

Sleep in Children with Autism: Helping Families Get the Rest They Need

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Questions we will address today

- What sleep concerns have been reported in children with autism spectrum disorders (ASD)?
- What are their causes? Neurobiological? Medical? Behavioral? What is the impact of sleep disorders (and their treatment) on autism?
- How do we screen for sleep disorders?
- What treatments exist for sleep disorders in ASD? Do behavioral treatments work? How do we implement them? How can parents, therapists, and health care providers work collaboratively?

Sleep Disturbance in ASD



Sleep disturbance is one of the most common concerns voiced by parents of children with autism.

The sleep community has identified autism as a priority population for targeting interventions for sleep disorders.

Poor sleep impacts on the child's health and daytime functioning, as well as the family unit.

Sleep disorders are **highly treatable**. However, evidence-based standards of care for the surveillance, evaluation, and treatment of sleep disturbance in the ASD population are greatly needed.

Prevalence of Sleep Concerns in ASD

- Multiple studies have documented that parentally – reported sleep concerns are prevalent in ASD
 - Couturier (2005): **78% ASD** (TD 26%)
 - Krakowiak et al (2008): **53% ASD** (DD 46%, TD 32%)
 - Souders et al (2009): **66% ASD** (TD 45%)
- For the most part, objective measures (polysomnography and actigraphy) have borne out these parent concerns.
- Sleep disturbances are highly prevalent across spectrum diagnoses (Asperger, PDD-NOS, autistic disorder) and cognitive levels (including children with normal/high IQs).

Couturier, 2005; Goodlin-Jones, 2008; Malow, 2006; Richdale, 2009; Souders, 2009; Krakowiak, 2008; Williams, 2004

What is the Most Prevalent Sleep Disorder in ASD?

Studies using parentally-completed measures, actigraphy and/or polysomnography report **insomnia**

"repeated difficulty with sleep initiation, duration, consolidation, or quality that occurs despite age-appropriate time and opportunity for sleep and results in daytime functional impairment for the child and/or family"
(Mindell et al, 2006)

- ✓ Prolonged time to fall asleep
- ✓ Preference for delayed bedtime (older children)
- ✓ Bedtime resistance (younger children)
- ✓ Sleep anxiety
- ✓ Decreased sleep duration
- ✓ Increased arousals and awakenings
- ✓ Early morning wake time

Causes of Insomnia in ASD

- ✓ Biological: neurotransmitter abnormalities, including melatonin, possibly GABA and serotonin.
- ✓ Medical and Neurological
- ✓ Psychiatric
- ✓ Medications
- ✓ Other Sleep Disorders
- ✓ Behavioral

Biology of Sleep Disturbance and ASD: Arousal Dysregulation

➤ Arousal dysregulation (hyperarousal) may tie together several features of ASD (Mazurek, 2013)

- ✓ Anxiety
 - ✓ Sensory over-responsivity
 - ✓ Functional GI problems
- Insomnia?



➤ Dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis occurs in both insomnia and ASD, in association with daytime stressors (Buckley, 2005 and Corbett, 2008 and 2009).

➤ Studies of autonomic function provide additional evidence for hyperarousal (elevated baseline heart rate; Kushki, 2013)

➤ Insomnia treatment studies designed to target hyperarousal provide an opportunity to measure biological markers of autonomic and HPA dysfunction

Biology of Sleep Disturbance and ASD: Melatonin

➤ Endogenous melatonin, produced by the pineal gland, promotes sleep and stabilizes circadian rhythms through actions on receptors of the SCN.

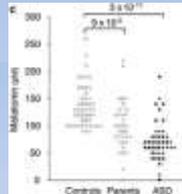
(Pandi-Perumal, 2006)

➤ Apart from hypnotic and circadian properties, melatonin inhibits ACTH responses in the human adrenal gland. (Campino, 2011)

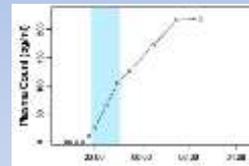
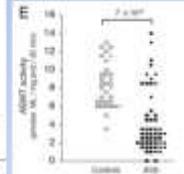
➤ Melatonin processing appears to be altered in ASD.

