

Operation Access Sleep

Victoria Dalzell, MD, FAAP Maine AAP Conference 2025

Barbara Bush Children's Hospital



Daytime Sleepiness in Children: Impact

- Mood and affect changes
- Behavioral problems
 - Internalizing
 - Externalizing (aggressiveness, hyperactivity, poor impulse control)
- Neurocognitive deficits
 - Attention
 - Memory
 - Executive functions
- Performance deficits
 - Academic, social, and work impairment
 - Drowsy driving
- Family disruption

Most of which can already be concerns in ASD...increasing the concern of inadequate sleep for this population



3

Sleep in ASD

- Studies vary but between 40-83% of children with an ASD present with sleep issues
- Some studies point to sleep as being one of the early signs of concern for ASD
- This compares to 26-32% for typically developing children
- Increased incidence is by parent report but has also been confirmed in studies using actigraphy and polysomnography
- Sleep problems more persistent
- Consistency across the globe with ASD and sleep
- concerns

Maine Health



A caveat- important to gather history in a way that acknowledges differences in beliefs, goals, and family living situations



BEARS 5 question screening tool- good baseline sleep measure

- B = Bedtime problems
 - Ask about whether child has regular bedtime, how easily they settle and fall asleep
- E = Excessive daytime sleepiness
 - Crankiness is infants to preschoolers, for older children- falling asleep in school or on short daytime car trip
- A = Awakenings during the night
 - Remember in older children parents may not know so need to ask child as well
- R = Regularity and duration of sleep
 - Consistent bedtime and waketime, naps, total hours, and whether schedule fairly consistent between weekdays and weekends
- S = Snoring
 - Every night vs. occasional important distinction



Most common sleep issues in ASD

- Sleep onset
- Sleep maintenance
 - Children with ASDs may not wake more frequently, but are awake for longer (up to 2-3 hours) and engage in more disruptive behavior while awake
 - Remember that part of sleep maintenance is social cues...
 - Parasomnias such as night terrors, confusional arousals, and sleep walking may be more common
- Sleep duration
- Behavior/environment vs biologic likely a combination
- Decreased REM sleep compared to typical and developmentally delayed children
- Obstructive Sleep Apnea/hypopneas should be consideredless clear data on prevalence with ASD



Keep in mind....

- There is a bidirectional influence of co-morbidities such as ADHD, anxiety, depression, GERD/GI concerns, intracranial process and seizure disorders, medication side effects, biologically based sleep concerns- consider first
- Sleep issues can be caused by less than ideal bedtime routines or bedtime associations so need to consider standard sleep hygiene recommendations...consider behavior next
- Child with poor sleep takes toll on the entire family



Sleep Habits Questionnaires if more information needed

- Sleep diaries
 - All ages
 - Record times of sleep, wake, night waking, naps and behavior
- Family Inventory of Sleep Habits
 - For ages 3-10
- Children's Sleep Habits Questionnaire
 - For ages 4-10
 - 45 items, graded responses 1-3
 - Can be completed by a parent/caregiver prior to the visit to assist with focused history
 - Preschool version readily available online
- Modified Simmonds and Parraga sleep questionnaire (varying versions)
 - Modified version for ASD and DD
 - For ages 5-18

Maine Health		EXCELLENCE		





Optimize Behavioral assistance

Parent-Based Sleep Education Workshop in Autism J Child Neurol, 2009 August: 24(8): 936-945

- 20 children with ASD between the ages of 3 and 10
- Pre and post sleep habits questionnaire, Family Inventory of Sleep Habits + others, and actigraphy (latter only available for 12 children)
- 3 two-hour educational group sessions over 3 consecutive weeks, break out sessions and homework for parents
- Daily data collection of sleep times and exercise, napping, and caffeine consumption
- More families planned relaxing activities, reported a regular routine after treatment
- Few families allowed electronics close to bedtime or fell asleep with their children after treatment
- Bedtime resistance, sleep onset delay, sleep duration, and sleep anxiety improved
- Night wakings, parasomnias, sleep disordered breathing, and daytime sleepiness did not improve

Maine	ealth		4	PATIENT CEN	ITERED			OWNERSHIP	VATION

11

What about early risers?

- Could be that infant/child has not learned to self-soothe but the night waking is just later so necessary to assess again sleep hygiene at beginning of night (think sleep onset associations)
- Begin by setting alarm with music or special alarm with green light for actual waketime all get up with alarm
- move time of alarm slightly later after several days and then again several days after that
- may buy an extra hour (if you can get anyone to try it...)



Environmental strategies as well...

