

Bringing Sleep and Autism into Community Settings

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Questions we will address today

- ✓What are their causes and contributors to sleep problems in children with autism?
- ✓What is the impact on the child-- at school and home?
- ✓Do behavioral treatments work? How deliver?

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How can we help Alex sleep?

Alex is a 10-year-old boy with autism, ADHD, epilepsy, and anxiety. Bedtime is 8:00 pm. He takes hours to fall asleep. His parents state that "he can't shut his brain down."

Alex takes methylphenidate (Ritalin) in the morning and afternoon for ADHD symptoms, takes lamotrigine (Lamictal) at night for seizures, and has Mountain Dew and plays video games after dinner.

He can't settle down to go to sleep and leaves his room to find his parents. They return him to his room and rub his back to help him fall asleep.

Once asleep, he awakens multiple times during the night. Sometimes he comes to his parents' bedroom and falls asleep there. He snores loudly in his sleep and is very restless with frequent leg kicks.

It is "nearly impossible" to awaken Alex in the morning for school. Alex's teacher describes him as being sleepy as well as hyperactive and in class. His parents are exhausted and very overwhelmed.

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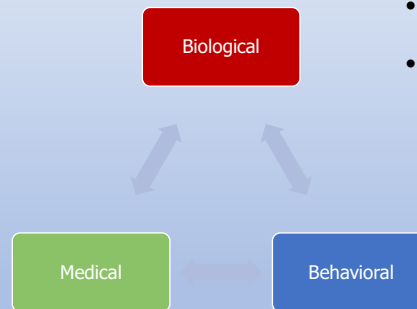
Alex- Case History- Revisited

Adenoid and tonsil removal resolved snoring and improved seizures. Alex still takes at least an hour to fall asleep, and wakes up at least once a night. He continues to have restless sleep.

What should be tried next?

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Contributors to Sleep Problems are multifactorial



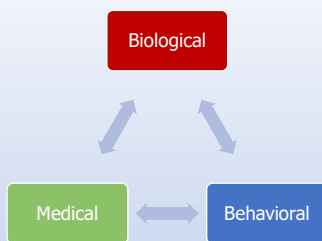
- Arousal Dysregulation
- Melatonin processing
- Genetics



difficulty with transitions, need for routine

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Practice Pathways



- Screen for sleep problems as part of the child's regular well exams
- Identify medical co-occurring conditions
- Start with behavioral strategies if the family is willing and able to implement them
- Medications should be used sparingly- to facilitate behavioral strategies
- Choose medications that treat co-occurring conditions and use low doses

Helping Your Child with Intellectual/Developmental Disability Prepare for a Sleep Study

Introduction

How do you prepare your child with an intellectual/developmental disability (ID) for a sleep study? This brief guide will help you to find ways to make your sleep study more successful. Included in this pamphlet are strategies to help a sleep study go more smoothly. This information may be helpful for individuals of all ages and for those with and without disabilities.

Do children with ID have sleep problems?

Sleep problems are more common in children with ID than typically developing children:

- Children with autism spectrum disorders often have problems falling asleep and also with waking during the night.
- Children with Down syndrome often have medical problems that affect their sleep, such as obstructive sleep apnea.



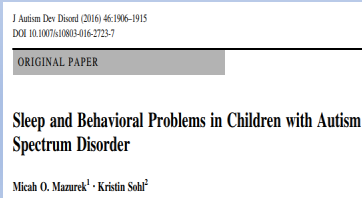
Malow 2012, Galion 2023

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Sleep: Emotional Regulation, Behavior, and Core Symptoms

fMRI studies have shown increased amygdala activation and decreased connectivity between prefrontal cortex and amygdala after sleep deprivation¹⁻²

> 2,714 children with autism in the Simons Simplex Collection, severity scores for core symptoms were increased for children reported to sleep \leq 7 hours per night³



- 81 children with autism, ages 3-19 years
- Sleep problems (particularly night wakings) were significantly associated with physical aggression, irritability, inattention, and hyperactivity.

¹Yoo, 2007; ²Reidy, 2016; ³Veatch, 2017



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Treatment of Insomnia

Parent training is feasible and effective and results in improved outcomes for the child and family¹⁻²

How translate to practice?
How deliver and motivate parents?

