

Supporting Parents with their Child's Sleep Difficulties



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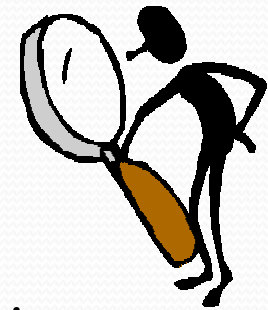
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Introduction



Research & Development at Queensmill



- Set up in September 2013, the R&D Board lead and monitor relevant research activities at the school;
- The board supports internal research projects and considers external research requests received to ensure these meet with the priorities of our students, staff and parents;
- Membership includes our R&D Coordinator, SMT representative, a class teacher, therapist, a teaching assistant, parent representative, a research assistant and an external R&D university consultant;
- The board publishes a termly newsletter for parents and staff to keep them up to date with research activities at school and to provide a summary of recent studies published in research journals.
- Visit our R&D page for more details:
www.queensmillschool.com/Research-and-Development

Seminar aims



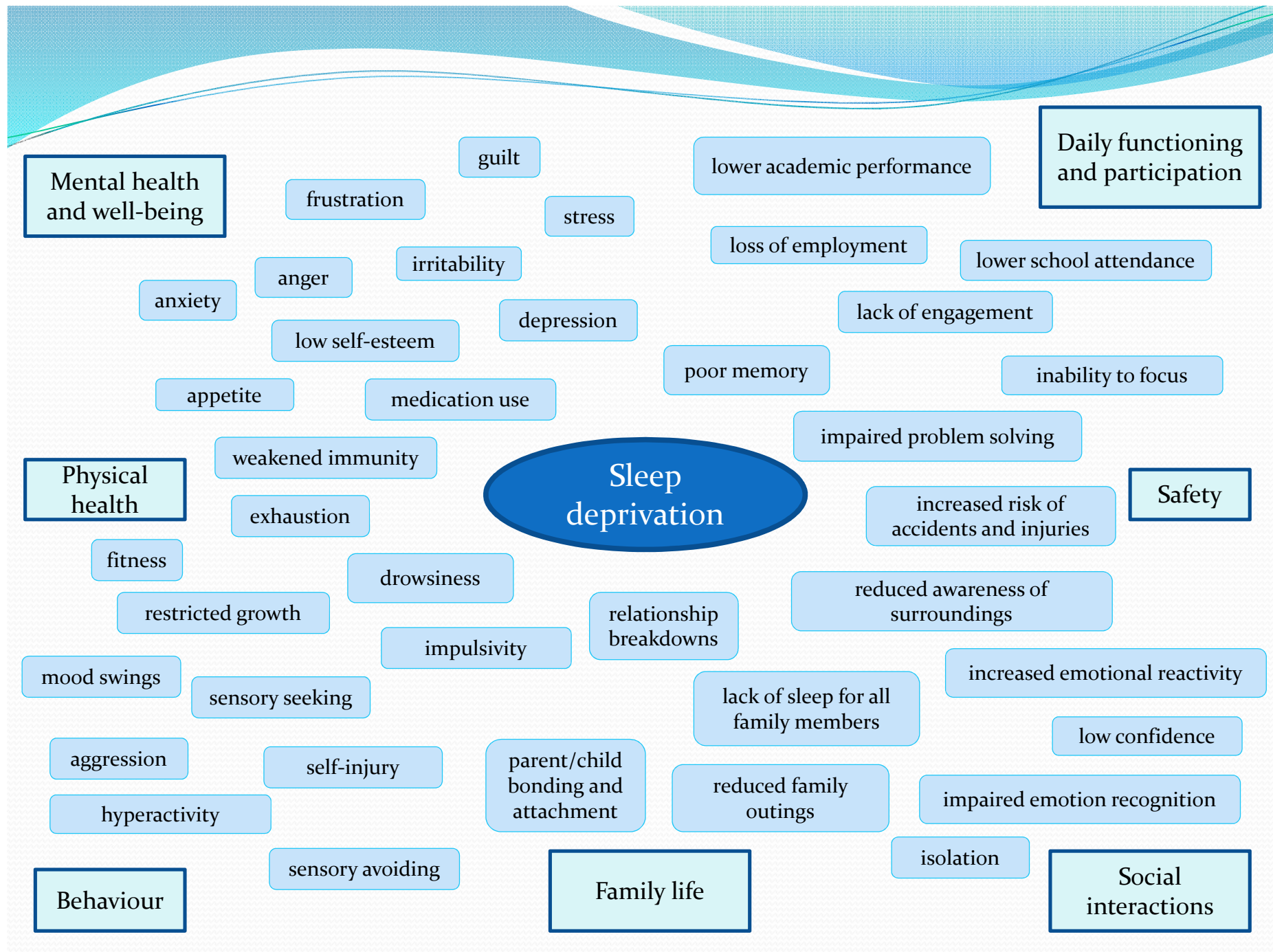
- To explore the prevalence, presentation and impact of sleep problems amongst individuals with autism;
- To provide an overview of a pilot research project at Queensmill focused on supporting families with their child's sleep difficulties;
- To offer examples of sleep interventions that families have found effective in improving the sleep patterns of their child with autism;
- To offer ideas and suggestions for professionals on providing sleep interventions for families of children with Autism.

