

Assessment and Management of ZZ Pediatric Sleep Problems



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Conflict of Interest

 We have no conflicts of interest to disclose related to this presentation.



Does this sound familiar?...

"She has always been a terrible sleeper"

"I want my child to sleep through the night"

"I can't fall asleep at night"

"He wakes up multiple times per night"

"My child needs to be rocked to sleep"

"She has a hard time waking up for school"





Objectives

- 1) To provide a broad understanding of pediatric sleep health and sleep problems and how this applies to persons with neurodevelopmental disorders.
- 2) To provide an understanding of pediatric sleep assessment tools and considerations.
- To provide an overview of behavioral interventions for managing pediatric sleep problems.





Sleep Health

"Sleep health is a multidimensional pattern of sleep-wakefulness, adapted to individual, social, and environmental demands, that promotes physical and mental well-being. Good sleep health is characterized by <u>subjective satisfaction</u>, <u>appropriate timing</u>, <u>adequate duration</u>, <u>high efficiency</u>, and <u>sustained alertness during</u> waking hours."

(Buysse, 2014)



Pediatric Sleep Health

Pediatric sleep health has been defined as "<u>subjective or</u> <u>caregiver-rated satisfaction</u>, <u>appropriate timing</u>, <u>adequate</u> <u>duration for age</u>, <u>high efficiency</u>, <u>sustained alertness</u> <u>during waking hours</u>, and <u>healthy sleep behaviors</u>"

(Meltzer, Williamson, & Mindell, 2021)





What is Sleep?

Sleep is a reversible, neurobehavioral state of reduced activity and is associated with decreased responsiveness to stimuli (Cirelli & Tononi, 2008)

Two distinct stages of sleep:

- Nonrapid eye movement (NREM)
- Rapid eye movement (REM)



NON-NEGOTIABLE BIOLOGICAL NEED!!

Stages of Sleep

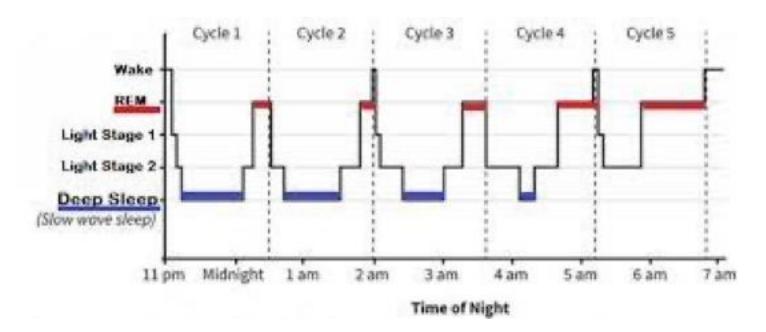
Stage 1: Light, brief sleep and occurs at transition between sleep time and wake time

Stage 2: Accounts for greatest proportion of the night

Stage 3: Slow-wave sleep or deep sleep

Majority occurs in the first third of the night

REM Sleep: When dreaming generally occurs. Occurs between 70 and 100 minutes after sleep onset. Duration increases over the night, with most in the last third of the night



Memory consolidation

Muscle recovery, Human Growth Hormone, Immunity Boost

Besedovsky L, Lange T, Born J. Sleep and immune function. Pflugers Arch. 2012 Jan;463(1):121-37. doi: 10.1007/s00424-011-1044-0. Epub 2011 Nov 10. PMID: 22071480; PMCID: PMC3256323.

Rasch B, Born J. About sleep's role in memory. Physiol Rev. 2013 Apr;93(2):681-766. doi: 10.1152/physrev.00032.2012. PMID: 23589831; PMCID: PMC3768102.



Circadian Rhythm System

Internal body clock

Localized in the hypothalamus of the brain

- Regulated by external cues:
 - Light-dark cycle
 - Meal times
 - Social activities





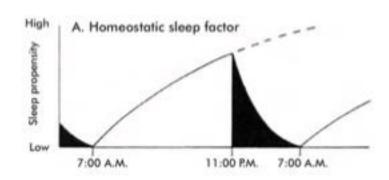
What controls how much and when we sleep

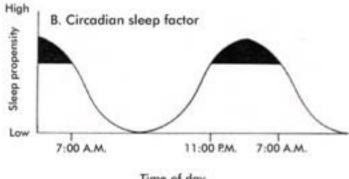
- Create a peak in wakefulness in the evening, a few hours before bedtime
- The strongest dip in wakefulness occurs between about 2 a.m. and 5 a.m.

Adenosine is the "sleepy chemical" antagonized by









Time of day

HOW MUCH SLEEP DOES A CHILD NEED?