Biology of Sleep Disturbance and ASD: Melatonin

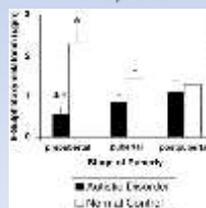
Examine melatonin synthesis and degradation pathways with both biochemical and molecular approaches



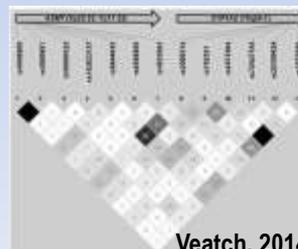
Melke, 2008



Goldman, 2014



Tordjman, 2005

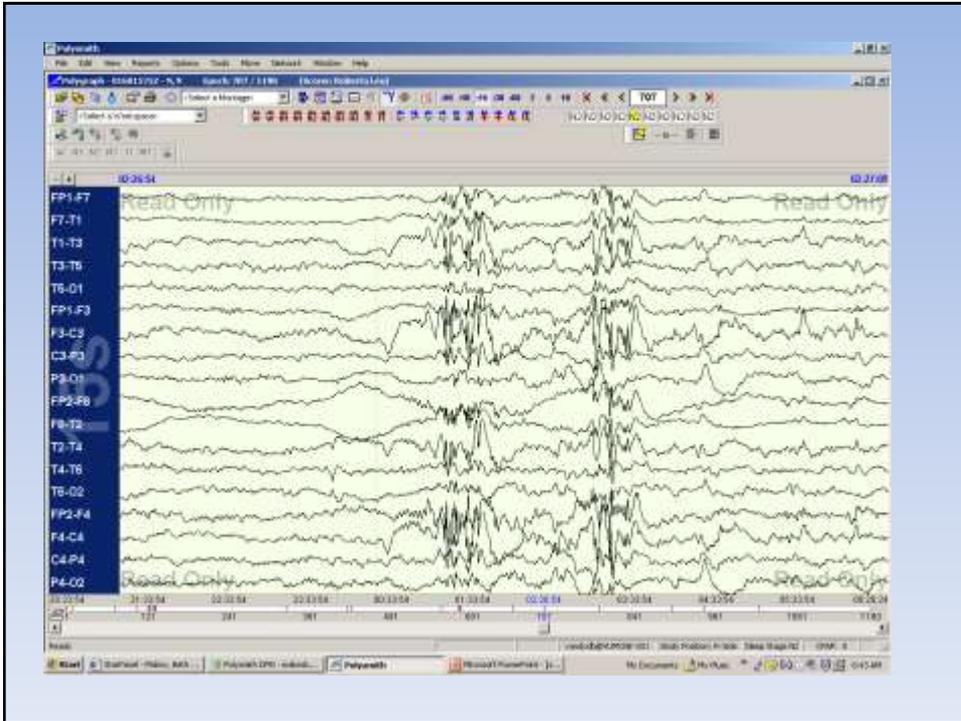


Veatch, 2014

Causes of Insomnia in ASD

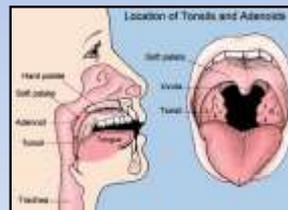
- ✓ Biological
- ✓ Medical (GI) and Neurological (epilepsy)
- ✓ Psychiatric (anxiety, bipolar disorder, depression, obsessive compulsive or ADHD symptomatology)
- ✓ Medications (serotonin reuptake inhibitors, stimulants, some antiepileptic drugs)
- ✓ Other Sleep Disorders
- ✓ Behavioral





Obstructive Sleep Apnea in Children

- Common (2-6%) and important to treat
- Diagnosis based on history alone can be challenging
 - ✓ Adenotonsillar hypertrophy
 - ✓ Obesity
 - ✓ Allergic rhinitis
 - ✓ Craniofacial abnormalities
 - ✓ Neuromuscular (hypotonia)



Often multiple factors.

