Person-Centered Sleep Strategies: Addressing Biopsychosocial Impacts of Sleep Challenges in the IDD Population

Stephanie Parker MD, Adalia Ortiz, Lexy Johnston

CA START Golden Gate

ABSTRACT

Sleep challenges are prevalent in people with intellectual and developmental disabilities (IDD) and are associated with significant biopsychosocial impacts, including mood, cognition and overall wellbeing. This study explores a person-centered intervention designed to improve sleep quality and mitigate its adverse effects on the IDD population. Eight participants, with varying diagnoses and communication skills, were recruited on self- or caregiver-reported sleep difficulties and recognition of their negative impacts.

The intervention was structures around two categories of strategies- daytime and nighttime routines- with five evidenced-based options in each. Participants selected three strategies from each category, tailored to their preferences and abilities, to promote consistency and personalization.

Baseline and post-intervention data were collected using accessible surveys that assessed sleep quality and biopsychosocial outcomes. Findings showed that 50% of participants demonstrated a positive slope trend in improved sleep quality. Of the participants who did not have a positive trend, some had underlining clinical vulnerabilities that require more additional targeted support. This study highlights the importance of individualized, flexible interventions and the need to consider co-occurring conditions when addressing sleep challenges in this population.

INTRODUCTION

Sleep disturbances are common among people with IDD, often leading to significant biopsychosocial consequences. Poor sleep impacts emotional regulation, attention, daily functioning, and physical health. Yet, few interventions are tailored to the specific needs, preferences, and communication style of people with IDD.

This study represents the second year of a sleep-focused project under the SNTI framework, aiming to co-create a person-centered intervention with people we support, emphasizing both daytime and nighttime strategies to improve sleep quality and wellbeing.

MATERIALS AND METHOD

Participants: Screening survey which identified stress associated with sleep, sleep challenges, and any biological vulnerabilities associated with sleep such as sleep apnea.

- Inclusion criteria: enrolled in START, responded "Yes" on survey
- Exclusion criteria: biological vulnerabilities such as sleep apnea, responded "No" on survey

Design: Participated in planned coaching for 6 weeks to support caregivers understanding of sleep and how to implement the chosen strategies.

Intervention Format: Each participant selected 3-daytime strategies and 3-nighttime strategies to implement through planned coaching. These strategies were accompanied by therapeutic tools provided by START.

Assessment tools: Accessible pre- and post-surveys using simplified language, visual supports and caregiver input where needed; including a Sleep Diary to be completed daily rating sleep quality on a scale from 1-10.

STRATEGIES IMPLEMENTED

Daytime strategies

Morning light exposure: encouraging 15–30 minutes outdoors within two hours of waking to help align the circadian rhythm
Daily movement: 30 minutes of accessible activity such as walking, yoga, or dancing
Scheduled "screen-free" breaks: reduce overstimulation by incorporating time for puzzles, crafts, or sensory play.
Midday relaxation practice: deep breathing or calming sounds at a consistent time each day
Food plan: minimizing sugar and increasing whole foods to support energy balance