To promote optimal health, the American Academy of Sleep Medicine recommends that children get the following amounts of sleep on a regular basis:

- Infants 4 months to 12 months should sleep 12 to 16 hours per 24 hours (including naps).
- Children 1 to 2 years of age should sleep 11 to 14 hours per 24 hours (including naps).
- Children 3 to 5 years of age should sleep 10 to 13 hours per 24 hours (including naps).
- Children 6 to 12 years of age should sleep 9 to 12 hours per 24 hours.

Recommendations for infants younger than 4 months are not included due to the wide range of normal variation in duration and patterns of sleep.



Socio-ecological factors and pediatric sleep health

L.J. Meltzer, A.A. Williamson and J.A. Mindell

Sleep Medicine Reviews 57 (2021) 101425

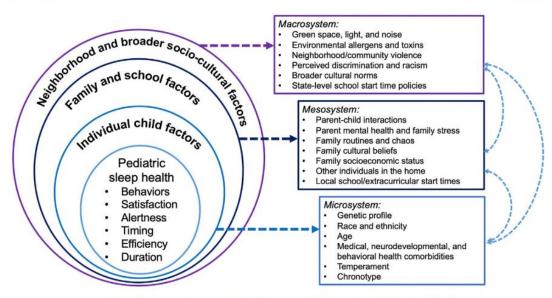


Fig. 1. Socio-ecological factors hypothesized to contribute to pediatric sleep health domains.



Pediatric Sleep and Neurodevelopmental Disorders

- Sleep disorders in children with neurodevelopmental disorders are extremely common.
- Sleep disorders are varied and not unique to these populations.
- Prevalence of sleep issues is higher and tend to be severe, chronic, treatment-resistant, and more likely to recur or relapse, compared to typically developing children.
- Studies have demonstrated higher rates of OSA diagnoses among youth with neurodevelopmental disorders and especially those with Trisomy 21.

(Mindell & Owens, 2015; Williamson, et al., 2016)

Pediatric Sleep and Neurodevelopmental Disorders

- Prevalence of caregiver-reported sleep problems in ASD ranges from 34% to 89%.
- Children with intellectual disabilities ranges from 44% to 86% (highest in younger children and those with more severe intellectual compromise).
- In autism, the prevalence of past or concurrent sleep problems has been estimated from 44% to 89%.

(Mindell & Owens, 2015)



Pediatric Sleep and Neurodevelopmental Disorders

- Shortened sleep duration
- Irregular sleeping cycles
- Delayed sleep onset
- Frequent nighttime awakenings
- Early morning wake times

(Mindell & Owens, 2015)



Clinical Assessment of Pediatric Sleep Health and Sleep Problems



Evaluation and Neurodevelopmental Disorders

- Evaluation of sleep problems is similar to screening and assessment in other pediatric populations
- Given high prevalence, regular screening is recommended

(Mindell & Owens, 2015)



Initial Screening for Sleep Health and Sleep Problems

In primary care settings, start with 2 initial screening questions:

- 1) "Do you (or your child) have problems sleeping?"
- 2) American Academy of Pediatrics recommends all children be screened for snoring

Simply asking a child or parent how much sleep a child gets each night, without these questions, is not sufficient



Clinical Assessment Considerations

- Developmental changes and transitions over first 18 years of life due to physiologic growth and neurologic development
- Family, social, and broader environmental factors that also change
- Ask children directly about their sleep, in addition to parent report



Clinical Assessment

- Clinical interview
- Sleep diary
- Questionnaires
- Overnight polysomnography (PSG)
- Daytime multiple sleep latency testing
- Actigraphy



Clinical Assessment - Behaviors

- Pre-bedtime practices ("What happens after dinner?")
- Sleeping arrangement (e.g., own bedroom, co-sleeping, room sharing)
- Bedtime routines
- Sleep-onset associations ("Is there anything you/your child needs to fall asleep?")
- Caffeine intake
- Use of electronic devices before bedtime, in bed, and/or during the night

(Meltzer, Williamson & Mindell, 2021; Meltzer & Paisley, 2023)

Clinical Assessment – Satisfaction/Quality

Subjective assessment of "good" or "poor" sleep

 Important to ask older school-aged children (> 8 years and older) and adolescents directly about this aspect of sleep health



Clinical Assessment – Alertness/Sleepiness

- Parents of younger children should be asked directly about daytime functioning
- Query hyperactivity: young children can become more hyperactive or energetic when sleepy
- Napping is age-appropriate in young children
- Children ages 8 and older should be directly asked about feelings of alertness/sleepiness
- Napping in adolescents should be considered within the context of insufficient sleep duration that is often a result of early school start times and other factors (e.g., increased academic demands, activities)



Clinical Assessment – Timing

• Involves the placement of sleep across a 24-hour day (sleep schedule)

 As children get older, discrepancy increases between parent- and child-report sleep timing





Clinical Assessment – Efficiency

- The ease of falling asleep and returning to sleep
- Older children and adolescents should be asked about sleeponset latency and night waking frequency/duration

"How long does it take you/your child to fall asleep once you turn the light off/try to fall asleep?"