Symptoms of Sleep-Disordered Breathing

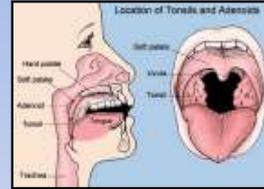
- Nocturnal Symptoms
 - loud, continuous nightly snoring
 - apneic pauses
 - paradoxical movement
 - restless sleep
 - sweating
 - abnormal sleeping position
- Daytime Symptoms
 - mouth breathing
 - chronic nasal congestion
 - hyponasal speech
 - difficulty swallowing
 - morning headaches
 - frequent infections
 - poor appetite

Consequences of Sleep-Disordered Breathing

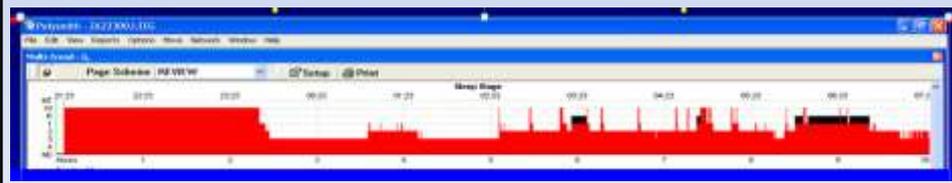
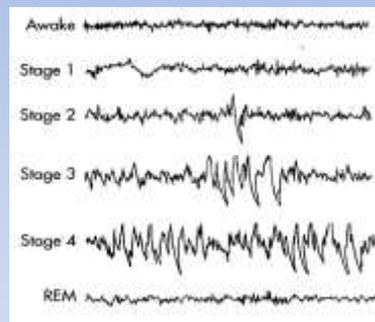
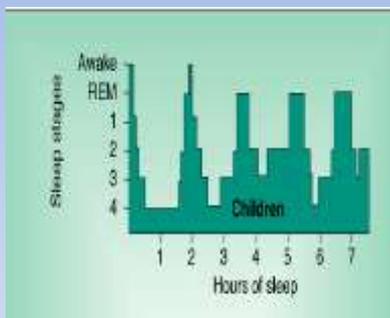
- Excessive daytime sleepiness
 - difficulty waking
 - falling asleep
 - increased naps
- Neurobehavioral Symptoms
 - mood changes
 - acting-out behaviors
 - inattention
 - “ADHD”-like behaviors
 - academic problems
- Other associated features
 - enuresis
 - growth failure
 - increase in partial arousal parasomnias
 - increase in seizure frequency

Sleep Apnea: Treatment Options

- Adenotonsillectomy is first-line treatment for children with obstructive sleep apnea
- Continuous positive airway pressure:
 - Useful for children without enlarged tonsils, and those with sleep apnea that persists despite surgery
 - Compliance a challenging issue
 - ~20% of children unable to tolerate CPAP therapy
 - requires one-on-one care – role of CPAP “desensitization,” behavior modification, positive reinforcement, etc.

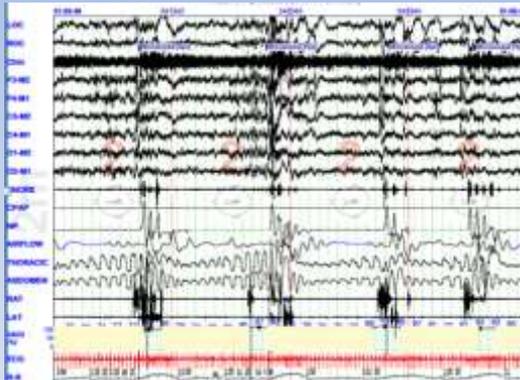


Polysomnography-Sleep Stages



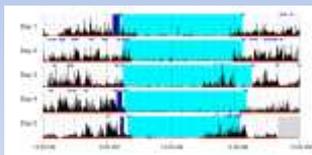
Polysomnography

Making PSG child friendly (Zaremba, 2005)



Actigraphy

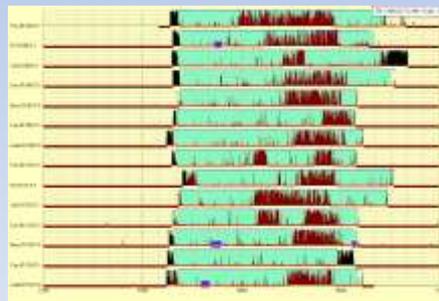
- Actigraphy is a promising technique for measuring sleep patterns and responses to treatment in children, especially those with neurodevelopmental disorders
- Commercially available, wireless, non-intrusive, relatively inexpensive, and amenable to weeks of data collection



