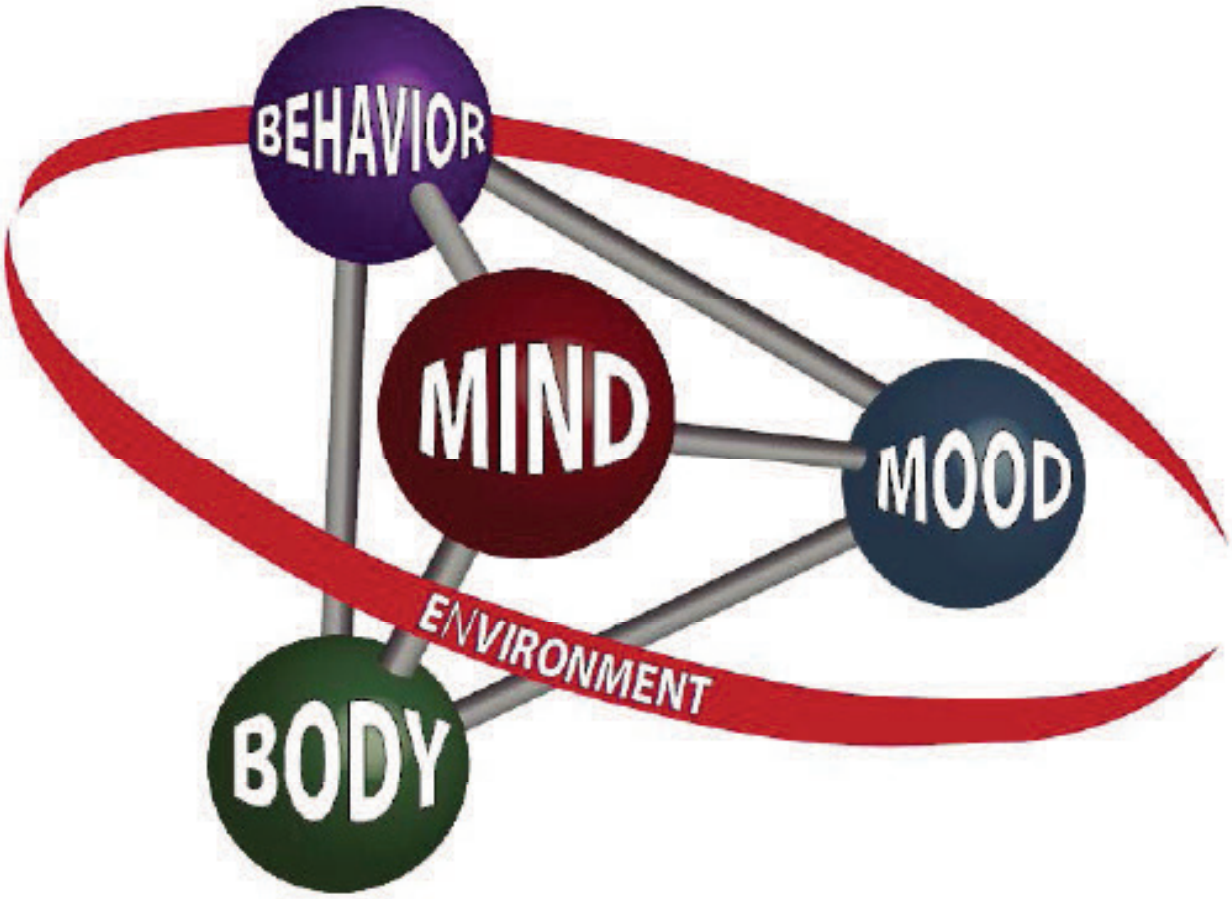
Children on the autistic spectrum have a weak central coherence, and tend to focus on details rather than the bigger picture. Consequently, they are less likely to pick up on signals, both in their bodies and in the environment, telling them that it is time for sleep. Because they have difficulties making connections and generalising, they might not make connections in terms of pre-bedtime activities.

These children also have difficulty with their executive functioning, the cognitive mechanisms mediated by the frontal lobes of their brains. As executive functioning is necessary for goal-directed behaviour and self-monitoring, they may not see the point of particular tasks, such as going to sleep.

