

# Helping Your Child with Intellectual/Developmental Disability Prepare for a Sleep Study

## Introduction

How do you prepare your child with an intellectual/developmental disability (IDD) for a sleep study? This brief guide will help you to find ways to make your sleep study more successful. Included in this pamphlet are strategies to help a sleep study go more smoothly. This information may be helpful for individuals of all ages and for those with and without disabilities.

### ❑ **Do children with IDD have sleep problems?**

Sleep problems are more common in children with IDD than typically developing children.

- Children with autism spectrum disorders often have problems falling asleep and also with waking during the night.
- Children with Down syndrome often have medical problems that affect their sleep, such as obstructive sleep apnea.
- Children with cerebral palsy often have disordered breathing that can affect their sleep and may have different sleep patterns than other children.
- Children with developmental disabilities may also have sleep terrors and demonstrate sleepwalking.

### ❑ **Why do children with IDD have sleep problems? Some reasons include:**

- Behavioral issues
  - Children with intellectual/developmental disabilities may have trouble setting and sticking to a routine at bedtime. Difficulty with self-regulation and challenges with communication can make having a consistent bedtime and routine challenging.



- Neurological issues (such as epilepsy)
- Other medical issues (such as esophageal reflux)
- Psychiatric issues (such as anxiety, depression)
- Side effects from medications (such as stimulants, antidepressants)
- Sensory processing difficulties can cause children with disabilities to have trouble falling asleep and can cause them to wake up more often because they have trouble with relaxation and arousal.
- Factors in the environment that may not impact a typically developing child's ability to fall asleep or stay asleep may affect a child with IDD. Some examples of these factors are:
  - Room temperature (too hot or too cold)
  - Tactile sensitivities (to fabrics, bedsheets, or other objects touching them in a certain way)
  - Noises while the child is falling asleep or is sleeping
  - Lights

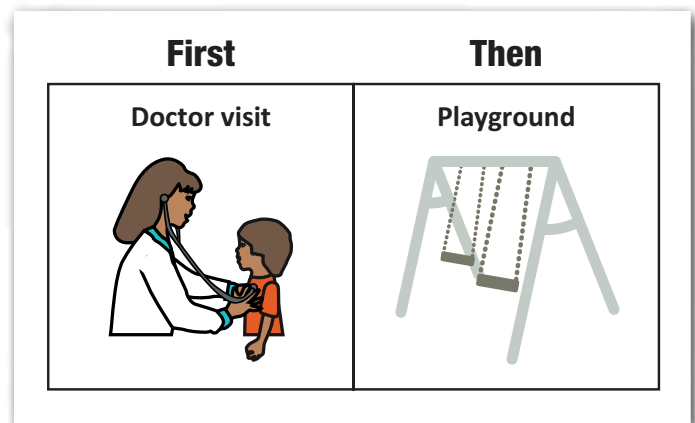
❑ **Why might a sleep study be hard for my child with IDD?**

- New situations can cause anxiety for children, particularly if they do not know what to expect or what may happen to them.
- Speech and other problems with communication can make it difficult for children to let the parents or sleep study technicians know that they are scared. They also may not be able to understand what is said to them about the steps of a sleep study. They may then worry that they may get a shot or have something painful happen to them.
- Expectations of a sleep study should be appropriate for the child's developmental age. For example, if the child is eight but acts more like a two-year-old, then it is helpful for those working with the child to adjust their expectations.
- In children with sensory issues, participating in a sleep study may be anxiety-provoking. Having sensors placed on their skin, being in a different bed, being in a new room, having different sheets, and experiencing new environmental sounds are all factors that can keep the child from falling asleep easily or staying asleep.

## What Can I Do To Help My Child Prepare for a Sleep Study?

❑ **In preparation for the study**

- Arrange a practice visit to the center to introduce your child to the rooms and equipment that will be used.
- Use visuals and behavioral supports to prepare your child for the experience.
- Use a First-Then board to help your child establish expectations for the study and related visits.



**Sample First-Then Board**

written to help your child understand expectations and social cues in a given situation. You can write your own! For example, a Social Story™ for a sleep study might begin like this:

*My name is John. I am seven years old. Sometimes, children go to the doctor to make sure they are healthy. Sometimes the doctor needs to do tests. That is okay. When the doctor needs to see how a child is sleeping, he will ask for a sleep test. In a sleep test, a child like me will go to a hotel and go to sleep in the hotel bed. Mom or Dad will come too. The child will wear special stickers to measure them while they sleep. This is okay and does not hurt.*

- Prepare your child by practicing applying sensors and stickers like those used in the study.
- Use a visual schedule (see example on back cover) to help prepare your child for each step of the study.
- Arrange small rewards for your child for successfully completing each step of the study.



❑ **The day of your child's study**

- Bring your child to the center fed, bathed, and possibly dressed in pajamas.
- Try to ensure your child is sleep deprived (wake him/her earlier than usual, skip nap that day).
- 4-6 hours of quality sleeping data is usually needed to get results from the study.
- Maintain as much normalcy as possible.
- Bring familiar sheets, pillows, and blankets from home.
- You or another caregiver will likely stay overnight in the room with the child while the sleep study is taking place.


