Sleep Health and m-Health Interventions in Pediatric Chronic Conditions

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UNIVERSITY of WASHINGTON
Objectives

- Describe common sleep problems
- Identify the current gaps in pediatric sleep interventions
- Describe community-based participatory approaches in the development and testing of interventions to improve sleep in children
- Describe current mHealth pediatric sleep interventions
- Discuss recommendations
Conflicts of Interest

Financial Support: NIH/National Institute of Nursing Research, P30 Center for Innovation in Sleep Self-Management (P30 NR016585); NIH/National Institute of Nursing Research, R21NR017471
Why Focus on Sleep?

HOW DO I PUT THIS?

YOU WILL NEVER "SLEEP IN" AGAIN.
Why Focus on Sleep?

> Major public health concern
> One of the top 5 complaints presented to primary care clinicians
  > Infants up to 40%
  > Preschool 25% to 30%
  > School-age & Adolescents 10% to 60%
> Up to 30% of children and 66% of adolescents experience Insomnia symptoms

Owens J & Chervin R (2019); Dewald-Kaufmann, de Bruin, Gradisar (2019)
Consequences of Sleep Deficiency

- Co-morbid with acute & chronic illnesses
- Developmental transitions
  - Age, work, family
- Self-imposed due to unhealthy lifestyle choices
- Physiologic & behavioral consequences
  - ↓ Quality of Life
  - Health consequences
    - Mental health
    - Obesity
    - Inflammation
Cognitive Behavioral Therapy for Insomnia (CBT-I)

> First line of therapy for pediatric insomnia.
  • Targets both behavioral and cognitive components
  • Few RCTs in school-age children and adolescents

> Face-to-face or telephone sessions can produce significant improvement in sleep duration, patterns, and behaviors.
  • 2 to 6 sessions

**Systematic Review of CBT-I in Children**

**Characteristics of the Intervention**

<table>
<thead>
<tr>
<th></th>
<th>Sleep Education</th>
<th>Sleep Hygiene</th>
<th>Sleep Restriction/Bedtime Fading</th>
<th>Stimulus Control</th>
<th>Cognitive Therapy</th>
<th>Relaxation/Mindfulness</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blake et al., 2016</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>CBT-a</td>
</tr>
<tr>
<td>Cain et al., 2011</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Clarke et al., 2015</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>CBT-d</td>
</tr>
<tr>
<td>de Bruin et al., 2015</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Moseley et al., 2009</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Paine et al., 2011</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
</tbody>
</table>

CBT-a = cognitive behavioral therapy for anxiety, CBT-d = cognitive behavioral therapy for depression.

**Key Findings:** Significant differences in total sleep time and sleep onset latency posttreatment favoring the sleep-specific CBT-I as compared to wait-list and active control groups.

- effect sizes for actigraphy and self-reported sleep onset latency 0.4 and 0.81
- effect size for WASO 0.5

Åslund L. et al., *J Clin Sleep Med*. 2018
Limitations of Current RCTs in Children

- Primarily conducted in adolescents
  - Child report of sleep and daytime function
- Small sample sizes
- High risk of bias due to lack of blinding
  - Attention control groups
- Heterogeneity in participants, treatment regimens and delivery
- Longer follow up periods
Gaps In Sleep Interventions

- Lack of pediatric providers trained in how to manage behavioral sleep problems.
- Long waiting times and referrals.
  - Cost and time
  - Missed work and school
- Stakeholders (e.g., parents and children) are not involved in developing of the intervention.
- Few interventions incorporate shared-management skills (activation, motivation, self-efficacy)
- Few sleep interventions focus on marginalized communities.

mHealth/ eHealth

> Use of mobile technology to improve sleep
  – Mobile applications
  – Web-based applications
  – Text messaging

> Few studies have examined mHealth to improve sleep in children.

Shared Management

> Caregivers are an essential component of the care of the child.
  - Activation
  - Motivation
  - Self-efficacy

> Empower both caregivers and children to set goals and problem solve.

> mHealth interventions have been shown to improve patient activation and engagement, making them a possible solution to improve outcomes.

> Few studies evaluate the use of mHealth in the parent-and-child dynamic to better understand optimal use of mHealth for both parts of this dynamic.

Integration of Technology to Improve Sleep

User Centered Design Approach

STAGE GOALS

I. Research
Discover goals & needs
- Learn about stakeholders
- Discover goals and needs
- How is it done now?
- What is wanted?
- What else has been tried?