¹Johnson 2013; ²Malow 2014



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A Parent Centered Approach: Start with Sleep Hygiene/Habits

- Daytime habits
- Evening habits
- Sleep environment
- Bedtime routine



DIRECTIONS: For each item below, please indicate how often it was true within the last month:

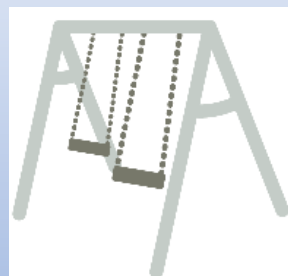
	Never	Occasionally	Sometimes	Usually	Always
1. My child gets exercise during the day.	1	2	3	4	5
2. My child wakes up at about the same time each morning.	1	2	3	4	5
3. In the hour before bedtime, my child engages in relaxing activities.	1	2	3	4	5
4. My child has drinks or foods containing caffeine after 5 pm (examples: chocolate, Coca Cola).	1	2	3	4	5
5. In the hour before bedtime, my child engages in exciting or stimulating activities (examples: rough play, video games, sports).	1	2	3	4	5
6. My child's room is dark or dimly lit at bedtime.	1	2	3	4	5
7. My child's room is quiet at bedtime.	1	2	3	4	5
8. My child goes to bed at the same time each night.	1	2	3	4	5
9. My child follows a regular bedtime routine that lasts between 15 and 30 minutes.	1	2	3	4	5
10. I stay in my child's room until he/she falls asleep.	1	2	3	4	5
11. After my child is tucked in, I check on him/her before he/she falls asleep.	1	2	3	4	5
12. My child watches TV, videos, or DVDs to help him/her fall asleep.	1	2	3	4	5

Family Inventory of Sleep Habits; *Malow, 2009*

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Components of Successful Sleep: Daytime Habits

- Exercise
- Abundant light
- Limit caffeine
- Limit naps
- Selective bedroom use



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Components of Successful Sleep: Evening Habits

- Limit stimulating activities
- Less light
- Routines



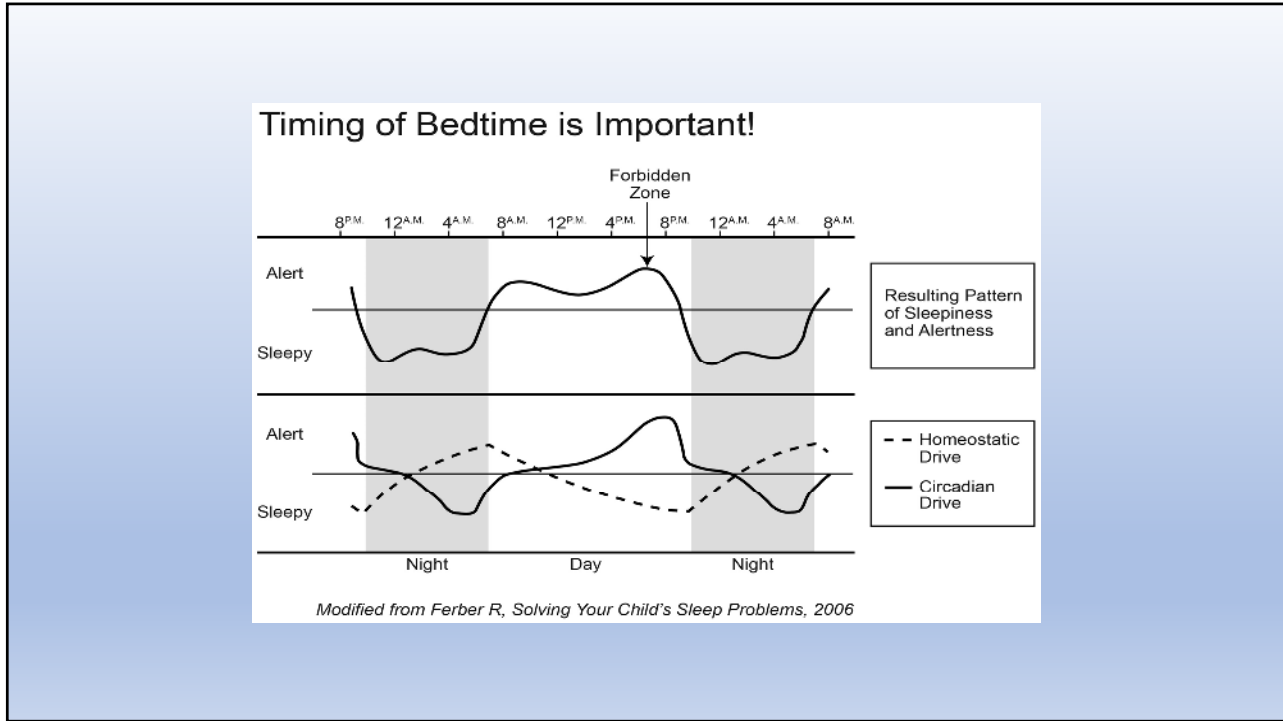
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Components of Successful Sleep: Sleep Environment