Actiwatch (Philips Respironics)



Pocket placement (Souders, 2009; Adkins, 2012)



AMI device

Causes of Insomnia in ASD

- ✓ Biological
- ✓ Medical & Neurological
- ✓ Psychiatric
- ✓ Medications
- ✓ Other Sleep Disorders
- ✓ Behavioral: poor sleep habits...and also features related to ASD such as difficulty with transitions and sensory sensitivities. Exhausted parents may think poor sleep is part of autism and be unaware that behavioral approaches can help.

Children's Sleep Habits Questionnaire (Owens, 2000)

- ✓ Used widely in studies of autism and related neurodevelopmental disorders (ages 4-10)
- ✓ 45-item questionnaire. 35 items retained in subscales
- ✓ Eight Subscales:
 - Bedtime Resistance
 - Sleep Onset Delay
 - Sleep Duration
 - Sleep Anxiety
 - Night Wakings
 - Parasomnias
 - Sleep Disordered Breathing
 - Daytime Sleepiness

The image shows a portion of the Children's Sleep Habits Questionnaire (CSHQ) form. It includes a header with the title 'Children's Sleep Habits Questionnaire' and 'Owens, 2000'. Below the header, there are several rows of items, each with a corresponding response scale. The items are numbered 1 through 11. The response scales are labeled 'None at all', 'A little', 'Somewhat', 'Quite a bit', and 'Very much'. The items are: 1. 'Does your child have any of the following sleep problems?', 2. 'Does your child have any of the following sleep problems?', 3. 'Does your child have any of the following sleep problems?', 4. 'Does your child have any of the following sleep problems?', 5. 'Does your child have any of the following sleep problems?', 6. 'Does your child have any of the following sleep problems?', 7. 'Does your child have any of the following sleep problems?', 8. 'Does your child have any of the following sleep problems?', 9. 'Does your child have any of the following sleep problems?', 10. 'Does your child have any of the following sleep problems?', 11. 'Does your child have any of the following sleep problems?'.

Daytime Consequences of Sleep Disturbance

In typically developing children, sleep disturbance has been associated with ADHD symptomatology, with improvement with treatment

In ASD:

✓ Schreck et al, 2004: Short sleep duration was associated with greater autism symptoms

✓ Gabriels et al, 2005: Presence of sleep problems was associated with repetitive behaviors, although this effect appeared mediated by non-verbal IQ.

✓ Doo and Wing, 2006: Using the Parenting Stress Index-Short Form and the CSHQ, presence of sleep problems was associated with higher levels of parenting stress.

Why do we sleep?

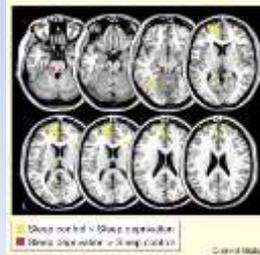
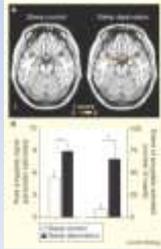
- ***Restorative Theory***: Sleep “restores” and repairs what is lost in the body when we are awake. Some of these areas include:
 - Emotions
 - “Cleaning Out” Clutter
 - Managing Sensory Overload



Biology of Sleep Disturbance and ASD: Emotional Regulation

Sleep deprivation affects the neural circuitry underlying emotional regulation, including connectivity of the amygdala and prefrontal cortex. (reviewed in Maski, 2013). This abnormal connectivity also exists in ASD.

- ✓ An fMRI study in which sleep-deprived healthy adult participants were compared with those who had slept showed increased amygdala activation after viewing images that were emotionally aversive. (Yoo, 2007)
- ✓ In addition, the functional connectivity was stronger between the medial-prefrontal cortex and the amygdala in the sleep control group, and the autonomic brainstem regions and the amygdala in the sleep deprived group.