Sleep disturbance - prevalence

Estimates of the prevalence of sleep problems vary depending upon differences in definitions and methods of assessment however examples of figures of reported sleep problems in the following groups are:

- ~25-30% of typically developing children.
- ~25-50% of children with ADHD.
- ~40-80% of children and young people with ASD.
- Up to 86% of children with intellectual/learning disability.





Hypnograms showing sleep stages

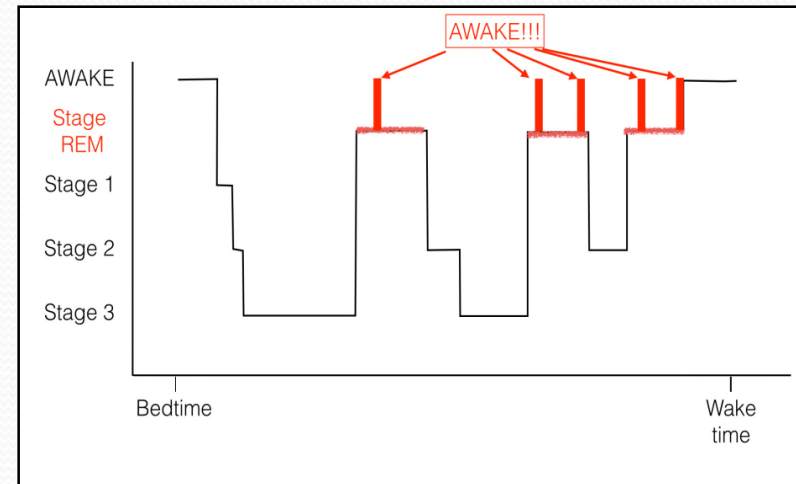
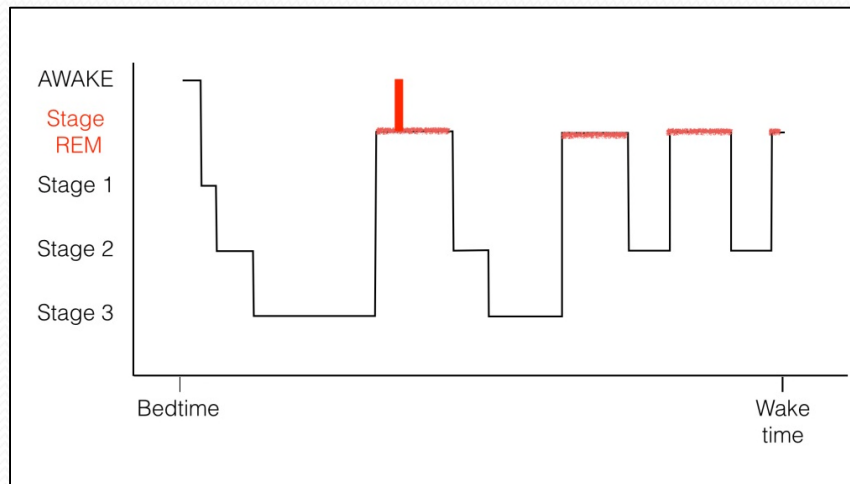


Image source -

Canapari, C. (2015) *Behavioural Sleep Problems in Children: Toddler Night Wakings*

<https://drcraigcanapari.com/behavioral-sleep-problems-in-children-part-1-inappropriate-sleep-associations/>

Sleep problems in individuals with Autism



- Bedtime resistance;
- Difficulties initiating sleep;
- Night time waking;
- Early morning waking.