Nighttime strategies

Bedtime activity checklist: to create a routine that provides structure and consistency.
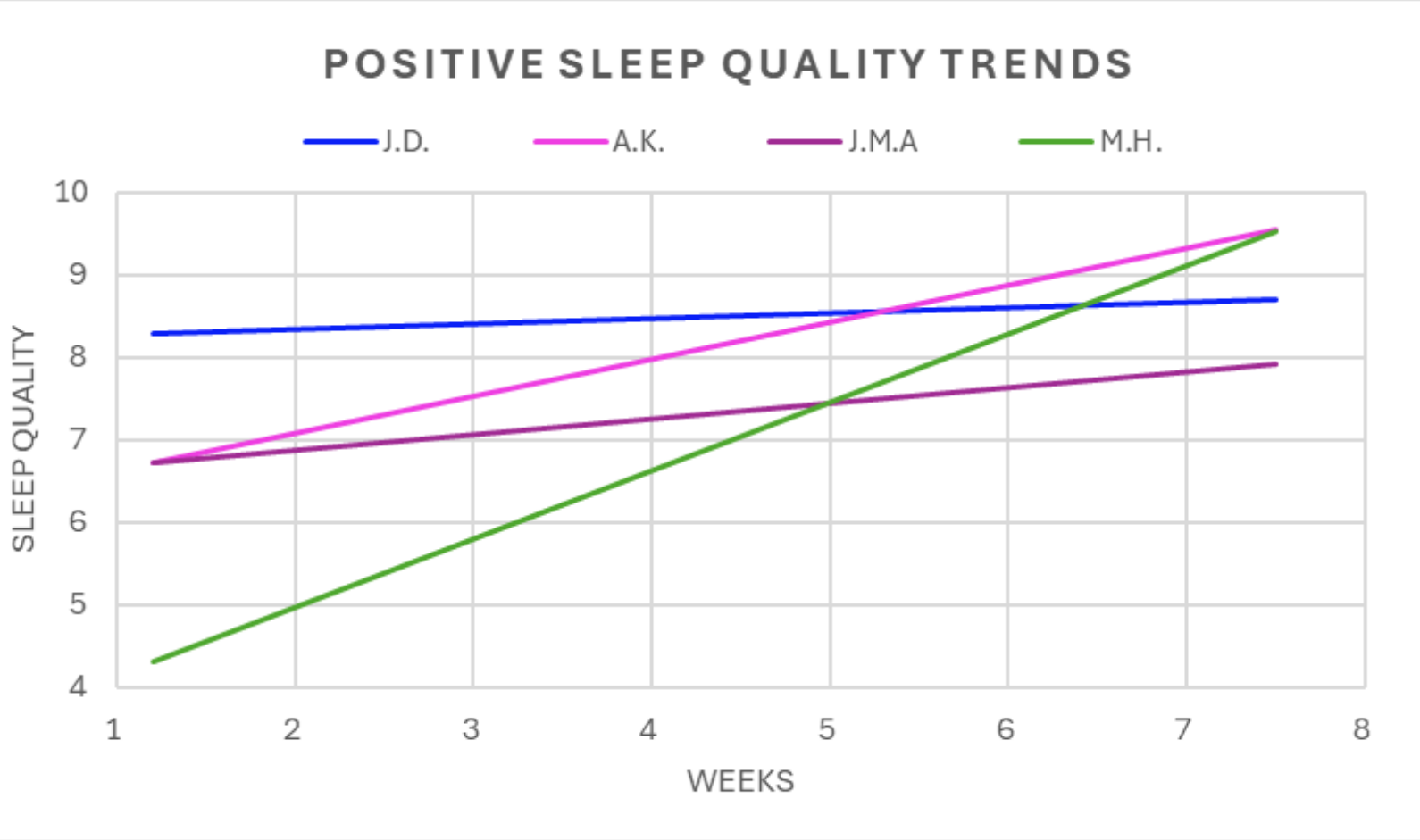**Technology shutoff:** to reduce blue light 1–2 hours before bed
Bedtime comfort: bundle materials to enhance the environment (lavender diffuser, eye masks, sunrise light and white noise machine)
**Guided meditation:** before sleep using calming audio or cards
Food plan: to support digestion and minimize late-night alertness.