- Temperature
- Texture
- Sound
- Light
- Electronics



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Bedtime Routine

Time for bed

- Put on pajamas
- Use the bathroom
- Wash hands
- Brush teeth
- Get a drink
- Read a book
- Get in bed and go to sleep

Line Drawings

Checklist

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Strategies for Sleep Resistance

- **The Rocking Chair Method**

- Let your child fall asleep on his/her own but stay in the room, sitting in the rocking chair, with your back to your child
- Move the chair closer to the door each night until you are out of the door



- **Rewards: Morning stickers or basket of presents.**

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Strategies for Night Wakings

- The first step to minimizing night wakings is to help your child fall asleep on his/her own
- A child who can fall asleep on his/her own can go back to sleep alone
- Watch out for items that the child becomes dependent on to fall asleep that may not be there when the child wakes up.

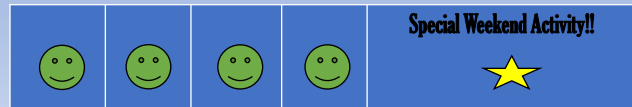


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Strategies for Night Wakings

- Respond quickly to distress
- Comfort and reassure yet remember “brief and boring.”
- Yet avoid over-responding
- Use visual reminders.
- Choose realistic goals.
- Rewards

Staying in my bedroom until Mom comes to get me in the morning = 😊

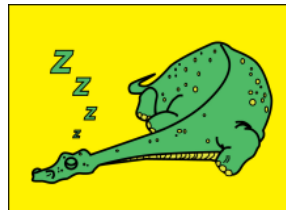


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The Bedtime Pass (P. Friman)



Bedtime pass



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Sample Story to Support Bedtime Pass

People need sleep. Sleep helps people feel rested and have more energy. Sleep helps people stay calm during the day. Sleep helps people do better in school.

My parents want to help me get a good night sleep. They want me to be rested, calm, and do well in school. My parents have made a bedtime pass to help me. They will give me the bedtime pass when I go to bed. The bedtime pass is like a ticket. If I need anything extra, I have to trade the bedtime pass. If I ask for a drink of water or get out of bed, I have to give my parent the bedtime pass. When I stay in bed all night, I get to keep the pass. This is a good thing! In the morning I can trade the bedtime pass for something really special.

A good night sleep will help me be rested, feel better, and do well in school. My parents like it when I get a good night sleep.

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Sample Images for Bedtime Pass




Resources






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Sleep Education Classes For Parents of Children with Autism Spectrum Disorders

This research project, part of the Autism Treatment Network (ATN) Repository, provides parents with tools to help their 2 to 10 year-old child fall asleep.



Tools may include:

- ★ Sleep education pamphlet
- ★ 1 hour of individualized education with a nurse
- ★ 4 hours in small group classes led by a nurse

We will ask you to:

- ★ Attend a class to learn about study procedures
- ★ Have your child wear a watch that measures activity and sleep
- ★ Keep a diary of wake and sleep times for 7 days at a time
- ★ Fill out sleep survey forms before and after education
- ★ Come for classes at Vanderbilt Children's Hospital

Debbie Wofford at (615) 936-2004 or
autismsleepresearch@vanderbilt.edu
Study conducted by Beth Malow, MD, MS, Professor of Neurology

Date of IRB Approval: 4-14-2009

Sleep Education Multicenter Trial

- ✓ We carried out a two-phase study in parents of children with autism with sleep onset delay of 30 minutes or greater on 3 or more nights/week.
- ✓ Phase 1: 36 parents were provided either a sleep education pamphlet or no intervention.
- ✓ Phase 2: 80 parents were randomized to either group or individualized classes by a trained sleep educator.
- ✓ Sleep and behavioral measures obtained at baseline and 1 month post-treatment.