Possible causes/contributing factors:

- Inability to self-settle;
- Lack of appropriate bedtime routine;
- Anxiety;
- Hunger/thirst;
- Medical issues/Specific sleep disorders;
- High arousal levels/Overstimulation;
- Genuinely not tired;
- Sensory processing difficulties;
- Temperature regulation difficulties;
- Low melatonin levels;
- Diet;
- Screen time;
- Bedwetting;
- Daytime napping;
- Sleep associations.



Gathering information

- Detailed sleep interview;
 - Sleep disturbance index;
 - Child Sleep Habits Questionnaire;
 - Sleep diaries;
 - Home visits;
 - Photographs of the bedroom environment.
-
- Consideration of indirect measures where relevant?



Sleep interventions

“Sleep hygiene is a variety of different practices that are necessary to have normal, quality night time sleep and full daytime alertness.” (National Sleep Foundation)

- Bedtime routine;
- Regular sleep pattern;
- Consideration of: Screen use, exercise, diet;
- Sensory strategies;
- Bedroom environment adaptation;
- Behavioural strategies.



Challenges for families

Remember ‘Sleep deprivation’ slide +

- Time and energy;
- Space/housing;
- Mental health;
- Professionals’ expectations;
- Parent expectations;
- Lack of consistency across settings;
- Difficulties persisting (things get worse before they get better);
- Lack of ongoing support.



Sleepwise

- Developed by Annie O'Connell, Occupational Therapist (2003-2015) as part of her work for Child and Youth Disability Services in South Australia to address sleep disturbance in young people with developmental disabilities;
- The Sleepwise approach offers parent training and a wide range of strategies that can be tailored for individual children and their families;
- Two research grants from the Apex Foundation (for Research into Intellectual Disability) enabled evaluation of the Sleepwise approach for children 2–6 years of age and 8–18 years of age;
- Queensmill ran the Sleepwise programme (O'Connell 2005), as a pilot, for ten pupils (aged three to eight) and their families at Queensmill School to see how far it could help improve their sleep habits.



Sleepwise – evidence base

- Positive changes in sleep patterns have been seen in individual case studies with families with support from a health professional over several months. (O'Connell, 2009)
- Six parents of children with developmental delay attended three workshop sessions and implemented individualized treatment plans. Initial results revealed significant posttreatment reductions in child sleep disturbances and behavioral problems, with high treatment acceptability ratings by parents. Outcomes were generally maintained at 1-month follow-up. (Austin et al. 2013)
- Twenty-six families of children with developmental disability (fifteen with autism) aged 8–17 years participated in a study comparing a treatment group and a wait-list control group at baseline, post-treatment and 2 months post-treatment on measures of child and parent functioning. Results demonstrated that the Sleepwise approach was effective in reducing sleep disturbance and parent stress. (Moss et al. 2014)



Sleepwise at Queensmill:

The programme included:

- Two 3 hour workshops (one week apart) exploring in depth the issues around sleep and strategies that may help (including sensory, behavioural, environmental strategies);
- Parents completing a sleep diary of their son/daughter's sleep habits in between the two training sessions;
- Meetings with Occupational Therapist and/or Family Support Practitioner in their home to complete a comprehensive sleep assessment;
- Parents undertaking (over three months) the actions agreed in the individualised sleep programme drawn up by the Occupational Therapist and Family Support Practitioner with opportunities for ongoing support and review of plan.

Sleep plan examples

Queensmill School Occupational Therapy and Family Support

EXAMPLE 1: E's Sleep Plan

Family's main concern/priority: E's distressed response to being told 'bedtime,' transitions to bed (currently very extended and stressful), settling to sleep (currently taking over an hour).

