



CENTRE FOR AUTISM  
MIDDLETOWN

## Autism and Sleep



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## INTRODUCTION

This is the thirty-first Research Bulletin produced by Middletown Centre for Autism, providing summaries of nine articles from 2018 to 2019.

The Bulletin commences with an interview from Edel Quinn and Tara Vernon.

Edel Quinn is an autism trainer and advisor in Middletown Centre for Autism. Before taking up this post, Edel worked in the National Health Service (NHS), Northern Ireland, developing and delivering home programmes for children and young people with autism and their families. Edel holds a psychology degree and an MSc in autism from Queen's University, Belfast, and a postgraduate diploma in cognitive behaviour therapy. Edel's main specialisms are in early intervention and delivering training in the implementation of visual strategies and positive behaviour. Edel is a certified TEACCH trainer with division TEACCH North Carolina. Edel has developed and delivered anxiety training and anxiety research projects to parents and professionals across Ireland. She has presented at the Autism and Mental Health Conference, National Autistic Society (NAS) and the Autism Congress. Edel is an associate lecturer on the postgraduate autism certificate with

Mary Immaculate College, Limerick, and with Stranmillis College, Belfast. Edel is registered with the British Association for Counselling and Psychotherapy as a cognitive behaviour therapist. Edel has also completed the five-day sleep counsellor training with Sleep Scotland.

Tara Vernon is an autism trainer and advisor for Middletown Centre for Autism. Prior to joining the Middletown team Tara worked across home, school and external agency settings to provide autism-specific specialist teaching, training and behavioural support in these environments. Tara holds a degree in psychology and is a CABAS-board-certified teacher in applied behaviour analysis. She is a member of both the Psychological Society of Ireland and the Teaching Council of Ireland and is a certified sleep counsellor.

*Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism. Reviewers have, where possible, used the original language of the article, which may differ from UK and Ireland usage and the usage of a range of terminologies for autism.*

## AN INTERVIEW WITH EDEL QUINN AND TARA VERNON

### 1. How can autism affect sleep?

Autism can affect sleep in several ways. Sensory differences may play a role in that the child or adult has an increased sensitivity to light, sound or touch, which may contribute to difficulty in falling asleep and staying asleep. Melatonin, the sleep hormone, can be irregularly produced and/or be lower in individuals with autism, which may also lead to difficulty in falling asleep; some autistic individuals will have an atypical circadian rhythm or body clock, others may have sleep apnoea where breathing is disturbed during sleep. Medications prescribed for coexisting conditions such as attention deficit hyperactivity disorder (ADHD) or epilepsy, can negatively impact sleep as can gastrointestinal issues such as reflux and constipation. Poor sleep hygiene, or bad bedtime habits, may be in place, for example: screens just before bedtime will affect the production of melatonin thus delaying sleep onset. Some individuals will find it difficult to make the connection between the household going to bed and their need to sleep too. An obligation to adhere to specific routines or engage in repetitive behaviours may also prevent the individual from accessing sleep. Anxiety (discussed further below) and/or a difficulty in letting thoughts go may also play a role in impeding children and adults from settling, and in resettling if they wake, causing insomnia.

### 2. How common are sleep problems in children and young people with autism?

Sleep can be a significant issue for many children and adults who have been diagnosed with autism. Research studies suggest that over 80% of children and young people with autism experience sleep problems, including difficulty falling asleep and/or staying asleep at night.

Prevalence rates for sleep disorders in autism is highly variable depending on the type

of assessment used: subjective tools (sleep diaries and questionnaires) versus objective measurement (actimetry).

In a recent study by Research Autism, titled 'Sleep Problems and Autism', it was noted that the following sleep issues are common among children and adults with autism:

- Difficulty with sleep onset or falling asleep
- Difficulty with sleep maintenance or staying asleep throughout the night
- Early-morning waking
- Short-duration sleeping
- Sleep fragmentation (when a person has an erratic sleep pattern with frequent waking throughout the night)
- Hyperarousal or heightened anxiety around bedtime
- Excessive daytime sleepiness

Recent research reports that the most consistent sleep problems for children with autism are shorter sleep time, prolonged sleep latency (the amount of time it takes to fall asleep) and lower sleep efficiency.

### 3. How can good sleep hygiene be developed?

Good sleep hygiene can be developed through the following:

- Set a consistent sleep and wake time. This will strengthen the circadian cycle.
- Make sure the room is dark and quiet. A very low wattage night light (warm white), at floor level, can be used if necessary.
- Environmental noise should be kept to a minimum.

- Ensure the bedroom temperature is at a comfortable level. High room temperatures disturb sleep.
- Ensure that the child or young person is not hungry going to bed.
- Avoid drinks with additives or caffeine before bedtime; warm milk is a suitable alternative.
- Only quiet, non-stimulating activities in the hour before bedtime.
- No screens (television, tablets, console monitors or phones) in the hour before bedtime.
- The bedroom should be free of electronic equipment (television, consoles, phones etc.) and other distractions.
- Avoids naps, especially in the late afternoon.
- Help the child or young person to learn to fall asleep, on their own, in their own bed.

### 4. Where and how can good sleep hygiene be promoted at home and in schools?

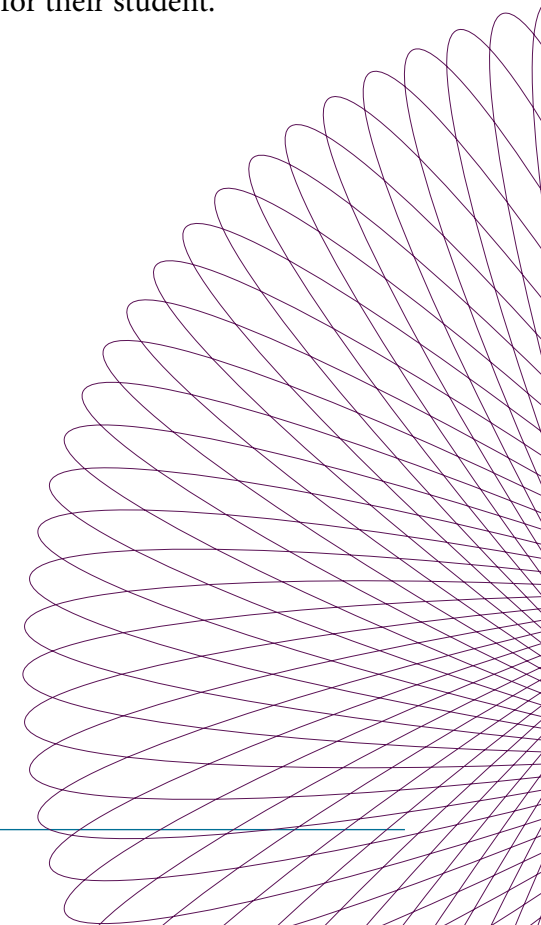
Good sleep hygiene can be promoted at home through the sharing of information on good sleep practices with parents. Parental beliefs, thoughts and feelings around sleep influence the behaviour of both the child and the parent and the possibilities for change. While children learn at different rates and change takes time, poor sleep practices can be unlearned and treated.

Good sleep hygiene can be promoted in schools through individual and whole-class teaching on the importance of sleep through resources such as Sleep Scotland's Sound Sleep programme for primary and secondary school. Additionally, schools can help to ensure that the importance of a healthy diet and daily physical exercise is promoted within the curriculum and ethos of the school. Furthermore, schools can ensure that

students have the opportunity to participate in physical activities during the course of their day.

### 5. How can schools support families caring for a child with sleep difficulties?

Schools can support families caring for a child with sleep difficulties through greater understanding of the impact of poor sleep on the child's capacity to engage during their school day. Given that sleep deprivation has a negative impact on occupational and cognitive functioning, children who do not get adequate sleep may be less able to meet the inherent demands of school and may, as a result, exhibit behaviours of concern. Furthermore, as sleep is necessary for memory consolidation, learning and brain development, children with sleep difficulties may not be achieving their potential. When educators understand the associated consequences of poor sleep, they are better placed to make the necessary accommodations that in turn will create more positive outcomes for their student.





## 6. Where can families go for more advice on specific sleep issues?

Families can avail of advice and support for specific sleep issues from a range of websites, books and organisations.

- Middletown Centre for Autism: parents and professionals can access online training specific to autism and sleep via the centre's Virtual Learning Environment <https://vle.middletownautism.com/>
- Sleep Scotland provides free sleep counselling services to families across the UK and Ireland. Parents and carers seeking support for their child's sleep problems can contact the organisation's sleep advisors for more information: <https://www.sleepscotland.org/>
- National Autistic Society provides information and advice pertaining to strategies that can be implemented to improve an autistic child's sleep: <https://www.autism.org.uk/about/health/sleep.aspx>
- The Children's Sleep Charity provides support to families for sleep difficulties in children: <http://www.thechildrenssleepcharity.org.uk/>

Books:

- *Sleep Better!: A Guide to Improving Sleep for Children with Special Needs* by V. Mark Durand
- *Solving Sleep Problems in Children with Autistic Spectrum Disorders* by T Katz and B Malow
- *What to Do When you Dread Your Bed: A Kid's Guide to Overcoming Problems with Sleep* by D Heubner

If you are struggling with long-term lack of sleep, you may benefit from support outside the family, such as your GP, social worker or your child's school, for help and advice.