 Greater emphasis should be placed on the subjective experience rather than objective measures



Clinical Assessment – Duration

- Includes sleep across the 24-hour window, including during the daytime ("Does your child nap during the day?")
- Expectations for sleep duration change across development
- Child must have a developed sense of time to estimate hours they are sleeping



Assessment - Measures

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Table 3Examples of subjective pediatric questionnaires and the domains of sleep health measured.

Subjective Measures	Satisfaction	Alertness/Sleepiness	Timing	Efficiency	Duration	Behaviors	Age	Items	Reporter
Children's Sleep Habits Questionnaire [118]	✓	1	/	/	/	✓	2-10 yrs	33/45	Parent
Children's Report of Sleep Patterns [119-121]	✓	✓	✓	/	✓	✓	8-18 yrs	60	Self
School Sleep Habits Survey [122]	✓	✓	✓	/	✓	✓	13-19 yrs	45	Self
Brief Infant Sleep Questionnaire [123, 124]	✓		✓	/	✓	✓	0-3 yrs	$13/25^{a}$	Parent
BEARS [113]		✓	✓		✓	✓	2-18 yrs	7-8	Parent/Self
PROMIS Pediatric Sleep Disturbance [168]	✓						8-18 yrs	4/8/15	Self
							5-18 yrs	4/8/15	Parent-proxy
Sleep Disturbance Scale for Children [114]		✓			/		6-15 yrs	27	Parent
Modified Epworth Sleepiness Scale [169]/Epworth		✓					12-18 yrs	8	Self
Sleepiness Scale for Children and Adolescents [170]							2-18 yrs	8	Parent-proxy
Pediatric Sleep Questionnaire [171]		✓					2-18 yrs	22	Parent
Pediatric Daytime Sleepiness Scale [172]		✓					11-15 yrs	8	Self
PROMIS Pediatric Sleep Related Impairment [168]		✓					8-18 yrs	4/8/15	Self
							5-18 yrs	4/8/15	Parent-proxy
Morningness-Eveningness Questionnaire for Children [173]			✓				11–12 yrs	10	Self



POLYSOMNOGRAPHY

- It is the most complete evaluation of your child's sleep.
- You will be required to stay overnight at a sleep center, hospital or a hotel room.
- One adult will accompany the child during the study.
- It records brain waves, heartrate and breathing as you sleep. It also tracks your eye, leg and arm movements, and oxygen levels in your blood.





HOW TO PREPARE FOR SLEEP STUDY?? (1/2)

On the day of your sleep study, you should:

- Follow your regular routine as much as possible
- Avoid napping
- Avoid caffeine
- Avoid using hair sprays or gels that can interfere with the sleep recording

HOW TO PREPARE FOR SLEEP STUDY?? (2/2)

- Bring any items that you need for your nightly routine.
- Prepare for the sleep study as if you are staying at a hotel for a night.

You may want to bring:

- Comfortable pajamas or clothes to sleep in
- A toothbrush, toothpaste and dental floss
- Makeup remover (for teenagers using make up).
- Reading material
- Clean clothes for the morning
- Extra pull ups, diapers
- Any medical equipment that your child needs overnight at home like tube feeds.



UNDERSTANDING SLEEP STUDY RESULTS



Sleep Study: What to look for?

1. Sleep Efficiency (SE):

[% of the night slept during the sleep study]

2. Hours of Sleep during the study

- 3. Average Oxygen Saturations
- 4. Oxygen Saturation Nadir: [Lowest oxygen level while sleeping]

5. Obstructive Apnea-Hypopnea Index [Average number of airway closures/partial closures per hour of sleep]

- Obstructive Sleep Apnea Severity:
 [average 2-5/hour= mild; average 510/hour= moderate; average 10+/hour= severe]
- 7. Periodic Limb Movement Index:

[Average number of limb movements per hour of sleep. Goal ≤5]