Short-term goal: E transitions downstairs at bedtime calmly and within 20 minutes

Long-term goal: E settles to sleep within 20 minutes

Sensory strategies:

- Turtle light as part of calming routine before bed
- Blackout blinds
- Calming music

Communication Strategies:

- Cues leading up to bedtime: tidying away, turning off lights and closing door in kitchen, quieter activities, turning off TV.
- Verbal warning "5 more minutes" before transition downstairs. Then verbal count down
- First and then/next board visual (first 'bathroom', then 'special light', then 'bed') shown to support transition downstairs (objects of reference can also be used to support moving from one activity to the next if visual not effective e.g. towel for bathroom)
- Use objects of reference for tooth brushing, nappy, pyjamas.

Reinforcement:

- Use of motivating objects to support transition (current preferred book or toy to come to bed with him). Save most motivating items for bed time (as long as these are not overstimulating for him).
- Turtle light/ other preferred sensory toys as part of bedtime routine.
- Praise for following instructions. Positive interactions and use of preferred activities and items to encourage participation in bedtime routine as modelled (for example, favourite character gets dressed in pyjamas, singing preferred songs whilst changing or brushing teeth).

Other strategies:

- Safe space to be considered
- Regular review of motivators as they change
- Stairgate at the top of the stairs
- Locking the lounge from the outside so can't access this space in the night

Short-term goal for sleep:

- 100 % E transitions downstairs when prompted, calmly and within 20 minutes 5-6 nights a week
 75% E transitions downstairs when prompted, calmly and within 20 minutes 4 nights a week
 50% E transitions downstairs when prompted, calmly and within 20 minutes 3 nights a week
 25% E transitions downstairs when prompted, calmly and within 20 minutes 2 nights a week
 0% E does not transition downstairs at bed time within 20 minutes.

Sleep plan adapted from [Sleepwise](#) Information Booklet for Parents and Carers, Appendix 6, p.37 in: Intellectual Disability Services Council (2005) [Sleepwise: A Resource Manual. Positive Sleep Practices for Young Children with Developmental Delay](#), Government of South Australia.

Queensmill School Occupational Therapy and Family Support

EXAMPLE 2: M Sleep Plan

Family's main concern/priority: M is unable to sleep on his own and does not like to go in his own bed. He takes a long time to settle to sleep and wakes many times through the night and demonstrates challenging and sensory seeking behaviours when wakes. He currently sleeps in mum's bed with her.

Short-term goal: Sleeping in own bed and settling back to sleep with support from mum within 20 minutes.

Long-term goal: Sleeping in own bed and settling self back to sleep when he wakes.

Things to do during the day (diet, exercise, naps)

- Physical exercise : afternoon
- Trampoline
- Park

Bedtime routine:

- Trampoline: 20 minutes/Rocker/Dinner /Choosing quiet play activities (Lego, cars, trains, leaflets)/Bath/Massage and pyjamas on/Rocker/Bed

Sensory strategies:

- Bubble machine in bath
- Lavender oil in bath and massage afterwards
- Rocker
- Singing at bedtime

Behavioural strategies:

- No iPad/TV after 6pm
- Taken to same bedroom consistently at bed time (his own)
- 'Gradual retreat' approach
- Consistent response when he wakes-show visual

Communication Strategies:

- Visual schedule for evening routine
- Visual showing bedtime
- Time timer for rocker as needed

Goal (s) for sleep:

- 100 % M falls asleep in his own bed 5-6 nights a week
 M settles to sleep/back to sleep with 20 minutes 5-6 nights a week
 75% M falls asleep in his own bed 4 nights a week
 M settles to sleep/back to sleep with 20 minutes 4 nights a week
 50% M falls asleep in his own bed 3 nights a week
 M settles to sleep/back to sleep with 20 minutes 3 nights a week
 25% M falls asleep in his own bed 2 nights a week
 M settles to sleep/back to sleep with 20 minutes 2 nights a week
 0% M falls asleep in mum's bed or on the sofa 6+ nights a week.
 M takes more than 20 minutes to settle to/ back to sleep 6+ nights a week.

Sleep plan adapted from [Sleepwise](#) Information Booklet for Parents and Carers, Appendix 6, p.37 in: Intellectual Disability Services Council (2005) [Sleepwise: A Resource Manual. Positive Sleep Practices for Young Children with Developmental Delay](#), Government of South Australia.