FINDINGS

Graph 1: Participants with Positive Sleep Improvement Trends

- 50% of participants showed a positive slope trend in sleep quality over the intervention period
- 1 participant showed no change in sleep quality
- 3 participants experienced a negative slope; two of these, had notable vulnerabilities impacting sleep that were not identified in the initial screening:
  - Trauma related nightmares
  - Seizure activity
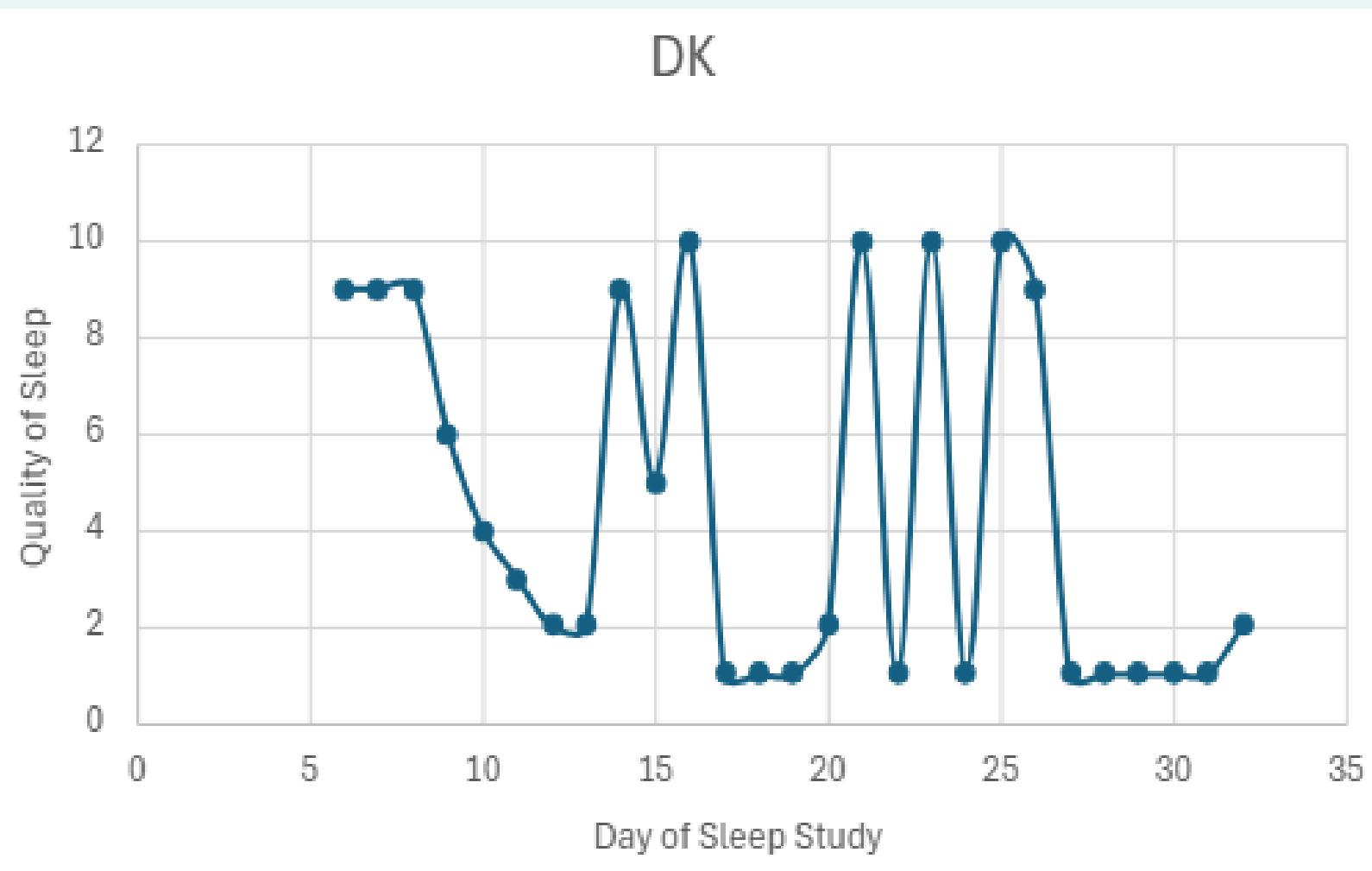
Graph 2: Impact of Co-occurring Nightmares on Sleep Outcomes

LIMITATIONS

While this study provides promising insights, several limitations should be noted:

- Small sample size
- Variability in support needed: Although we aimed to provide a person-centered study, each person requires a 100% individualized sleep improvement plan.
- Caregiver involvement: The degree of interdependent support varied which had a direct impact on the results.
- Duration of Intervention: Cannot capture long-term sleep improvements or sustainability of strategies.

CONCLUSIONS

This person-centered sleep intervention tied to START Therapeutic Planned Coaching shows promise for supporting people with IDD in improving sleep quality through simple tailored strategies. While half of the participants showed measurable improvements, others require more targeted supports for complex co-occurring vulnerabilities. Consistency, personalization and caregiver engagement were key factors in success.

NEXT STEPS

Creating awareness of the importance of sleep, particularly in the context of people with IDD and mental health conditions, requires a multi-faceted approach. Here are some of the identified next steps the CA START Golden Gate team will explore:

- Continue to create awareness of sleep's biopsychosocial impact with the people and systems we work with.
- Offer clinical support with ongoing coordination work to those who require specialized sleep support to address co-occuring vulnerabilities.
- Fostering partnerships with the community to promote sleep awareness and host events such as Clinical Education Teams (CETs) and Community Trainings for collaboration and capacity building.