II. Ideate
Generate ideas
- Generate lots of ideas
- Grasp issues and potential solutions

III. Prototype
Produce something tangible
- Produce something tangible
- Identify challenges
- Uncover subtleties

IV. Evaluate
Determine usability & usefulness
- Discover problems
- Assess progress
- Determine next steps

V. Produce
Build, Measure, Learn
- Build final product
- Ramp up marketing, support, and maintenance
Explore

> Identify stakeholders
  - Patients
    > Children
    > Older Adults
  - Caregivers
    > Parents
    > Spouses
  - Healthcare Providers
    > Nurses
    > Doctors
  - Community
    > Community health navigators
Participatory Design
- Incorporate stakeholders throughout the design process
- Example:
  > Sticky Note Exercise
  > Facilitator
  > RAs for notetakers
Prototypes
Participatory Design
Prioritize features

- How important is the feature
- How well the need is met by existing solutions
Welcome to SLEEPSMART
Sleep Shared-Management Intervention for Children with Juvenile Idiopathic Arthritis

1) Sleep Education
2) Recognizing stress and negative emotions
3) Operant strategies I (reinforcing behaviors)
4) Positive Reinforcement
5) Modeling
6) Communication
7) Lifestyle
8) Relapse Prevention

Ward et al., Nurs Outlook, 2020
### Key Components of Behavioral Sleep Interventions

<table>
<thead>
<tr>
<th>Cross-Cutting Modules</th>
<th>Common Transdiagnostic Sleep-Circadian Problems</th>
<th>Treatment Module</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Formulation</td>
<td>Establishing regular sleep-wake times</td>
<td>Core Module 1</td>
</tr>
<tr>
<td>Education</td>
<td>Learning a wind-down routine</td>
<td>Core Module 1</td>
</tr>
<tr>
<td>Behavior Change &amp; Motivation</td>
<td>Learning a wake-up routine</td>
<td>Core Module 1</td>
</tr>
<tr>
<td>Goal Setting</td>
<td>Improving daytime functioning</td>
<td>Core Module 2</td>
</tr>
<tr>
<td></td>
<td>Correcting unhelpful sleep-related beliefs</td>
<td>Core Module 3</td>
</tr>
<tr>
<td></td>
<td>Improving sleep efficiency</td>
<td>Optional Module 1</td>
</tr>
<tr>
<td></td>
<td>Reducing time in bed</td>
<td>Optional Module 2</td>
</tr>
<tr>
<td></td>
<td>Dealing with delayed or advanced phase</td>
<td>Optional Module 3</td>
</tr>
<tr>
<td></td>
<td>Reducing sleep-related worry/vigilance</td>
<td>Optional Module 4</td>
</tr>
<tr>
<td></td>
<td>Maintenance of behavior change</td>
<td>Core Module 4</td>
</tr>
</tbody>
</table>

The above with a highly trained SLEEP COACH

Chen et al., JMIR, 2019
Weekly Email

Hello and welcome to your first week of the SleepSmart study; we are so excited that you are taking part!

This week you will be learning all about sleep. Below are outlined the steps for you to complete for this week’s learning module. Please note that it is up to you, as parent and child, if you would like to go through the lesson (Step 1) together or separately.

**Steps for Child**
1. Sleep Education Lesson
   a) Go to the [Sleep Education lesson page](#) on the SleepSmart website.
   b) Click through the slides to learn “all about sleep.”
   c) Take the 5 question quiz to see what you’ve learned.

2. This Week’s Activities
   a) Under “For Kids” in the “Weekly Activities” activities, you will find the 4 worksheets that you need to complete for this week.
   b) Click on the button with each worksheet’s name. You can then either print it out and fill it in by hand, or you can complete the worksheet on your computer.
   c) Once you’ve finished, give your completed worksheets to your parent so that they can upload them onto the REDCap site on [this child link](#).

**Steps for Parent**
1. Sleep Education Lesson
   a) Go to the [Sleep Education lesson page](#) on the SleepSmart website.
   b) Click through the slides to learn “all about sleep.”
   c) Take the 5 question quiz to see what you’ve learned.

2. This Week’s Activities
   a) Go to [this link](#) on the REDCap website.
   b) Follow the instructions to answer the questions related to the “Pros and Cons of Changing Sleep Habits.”
   c) Upload your child’s worksheets from this week.
   d) Click “Submit” and your weekly learning module is complete!

Please remember if at any time you need support from our team, you can email us at sleepsmartstudy@uw.edu. Thank you again for your participation in this study!