## 7. Can sleep and its benefits to overall well-being be taught to children?

Yes, sleep and its positive impact on overall well-being can be taught to children through a variety of commercially available resources. As with other learning it needs to be individualised to the child and pitched at a level that will be understood. For children who are comfortable with concrete concepts, this may involve using visual supports, other children may benefit from social stories, explicit teaching on the benefits of sleep or a cognitive behavioural approach.

## 8. Is there a connection between anxiety, mental health and poor sleep for those with autism?

There appears to be a bidirectional relationship between anxiety and/or mental health disorders and sleep. This means the presence of anxiety or mental health disorders can worsen sleep and poor sleep can worsen emotional well-being or mental health.

Many research studies have reported that anxiety is associated with psychological hyperarousal. Hyperarousal for a child may make falling asleep difficult or increase insomnia. When a child or young person experiences increased intrusive thoughts or worries prior to bedtime it can delay sleep onset.

Mood disorders such as depression, which can be experienced by young people with autism, are also associated with overactive cognitive activity and hyperarousal and negatively impact sleep. There is an increasing body of research that suggests that this relationship between anxiety and/or mood symptoms and sleep difficulties is the same for individuals with autism. As anxiety is common for children and young people with autism (the general consensus is that approximately 50% experience anxiety) it

is possible that anxious children with autism experience sleep problems due to anxiety, as well as other factors related to autism.

Sleep performs an important role for our physical and cognitive function. The restoration model of sleep indicates sleep helps us to recover from physical and mental fatigue. In fact, during sleep the flow of fluid that bathes and cushions the brain (cerebrospinal fluid) is greater (due to >60% increase in interstitial space), which means more toxins are cleared from the brain. Disordered sleep or lack of sleep affects our emotional well-being, it may increase risk of mood disorders, anxiety, stress and inability to regulate emotions. Research has shown that in children with autism there is a connection between lack of sleep and feeling less motivated, difficulty concentrating, impulsive or irrational behaviour and stronger, less controllable, emotions. Therefore, not getting a good night's sleep can seriously impact a child's overall mental well-being.

## 9. If we tackled the underlying difficulty, anxiety or mental health, would this go some way to improving sleep?

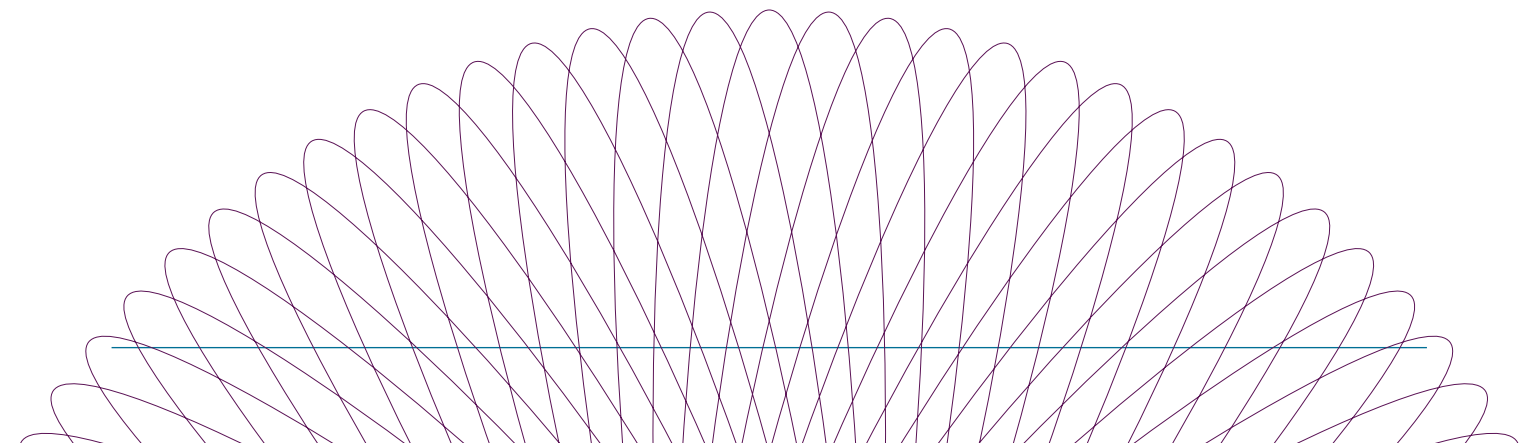
Yes, research studies investigating sleep difficulties in children with autism have found that reducing anxiety levels for children has a positive impact on sleep, with less parent-reported sleep difficulties. These studies suggest that when symptoms of anxiety are treated it results in improvement of sleep for children.

Sleep cycles are affected by two main hormones, melatonin and cortisol. Melatonin is the hormone that makes you start to feel sleepy (it doesn't actually make you fall asleep) and is produced in a big burst, ideally just before your bedtime. Cortisol is the hormone that wakes us up and keeps us going all day. It is produced by the adrenal gland and inhibits sleep. You may have heard it referred to as 'the stress hormone' as its production is increased when you are physically or mentally stressed.

This means that when children experience stress or anxiety they have higher levels of cortisol in their body, and so may find it hard to feel sleepy or can experience sleep fragmentation or deprivation. Sleep deprivation is a form of physical and mental stress, so if a child is sleep-deprived, they may produce more cortisol, which will make it even harder for them to sleep.

Anxiety management strategies incorporated into evening routines and bedtime routines can reduce stress and anxiety experienced by children. Advice and guidelines include:

- Replace stimulating activities in the evening with activities that are calming for your child and promote relaxation.
- Read a bedtime story to your child or allow them to look at a magazine, possibly related to something they are interested in, as part of their bedtime routine.



- Your child may enjoy listening to calming music. If you are using music, make sure it is not on a device that is going to produce light that their eyes will pick up.
- Encourage the use of relaxation techniques to relax the muscles in the body, for example progressive muscle relaxation or calm breathing strategies. Relaxation techniques take time to take effect and should be completed consistently with your child or young person for at least a few weeks to become effective.
- Encourage your child to share their worries with someone they trust. Ideally this should happen throughout the day rather than waiting until bedtime. You may wish to use a worry jar or box where the child writes down or draws their worries throughout the day or early evening. This can help avoid feeling anxious or stressed before bedtime.

Assessments can be challenging for any child, but there are particular challenges for those with autism. At the core of our postgraduate autism lectures is my lecture on psychological theories of autism, which looks at the nature of autistic difficulties and the mechanisms underlying these. This highlights areas that point to where some of the key challenges are likely to lie.

First, there is executive function, usually compromised in autism. This includes difficulties

in organisation, monitoring, planning and attention shifting, together with weaknesses in working memory and processing speed. All of these factors are normally involved in how assessments are tackled and how all parts of them are completed in time. Then there is central coherence, the ability to move from detail to the bigger picture, from text to context, a crucial factor in comprehension. In addition, there is theory of mind, the ability to understand the thoughts and intentions of another party. For many children with autism they will not read the situation intuitively in the way other children will and understand why someone else is wanting them to work at their fastest, to do their best or to answer questions whether they find them interesting or not.

In addition, as many of the children will have a range of sensory issues, there may often be aspects of the assessment environment that present a challenge but which may not be very obvious. Many children also have a built-in demand avoidance, so getting them to perform in an assessment and to follow instructions may prove futile.

Awareness of these factors can point to some of the accommodations that will help. This can include breaking the assessment down into parts and doing them one part at a time.

## QUALITATIVE STUDY ON PARENTS' PERSPECTIVES OF THE FAMILIAL IMPACT OF LIVING WITH A CHILD WITH AUTISM SPECTRUM DISORDER WHO EXPERIENCES INSOMNIA

### BACKGROUND

Previous studies report that insomnia impacts the individual and the family; however, there are limited studies on parents' viewpoints of its implications. This study addresses this research gap.

### RESEARCH AIM

This study aims to:

- present findings from parents' perspectives on the impact of identified challenges of insomnia on their child and family.
- enrich quantitative findings with individual accounts of the differing consequences insomnia has on the individual and their families.

### RESEARCH METHODS

Participants comprised three focus groups representing fifteen families of children with autism aged between four and twelve years. Set questions were used to glean the following:

- The impact of insomnia on the child with autism and the family.
- To determine what type of sleep difficulties were faced by the child and the family.
- To gather information on what, if any, strategies parents may use to address insomnia.

Participants completed two questionnaires:

- The Pittsburgh Sleep Quality Index
- The Children's Sleep Habits Questionnaire



The following themes were highlighted from the data:

- Anxiety
- Dietary implications
- Bedtime routine
- Social exclusion
- Familial implications
- Impact on education

RESEARCH FINDINGS

The findings from this study:

- confirm that sleep is hugely challenging for individuals with autism and its impact is significantly felt by their families.
- support the theory that insomnia has a significant and far-reaching impact upon children with autism and their families.
- highlight that a significant number of parents had no experience of using strategies to help with sleep within this sample.
- note that social exclusion had a significant impact on all families, resulting in the families becoming more isolated.

IMPLICATIONS FOR PRACTICE

This study:

- illustrates that providing parents with a channel to express their perceptions of the familial impact of living with a child with autism spectrum disorder who experiences insomnia could complement other methods used to study sleep.
- acknowledges that a larger sample across a range of organisations may provide useful information on the impact of insomnia.
- highlights that further studies that focus on particular interventions to help with sleep are required and should involve all family members to have maximum benefit.
- notes that further studies featuring the impact of insomnia on everyday-life experiences of family finances, leisure and social relationships could emphasise particular areas where families require help

Full Reference

Kirkpatrick, B., Gilroy, S.P. and Leader, G., (2019). Qualitative study on parents’ perspectives of the familial impact of living with a child with autism spectrum disorder who experiences insomnia. *Sleep Medicine*. 62, pp. 59–68.