Sleep Scotland's Cognitive Behavioural Intervention Model

The above provides a background to why many children on the autistic spectrum experience behavioural sleep difficulties and explains the success of Sleep Scotland's cognitive behavioural model in addressing these challenges. The model looks at non-sleeping as a form of behaviour, which can therefore be addressed with a cognitive behavioural approach. The good news is that as a learned behaviour, it can also be unlearned.

Sleep Scotland sleep counsellors begin by focussing on sleep hygiene - getting the environment right. Having a dark, quiet, unstimulating bedroom, for example, will help promote sleep. Sleep counsellors then move on to cognitive behavioural strategies.



Sleep Scotland's intervention model includes a number of helpful strategies which are usually used together:

- Cognitive behavioural strategies and routines
- Social stories
- Visual support/checklists
- Using motivators
- Relaxation techniques
- Diet
- Exercise

Sleep counsellors aim to involve the child in this process, consulting them when at all possible. We have also found that parents' changing cognitions and feelings are integral to the intervention process. Changes in parental behaviour have a positive impact on their child's difficulties in sleeping.

The three main ingredients in this cake are routine, consistency, and positive reinforcement. The following case study, which includes a typical sleep programme drawn up by a sleep counsellor, demonstrates the importance of all these three elements.

Case study

C is a 4 year old boy with autism, fragile X syndrome and severe asthma.

- C lives with mum and 3 older brothers. He attends nursery at the local child and family centre. His health visitor suggested his mum register with Sleep Scotland for support with C's sleep.
- C would regularly fall asleep at 5 pm and sleep until 9 pm. If he didn't fall asleep, he'd be very grumpy – then 'come alive again'. C's mum would try and feed him again around 9 pm to calm him down.
- Regardless of whether he slept before 9 pm or not, C still would not fall asleep until 2:30-3:00 am. He would fall asleep on the couch or in the kitchen.

- If C awoke during the night he went through and disturbed his mum and brothers, so the whole family were exhausted.
- C's mum had to wake him every morning. He would be very grumpy and would sleep longer at weekends if allowed.
- During the day, C was very tired and it was difficult, if not impossible to engage him in play.
- C would regularly scream and kick if he did not like something.

A Sleep Scotland sleep counsellor worked with C's family, drawing up a sleep programme, and supporting the family in the ensuing week to follow it through.

C's Sleep Programme

- When home from nursery, C to wear 'play clothes' in place of pyjamas.
- Nap time should be encouraged after lunch, but no later than 1 pm. If C does sleep he should be woken by 2 pm. This could be phased out eventually.
- Afternoon free play time until dinner time.
- After dinner (approx. 5pm) until 6pm, C to have calming play time session with Mum. TV and electronic games must be withdrawn at this time. Special play time not to be held in the bedroom.
- Pictorial social story to be followed including snack, drink, bath, pyjamas on, teeth brushed (no returning to the living-room area), story in bed, main light out and dull touch light on.
- 7pm – sleep.
- Use of gradual approach when initially settling C.
- If C gets out of bed, robotic returning, remain calm, no verbal communication.
- Continue this throughout the night as often as required.

Sleep counselling results

- C was settling quickly and going to sleep at 7 pm.
- C was sleeping through the night.
- C's daytime behaviour improved.
- Naps also stopped after 5 weeks.
- C's mealtimes were regular and his diet improved.

The Future

In May 2013 Sleep Scotland was selected by the Scottish Government to receive funding through its third sector Strategic Funding Partnerships, and we are looking forward both to enhancing our sleep counselling and training services, and expanding our work with vulnerable families and teenagers.

Conclusion

A pressing need for our sleep counselling service remains among families with children with additional support needs, where sleep deprivation can lead to mental and physical deterioration for parents and siblings, and can potentially lead to family breakdown. Children and young people with autism spectrum disorder demonstrate particular difficulties with sleep. Sleep Scotland's cognitive behavioural intervention model, tailored to each individual family, is ideally placed to provide support to them.

GP Comment.

What have I learned from this paper?

1. This paper made me understand about the sleep problems which are more common in people with autism spectrum disorder and that severe sleep deprivation can have a major impact on physical and psychological health of not only the patients but also parents and siblings with a potential for family breakdown.

2. It is great to learn about Sleep Scotland and the excellent training and service they provide to sleep counsellors and families.

3. After reading about the case study, sleep hygiene measures and the cognitive behavioural intervention model, I recognised the significance of parents implementing routine, consistency and positive reinforcement in order to alleviate their child's sleep problems

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References

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