Malow, 2014

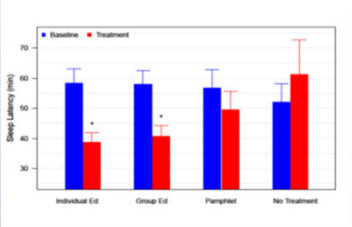
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Sleep Education Multicenter Trial

Sleep Latency (time to fall asleep, minutes) as measured by actigraphy, significantly improved in parents receiving sleep education (vs. pamphlet). Individual vs. group education did not differ (*both p values = 0.0001).

Significant treatment improvements were also noted on:

- Children's Sleep Habits Questionnaire (insomnia domains)
- Repetitive Behavior Scale-Revised (restricted, stereotyped)
- Child Behavior Checklist (attention, anxiety)
- Pediatric Quality of Life Scale (total)
- Parenting Sense of Competence (efficacy, satisfaction)



Group	Baseline (min)	Treatment (min)
Individual Ed	~55	~40
Group Ed	~55	~40
Pamphlet	~55	~45
No Treatment	~55	~65

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Sleep Education in Community Practices

- ✓ Parents of 30 children with autism and insomnia received sleep education (60-90 minutes with two follow-up sessions)
- ✓ Community therapists trained parents
- ✓ Pediatric providers made referrals and evaluated for medical conditions

Therapists achieved fidelity goals during training and sessions

- ✓ Parents achieved scores of good to excellent understanding, comfort and implementation on the Parent Absorption Scale
- ✓ Parent report of sleep patterns and sleep habits improved with treatment
- ✓ Qualitative analysis highlighted that parents were satisfied with the structure, expertise, and support provided by a trained sleep educator



MacDonald, 2021

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Dissemination and Implementation of Sleep Education

Five states: TN, NH, VT, GA, CO

Diverse Advisory Committee Meets Quarterly to Guide the Project

To date, have trained 21 therapists (BCBA, OT, SLP)

To date, have enrolled 34 families



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Sleep Education in Community Practices

• Training Portion

- Therapists are provided a sleep education manual and links to sleep education videos
- Therapists are asked to review the manual and watch recorded sessions
- Therapists participate in a check-off session on Zoom to practice parts of the sleep education curriculum and receive support.

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Sleep Education in Community Practices

Implementation Portion

- Therapists identify families ages 2-12 with a DSM-5 diagnosis of autism. After consenting, parents complete the Children's Sleep Habits Questionnaire (CSHQ) and Family Inventory of Sleep Habits (FISH) which are shared with therapists.
- CSHQ/FISH collected again after education. We've added a Spanish component
- Therapists also receive referrals from outside pediatric providers
- Therapists encouraged to participate in monthly Zoom meetings to discuss challenging cases and issues related to billing and marketing.
- A subset of community professionals and parents are invited to participate in qualitative interviews.

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Mostly Understudied Medications

- **Gabapentin**¹ (also helps restless legs/restless sleep)
- **Alpha-adrenergic agonists**²⁻³ (clonidine)
- Trazadone
- Hydroxyzine
- **Mitazapine**⁴
- Benzodiazepines—helpful in sleepwalking and other disorders of arousal
- Non-benzodiazepine receptor agonists (zolpidem, eszopiclone)
- Tricyclic antidepressants
- CBD – unknown effects on developing brain

Bold means some studies, although sparse

¹Robinson 2013; ²Ming 2008; ³Ingrassia 2011; ⁴Posey 2001

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Summary

- ✓ Sleep problems are common in autism, and can impact daytime functioning
- ✓ Once the cause is identified, sleep difficulties are highly treatable, and behavioral approaches DO work
- ✓ Medications have side effects, but are sometimes appropriate
- ✓ Future comparison studies of medications and behavioral approaches, with input from families, is vital to improving sleep in this population.

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