THE EFFECTIVENESS OF FUNCTION-BASED INTERVENTIONS TO TREAT SLEEP PROBLEMS, INCLUDING UNWANTED CO-SLEEPING IN CHILDREN WITH AUTISM

BACKGROUND

Sleep disturbances including unwanted co-sleeping, sleep onset delay (SOD), frequent and prolonged night wakings (NWs) and early-morning wakings, affect as many as 83% of children with autism spectrum disorder. Although many families may intentionally co-sleep, this study focuses on reactive co-sleepers, where this strategy is used as a response to various sleep disturbances even though parents would prefer independent sleep. Although sleep problems may well be explained from a variety of biological, environmental, psychological and behavioural perspectives, previous research has demonstrated that behavioural interventions can be effective. Given the multiple variables that impact sleep disturbance, a comprehensive assessment is needed to identify those variables targeted in treatment. Functional behavioural assessment (FBA) can identify these factors unique for an individual; however, few studies have investigated FBA in relation to sleep disturbance.

RESEARCH AIMS

The current study aims to use FBA procedures to identify the likely antecedents and consequences of maintaining sleep disturbance and co-sleeping. The FBA will then be used to develop an individualised plan for intervention for each participant with a view to reducing and/or eliminating sleep disturbances.

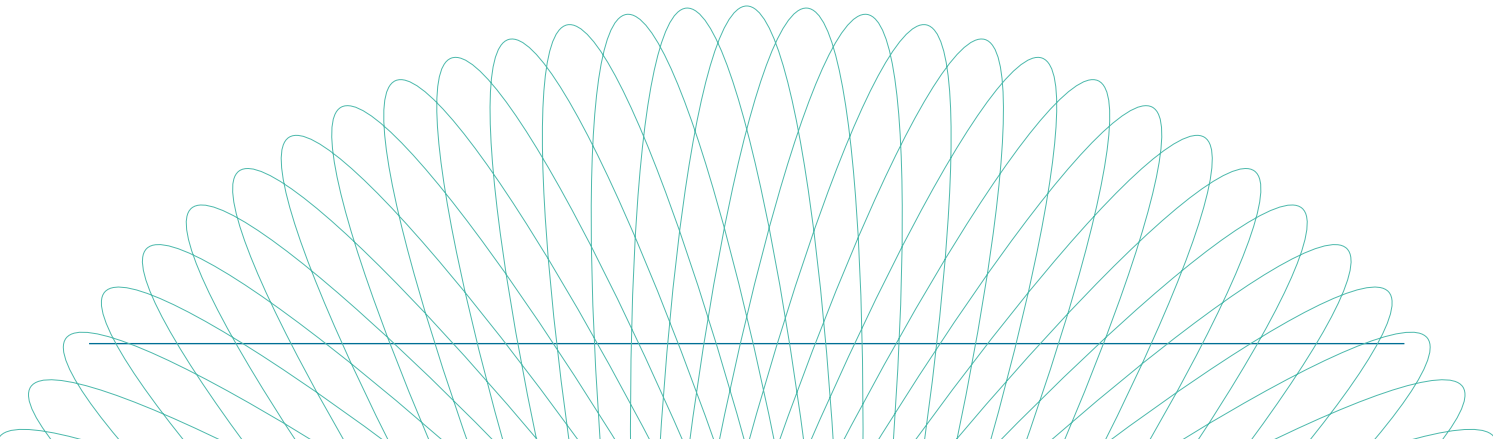
RESEARCH METHOD

Seven families with middle-to-high socio-economic status in urban New Zealand participated in the study. Participant children included two females and five males aged between two and five years with a formal diagnosis of autism. Each child was reported as having sleep disturbances including SOD, NWs, early-morning wakings and unwanted co-sleeping.

An FBA was conducted using information from clinical interviews with parents, the Sleep Assessment and Treatment Tool (SATT) and parent-recorded sleep diaries. Videosomnography (VSG) was used to gather inter-observer agreement data and a sleep-problem severity score was calculated for each child.

During baseline parents responded to their children’s sleep in a typical manner and the data was gathered. Following this, each child was provided with their individual hypothesised function(s) for the sleep disturbance behaviour and a subsequent intervention plan.

During intervention all parents were contacted regularly to allow parents to ask questions about the treatment procedures and to assess progress. Treatment components were selected from the following options, all considered to have empirical evidence for their use with typically developing children.



- Social Story ©: an individualised storybook was provided for each child that included texts, pictures and photographs depicting the bedtime routine and expectations for sleep. Reward schedules were also included for good sleeping. Each child was read their story prior to bedtime.
- Systematic fading of parent presence then planned ignoring: as there was an attention-seeking function for all children, planned ignoring (extinction) or modified extinction was used. Fading of parental presence (FPP) was implemented during sleep onset and NWs for all but one child. This involved the parents sitting beside their child's bed, then moving one metre from the bed, sitting two to three metres from the bed, sitting beside the bedroom door, sitting outside the door with only legs visible and sitting outside the room out of sight. Once parental presence was faded and child responding reduced, the intervention continued as planned ignoring. This involved parents only responding to sleep disturbances as a safety check.
- Gro clock: this digital clock with a large display screen was used to visually indicate wake time and sleep times.
- Positive reinforcement: all children were provided with some form of tangible reinforcement or social rewards each morning upon sleeping in their own bed without the presence of a parent. If co-sleeping occurred, the behaviour was not reinforced.

Once parents were satisfied with the intervention results, researcher contact temporarily ceased and parents were instructed to attend to their child and respond minimally during sleep disturbances. This was seen as the ultimate goal of treatment,

where parents would respond typically as most would to a child that sleeps well.

Follow-up diaries were then recorded for one week, at six to eight weeks (short-term) and twelve to fourteen (long-term) weeks post intervention.

## RESEARCH FINDINGS

Two children dropped out of the study during the planned ignoring phase; however, their data continues to be included up to this point.

Co-sleeping was eliminated for during sleep onset and NWs for all remaining five participants by the short- and long-term follow-up phases.

SOD results varied across each intervention stage for each child; however, all remaining participants demonstrated stable SOD during the follow-up phases.

Frequency and duration of NWs were considered problematic for all children during the baseline stage. Two children demonstrated no NWs during the intervention phases and this was maintained during the follow-ups. NWs both improved and deteriorated for the remaining children during intervention; however, all demonstrated a stable reduction and frequency of NWs once the planned ignoring procedure was implemented.

All children showed clinically significant reductions in overall sleep-problem severity scores.

## IMPLICATIONS FOR PRACTICE

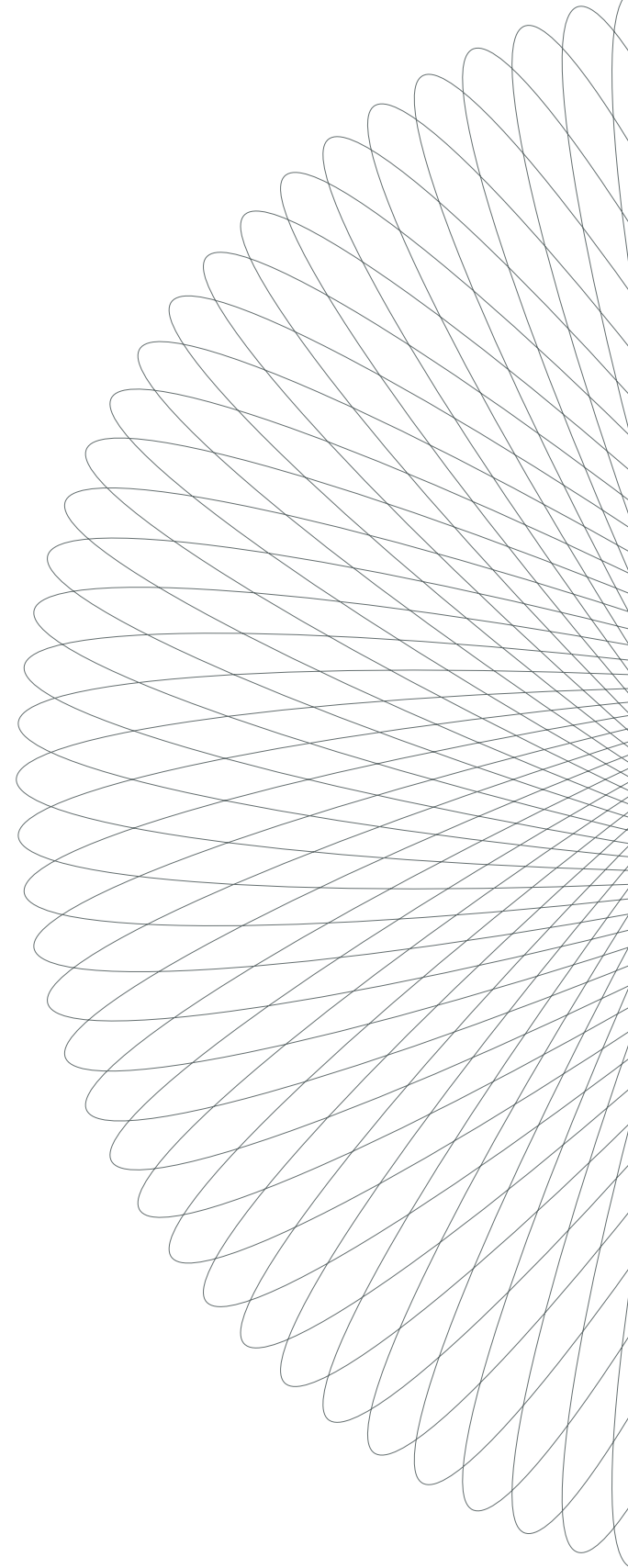
A guided participation model is effective in communication of the FBA and support throughout a sleep-based intervention.