- Consolidate sleep
- Chronotherapy
 - If phase delay <3 hours, may attempt gradual phase advance (moving bedtime slowly back)
 - If more severe phase delay, may need to delay sleep phase "around-the-clock" (moving bedtime forward and not allowing naps)
- Room darkening at night, bright light therapy in am
- Sound machines (be careful of Db level)

Maine**Health**

13

Sleep-Wake Transition Disorders

Rhythmic Movement Disorders

- Body rocking, head banging, head rolling
- Repetitive, stereotypic movements involving large muscle groups
- Occurs at sleep onset (bedtime, nighttime arousals)
- Self-soothing
- Injury RARE, but parents often concerned
- Male>female
- Infrequently associated with developmental delay



Pharmacological treatment in autism: a proposal for guidelines on common cooccurring psychiatric symptoms Manter et al Biomedcentral Medicine 23, article 11 (2025)





Melatonin and ASD

- Tordjman et al. (2005):
 - N=50 kids with ASD vs N=88 controls
 - Kids with ASD had a 42% lower amount of sulfated 6hydroxymelatonin inactive metabolite of melatonin (p=0001)



Maine**Health**

17

Melatonin for sleep (continued)

Melatonin

- Dosing 1 mg-3 mg (can try up to b/w 6-10 mg but...)
 - Lower dosing may be more effective
 - Give 1 hour before desired sleep onset
 - Effects last 4-6 hours
 - Is available as pharm grade-controlled release, Mainecare reimbursed but have to swallow whole
 - Newer PedPRM version promoising but not available in US
- 2 actions of sedating and adjusting clock so may take up to 2 weeks to fully trial a dose
- If only difficulty initiating sleep can try 0.5 mg 5-6 hrs before sleep
- Evidence for efficacy in children with ASDs (meta-analysis Rossignal and Frye 2011) for sleep onset, duration and improved daytime behavior
- Possibly better evidence than for other sedative/hypnotics



Other medications

Clonidine: alpha agonist with side effect of sedation, also helps impulsivity, hyperactivity. Can cause nightmares, constipation, headaches, bradycardia, hypotension – open label trials only, comes in long-acting form if able to swallow

- 0.05 mg-0.2 mg, mindful of BP
- **Hydroxyzine:** antihistamine, may have paradoxical effect- esp in younger children, only good for short term, sleep onset 10 mg-25 mg
- **Trazadone:** also not formally studied but used occasionally priapism can be a concern need to check carefully for interactions with other medications, starting dose 25 mg, can be dosed as high as 100-150 dependent on body weigh
- **Mirtazapine, zolpidm, amitryptiline-** all mentioned in article, I do not personally use

Summary	
A Clinical Guide to Pediatric Sleep	 Sleep is extremely important, and we don't know all of its functions
SLEEP	• Sleep is critical to all developing kids
Diagnosis and Management of Sleep Problems THIRD EDITION	Sleep disturbances are common in kic with ASD
Jodi A. Mindell Judith A. Owens	 There is some evidence that there is a neurobiological basis for some of the disturbances
C/J	• There should be a low threshold to treat with melatonin



Obstructive sleep apnea: Risk Factors

- Adenotonsillar hypertrophy
- Craniofacial anamolies
 - Retrognathia, mid-face hypoplasia, choanal atresia, etc.
 - Congenital syndromes (Pierre-Robin, Hunter's, Hurler's, Achondroplasia, etc.)
- Trisomy 21
- Hypotonia/neuromusclar disorders
- Chronic allergies, asthma
- Gastroesoghageal reflux
- Repaired cleft palate
- Obesity
- central distribution, neck size
- congenital syndromes Prader Willi, etc.

Maine**Health**

OSAS in Childhood: Symptoms

- Nocturnal symptoms
 - Loud, nightly snoring
 - Respiratory pauses, snorts, gasps, choking but in children may not see true apneas
 - Increased respiratory effort/paradoxical breathing
 - Restless sleep
 - Sweating
 - Unusual sleeping positions (neck hyperextended)
 - Parental anxiety level predictive

Maine Health							
--------------	--	--	--	--	--	--	--



No combination of symptoms/physical findings reliably differentiates OSAS from primary snoring - sleep study necessary if possible

Maine Health

Restless Legs Syndrome (RLS) and Periodic Limb Movement Disorder

- RLS: bedtime problems leads to decreased sleep quantity
 - Dyesthesias ("pins and needles" growing pains) increased at rest; relieved by movement
 - Increased activity and "fidgetiness" at bedtime
 - Difficulty falling asleep, may exacerbate bedtime resistance
 - Difficult history to elicit in ASD
- PLMD: sleep problems decreased sleep quality
 - Restless sleep, rhythmic jerking movements legs throughout the night after sleep onset
 - Causes frequent arousals and fractured sleep
- Ferritin levels should be checked if suspected as can be related to iron deficiency

Maine Health

25

Partial Arousal Parasomnias

Night terrors, sleep walking, confusional arousals

- Usually occur in stage 3 slow wave sleep in1st third of night when most slow wave sleep occurs (unlike nightmares that occur in REM sleep later)
- Amnesia for events (unlike nightmares)
- Exacerbation by factors increasing SWS, sleep fragmentation
- Genetic predisposition
- Need to consider nocturnal seizures in differential with overnight sleep study is suspicious



Partial Arousal Parasomnias: Treatment

- Parental reassurance, education
- Safety precautions (ie top bunk not a good plan)
- Avoid triggers, stress
- Increase sleep
- Scheduled awakenings
 - bringing child to a light wake 15-30 minutes before events usually occur- seems to break cycle
- Pharmacotherapy rarely needed, should likely see a specialist if felt to be needed, benzodiazepines