EXAMPLE 3: J's Sleep Plan

Family's main concern/priority: J falls asleep at 5pm or earlier every evening then wakes through the night and stays awake from around 2-3am. Parents have tried a range of strategies to keep him awake for longer in the evening and settle him back to sleep over a period of several years. He sleeps in mum's bed with her. When he is tired and ready for bed, other family members have to go to bed. He wakes all family members up when he wakes and is very loud and climbs all over parents in bed.

Short-term goal: Going to bed later (7pm at earliest) and getting up later (5am at earliest).

Long-term goal: J will sleep in his own bed.

Things to do during the day (diet, exercise, naps)

- Alerting activity on the bus home from school (singing). School staff and parents to liaise with transport staff about this.
- Trial of no swimming with school (this appears to make J very tired so he falls asleep earlier).
- Alerting activities on arrival home from school/late afternoon as modelled (bouncing or swinging, playing in garden or park where tolerated).

Bedtime routine:

- Dinner/rest of evening routine to be pushed forward by 5-10 minutes each evening (if successful, to be moved forward a further 5 minutes).
- Staying upstairs (in communal, better lit rooms) until bedtime.
- After dinner: playing with trains, pyjamas, milk, bedtime.

Sensory strategies:

- Alerting activities as modelled (bouncing, swinging, jumping) early afternoon
- 1000 lumens bulb to be used in living room – particularly during Autumn/Winter
- Use of window frosting film in the evening rather than closing blinds in lounge
- Blackout blind in bedroom

Communication Strategies:

- Visual schedule for new after school routine
- Visual schedule for bedtime routine so J can see what is happening before bed
- Social story provided.

Reinforcement:

- Use of praise, singing, positive interactions and giving choices to encourage and reinforce participation in additional activities as part of routine.

Other strategies:

- New 'car' themed bed introduced in a positive way within social story.

Goal (s) for sleep:

- 100% J will fall asleep at 7pm at the earliest 5-6 nights a week
- 75% J will fall asleep at 7pm at the earliest 4 nights a week
- 50% J will fall asleep at 7pm at the earliest 3 nights a week
- 25% J will fall asleep at 7pm at the earliest 2 nights a week
- 0% J will fall asleep before 7pm 6 or more nights a week

Sleep plan adapted from [Sleepwise](#) Information Booklet for Parents and Carers, Appendix 6, p.37 in: Intellectual Disability Services Council (2005) [Sleepwise: A Resource Manual. Positive Sleep Practices for Young Children with Developmental Delay](#), Government of South Australia.

Example 4: A's Sleep Plan

(Sleep plan only to be implemented when family is ready)

Family's main concern/priority: A is unable to fall/stay asleep without mum being next to him in the bed and cuddling him. He often wakes and becomes distressed if mum moves away. He wakes regularly through the night and will get into bed with parents if mum is not sleeping next to him. He refuses to go back to his own bed. Mum unsure as to whether she is ready to work on this or not.

Short-term goal: To remain in his own bed through the night with support from parents to settle.

Long-term goal: To sleep in his own bed throughout the night, and settle back to sleep if he wakes.

Things to do during the day (diet, exercise, naps)

- Swimming
- Walks at school

Bedtime routine:

- Change clothes/Milk/Play with siblings/Dinner/Play with dad/Bath/Pyjamas on/Massage and music/Bed

Sensory strategies:

- Mum's nightshirt or T-shirt on teddy or pillow to cuddle
- Massage before bed
- Blanket with weights either side/bedding tucked into wall/cocoon sleeping bag to provide calming deep pressure.
- Calming activities to settle him to sleep (music, soft music, rocking) or get back to sleep

Behavioural Strategies

- Gradual retreat approach

Communication Strategies:

- Bedtime visual of A's bed to be shown to him if he wakes. Guided back to bed by parent.
- No talking (in the middle of the night)

Reinforcement:

- Praise, reassurance

Other strategies

- Own bedroom in playroom rather than with sibling (if in own room more opportunity to introduce strategies)
- All toys put away in cupboards