Parents were empowered to make changes to their own behaviour with this model, and subsequently positive changes to bedtime routines and sleep occurred.

The use of social stories, fading parental presence, planned ignoring, visual supports and reinforcement were all evident as effective strategies for achieving sleep goals.

### Full Reference

McLay, L.K., France K.G., Knight, J., Blampied, N.M. and Hastie, B., (2019). The effectiveness of function-based interventions to treat sleep problems, including unwanted co-sleeping, in children with autism. *Behavioral Interventions*. 34 (1), pp. 30–51.





## PROBLEM BEHAVIOR IN AUTISM SPECTRUM DISORDER: CONSIDERING CORE SYMPTOM SEVERITY AND ACCOMPANYING SLEEP DISTURBANCE

### BACKGROUND

Many autistic individuals present with problem behaviours additional to the core features of autism. The authors of this study define problem behaviours as: ‘any significant emotional or behavioral issue captured by the Child Behavior Checklist (CBCL) including anxiety, depression, withdrawal, somatic complaints, problems with socialization, thought or attention, rule-breaking, and aggression.’ (p. 1)

Some people with autism will not experience any of these challenges, while others may have multiple examples of these behaviours. It is important to determine factors that predict the emergence of such behaviours as the long-term presence of problem behaviours impacts mental health and academic achievement. Sleep disturbance is one such factor frequently identified in research.

It is estimated that poor sleep patterns affect 40–80% of autistic children. This can include a reluctance to go to bed, a delay in falling asleep and waking frequently during the night. These sleep disturbances have been shown to increase the incidence of problem behaviours such as tantrums, physical aggression, inattention, self-injury and mood variability. Some research has also indicated a link between long-term sleep disturbance and later anxiety.

Research findings have confirmed a link between the severity of sleep disturbance and the severity of problem behaviours. An association has also been found between the severity of autistic symptoms and the severity of problem behaviours; however, it is unclear if sleep disturbances affect the relationship between symptom severity and problem behaviours.

### RESEARCH AIMS

This study aimed to determine if sleep disturbance is a moderating factor between symptom severity in autism and problem behaviours. In other words, to examine whether the severity and type of sleep disturbance an individual experiences differentially affects the relationship between autistic symptoms and problem.

### RESEARCH METHODS

The study included forty boys aged 5–12 years with a confirmed diagnosis of autism. There was no exclusion criteria regarding level of functioning or co-morbidities as the researchers wanted the study to reflect a broad range of ability.

The following assessments were used:

1. Demographic information via parent report.
2. Vineland Adaptive Behavior Scale—Third Edition (VABS-3). This measures adaptive functioning in communication, daily living and social skills.
3. The Social Responsiveness Scale—Second Edition (SRS-2) School Age Form. This measures symptom severity in autism.
4. The Children’s Sleep Habits Questionnaire (CSHQ). This measures eight domains of sleep problems, including sleep duration, night waking and daytime sleepiness.
5. The Child Behavior Checklist (CBCL). This measures emotional and behavioural problems.

### RESEARCH FINDINGS

The study found that the relationship between autistic symptoms and problem behaviours was only significant in participants who had no or minor sleep disturbances. In these cases, mild autistic symptoms were positively correlated with mild problem behaviours when there were no or minor sleep disturbances.

The relationship between severity of autistic symptoms and problem behaviours was not significant in those who had moderate to severe sleep problems. Participants with moderate to severe sleep disturbances were more likely to present with more significant problem behaviours, regardless of the severity of their autistic symptoms.

This means that in children with no or minor sleep disturbances, problem behaviours are likely to significantly increase as autistic symptoms increase in severity; however, this relationship between autistic symptoms and problem behaviours is less likely in children with moderate or severe sleep disturbances.

Sleep duration, disordered breathing and daytime sleepiness were the three factors found to be significant moderators between autistic symptomatology and problem behaviours. Participants who had difficulties with sleep duration, disordered breathing or daytime sleepiness were more likely to have problem behaviours, regardless of the severity of their autistic symptoms.

The authors acknowledge some study limitations; specifically the small sample size, the broad age range and that it was an exclusively male sample. They also acknowledge that more research is required to determine the causality between autistic symptoms, problem behaviours and sleep disturbances, as it is possible that sleep disturbances increase the severity of autistic symptoms.

### IMPLICATIONS FOR PRACTICE

(by the authors and reviewer)

- Identifying autistic individuals who have sleep disturbances is useful as this is a predictor for problem behaviours. It may therefore allow such behaviours to be addressed earlier by providing interventions to promote improved sleep routines.
- Assessment of sleep patterns is important in autistic individuals presenting with problem behaviours (regardless of the severity of their autism) as it may be a significant contributing factor to problem behaviours.
- Addressing sleep disturbances through appropriate interventions can have a positive impact on the daily functional ability of autistic people.
- Individuals who have difficulties with sleep duration, disordered breathing or daytime sleepiness are more likely to develop problem behaviours and so these difficulties may be highlighted as significant risk factors.
- Autistic people who have a significant issue with sleep disturbance are more likely to have other significant issues and co-morbidities (e.g. mental health issues) and so early intervention for sleep disturbances may reduce the risk of developing other significant concerns.

#### Full Reference

Lindor, E., Sivaratnam, C., May, T., Stefanac, N., Howells, K. and Rinehart, N., (2019). Problem behavior in autism spectrum disorder: considering core symptom severity and accompanying sleep disturbance. *Frontiers in Psychiatry*. **10**, Article 487.

# SLEEP DYSFUNCTION AND BEHAVIORAL DAYTIME PROBLEMS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS: A COMPARATIVE STUDY

## BACKGROUND

Previous studies acknowledge challenges with sleep in children with autism and its impact on their families. There are studies that highlight the correlation between sleep difficulties and behavioural presentations in typically developing children but few in children with autism. From information gathered from parents, this study seeks to compare the sleep performances of children with autism with their peers before the authors subsequently explore the connection between sleep difficulties and behavioural challenges seen during the day from a parent’s perspective.

## RESEARCH AIMS

The purpose of this study was to:

- identify and compare the differences in sleep behaviours between children with autism and their peers from their mothers’ perspectives.
- examine the links between behavioural difficulties presented during the day and sleep problems in children with autism.
- explore the impact of dysfunctions in sleep on children with autism and their families.

## RESEARCH METHODS

This cross-sectional study took place in India, with sixty children who had a recent diagnosis of autism recruited within a two-year period from a psychology unit within a paediatric hospital department. The sample was matched in both age and socio-economic position to participants from a typically developing group from a different department within the same hospital. Males made up 85% of the children with autism compared to 50% from the typically developing group. Only mothers of both sets of children participated in the study.

## ASSESSMENTS AND QUESTIONNAIRES

In both groups the Children’s Sleep Habits Questionnaire (CSHQ) was used to quantify sleep difficulties with the Childhood Psychopathology Measurement Scale (CPMS) examining the behavioural difficulties that presented during the day.

The Childhood Rating Scale (CARS) was used to classify children according to the severity of their autism and the Developmental Profile 3 (DP-3) was used to assess their cognitive ability.

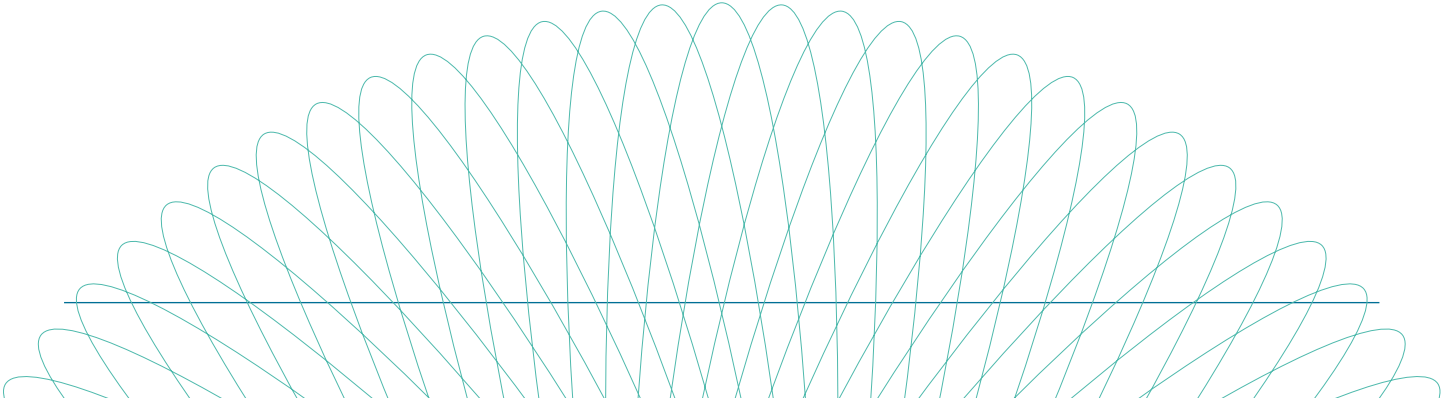
A multivariate regression analysis was completed to examine the possible reasons why there are challenges in sleep for individuals with autism and to provide robust evidence on influential factors that have significant impact.