Sincerely,
The SleepSmart Study Team
About this Lesson

In this week’s lesson you will learn about the importance of sleep, different types of sleep, and sleep biology and rhythms. The lesson will include:

1. A video slideshow
2. An interactive quiz
3. Activities to complete this week
4. Handouts with additional information about sleep

As part of this lesson, we want you to be reflecting upon your sleep-related behaviors, thoughts, feelings, and consequences at bedtime, during the night, on waking, and during the day sleep habits and struggles.
Pros & Cons of Changing Sleep Habits

There are advantages and disadvantages to making any change in your life. Think about the changes you might make to help your child's sleep habits. What are some pros and cons?

<table>
<thead>
<tr>
<th>1) Pros?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>2) Cons?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>3) Please upload the Session 1 Assignment Sheet here</th>
</tr>
</thead>
</table>
Better Nights Better Days (BNBD)- ADHD

> **Primary Aim:** To determine the effect of a distance BNBD intervention on children’s sleep onset latency, bedtime resistance, and sleep duration as measured by parent report.

> **Secondary Aims:**
  - To evaluate change in sleep as measured by actigraphy,
  - To evaluate whether children with ADHD responded similarly to the distance sleep intervention as typically developing (TD) children
  - To determine whether changes in sleep resulted in changes in daytime functioning

Better Nights Better Days Intervention with Sleep

### Intervention sessions.

<table>
<thead>
<tr>
<th>Session</th>
<th>Topic overview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep information</td>
<td>Characteristics of sleep; types of sleep problems, sleep need; how sleep problems develop; impact and treatment of sleep problems</td>
</tr>
<tr>
<td>Healthy sleep practices</td>
<td>Daytime and bedtime routines; sleep hygiene/healthy sleep practices; sleep scheduling (including napping) and sleep routines</td>
</tr>
<tr>
<td>Independent settling at bedtime</td>
<td>Settling at bedtime; parents choose a sleep intervention that best fits their needs from 3 intervention strategies: controlled comforting,</td>
</tr>
<tr>
<td></td>
<td>camping out, and bedtime fading</td>
</tr>
<tr>
<td>Night waking, napping, and early morning awakenings</td>
<td>Applying strategies to night waking; applying strategies to early morning awakenings; applying strategies to napping</td>
</tr>
<tr>
<td>Looking back and ahead</td>
<td>Relapse prevention; looking back at goals and progress; common pitfalls/roadblocks; what to expect at new developmental milestones; dealing</td>
</tr>
<tr>
<td></td>
<td>with other sleep problems; making a plan</td>
</tr>
</tbody>
</table>

**Sleep Coach**
- 5 weekly telephone calls (30 to 45 minutes)
- parent manual
## Better Nights Better Days - Study Eligibility

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age 5 to 12 years</td>
<td>• Age 5 to 12 years</td>
</tr>
<tr>
<td>• Child experience trouble falling asleep, with/without bedtime resistance</td>
<td>• Child experience trouble falling asleep, with/without bedtime resistance</td>
</tr>
<tr>
<td>→ SOL &gt; 25 minutes &amp; occurring &gt; 3 times per week</td>
<td>→ SOL &gt; 25 minutes &amp; occurring &gt; 3 times per week</td>
</tr>
<tr>
<td>• Duration of sleep problem &gt; 1 month, with impairment to daily functioning</td>
<td>• Duration of sleep problem &gt; 1 month, with impairment to daily functioning</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• + Sleep apnea screening</td>
<td>• + Sleep apnea screening</td>
</tr>
<tr>
<td>• Moderate/severe cognitive impairment</td>
<td>• Moderate/severe cognitive impairment</td>
</tr>
<tr>
<td>• Neurological disorder (epilepsy)</td>
<td>• Neurological disorder (epilepsy)</td>
</tr>
<tr>
<td>• Mental health disorder (anxiety, depression) other than ADHD</td>
<td>• Mental health disorder (anxiety, depression) other than ADHD</td>
</tr>
<tr>
<td>• Participation in behavioral sleep intervention over the last 6 months</td>
<td>• Participation in behavioral sleep intervention over the last 6 months</td>
</tr>
<tr>
<td>• Co-sleeping</td>
<td>• Co-sleeping</td>
</tr>
</tbody>
</table>

Methods

> Sample: 61 children (n=31 ADHD)
  – 5 to 12 years of age
> Sleep – actigraphy (SOL, duration), CSHQ
> Single Center, parallel group RCT
  – Randomized to intervention (n=30) or waitlist control (n=31)
> 5-week telephone intervention with sleep coach