Goal (s) for sleep:

- 100% A to go back to his bed after waking 5-9 nights a week
- 75% A to go back to his bed after waking 4 nights a week
- 50% A to go back to his bed after waking 3 nights a week
- 25% A to go back to his bed after waking 2 nights a week
- 0% A does not stay in his own bed though the night - stays in parent's bed 7 nights a week

Sleep plan adapted from [Sleepwise](#) Information Booklet for Parents and Carers, Appendix 6, p.37 in: Intellectual Disability Services Council (2005) [Sleepwise: A Resource Manual. Positive Sleep Practices for Young Children with Developmental Delay](#), Government of South Australia.

Example 6: L's sleep plan

Family's main concern/priority: L wakes through the night. When he wakes he is unable to fall back to sleep. He is very noisy, overexcited and wakes his siblings. He gets all of his toys out to play with them. L fixates on his toys and is easily distracted by the visual environment.

Short-term goal: L will remain in bed until Gro-clock shows morning (with mum/dad present).

Long-term goal: L will remain in bed until Gro-clock shows morning quietly on his own.

Things to do during the day (diet, exercise, naps):

- Structured exercise when home from school (walk then sensory circuit)
- Use bean bag and weighted blanket for quiet time
- Rocker for calming as needed

Bedtime routine:

- Tidy up toys and put these away (parents to lock cupboard)
- Brush teeth
- Pyjamas on
- Listen to music (choosing 2 songs only from choice of calming music)
- Drink (Melatonin)
- Dark den
- Bed
- Sleep

Sensory Strategies:

- Dark den underneath bed (to be used before bed and when wakes/in morning as needed to support calming/quiet activity until siblings get up)
- Black out curtains
- All lights turned off once pyjamas on
- Lavender spray on pillow
- Items for calming if wakes early (music/fidgets – no 'toys' until Gro-clock shows morning)

Behavioural strategies:

- Toys locked away in the evening
- If wakes early, parents to show visual and remain with him to support settling
- Use of Gro-clock – 'morning' time to be set for around the time he usually wakes initially (to ensure 'success') then moved gradually forwards by a few minutes each day.

Communication strategies:

- Social story (to read at relaxation time and at school)
- Visual schedule for evening routine
- Visual to show if wakes during the night (photograph of Gro-clock showing star then bedtime and quiet symbol)

Reinforcement:

- Thomas stickers (for staying in bed until Gro-clock shows morning)

Other strategies:

- Declutter room

Sleep plan adapted from [Sleepwise](#) Information Booklet for Parents and Carers, Appendix 6, p.37 in: Intellectual Disability Services Council (2005) [Sleepwise: A Resource Manual. Positive Sleep Practices for Young Children with Developmental Delay](#), Government of South Australia.

Goal for sleep:

- | | |
|------|------------------------------------------------------------------------|
| 100% | L will remain in bed until Gro-clock shows morning 5-6 days per week |
| 75% | L will remain in bed until Gro-clock shows morning 4 days per week |
| 50% | L will remain in bed until Gro-clock shows morning 3 days per week |
| 25% | L will remain in bed until Gro-clock shows morning 2 days per week |
| 0% | L gets out of bed before the Gro-clock shows morning 6+ days per week. |

(N.B. Time that Gro-clock shows morning to be changed very gradually, starting with the time he wakes anyway then moving forward no more than 5 minutes per day and only if L successfully achieved staying in bed the day before)