## RESEARCH FINDINGS

This study found that:

- the prevalence of sleep difficulties in children with autism was double that of those from the typically developing group.
- over 28.3% of the parents of the children with autism highlighted five or more specific sleep problems in comparison to 8.3% from the control group.
- the following specific areas were identified among others as being problematic for children with autism in comparison to peers:
  - a) Resisting going to sleep (four times more likely to have challenges in preparing to sleep).
  - b) Not staying asleep (one third remaining asleep through the night).
  - c) Not getting enough sleep (the control group slept for an extra hour and the group with autism slept late).
- parents of the children with autism believed there was a noteworthy connection between behaviours seen during the day and sleep problems. This concurs with previous studies on the correlation between the challenges of sleep and its effects on the emotional competence and subsequent behaviours of the child with autism.

- the behaviours seen during the day were in keeping with previous research on the relationship between sleep difficulties and the behaviours of children with autism during the day. They were:
  - A) Showing aggression
  - B) Emotional dysregulation
  - C) Anxiety
  - D) Executive-functioning difficulties
- two variables provided a reason as to why there were inconsistencies in the number of behavioural problems that occurred during the day in children with autism:
  - a) The total of scores accumulated across the CSHQ highlighted a definitive difference in both parents’ perceptions of their children’s challenges with sleep with a variety of reasons provided.
  - b) The length of time children with autism stayed awake at night was significantly higher in comparison to their peers. No statistic was recorded against children from the control group having difficulties with getting enough sleep, whereas 30% of parents from the comparative group identified it as a reason for sleep problems. This provided an opportunity for parents to connect their child’s poor sleep pattern with subsequent negative behaviours observed during the day.
- difficulties relating to sleep are not limited to the impact of social status, the acuteness of autism or the learning ability of children with autism.





## IMPLICATIONS FOR PRACTICE

- Conclusions are reached as a result of a study of the correlational impact on sleep difficulties and behavioural presentations during the day on children with autism. The authors highlight that the reverse impact of this relationship may also provide noteworthy considerations.
- The significance of the relationship between the increased number of times children with autism were awake and the management of their behaviours and emotions may warrant further study.
- The study could be replicated in another country using the same research materials and procedures to test for similarities and differences in the relationship between sleep problems and behavioural challenges in children with autism.
- The authors consider the limitations of using only evidence gleaned from parents. To supplement this evidence future studies may also use data from observations of behaviours both at home and school and information from sleep diaries.
- A sample that represented a higher number of girls with autism may provide specific information on differences and similarities in the connection between sleep challenges and behaviour between girls and boys.

- To use the findings to request that paediatricians assess children with autism for sleep difficulties and provide parents and professionals with strategies to support these challenges.
- To further study the impact of the dysfunctional relationship between sleep problems and daytime behaviours on the quality of life of both the individual with autism and their family.

### Full Reference

Malhi, P., Kaur, A., Singhi, P. and Sankhyan, N., (2019). Sleep dysfunction and behavioral daytime problems in children with autism spectrum disorders: a comparative study. *Indian Journal of Pediatrics*. **86** (1), pp.12–17.

# EXAMINING THE IMPACT OF PHYSICAL ACTIVITY ON SLEEP QUALITY AND EXECUTIVE FUNCTIONS IN CHILDREN WITH AUTISM SPECTRUM DISORDER: A RANDOMIZED CONTROLLED TRIAL

## BACKGROUND

The positive impact of physical exercise on sleep difficulties and learning processes in typically developing children is widely acknowledged. There are also extensive studies on sleep problems in children with autism and some highlight the link between sleep problems and impairments in cognitive functions. This study investigates the impact of physical exercise on the sleep patterns of children with autism and its effects on two executive functions: inhibitory control and working memory. Prior to data collection the authors hypothesised that physical exercise would have a noticeable effect on sleep and executive functioning in children with autism.

## RESEARCH AIMS

The purpose of this study was to:

- test the hypothesis that physical exercise would have a positive impact on the standard of sleep and the cognition of children with autism.
- investigate the effects of physical activity on the quality of sleep and cognitive ability on children with autism in comparison to their peers who did not partake in the intervention.
- examine the impact of physical exercise on four parameters related to sleep:
  - a) Sleep efficiency
  - b) Sleep onset latency
  - c) Sleep duration
  - d) Wake after sleep onset
- analyse the influence of physical exercise on the following executive functions in children with autism:
  - a) Inhibitory control
  - b) Working memory

## RESEARCH METHODS

The participants were recruited from different schools using an initial screening process. Examples of some of the applied criteria are listed below:

- Diagnosis of autism
- Non-verbal IQ above 40
- Able to follow directions
- Able to partake in the physical intervention and executive function tests

A sample of fifty was then identified with all participants attending four special schools in the locality. A randomised sample was then completed to assign the participants to either the physical intervention group or the control group.

Prior to commencement and after the completion of the physical activity all participants completed assessments across a one-week period. These tests measured their sleep routines, their ability to control impulsive behaviours, and recall information to support learning. The administrators of the tests were blinded to which participants were taking part and the same materials were used in both groups across both weeks.

## MATERIALS

An actigraphy accelerometer was used to record data on the identified areas of sleep.

A sleep diary was kept by all participants and help was given by parents to record data on points such as the time sleep occurred and waking time.

To test inhibition control participants completed the Go/No-Go Task online that measured participants' response time to pressing the correct button when following visual instructions.

There may be some limitations to the use of this assessment as while the results were recorded they were not examined due to reliability issues on how data was documented. Part of the exclusion criteria was applied at this stage, removing ten participants who scored less than 50% in this test.

As a result of this applied criteria, ten children were excluded. The final sample of forty comprised of:

- Physical Exercise group: 14 boys and five girls
- Control group: 18 boys and three girls

To test working memory the Corsi block-tapping task was used. Instructions were given to test both visual-spatial and auditory working memory processes.

## PHYSICAL INTERVENTION

The impact of physical activity across a 12-week period on four areas relating to sleep and two relating to executive functioning was investigated.

The physical activity selected was basketball. The authors selected this game as ability is required in areas of executive functioning such as paying attention, remembering rules and motor planning.

The physical activity group met twice per week for 45 minutes in the morning. Each session was matched in terms of length and activities. The control group did not participate in this physical intervention and were asked to follow their daily routines.

To further examine the relationship between changes in sleep and executive functions the following tests were completed:

1. Spearman's correlations were applied to two of the sleep areas (sleep efficiency and sleep duration) to identify any relationship between the sleep diary and the actigraphy test. This was also used to confirm whether the sleep log was a valid measuring tool for this study.
2. Analysis of covariance tests were used to examine data gathered on both tested areas of executive functioning. This assisted in measuring the impact of the physical intervention on the identified executive functions of children with autism.

## RESEARCH FINDINGS

This study found that:

- all the areas relating to sleep that were studied were positively impacted by taking part in the physical intervention.
- sleep onset latency, sleep duration and sleep efficiency were significantly better during the week for the participants who took part in the physical intervention.
- progress made in the areas of sleep efficiency and sleep onset in relation to controlling responses may suggest that both these areas of sleep have an impact on this area of executive functioning.
- improvements in controlling their actions were recorded in participants from the intervention group.
- there was no noticeable improvement in the tested sleep areas of the control group or in their ability to inhibit their responses.
- no difference was recorded in the working memory scores of either group. The authors account for this result by surmising that because the skills of working memory were not predominately tested during the physical

intervention they did not appear changed as a result.

- there were benefits in emphasising the importance of physical activity and its positive impact on the quality of sleep and learning processes of children with autism.
- most of the studied areas of sleep illustrated notable correlations as measured by the sleep diaries and the actigraphy assessment. Therefore, both these assessments may be used in tandem to measure sleep routines in children with autism.

## IMPLICATIONS FOR PRACTICE

- As there is limited literature on this area, this study seeks to provide evidence on the impact of physical activity on the quality of sleep and the executive functioning of children with autism.
- The findings of the study may be of interest to parents and professionals as they seek to provide effective interventions that target areas of challenge for children with autism.
- The authors concede that the study had the following limitations:
  - a) Prior to completing the randomised sample, no information was gathered on what type or how much physical activity any of the participants did prior to their involvement in the study. The participants' levels of basketball skill were also not investigated prior to randomisation. This may have influenced findings as it is unclear if some participants had an advantage in terms of their fitness or their understanding of the game.
  - b) Data was measured at just two time points, which limited investigations into reasons why there may be links between physical activity, sleep and executive functioning in children with autism.

c) The randomised control trial etiquette was not made known prior to it taking place, therefore reducing the value and authenticity of the study.

- Future studies may wish to investigate:

- a) the impact of physical activity on a sample selected from a different school type to reflect generalised findings.
- b) a different type of physical activity and its impact on sleep and executive functioning.
- c) the impact of the activity on different areas of executive functioning.
- d) comparisons between a group with autism and typically developing children using the same method procedures.
- e) data recorded at a third time point to examine the causal relationship between sleep, executive functions and physical activity in children with autism.
- f) the impact of physical exercise on the ability to self-regulate behaviours. The skills involved in playing basketball may have improved participants' ability to self-regulate, for example attending to instructions and controlling motor movements, therefore there may be value in identifying a specific physical activity that could positively impact an area in executive functioning.

## Full Reference

Tse, C.Y.A., Lee, H.P., Chan, K.S.K., Edgar, V.B., Wilkinson-Smith, A. and Lai, W.H.E., (2019). Examining the impact of physical activity on sleep quality and executive functions in children with autism spectrum disorder: a randomised controlled trial. *Autism*. 23(7), pp. 1699–1710.



