Autism Spectrum Disorder and Sleep

Jack Dempsey, Ph.D.
3 Things

- Sleep Chart
- Bedtime Routine
- Independent Sleep
The Big 4

- **Sleep**: Get more sleep
- **Exercise**: Exercise more
- **Eat**: Eat healthier
- **Be**: Be more mindful
## Getting Enough Sleep?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Age Range</th>
<th>Hours per 24 hours (including naps)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant</td>
<td>4–12 months</td>
<td>12–16 hours</td>
</tr>
<tr>
<td>Toddler</td>
<td>1–2 years</td>
<td>11–14 hours</td>
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<tr>
<td>Preschool</td>
<td>3–5 years</td>
<td>10–13 hours</td>
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<tr>
<td>School Age</td>
<td>6–12 years</td>
<td>9–12 hours</td>
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<tr>
<td>Teen</td>
<td>13–18 years</td>
<td>8–10 hours</td>
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<tr>
<td>Adult</td>
<td>18–60 years</td>
<td>7 or more hours</td>
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<td>61–64 years</td>
<td>7–9 hours</td>
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<td>65 years and older</td>
<td>7–8 hours</td>
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</table>
What Sleep Improves

- attention
- behavior
- learning
- memory
- emotional regulation
- quality of life
- mental health
- physical health
Insufficient Sleep

• Attention, behavior, and learning problems.
• Increased risk of accidents, injuries, hypertension, obesity, diabetes, and depression.
• Increased risk of self-harm, suicidal thoughts, and suicide attempts in teens
• Challenging behaviors in children with ASD
Definitions

- Pediatric Insomnia
  - repeated episodes of difficulty initiating and/or maintaining sleep, including premature awakenings, leading to insufficient or poor-quality sleep.
  - These episodes result in functional impairment for the child or other family members
Prevalence of Sleep Problems in ASD

• Most estimates indicate 50-80%
• Direct comparison to peers: 50% vs 82% all ages
• In peer comparison group: sleep issues improve with age
• In ASD: sleep issues do not improve with age
Causes of Sleep Difficulties in ASD

- Biological
- Medical
- Behavioral
Biological Causes

- Melatonin dysregulation
- Disordered sleep architecture
- Insistence on sameness
Medical Causes

- Disordered breathing
- Anxiety
- Epilepsy
- Restless legs
- GI issues
Behavioral Causes

- Inconsistent bedtime/wake-time
- High level of activity before bed
- Screen time before bed
First Step

Partner with health care provider to rule-out medical causes

What to say:

Sleep problems are present

Want child to sleep more

Documentation (e.g., sleep chart)
Outcomes

• Referral to Specialist
• Ordering test
• Starting medication
  • Iron, melatonin
• Handout on sleep hygiene
What Gets Measured Gets Managed  
(Second Step)

Universal Principle
• Work Productivity
• Exercise
• Diet
• Sleep

How To
• Screening Measures
• Sleep Chart
Screening Measures

• Children’s Sleep Habits Questionnaire (CHSQ)
  • assess multiple domains of sleep problems including breathing disorders, anxiety, resistance and daytime sleepiness

• Family Inventory of Sleep Habits (FISH)
  • assess bedtime routines, parental interactions, daytime behaviors
Quick Detour: Practice Pathway

1. All children who have ASD should be screened for insomnia;
2. Screening should be done for potential contributing factors, including other medical problems;
3. The need for therapeutic intervention should be determined;
4. Therapeutic interventions should begin with parent education in the use of behavioral approaches as a first-line approach;
5. Pharmacologic therapy may be indicated in certain situations; and
6. There should be follow-up after any intervention to evaluate effectiveness and tolerance of the therapy.
Key Screening Items

(1) child falls asleep more than 20 minutes after going to bed;
(2) child falls asleep in parent’s or sibling’s bed;
(3) child sleeps too little; and
(4) child awakens more than once during the night.
(1) all children who have ASD should be screened for insomnia;
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Malow, Byars, Johnson, et al., 2012
“Educational/behavioral interventions are the first line of treatment, after excluding medical contributors. However, if an educational (behavioral) approach does not seem feasible, or the intensity of symptoms has reached a crisis point, the use of pharmacologic treatment is considered” (p. 121)
ATN Toolkit

(1) providing a comfortable sleep setting;
(2) establishing regular bedtime habits;
(3) keeping a regular schedule;
(4) teaching your child to fall asleep alone;
(5) avoiding naps (in children who have outgrown the need for a daytime nap); and
(6) encouraging daytime activities that promote a better sleep/wake schedule.
Practice Pathway

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(2) screening should be done for potential contributing factors, including other medical problems;
(3) the need for therapeutic intervention should be determined;
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(5) pharmacologic therapy may be indicated in certain situations; and
(6) there should be follow-up after any intervention to evaluate effectiveness and tolerance of the therapy.
Reasons Toolkit Failed

• Parent comments:
  • Valuable information
  • Needed guidance on
    • Implementation
    • individualization

• Suggested solution: guidance from a health care provider
Education vs Training

• Parents were randomly assigned to one of two interventions: a group education program (two 2-hour sessions conducted one week apart over two weeks with two follow-up phone calls) or an individualized program (one 1-hour session with two follow-up phone calls).