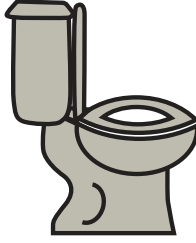


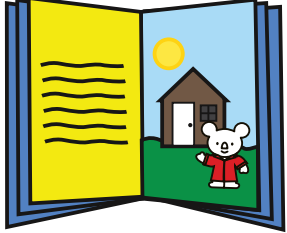
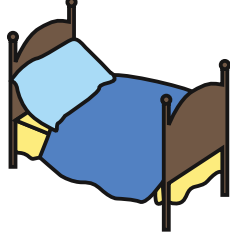
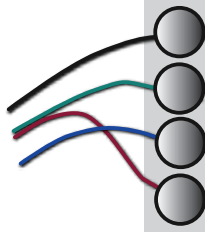

- A pulse oximeter, which looks like a flashlight that clips onto the finger (can refer to this as a "glowing light")
- Sensors on the head to look at whether there is seizure activity (can refer to these as "hair jewelry")
- Sensors on legs to look at leg movements during sleep

❑ **What will the steps of the sleep study be?**

- You and your child will check in at the sleep center.
- You will be taken to a room that looks like a regular hotel room. There is a video camera in the room so sleep technicians can see your child sleeping.
- The sleep technician will talk to you and your child about what to expect that night and answer any questions you have.
- The sleep technician will put sensors on your child, which may include the following:
  - Respiratory belts around chest to look at air flow
  - Sensors on chest to look at heart rhythm during sleep
  - A nasal cannula, which is a piece of plastic that is worn around the nose area (can refer to this as a "mustache")

❑ **Other tips that may be helpful**

- Follow your child's regular bedtime routine as much as possible at the sleep study.
- Bring rewards for the child, such as stickers or small toys.
- Bring visuals your child uses at home or school.
- If your child uses a communication device or PECS, be sure to bring it.
- If your child uses a weighted blanket for anxiety, bring it.
- Bring your child's stuffed animals or other "lovies."
- Bring a nightlight and/or sound machine from home.
- Consider bringing a large nightshirt or nightgown to wear over bands and sensors. Your child may prefer to bring stickers or something else from home to place over the sensors.
- If your child has a behavior therapist at home, ask if it is possible for the therapist to come with you to the sleep study.
- If willing, ask the sleep technician if you can help place sensors on your child.

<p><b>Check in</b></p> 	<p><b>Go to the bathroom</b></p> 	<p><b>Wash face &amp; hands</b></p> 	<p><b>Put on pajamas</b></p> 
<p><b>Read a book</b></p> 	<p><b>Go to bed</b></p> 	<p><b>Sensors</b></p> 	<p><b>Go to sleep</b></p> 

**Sample Bedtime Routine Visual Schedule**

## Resources

- ❑ **Health Library, Monroe Carell Jr. Children's Hospital at Vanderbilt**  
[www.childrenshospital.vanderbilt.org/library/](http://www.childrenshospital.vanderbilt.org/library/)
- ❑ **Helping Your Child (and Family) Sleep Better**  
[vkc.mc.vanderbilt.edu/assets/files/tipsheets/sleeptips.pdf](http://vkc.mc.vanderbilt.edu/assets/files/tipsheets/sleeptips.pdf)
- ❑ **National Institutes of Health Sleep Studies**  
[www.nhlbi.nih.gov/health-topics/sleep-studies](http://www.nhlbi.nih.gov/health-topics/sleep-studies)
- ❑ **Sleep and Health Education Program**  
[healthysleep.med.harvard.edu/portal/](http://healthysleep.med.harvard.edu/portal/)
- ❑ **Vanderbilt Sleep Center**  
[www.vanderbilthealth.com/sleepcenter](http://www.vanderbilthealth.com/sleepcenter)
- ❑ **Visual Supports**  
[vkc.mc.vanderbilt.edu/assets/files/resources/visualsupportsdd.pdf](http://vkc.mc.vanderbilt.edu/assets/files/resources/visualsupportsdd.pdf)
- ❑ **WebMD Sleep Disorders Health Center**  
[www.webmd.com/sleep-disorders/](http://www.webmd.com/sleep-disorders/)

This publication was developed and written by Vanderbilt Consortium LEND trainees Kathryn Makowiec, Doctor of Audiology student; and Alexandra Thompson, Master of Science in Nursing student; and LEND faculty member Jennifer Stevens, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine. It was edited, designed, and produced by the Dissemination and Graphics staff of the Vanderbilt Kennedy Center UCEDD. We are grateful for review and suggestions by Beth Malow, MD, MS, Burry Chair in Cognitive Childhood Development, Professor of Neurology and Pediatrics, Director, Vanderbilt Sleep Disorders Division.

This publication may be distributed as is or at no cost. View more printable resources and materials online at: [vkc.vumc.org](http://vkc.vumc.org).

*This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number T73MC30767, Vanderbilt Consortium LEND. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government. Revised August 2018.*



**VANDERBILT KENNEDY CENTER  
 VANDERBILT CONSORTIUM LEND**