# SLEEP DISTURBANCES INCREASE THE IMPACT OF WORKING MEMORY DEFICITS ON LEARNING PROBLEMS IN ADOLESCENTS WITH HIGH-FUNCTIONING AUTISM SPECTRUM DISORDER.

## BACKGROUND

Research posits that children and adolescents with autism are especially vulnerable to sleep disturbances (SD), with several studies showing SD is a common co-occurring condition with autism, and that autistic children and adolescents experience greater levels of problematic sleep in comparison to children and adolescents with other developmental disabilities. In fact, comparison group studies have shown that the prevalence of parent-reported SD ranges from 40–83% in autism compared with 9–50% in the comparison groups.

However, while the prevalence of SD in autism is widely recognised, not as much is known about the impact of SD on cognition and learning in adolescents with high-functioning autism (HF-ASD). This study is the first of its kind to consider if clinically elevated SD plays a role in the relationship between working memory and learning difficulties in high-functioning autistic adolescents. As adolescence is a developmental stage particularly vulnerable to the consequences of SD, and given that recent research has found that outcomes are poor for adolescents with autism following their transition to adulthood – in particular for those with HF-ASD – the authors of this study opine that the prevalence of co-occurring conditions such as SD and impairments in executive function such as poor working memory in adolescents with HF-ASD contribute to these poorer outcomes in adulthood.

## RESEARCH AIM

This study looked to examine the relationship between parent-reported SD, objectively measured working memory, and learning difficulties in HF-ASD adolescents as reported by parents. The research aims were:

- a) to examine the association of SD and working memory with learning difficulties.
- b) to examine the role of SD on the association of working memory with learning difficulties.
- c) to identify the sleep characteristics in HF-ASD adolescents.

## RESEARCH METHODS

Ninety-six children with a diagnosis of autism and a full-scale IQ of 80 or above participated in the study. The children were aged between 11:0 and 17:11 years old. Participants were assessed using the following measures: the Checklist for Autism Spectrum Disorder (CASD) and the Paediatric Behaviour Rating Scale (PBRs), which was utilised to assess learning problems (LP) and sleep disturbances (SD).

## RESEARCH FINDINGS

The data from this study showed that 50% of participants had clinically elevated SD. The most prevalent sleep problem was difficulty in falling asleep (62.4%), followed by restless sleep (58.3%) and nightmares (47.9%). Almost 47% experienced difficulty staying asleep, with 42.7% experiencing early-morning awakening. The study also found that 40.6% of participants slept less than other children, 32.3% sleepwalk or talk and 24% slept more than other children.

In terms of the relationship between working memory and LP, the data revealed a positive correlation among adolescents with clinically elevated SD but did not indicate a relationship among those without a clinically elevated SD. The study also found that the positive correlation between clinically elevated SD, working memory and learning difficulties was specific to clinically elevated SD and does not pertain to other neurocognitive domains or behavioural difficulties.

## IMPLICATIONS FOR PRACTICE (by the authors)

- Clinicians need to be aware of three primary phenotypes (observable traits) in adolescents with HF-ASD as these have direct implications for treatment:
  1. Insomnia symptoms (difficulty with both falling and staying asleep) only, where first-line treatment should involve sleep hygiene and evidenced-based cognitive behaviour therapy for insomnia (CBT-I) with pharmacological sleep treatments considered if SD remain.
  2. A developmentally driven circadian delay (sleeping more, restless or unrefreshing sleep in individuals who have difficulty falling asleep) only where treatment should involve further evaluation into circadian delay and if found, treated with light therapy and low-dose timed melatonin.
  3. Non-REM parasomnias (sleepwalking or talking) and less sleep in individuals without insomnia symptoms where treatment should involve scheduled awakening.
- The study had the following limitations: the use of parent-reported data over self-reported data; that the results may not be applicable to autistic individuals with a co-occurring intellectual disability; that the definition of SD used was symptom based rather than a syndrome or disorder; that sleep disorders such as sleep disordered breathing or delayed sleep phase disorder, while highly prevalent in the age group studied, were not excluded due to a lack of objective measures such as actigraphs or polysomnographs.

- The findings in this study contest the belief that lower IQ underpins LP in individuals with HF-ASD.
- HF-ASD adolescents should be routinely screened for sleep problems given the high risk of such in this population.
- Future studies should examine whether the impact of poor working memory on learning difficulties is ameliorated by improving sleep in adolescents with HF-ASD.

## Full Reference

Calhoun, S.L., Pearl, A.M., Fernandez-Mendoza, J., Durica, K.C., Mayes, S.D. and Murray, M.J., (2019). Sleep disturbances increase the impact of working memory deficits on learning problems in adolescents with high-functioning autism spectrum disorder. *Journal of Autism and Developmental Disorders*. Available at: <https://doi.org/10.1007/s10803-019-03928-y>

# SLEEP PROBLEMS IN AUTISM SPECTRUM DISORDERS: A COMPARISON TO SLEEP IN TYPICALLY DEVELOPING CHILDREN USING ACTIGRAPHY, DIARIES AND QUESTIONNAIRES

## RESEARCH AIMS

Sleep is a vital function for everyone. During childhood, the activity of sleeping is particularly important for brain development and maturation. Children with autism often experience sleep problems and research suggests that the severity of autism symptoms predicts poor sleep.

The current study used actigraphy (a wrist-worn device that measures movement and activity) and parental report (using diaries and questionnaires) to compare sleep in children with and without autism to understand the presentation of sleep problems among young people with autism.

## RESEARCH METHODS

The sleep of sixteen children with autism aged 5–15 years having a parentally reported sleep problem were compared to the sleep of a matched group of children without autism.

Each child wore an Actiwatch 2 (Philips Respironics) on their non-dominant wrist for a continuous period of seven to eight days to elicit an objective measurement of sleep behaviours. Sleeping behaviours were calculated automatically using Actiware software. During this time, parents completed a sleep diary that included questions about their child's sleep e.g. time they went to bed, time lights were turned out, etc. Parents also completed a pack of standardised sleep questionnaires within a week of finishing the objective measurement of sleep.

## RESEARCH FINDINGS

No group differences were identified through actigraphy or diary measures.

- Over a week of recordings, no significant differences between groups were observed in sleep duration (as measured through total sleep time) and quality of sleep (as measured through sleep onset, wake after sleep onset, and sleep efficiency).
- There were no significant differences between groups on diary-reported measures, although there were trends towards children with autism going to bed earlier and rising earlier than their typically developing peers.
- The authors of this study reflected that actigraphy may not be a sensitive enough measure of sleep for this population as measures of different types of sleep quality cannot be assessed and there is a possibility that 'restful' or 'still wakefulness' may have been recorded as 'sleep' by the movement recording device.
- Questionnaire data confirmed that the children with autism had a higher prevalence of sleep problems. In this study, children with autism experienced significantly more difficulties with:
  - a) Parasomnias. A frequent problem for 79% of the children with autism in this study, parasomnias are disruptive sleep disorders that can occur during light arousals from sleep resulting in undesirable physical or verbal behaviours such as walking or talking during sleep.
  - b) sleep onset (43%). Sleep onset is described as the transition from wakefulness to sleep.
  - c) daytime sleepiness (64%).

## IMPLICATIONS FOR PRACTICE

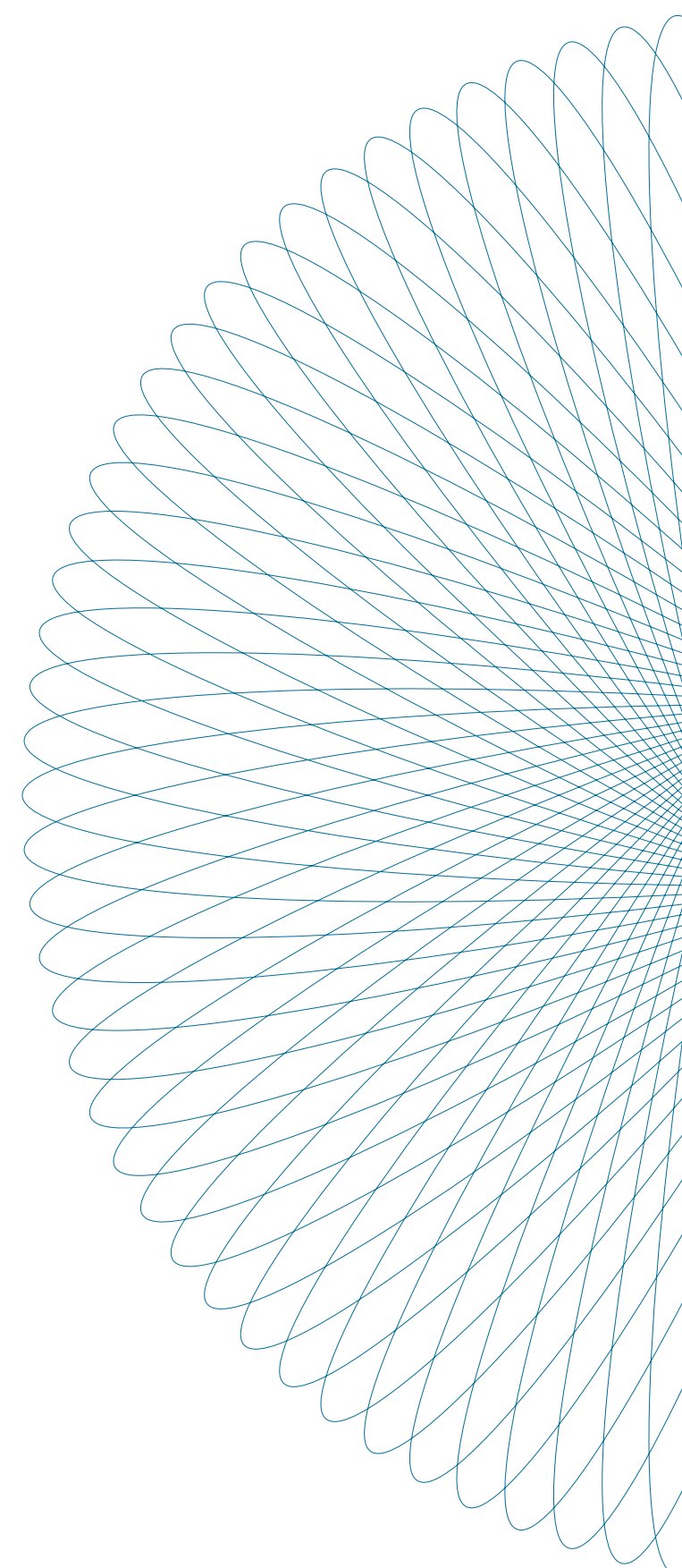
If a child has sleep problems, it may be important to consider using a range of measures to assess the quality, quantity and impact of sleep.