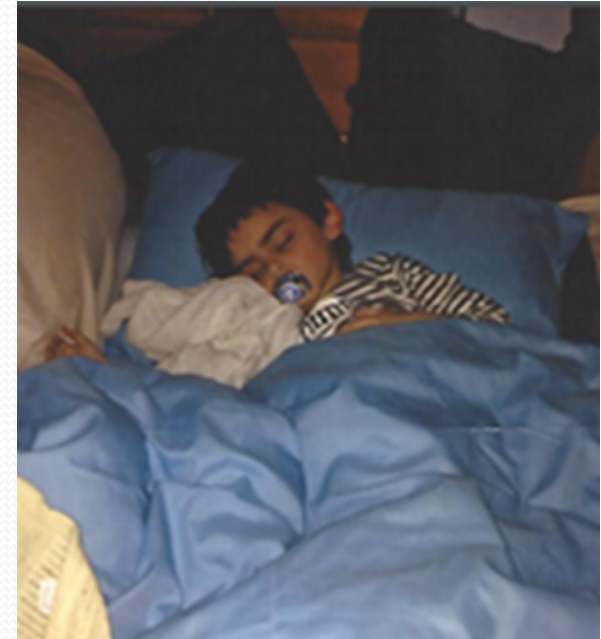
Sleep plan adapted from [Sleepwise](#) Information Booklet for Parents and Carers, Appendix 6, p.37 in: Intellectual Disability Services Council (2005) [Sleepwise: A Resource Manual. Positive Sleep Practices for Young Children with Developmental Delay](#), Government of South Australia.

Findings

Children's Sleep Habits Questionnaire (CSHQ)

Improvement in mean score across 18 out of 31 items

- Areas of marked improvement in the following areas:
 - Falling asleep within 20 mins of going to bed
 - Falling asleep in own bed
 - Sleeping alone
 - Sleeping away from home
 - Waking through the night
- Improved scores were demonstrated in all of the following areas:
 - Bedtime resistance
 - Sleep onset time
 - Sleep duration
 - Sleep anxiety
 - Night waking
 - Daytime sleepiness



I came away from the trainings feeling empowered and confident to put strategies and routines in place.

I felt a bit dazed after having a few extra hours of sleep as I wasn't used to it!

We found the **sleep diary** useful for reflection. We noticed that the days O was watching TV during the week, his sleep would be disrupted. We cut out TV during the week and saw improvements in his sleep.

The staff are familiar so work better collaboratively with us. We are more trusting and open because you know our children. Someone external would stick to the programme and may not be able to individualise as much as someone who knows our child well.

The sleep plans and home visits were most useful in providing strategies and support in the areas of sleep you need help with.

- All but one of the parents reported fewer problem areas of sleep at the end of the intervention.
- For these parents the number of sleep problems had almost halved.
- Each parent reported an average of 8 areas of progress – ranging from 6-12.



Tips for professionals

- Self-referrals only?
- Listen;
- Parents/carers as experts;
- No judgement;
- Offer choices rather than a set of rules to follow;
- Individualise strategies to suit the child and family;
- Be flexible – respond to the family's needs;
- Offer ongoing support;

To provide rationale to commissioners for offering sleep support: Reference cost impact and analyses in addition to research.

Next steps...

Lifespan Learning and Sleep Lab Personal Accounts on Sleep in Autism

Investigators : Dagmara Dimitriou
Georgia Pavlopoulou
Advisor: Richard Mills



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The Teen Sleep Project

Recruiting Now

Boys and Girls
12-18 Years Old

Help researchers learn more about sleep in adolescence

In return we offer:

Training on how your sleep works
Your personal sleep report printed by scientists at UCL
A free photo design seminar

£15 voucher to spend in your favourite shop
Participation in photo exhibition (optional)

What you will need to do:

1. Complete a questionnaire
2. Wear an actigraphy watch for a week
3. Take up to 20 photos of things that are important to you over the course of a week
4. Talk about your photos over the course of a few 45 minute meetings

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Further information and support

- **Encouraging Good Sleep Habits in Children with Learning Disabilities** (Leaflet produced by Research Autism)
- **National Autistic Society:**
<http://www.autism.org.uk/about/health/sleep.aspx>
<http://www.autism.org.uk/services/helplines/parent-to-parent.aspx>
- **Cerebra:** <https://w3.cerebra.org.uk/help-and-information/sleep-service/>
- **Scope:** <https://www.scope.org.uk/support/services-directory/sleep-solutions>
- **Children's Sleep Charity:**
<http://www.thechildrenssleepcharity.org.uk/>
- **Sleep Scotland:** <http://www.sleepscotland.org/>
- **Tired Out:** <https://www.familyfund.org.uk/tired-out>
- **Infant Sleep Information Source:** <https://www.isisonline.org.uk/>

Questions



References available on request

“Being able to give the gift of sleep to a family is the most rewarding role”



(Vicki Dawson, Founder, Children's Sleep Charity)