## Demographics

<table>
<thead>
<tr>
<th></th>
<th>Intervention (n=31)</th>
<th>Waitlist Control (n=30)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (months, SD)</td>
<td>108.0 (23.6)</td>
<td>110.6 (23.7)</td>
<td>.67</td>
</tr>
<tr>
<td>Sex (female, %)</td>
<td>16 (51.6%)</td>
<td>17 (56.7%)</td>
<td>.69</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>25 (80.6%)</td>
<td>28 (90.3%)</td>
<td>.14</td>
</tr>
<tr>
<td>ADHD diagnosis</td>
<td>12 (38.7%)</td>
<td>10 (33.3%)</td>
<td>.66</td>
</tr>
<tr>
<td>Meds for ADHD (yes, %)</td>
<td>8 (67%)</td>
<td>6 (60%)</td>
<td>.59</td>
</tr>
</tbody>
</table>
Results

> Significant improvement for parent ratings on the CSHQ in the intervention group at 2- and 6-months post-intervention
  – SOL, bedtime resistance, and sleep duration
  – effect sizes small to moderate
> Actigraphy no differences over time
Limitations

> Low adherence to actigraphy

> Lack of child report measures of sleep and daytime functioning
  – sleep hygiene

> Shared Management measures
  – self-efficacy, motivation
Revised Better Nights Better Days

> Developed to determine its effectiveness on children’s sleep and psychosocial functioning

> **Parent-guided e-Health intervention** to treat behavioral insomnia
  - Accessible program to empower parents to implement strategies independently
  - ADHD, Typically Developing, Neurodevelopmental Disorders

> Based on evidence-based practices and tailored content
  - participants create personalized sleep routines, set individualized goals, and receive custom feedback on progress
  - age-specific information delivered primarily through videos and interactive elements to engage and encourage parents
  - access to built-in tools and supports, such as sleep diaries and goal setting and tracking, provides feedback on participants’ progress.

The purpose of the RCT trial is to evaluate the effectiveness of BNBD, an eHealth intervention for insomnia in children 1 to 10 years of age.

- RCT across Canada
- Canadian Institutes of Health Research

**Implementation and sustainability**

- Who does this intervention work for?

https://betternightsbetterdays.ca/information-media

Corkum P, et al., *JMIR*, 2018
Better Nights Better Days - Study Eligibility

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Child</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age 1-10 years</td>
<td>• Caregiver of a child</td>
<td></td>
</tr>
<tr>
<td>• Speak/understand English</td>
<td>• Read/understand English &amp; French</td>
<td></td>
</tr>
<tr>
<td>• Internet access</td>
<td>• Internet access</td>
<td></td>
</tr>
<tr>
<td>• Insomnia (sleep onset disturbance)</td>
<td>• Reside in Canada</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion</th>
<th>Child</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>• + Sleep apnea screening</td>
<td>• Bedsharing with the child</td>
<td></td>
</tr>
<tr>
<td>• Medical and/or mental health disorder (developmental disability, medication for ADHD)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Corkum P, et al., *JMIR*, 2018
Web-Based Sleep Intervention for Kids and Parents (SKIP): A Pilot Study

> A Shared Management Pilot Study

> Develop and pilot test SKIP, a web-based tailored intervention for sleep deficiency in 6-to-11 year-old children with asthma and their parents.

> Study Aims:

1: Describe the feasibility & acceptability of SKIP
2: Explore changes in sleep deficiency measures

Sonney et al., J Clin Med, 2020
## Study Eligibility

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Asthma diagnosis</td>
<td>• 18+ years</td>
</tr>
<tr>
<td>• Age 6-11 years</td>
<td>• Read/understand English</td>
</tr>
<tr>
<td>• Speak/understand English</td>
<td>• Reside with child (50% +)</td>
</tr>
<tr>
<td>• Prescription for daily asthma medication</td>
<td>• Legal guardian</td>
</tr>
<tr>
<td>• Sleep deficient (CSHQ)</td>
<td>• Internet access</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>• Traumatic brain injury</td>
<td>• Diagnosed sleep disorder</td>
</tr>
<tr>
<td>• Developmental delay</td>
<td>• Night shift worker</td>
</tr>
<tr>
<td>• ASD, ADHD, Cancer</td>
<td>• Use sleep medication</td>
</tr>
<tr>
<td>• Diagnosed sleep disorder</td>
<td></td>
</tr>
<tr>
<td>• + Sleep apnea screening</td>
<td></td>
</tr>
<tr>
<td>• Use sleep medication</td>
<td></td>
</tr>
</tbody>
</table>
Methods

> May 2017 - July 2018
> Single group 8-week tailored intervention
> Study structure:

- Baseline Sleep Assessment
- Intervention (8 weeks)
- Immediate Post-Intervention
- 12 Week Post-Intervention
Data Sources

**Parent**
- **Objective**
  - Actigraphy
- **Subjective**
  - Self-report & proxy surveys
  - Sleep diaries

**Child**
- **Objective**
  - Actigraphy
  - Spirometry
  - Weight, height
- **Subjective**
  - Self-report surveys
  - Sleep diary

**Dyad**
- **SKIP**
  - Engagement
  - Goal-setting, progress reports
- **Semi-structured interview**
Web-Based SKIP Intervention

> Dyads select from 3 modules
> Educational video
> Weekly activities
  – Goal setting
  – Anticipating barriers & problem solving
  – Weekly progress report (weeks 2-8)
Module Activities

Evidence-Based Goal Setting

Anticipated Barriers & Problem Solving

Progress Reporting
Results

Feasibility
- Enrollment response
- 14% attrition

Acceptability
- Acceptable & helpful
- Easy to use

Efficacy
- Parent & child improvements
- Post intervention & 3 month follow-up
## Efficacy Results Continued

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Baseline Mean (SD)</th>
<th>3-Month FU Change (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep Time (min)</td>
<td>479 (74)</td>
<td>7.5 (-3.5 to 18.5)</td>
</tr>
<tr>
<td>Bedtime consistency (min)</td>
<td>171 (104)</td>
<td>-35.2 (-42.9 to -27.5)*</td>
</tr>
<tr>
<td>Wake after Sleep Onset (WASO, min)</td>
<td>109 (64)</td>
<td>-37.1 (-44.5 to -29.7)*</td>
</tr>
<tr>
<td>Sleep Efficiency (%)</td>
<td>82 (10)</td>
<td>5.4 (4.2 to 6.5)*</td>
</tr>
<tr>
<td>Sleep Time (min)</td>
<td>421 (78)</td>
<td>6.5 (-7.5 to 20.4)</td>
</tr>
<tr>
<td>Bedtime consistency (min)</td>
<td>223 (168)</td>
<td>-35.3 (-51.0 to -19.7)*</td>
</tr>
<tr>
<td>Wake after Sleep Onset (WASO, min)</td>
<td>70 (40)</td>
<td>-13.9 (-19.5 to -8.2)*</td>
</tr>
<tr>
<td>Sleep Efficiency (%)</td>
<td>86 (7)</td>
<td>2.7 (1.7 to 3.7)*</td>
</tr>
</tbody>
</table>

* p < .001
Implications & Next Steps for SKIP

> SKIP was feasible, acceptable and effective
> Next steps:
  – Refinements
  – Testing in a larger trial
Moving Forward - Recommendations

> Integration of community-based participatory approaches
> Sample
  – consideration of who is and is not included
> What interventions work for whom?
> Sharing Protocols
> Intervention Fidelity
> Validation of the technology to measure sleep
> Security & Privacy concerns
Current Research at UW School of Nursing

Center for Innovation in Sleep Self-Management

> Online Prenatal Trial in Mindfulness Sleep Management (OPTIMISM) Dr. Ira Kantrowitz-Gordon

> Sleep Innovations for Preschoolers with Arthritis (SIPA) Dr. Weichao Yuwen

> Latino Caregivers of Children with Special Healthcare Needs Dr. Maggie Ramirez

https://cissm.nursing.uw.edu/
Current Ongoing Studies at UW

- Sleep Shared-Management Intervention in Children with Juvenile Idiopathic Arthritis (SLEEPSMART) Dr. Teresa Ward
- The Role of Sleep Deficiency in Youth with Chronic Pain Dr. Tonya Palermo
- Mobile Motivational Physical Activity Targeted Intervention – Dr. Oleg Zaslavsky
- Better Sleep for Breast Cancer Survivors: A Chat Bot Intervention Dr. Kerryn Redding
ACKNOWLEDGEMENTS

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• Graduate Students: Dahee Wi, Yong Choi, Will Kearns, Jonika Metz Hash, Christina Hussain, Maeve Edstrom, Shumenghui Zhai, Jeff Matarresse
• Jenny Williamson, Outreach Coordinator
• Marni Levy, Program Manager
• Allison Harvey, PhD, Professor, UC Berkeley
• Jim Rothermel, Research Scientist
• Barbara Snider Endowment for Sleep Innovation
• NIH/National Institute of Nursing Research, Center for Innovation in Sleep Self-Management (P30 NR016585)
PEDIATRIC SLEEP TEAM
Thank you!