Actigraphy alone may not be a sensitive enough measure of sleep.

Using questionnaires in addition to objective measurement may be a means to understand sleep problems in children with autism and an improved understanding of their impact on the family.

### Full Reference

Surtees, A.D., Richards, C., Clarkson, E.L., Heald, M., Trickett, J., Denyer, H., Crawford, H. and Oliver, C., (2019). Sleep problems in autism spectrum disorders: a comparison to sleep in typically developing children using actigraphy, diaries and questionnaires. *Research in Autism Spectrum Disorders*. 67, Article 101439.





# RELATIONS BETWEEN CAREGIVER-REPORT OF SLEEP AND EXECUTIVE FUNCTION PROBLEMS IN CHILDREN WITH AUTISM SPECTRUM DISORDER AND ATTENTION-DEFICIT/HYPERACTIVITY DISORDER

## BACKGROUND

It is widely recognised that many children with autism also have a co-morbid diagnosis of attention deficit hyperactivity disorder (ADHD). Studies have shown that this group also has challenges with sleep and with executive functioning (the ability to use advanced cognitive functions, some of which are inhibiting behaviours, use of memory to complete tasks and to shift attention).

This study is the first to look at whether the findings of a caregiver report on sleep problems along with difficulties in executive functioning could indicate ADHD symptoms in children with autism. This study raises the question: if sleep and executive functioning are influential on one another, do they play a part in why certain co-morbid disorders to autism occur?

## RESEARCH AIMS

This study aims to:

- ascertain if challenges in executive functioning and the results of a caregiver report on sleep can forecast that some children with autism will be symptomatic of ADHD.
- test the hypothesis that:
  - a) more symptoms of ADHD would be apparent in children with autism who also have impairments in sleep and executive functioning.
  - b) difficulties with executive functioning and sleep can both independently and jointly predict symptoms of ADHD in some children with autism.

## RESEARCH METHODS

This study used a sample of 101 children with autism aged 7–11 years with an IQ of above 80. Fourteen of the sample were females. The sample was sourced from participant registries and other connections from within the community. Participating caregivers were interviewed as to their child's suitability for the study.

Assessment tools used were:

- The Children's Sleep Habits Questionnaire (CSHQ)
- Behavior Rating Inventory of Executive Function (BRIEF)
- Child Behavior Checklist (CBCL). For the purposes of this study The ADHD subscale was used to evaluate its symptoms.

Parents of the current sample completed all three of the above assessments.

Teachers reported on fifty-two children from the sample using BRIEF. Teachers were only able to comment on working memory, therefore results on the relationship between this and ADHD symptoms may be limited. For example, there were definite differences between the findings of the caregiver report and the teacher report with the first highlighting the presence of ADHD symptoms in children who had challenges with executive functioning and sleep and the second drawing no predictions of the presence of ADHD symptoms.

A hierarchy of linear regressions were used to analyse if executive functioning and sleep impairments could forecast the presence of ADHD symptoms on this sample. Separate tests were used to review data gathered on the effect of whether:

- a) executive-functioning impairment influenced the relationship between ADHD and executive functioning.
- b) sleep difficulties influenced the relationship between executive functioning and ADHD.

The influence of sleep both as a singular variable and in interaction with executive functioning was interchangeably analysed to see if predictions of ADHD could be made on a sample of children with autism.

## RESEARCH FINDINGS

This study found that:

- it was more likely for children with autism to display symptoms of ADHD if they had executive functioning and sleep problems.
- sleep was not an influential factor in the relationship between ADHD and working memory; however, children who showed difficulties with working memory were more likely to have ADHD.
- if caregivers reported challenges in sleep and in executive functioning, their children were more likely to display symptoms of ADHD.
- the results of the caregiver report forecast that ADHD was a present co-morbidity in this tested sample in comparison to the findings from the teacher's report on working memory that indicated no such prediction.
- an autism subgroup may exist as a result of impairments in executive functioning and in sleep, leading to symptoms of ADHD.

## IMPLICATIONS FOR PRACTICE

- As this was the first study to evaluate whether the impact of sleep and executive-functioning impairments could predict symptoms of ADHD in children with autism there may be justification for further study of these relationships.
- Further studies may wish to evaluate the relationships between specific components of executive functioning and sleep parameters to ascertain if there are correlations between these and the onset of ADHD symptoms in children with autism.
- Further studies may also wish to consider the following:
  - a) A larger number of female participants.
  - b) The use of other assessments, particularly on measuring sleep, to further the robustness of similar studies.
  - c) How sleep and executive functioning influence emotional regulation. This may prove useful when examining the difficulties children with autism and ADHD have in regulating their emotional responses.
  - d) Identifying interventions that may be helpful in addressing the challenges of managing ADHD symptoms caused by poor sleep and executive-functioning difficulties.

## Full Reference

Cremone-Caira, A., Buirkle, J., Gilbert, R. and Nayudu, N., (2019). Relations between caregiver-report of sleep and executive function problems in children with autism spectrum disorder and attention-deficit/hyperactivity disorder. *Research in Developmental Disabilities*. **94**, Article 103464.

# SLEEPING SOUND WITH AUTISM SPECTRUM DISORDER (ASD): STUDY PROTOCOL FOR AN EFFICACY RANDOMISED CONTROLLED TRIAL OF A TAILORED BRIEF BEHAVIOURAL SLEEP INTERVENTION FOR ASD

## BACKGROUND

Co-occurrence of sleep disturbance in autism spectrum disorders has been estimated in the 40–80% range throughout recent research in this area, with sleep issues affecting individuals in the area of social-emotional functioning while parents are affected physiologically. Due to the pervasive impact of sleep disturbance the authors of this paper have outlined the study protocol of a research study that examines the effects of a short-term behavioural intervention on reducing sleep disturbance. The research was conducted using a randomised control trial (RCT) methodology to specifically investigate the efficacy of the Sleeping Sound ASD project. (Data analysis at the time of publishing this article was unavailable.)

## RESEARCH AIMS

The primary aim of the Sleeping Sound ASD project is to determine if a brief behavioural intervention is efficacious in treating sleep disturbance in comparison to a control group (treatment as usual). Evaluation was made based on a reduction in sleep disturbance symptoms in comparison to the control group three months post intervention.

Secondary research outcomes measured the effects on the intervention group's social-emotional functioning and their parents' physiological functioning at three-month and six-month follow-ups.

A final aim of this study was to consider the cost-effectiveness of the intervention recipients reducing service needs in the area of sleep disturbance, social-emotional function support and academic achievement.

## RESEARCH METHODS

A RCT methodology was employed with the aim of recruiting 234 children with a diagnosis of autism, aged 5–13 years, who experienced moderate to severe sleep problems. Participants were recruited from paediatrician clinics via social media. The project ran from July 2016 to the end of 2019 when all stages of the study, from recruitment to follow-up data collection at six months post randomisation, was executed.

The study protocol followed the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) reporting requirements and an outlined SPIRIT timeline.

Families interested in the study were screened for eligibility via telephone followed by a requirement to complete an online baseline survey to assess their child's sleep problems and family and child functioning. Informed consent was gained.

## PATIENT INVOLVEMENT

The intervention used in this study was based on the ADHD Sleeping Sound trial during which participant feedback on the acceptability and feasibility of the study was gathered. No reported concerns were collected.

## RECRUITMENT: STAGE 1

Paediatricians identified potential participants meeting set inclusion criteria whom they had seen in the last twelve months. A letter of invitation was sent to ask them to participate in the study. Advertisements providing details about the study were also made visible in the waiting areas of clinics and distributed through research, clinical and community-based groups.

## RECRUITMENT: STAGE 2

The research team contacted, via telephone, all interested primary parents who registered their interest to evaluate the inclusion and exclusion criteria. Those eligible were then provided with an information sheet, consent form and a baseline survey by either email or post. The child's primary parent was required to complete the survey and consent form. Online surveys were completed via a secure research database REDCap. Upon receipt of written consent, parents were asked to provide diagnostic and cognitive assessment reports where possible. If optional consent was given to contact the child's teacher, a link to an online survey was sent to the child's nominated teacher.