Pediatric Sleep Problems & Behavior Management Interventions



Pediatric Sleep Problems

- Bedtime problems
- Sleep-onset associations and nighttime awakenings
- Nighttime fears/nightmares
- Disorders of Arousal
- Insomnia
- Circadian Rhythm Sleep-Wake Disorders
- Medical/Other Sleep Disorders



Bedtime Problems

- Bedtime stalling, protests, and curtain calls
- Circadian and homeostatic factors
 - Bedtime fading
- Goal is to create consistency and set limits
 - Bedtime chart and consistent bedtime routine
 - Timers
 - Forced choices
 - Positive praise
 - Reward systems
 - Gradual removal of parental presence



Sleep-Onset Associations & Nighttime Awakenings

- Requiring parental/caregiver assistance to fall asleep or return to sleep (e.g., rocking, feeding)
- Goal is to help the child to learn to fall asleep and return to sleep independently by completely removing the sleep-onset association both at bedtime and during the night

(Meltzer & Crabtree, 2015)



Nighttime Fears

- Most common nighttime experience in the preschoolage period (3-5 years)
- Young children have difficulty distinguishing fantasy from reality
- Most children eventually outgrow nighttime fears
- Most school-age children have occasional worries that may worsen at bedtime

(Meltzer & Crabtree, 2015)



Nighttime Fears (con't.)

Management includes cognitive-behavioral interventions for nighttime fears, anxiety, and recurrent nightmares

- Monster spray
- Transition objects
- Exposure with response prevention
- Relaxation techniques (e.g., deep breathing, progressive muscle relaxation)
- Worry time
- Positive/helpful self-statements (e.g., "I am brave")
- Imagery rehearsal for managing recurrent nightmares

Disorders of Arousal

- Confusional arousals, sleep terrors, and sleepwalking are all disorders of arousal
- Partially awake and partially asleep
- Child may appear confused, distressed, or engage in behaviors as if awake, but actually sleeping during episodes
- Occur in the first part of the night (during slow-wave sleep)

Disorders of Arousal (con't.)

- Episodes are usually benign and self-limiting
- Primary triggers are insufficient or poor-quality sleep (e.g., late bedtime, early rise time, disruption to sleep schedule, or medical illness)



Disorders of Arousals (con't.)

How to manage:

- Make sure child is safe
- Do not try to wake your child as this will prolong the episode
- Do not discuss the events in the morning
- Have a consistent sleep schedule
- Try to increase your child's sleep duration
- Make sure caregivers/staff aware of history if attending sleepovers or overnight camps

(Meltzer & Crabtree, 2015)

Insomnia

- Difficulty initiating and/or maintaining sleep
- Management includes Behavioral and Cognitive-Behavioral Interventions
 - Stimulus Control Therapy
 - Sleep Restriction Therapy
 - Cognitive Restructuring (reframing negative beliefs, attitudes, expectations, and attributions)



Circadian Rhythm Sleep-Wake Disorders

- Diagnosed when the timing of an individual's sleep-wake cycle is not consistent with needs of daytime functioning
- Management includes:
 - Negotiating sleep schedules
 - Bright light therapy
 - Chronotherapy





Medical, PLMD, and Other Sleep Disorders

- Sleep-Disordered Breathing (e.g., Obstructive Sleep Apnea)
- Restless leg syndrome
- Periodic limb movement disorder
- Bruxism
- Excessive Daytime Sleepiness: Narcolepsy & Hypersomnias
- Nocturnal Enuresis



Medical, PLMD, and Other Sleep Disorders

- Excessive Daytime Sleepiness: Narcolepsy & Hypersomnias: includes behavior management of daytime sleepiness (e.g., consistent sleep schedule)
- Nocturnal enuresis: urine alarm therapy and overlearning intervention
- Sleep-Related Rhythmic Movements (head banging, body rocking, and head rolling)

(Mindell & Owens, 2015)



Medical, PLMD, and Other Sleep Disorders

Sleep-Related Rhythmic Movements:

- Discontinue attempts to protect the child
- Avoid reinforcement of the behavior
- Dampen the noise
- Increase sleep

(Mindell & Owens, 2015)



Positive Airway Pressure Adherence Management

- Patient education about OSA to improve PAP adherence
- Partner with medical team to ensure PAP is comfortable
- Graduated exposure of PAP
 - Series of steps based on child's age and cognitive functioning
 - Parents should be actively involved with each step of exposure
 - Includes daytime practice





Common CPAP Side Effects

To reduce or prevent these side effects, clean your CPAP machine regularly, and talk to your doctor about different mask and accessory options.