Questions and Answers



Have you seen this child?

- Alex is a 6-year-old boy with autism spectrum disorder (ASD). He takes hours to fall asleep. His parents state that “he can’t shut his brain down.” He drinks Mountain Dew with dinner, and plays video games after dinner. He can’t settle down to go to sleep and leaves his room repeatedly to find his parents.
- Once asleep, he awakens multiple times during the night. Sometimes he awakens his parents. Other times he wanders around the house, goes to the kitchen to eat, and falls asleep in a different room.
- It is “nearly impossible” to awaken Alex in the morning for school. His parents are exhausted and very overwhelmed. Alex’s teacher describes him as being hyperactive and disruptive in class.

Treatment of Insomnia: Behavioral Approaches



- “Behavioral treatment of sleep problems in children with intellectual disabilities and challenging daytime behavior reduces parental stress, increases parents’ satisfaction with their own sleep, their child’s sleep, and heightens their sense of control and ability to cope with their child’s sleep”
(Wiggs L, 2001)

Components of Successful Sleep (for any child)

- Daytime habits
- Evening habits
- Sleep environment
- Bedtime routines

Sleep Hygiene

Sleep hygiene is a term used to describe a person's daytime and evening habits that contribute to successful sleep.

Measuring Sleep Hygiene– The Family Inventory of Sleep Habits (FISH)

- We developed the FISH as a sleep habits questionnaire for use in our research

- The FISH contains 12 questions that ask about sleep habits in the child and family

- Excellent test-retest reliability and external validity with the Children's Sleep Habits Questionnaire (CSHQ)

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 3 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 (starts later 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 think no further action is needed to help her/him fall asleep.	1	2	3	4	5
12. My child watches TV, videos, or DVDs to help her/him fall asleep.	1	2	3	4	5

Malow et al, Child Neurol, 2009

Components of Successful Sleep (for any child)

- **Daytime habits**

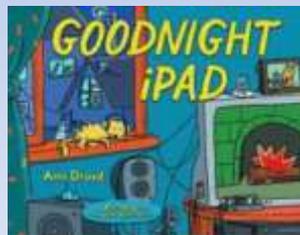
- Exercise
- Abundant light
- Limit caffeine
- Limit naps
- Selective bedroom use



Components of Successful Sleep (for any child)

- **Evening habits**

- Limit stimulating activities, TV, videos, and tablets
- Less light
- Routines



Components of Successful Sleep (for any child)

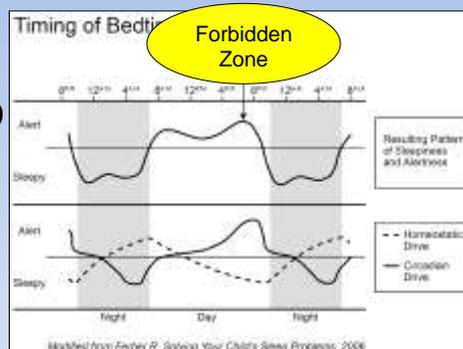
- **Sleep Environment**

- Temperature
- Texture
- Sound
- Light



Sleep Needs (for any child)

- Amount of sleep
- Timing of Sleep
- Regularity of sleep (bedtime / waketime)



Line Drawings

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

Checklist

Bedtime Routines Worksheet

Bedtime Routines Worksheet

Activities:	Occurs	Is the activity easy (E) or hard (H)?	Is the activity stimulating (S) or relaxing (R)?	Rank in order of preference (1, 2, 3.)
Taking a bath				
Washing hair				
Changing into pajamas				
Getting a drink				
Brushing teeth				
Using the bathroom				
Singing quiet songs				
Reading				
Other:				

Bedtime Routines Worksheet

Bedtime Schedule

Using the information from the Bedtimes Routine Worksheet, plan a bedtime schedule for your child

Order	Activity	Is the activity easy (E) or hard (H)?	Is the activity stimulating (S) or relaxing (R)?