## RANDOMISATION

Following the completion of baseline surveys and consents, participants were then randomly assigned, by an independent research assistant, to an intervention group or treatment as usual (TAU) comparative group. Treatment allocation was determined chronologically according to a computer-generated block randomisation sequence with 1:1 ratio between groups, with blocks of randomly varying size (4, 6 and 8). This was developed by an independent statistician who was not involved in the project. The randomised list was further uploaded to REDCap for security purposes. Owing to the lower diagnosis of autism in girls, randomisation was stratified by gender to ensure equal representation of girls, boys and other genders in both study arms. Siblings were also eligible to participate in the study if they met inclusion criteria. All families were sent a letter outlining their group allocation. A study clinician then contacted the families via telephone to book intervention sessions. The TAU group received standard community services and support and completed the same study-assessment follow-

up. If consent was provided to contact teachers, researchers contacted the school for consent to contact the child's teacher and to send a baseline survey to complete.

The behavioural sleep intervention was delivered by clinicians (paediatricians or psychologists) experienced in working with children with autism. Clinicians met regularly to ensure fidelity of the programme. Families in the intervention groups attended two face-to-face sessions lasting fifty minutes, on an individual basis, followed by a phone call with a trained clinician whereby families were provided with tailored behavioural sleep strategies to help manage their child's sleep difficulties.

These sessions and the telephone follow-up session were conducted with a two-week inter-session gap. Session one focused on assessment of the child's sleep difficulties, psycho-education about normal sleep and sleep cycles, good sleep habits and a tailored sleep-management plan for the child. Families received written handouts summarising the session. A standardised consultation record was kept for all children. Session two focused on reviewing the sleep-management plan (including a sleep diary), reinforcing strategies, solving problems and monitoring progress. A total of 117 participants were assigned randomly by computer generation to the research intervention group and the control group. Strategies (a newsletter and a four-stage reminder process) were put in place to encourage participation and completion of follow-ups.

Reports from teachers on sleep, behaviour and social function were also collected in addition to cognitive-ability assessments to act as measures blind to the treatment group.



## MEASURES

A range of measures were employed in this study to measure child, parent and economic outcomes. The research team chose the Children's Sleep Habits Questionnaire (CSHQ) as their primary outcome measure as this was deemed a widely utilised and validated measure of behavioural sleep problems in children and was used in the researcher's Sleeping Sound ADHD-ASD pilot study. To protect participant blinding, which is impossible in trials of this nature, the research team took measures as far as possible, including not informing teachers of a child's group status and asking parents not to impart such information, or if a family disclosed their group status to another team member, this was noted on the participant's file.

Additional baseline information, including family and child demographics and medical data was gathered. Medication information was taken at baseline and three- and six-month follow-up. The authors did not anticipate any risks to children completing the study measures. In the event that parents became distressed completing questionnaires, the researchers included information links to a psychologist within their research team as well as advice to contact their general practitioner.

## RESEARCH FINDINGS

This article reports on a study protocol as a means of providing information on research still in progress. Authors outline that the primary analysis will be intention to treat and will compare outcomes of children in the TAU and intervention groups at three and six months post randomisation time points. Analysis of the primary outcome (child sleep problems) and all secondary outcomes will be carried out using linear mixed effects regression with results presented as mean differences (at 95% confidence intervals).

An important secondary aim of the project will be to determine the cost-effectiveness of this intervention compared to TAU. The economic analysis will be conducted from a societal perspective, as interventions targeting children with autism are likely to have benefits and costs beyond such aspects as ASD services and productivity impacts for parents.

A three- and six-month follow-up is still ongoing. The evaluation, as approved by ethics, reports that dissemination of findings from this study will be published following completion of data analysis and write-up of which both are currently unavailable.

## IMPLICATIONS FOR PRACTICE

### (by the authors)

This study has been the largest randomised controlled trial study to date to address the efficacy of the Sleeping Sound project for children with autism. As the sleep intervention consisted of a brief behavioural intervention, the authors note that this may increase the possibility of this type of intervention being translated into clinical practice.

The article provided a detailed methodology of an RCT that could be replicated by others in the future; however, limitations were highlighted such as a lack of an objective measure, the inability to monitor families' use of additional sleep treatments post trial enrolment, in addition to the absence of a gold-standard autism diagnostic tool to validate diagnosis of participants. These are all aspects of the study that could be addressed in future studies.

### Full Reference

Papadopoulos, N., Sciberras, E., Hiscock, H., Williams, K., McGillivray, J., Mihalopoulos, C., Engel, L., Fuller-Tyszkiewicz, M., Bellows, S.T., Marks, D., Howlin, P. and Rinehart, N., (2019). Sleeping sound with autism spectrum disorder (ASD): study protocol for an efficacy randomised controlled trial of a tailored brief behavioural sleep intervention for ASD. *BMJ Open*. Available at: <http://dx.doi.org/10.1136/bmjopen-2019-029767>

CONCLUSION

Sleep issues are reported to be more common for autistic children, young people and adults. Research summarised in this Bulletin indicates that lack of sleep can have a broad impact across

- behaviour
- mental health
- physical health
- emotional dysregulation
- the presentation of difficulties related to ADHD

While insomnia is an issue, caregivers don’t seem to have knowledge of or access to strategies to support sleep.

What can help are the use of social stories, fading parental presence, visual supports and reinforcement. The use of these strategies requires behavioural changes for the child and the parent.

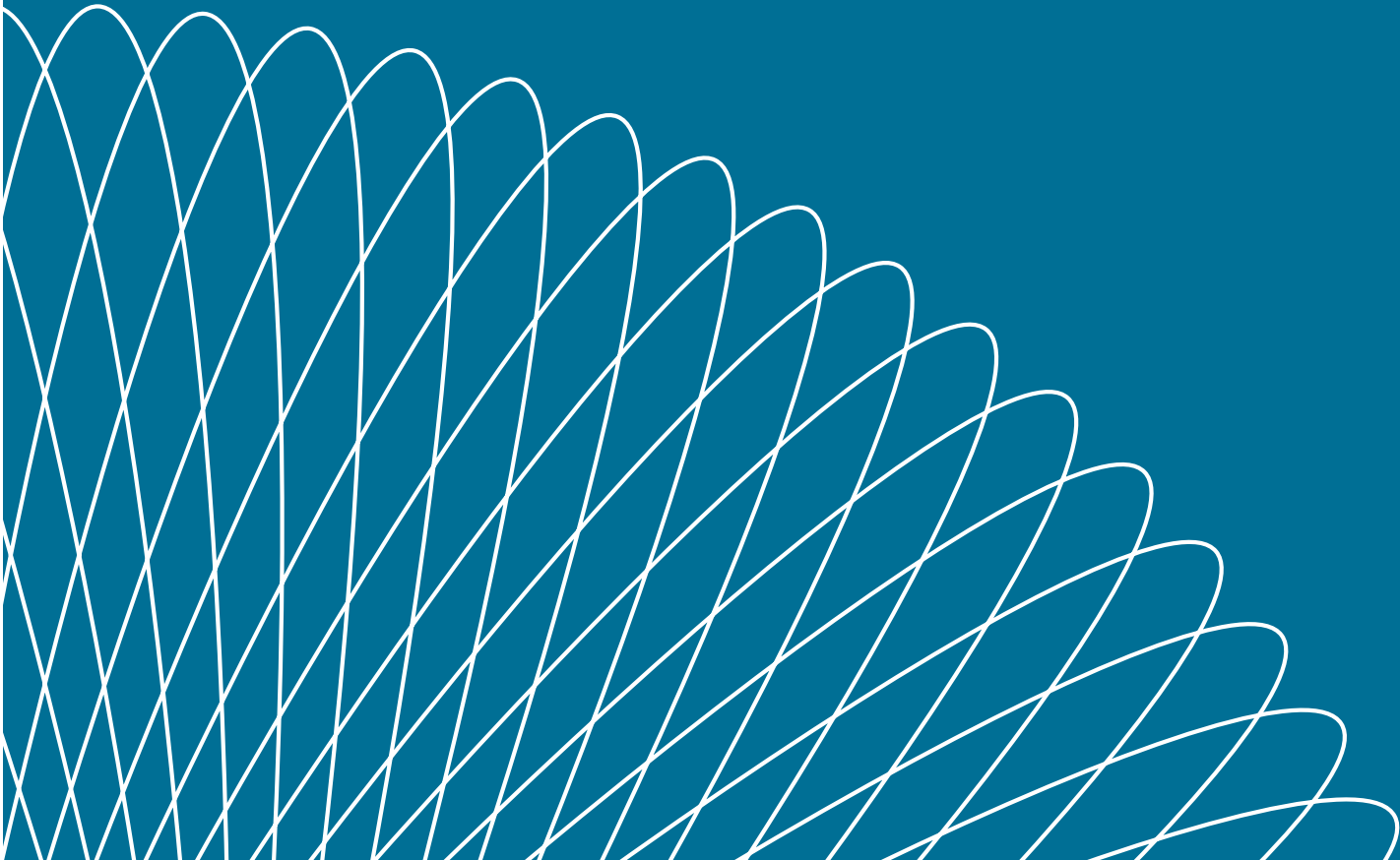
Physical exercise also has a role in falling asleep and staying asleep.

Formal programmes to promote sleep do exist but these may be difficult to access and this Bulletin provides details of resources and agencies that can help promote sleep.

YOUR OPINION

The Centre trusts that you have found this Research Bulletin informative. It would be appreciated if you would take a few minutes to provide the Centre with feedback in relation to this bulletin by clicking on the survey link below.

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Autism and Sleep







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