Behavioral Management Considerations

- Healthy sleep practices (e.g., routines, meal times, etc.)
 - Help to entrain circadian rhythm
- Sleep environment
 - Conducive to sleep that may need to be modified and particularly for persons with sensory and motor disabilities
- Sensory issues
 - OT techniques/devices to address sensory integration issues (e.g., weighted vests and blankets; white noise); consult with OT

(Mindell & Owens, 2015)

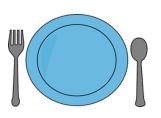


Behavioral Management Considerations

- Alarm system for monitoring if child has left bedroom
- Bedroom lighting may need to be adapted
- Bedtime routine
 - Predictable and consistent steps (e.g., bedtime chart)
 - Calming, gentle, rhythmic, repetitive, low-frequency movements, quiet sounds, light massaging, brushing, vibrating pillows and beds, and soft music
 - Transitional objects
- Support caregivers' need for sufficient sleep in treatment planning

(Mindell & Owens, 2015)







Healthy Sleep Promotion







Healthy Sleep Tips

- Limit light exposure in the evening (e.g., ambient light, tv, video games, and computer screens)
- Maintain a consistent sleep schedule (weekdays and weekends)
- WAKE TIME CONSISTENCY
- Establish a regular, relaxing bedtime routine (30 minutes before bed)
- Keep bedroom temperature cool (< 75 degrees)
- Light snack before bed is okay, but avoid heavy meal

Healthy Sleep Tips

- Avoid vigorous or strenuous physical activity right before bedtime
- Timing of naps should be early enough in the afternoon or avoid if having trouble falling asleep at bedtime
- Do not consume caffeine after 4pm or within 6 hours of bedtime
- Enjoy the sunshine, especially in the morning!



(Meltzer & Crabtree, 2015)



Summary

- Good sleep is vital to our health
- Important to screen pediatric sleep health and sleep problems in primary care settings
- Screen regularly for persons with neurodevelopmental disorders
- Pediatric sleep health needs to be viewed from developmental and socioecological contexts
- Important to include children (>8 years and older) in assessment
- Wide range of effective behavior management interventions for pediatric sleep problems. Consistency is key!
- Talk to your PCP or sleep provider for support



Resources

- ADDitude Online Magazine: https://www.additudemag.com/
- Autism Speaks: <u>www.autismspeaks.org/sleep</u>
- Hypersomnia Foundation: https://www.hypersomniafoundation.org/
- National Sleep Foundation: <u>www.thensf.org</u>
- Narcolepsy Network: https://narcolepsynetwork.org/



Resources

- Pediatric Sleep Council: <u>www.babysleep.com</u>
- Project Sleep: https://project-sleep.com
- Sesame Workshop: https://sesameworkshop.org/resources/breathe/
- Solving Sleep Problems in Children with Autism Spectrum Disorders: A
 Guide for Frazzled Families by Terry Katz, PhD and Beth Malow, MD, MS
- What to Do When You Dread Your Bed: A Kid's Guide to Overcoming Problems With Sleep by Dawn Huebner, PhD



References

Buysse, D. J. (2014). Sleep health: Can we define it? Does it matter? *Sleep*, 37 (1), 9-17. https://doi.org/10.5665/sleep.3298

Kamara, D. & Beauchaine, T. P. (2020). A review of sleep disturbances among infants and children with neurodevelopmental disorders. *Review Journal of Autism and Developmental Disorders*, 7, 278-294. https://doi.org/10.1007/s40489-019-00193-8

Meltzer, L. J. & Paisley, C. (2023). Beyond polysomnography: Clinical assessment of pediatric sleep health and sleep problems. *Sleep Medicine Clinics*, 18 (2), 147-160.

Meltzer, L. J., & Crabtree, V. (2015). *Pediatric sleep problems: A clinician's guide to behavioral interventions.* American Psychological Association.



References

Meltzer, L. J., Williamson, A. A. & Mindell, J. A. (2021). Pediatric sleep health: It matters, and so does how we define it. *Sleep Medicine Reviews*, 57, 1-13.

Mindell, J. A., & Owens, J. A. (2015). *A clinical guide to pediatric sleep: Diagnosis and management of sleep problems* (3rd ed.). Philadelphia: Wolters Kluwer.

Sheldon, S. H. (2014). *Principles and practice of pediatric sleep medicine* (2nd ed.). Philadelphia: Saunders.

Williamson, A. A., Patrick, K. E., Rubens, S. L., Moore, M., & Mindell, J. A. (2016). Pediatric sleep disorders in an outpatient sleep clinic: Clinical presentation and needs of children with neurodevelopmental conditions. *Clinical Practice in Pediatric Psychology*, 4 (2), 188-199.

Q&A