Bedtime Routines Worksheet

Completed Bedtime Routines Worksheet

Activities	Occurs	Is the activity easy (E) or hard (H)?	Is the activity stimulating (S) or relaxing (R)?	Rank in order of preference (1, 2, 3)
Taking a bath	X	E	R	7
Washing hair	X	H	S	8
Changing into pajamas	X	E	R	5
Getting a drink	X	E	R	4
Brushing teeth	X	H	S	6
Using the bathroom	X	E	R	3
Singing quiet songs				
Reading				
Other:				
Playing with cars	X	E	R	2
Watching videos	X	E	S	1

Bedtime Routines Worksheet

Completed bedtime schedule:

Order	Activity	Is the activity easy (E) or hard (H)?	Is the activity stimulating (S) or relaxing (R)?
1	Brushing teeth	H	S
2	Playing with cars	E	R
3	Getting a drink	E	R
4	Taking a bath	E	R
5	Using the bathroom	E	R
6	Changing into pajamas	E	R

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.**



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.



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



The Bedtime Pass



Bedtime pass



Friman, xx

Sample Bedtime Pass Story

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.

Children with Limited Verbal Skills

- Schedules with photos
- Object schedules
- Cues in the environment

Schedule Boards:

Some children are not able to use a visual schedule that uses words, photos, or icons. It may help to use objects instead.

Here's an example: If your child's bedtime routine consists of using the toilet, taking a bath, washing hair, brushing hair, having a massage, and listening to music, you might have a place near the bathroom or bedroom with the following items: a roll of toilet paper, a bar of soap, a bottle of shampoo, a hairbrush, a bottle of lotion, and a CD. Your child would get each object before the start of an activity and use this to guide his or her actions. Save a special object just for bedtime. This might be a special blanket, pillow, or stuffed animal. Once your child has this object, he or she should go into his or her bed. Even if you do not use objects, write down your child's schedule so that you are going through the same steps each night. Use single words or two-word phrases to label what you are doing.



Sensory Strategies

- Rocking and Swinging
- Snuggling
- Massaging
- Listening to music
- Calming scents
- Chewing gum, vinyl tubing
- Clothing
- Bedding
- Weighted blankets
- Mattresses
- Bed tents
- Night lights
- White noise



AS ATN Toolkits

<http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit>
 Or search for Autism Speaks Sleep Toolkit

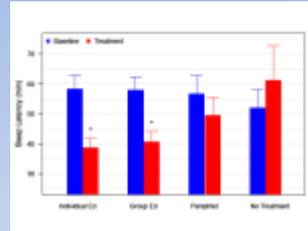
Parent Sleep Education in ASD: Methods

- ✓ We carried out a two-phase study in parents of children with ASD (meeting DSM-IV with confirmatory ADOS), ages 2-10 years 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. (Adkins, Pediatrics, 2012)
- ✓ Phase 2: 80 parents were randomized to either two 2-hour sessions in a group setting or one 1-hour session in an individual setting with a trained sleep educator. (Malow, J. Autism and Dev. Disorders, 2013)
- ✓ Sleep and behavioral measures obtained at baseline and 1 month post-treatment.

Sleep education curriculum: daytime and evening habits, sleep needs/timing, calming bedtime routine, saying “goodnight” to the iPad and other electronic devices, minimizing bedtime resistance, optimizing parent interactions with child at bedtime and upon awakening.

Parent Sleep Education in ASD: Results

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)

Future Directions:

- Develop and test innovative models for delivering behavioral interventions (therapists in community settings, books to teach parents)
- Integrate behavioral interventions with pharmacological treatments
- Expand our work to adolescents and young adults

Medication Treatment for Insomnia

- Educational/behavioral interventions are the first line of treatment, after excluding medical contributors.
 - Children with ASD have challenges understanding expectations about sleep due to difficulties with communication. Challenges with transitions and emotional regulation may also contribute. These challenges are all amenable to behavioral sleep education.
 - Children with ASD may not be able to communicate adverse effects of medications.
 - There is limited evidence for medications to treat insomnia in ASD.
- However, if an educational (behavioral) approach does not appear feasible, or the intensity of symptoms has reached a crisis point, pharmacological treatment is considered.