• Improved sleep habits
• Improved behavioral parameters related to anxiety/depression, withdrawal, attention, repetitive behaviors, parenting efficacy and satisfaction, and pediatric quality of life.
• Improved sleep onset latency
• Interaction in the individual sessions, parents were engaged one-on-one with the educator. In the group sessions, parents interacted with each other as well as the educator to share successes and challenges with the curriculum and “pearls” they had gained from the sessions. In group sessions involving more than three parents, concurrent breakout sessions were used to ensure that parents received sufficient time and attention from the educator. While parents received education encompassing many aspects of sleep, the sessions also emphasized the sleep concerns relevant to the participants. To accomplish this, in preparation for the educational sessions, the educator targeted specific areas based on the parent's responses to the CSHQ and Family Inventory of Sleep Habits (FISH; Malow et al. 2009) (e.g., a child with sleep onset delay who was engaging in stimulating activities before bedtime). At the beginning of the session, the parent was asked to state their major sleep challenge and what they hoped to achieve from the session to assure that the parent's identified sleep challenges were the focus of the session.

Malow, Adkins, Reynolds, et al., 2014
• Sleep hygiene, including daytime and evening habits and the sleep environment
• Sleep amount/timing/regularity
• Bedtime routine, including completion of a worksheet labeling activities as stimulating or relaxing, and hard or easy for the child and ordering them into a schedule.
• Strategies related to minimizing bedtime resistance, night wakings, and co-sleeping,
  • Rocking chair method
  • Bedtime pass
• Homework: written datasheet to complete each night including strategies for bedtime resistance
• Educational phone calls-- the educator called the parents at one and two weeks to review homework and answer any questions the parents might have.
Sleep Diary

• Widespread agreement that a sleep diary should routinely be included in insomnia research/treatment

• Primary outcome measure for meta-analyses of treatment

• Not one standard format
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## Expanded Sleep Diary

<table>
<thead>
<tr>
<th>Sleep Environment</th>
<th>Daytime Activities</th>
</tr>
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<tbody>
<tr>
<td>• Comfort object?</td>
<td>• Exercise?</td>
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<tr>
<td>• Parent present?</td>
<td>• Timing</td>
</tr>
<tr>
<td>• TV/Radio?</td>
<td>• Caffeine?</td>
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<tr>
<td>• Lights on/off?</td>
<td>• Naps?</td>
</tr>
<tr>
<td>• Bedroom?</td>
<td>• Natural light?</td>
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Bedtime Routine

• Structure, Structure, Structure
• Systematic:
  • Stimulating to calming
• Explicit
  • Visual schedule
  • Video Self-Modeling
• Consistency
Stimulating → Calming

1. Where are the battles?
2. Pick the battles early
3. Use rewards
4. Make sure there are activities the child enjoys
   - quiet singing,
   - weighted vest,
   - smelling lavender,
   - back scratch
5. Moving towards the bedroom
### Rewards and Negotiation

<table>
<thead>
<tr>
<th>Transition stimulating nighttime activities to the morning</th>
<th>Screens to other “addictive” reinforcers</th>
<th>Your presence is a reinforcer</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Allow longer playtimes</td>
<td>• Chocolate</td>
<td>• Dimming the lights</td>
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<tr>
<td></td>
<td>• Back scratch</td>
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Explicit

Visual Schedule

Social Story

Video
Independent Sleep

**Why**
- Fall asleep on own = get back to sleep on own
- Get rid of parent presence at bedtime

**How**
- Cry it out
- Graduated extinction
- Rocking chair
Extinction

Cry it out
• "Goodnight"
• Leave
• Don’t come back
• Not recommended

Graduated Extinction
• “Goodnight”
• Leave
• Come back if upset
  • Progressively longer intervals
  • Quick & Boring
• Not Recommended
The Reason
Fading Parental Presence (Rocking chair)
Start Bedside
Leave the Room
Bedtime Pass

BEDTIME PASS
Before Using the Pass

1. Collaborate with child to make pass
2. Explain pass exchange
   • hug
   • Kiss
   • Drink of water
3. Choose rewards for keeping pass
Using the Pass

• Remind at bedtime about using the pass
  • Leave visual reminders in the room (pictures of prizes)

• If pass is used keep contact brief & boring and return him to room

• Celebrate with immediate reward and praise if he keeps pass
Sleeping Alone
Decorate
Gradual Transition

- Pillow between you
- Separate bed in room
  - Sleeping bag
- Bedding in hallway
- In own room
Safety

- Audio/visual monitors
- Bell on bedroom door
- Sharps up high
- Doors locked
- Safety bed
  - Consult health provider
Waking Up Too Early

• Have activities ready
  • Picture schedule or chart for reminders

• Visual/auditory signal for when OK to leave room

• Social story of waking up early

• Move bedtime back
3 Things

- Sleep Chart
- Bedtime Routine
- Independent Sleep