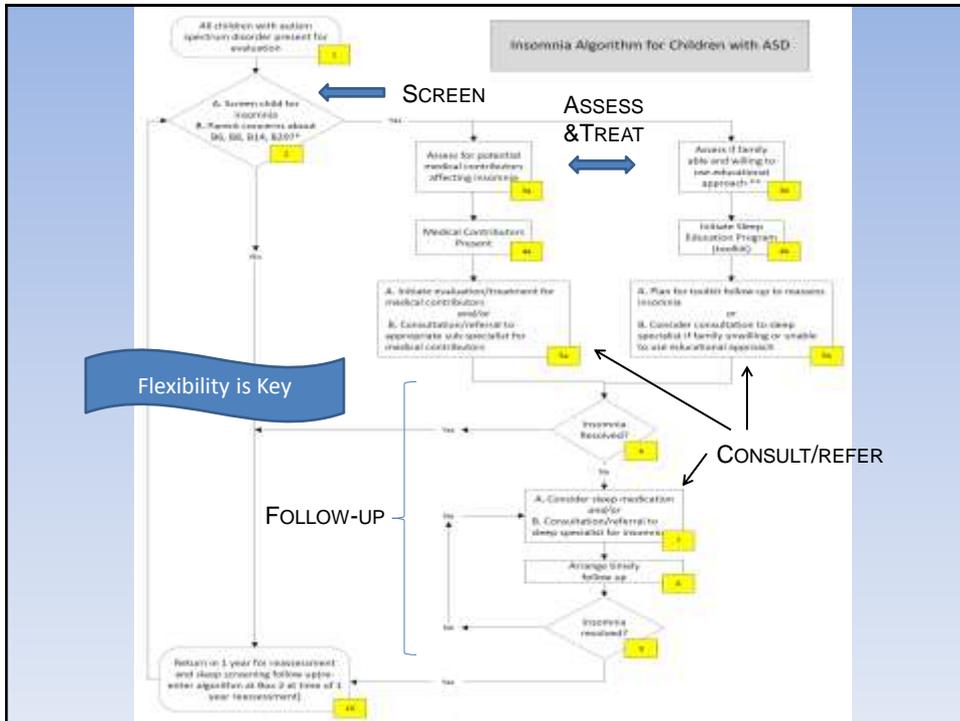
Medication Treatment for Insomnia

- Best used after behavioral treatments have been tried unsuccessfully, and in combination with behavioral therapies
- Whenever possible, choose a medication that will treat a comorbidity such as epilepsy, anxiety, or a mood disorder
- Start at low doses, especially in children with developmental disorders (less able to communicate adverse effects effectively)
- For primary insomnia, no FDA-approved drugs. We have reported success and minimal adverse effects with melatonin (Andersen, 2008; Malow, 2012) and gabapentin (Robinson, J Child Neurol, 2013). An extended-release "microtablet" (3 mm) preparation of melatonin is under study.
- Other options clinicians use include clonidine, mirtazapine, niaprazine, zolpidem, zaleplon, ramelteon, and resipridone. None of these has been tested in definitive trials, and side effect profile is important.

Practice Pathway

- The Autism Speaks Autism Treatment Network Sleep Committee has developed a practice pathway for the surveillance, diagnosis, and treatment of insomnia in ASD
- Surveillance/Diagnosis: Health care providers ask families about insomnia, and review targeted questions on the Children's Sleep Habits Questionnaire (CSHQ). The specialists also address potential medical issues contributing to insomnia (including GI, seizures, sleep disordered breathing) and refer to a medical or sleep subspecialist as indicated.
- Treatment: If the family is willing and able to consider behavioral therapy as a first line approach, autism specialists and their team will provide the family with behavioral sleep education.

"Plan B" involves the use of medications in conjunction with behavioral therapy, with referral to a sleep subspecialist as indicated. (Malow, 2012)



Summary

- Sleep concerns are very common in children with autism spectrum disorders
- There are multiple causes ranging from biological to medical to behavioral
- Sleep disorders impact child behavior and family functioning
- Treatments are often successful for children with ASD and sleep problems. Behavioral approaches do work, and represent an opportunity for partnership between parents, health care providers, and therapists.

Wrap Up Questions and Answers

