

Helping an Adult with Intellectual/Developmental Disability Prepare for a Sleep Study

Introduction

How do you prepare an adult 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 adults with IDD have sleep problems?**

Sleep problems are more common in adults with IDD than typical adults.

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

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

- Behavioral issues
 - Adults 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 adults 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 typical adult's ability to fall asleep or stay asleep may affect an adult 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 person is falling asleep or is sleeping
 - Lights

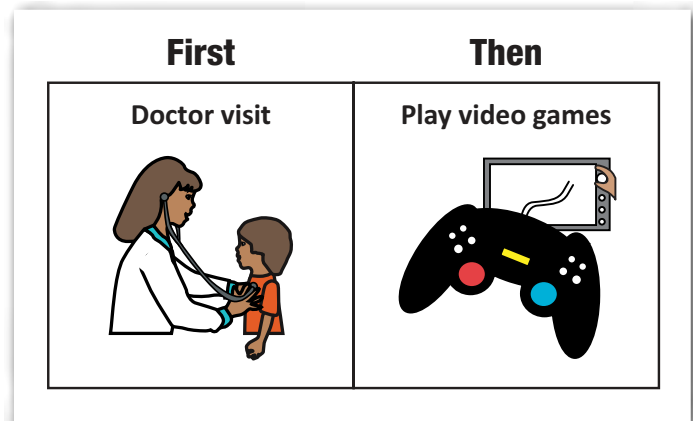
❑ **Why might a sleep study be hard for an adult with IDD?**

- New situations can cause anxiety for individuals, 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 the person to let a parent/caregiver or sleep study technicians know that they are frightened or upset. They also may not be able to understand about the steps of a sleep study. They may then worry that they may have something painful happen to them.
- Expectations of a sleep study should be appropriate for the adult's developmental age. It is helpful for those working with the person to adjust their expectations.
- In adults 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 person from falling asleep easily or staying asleep.

What Can I Do To Help An Adult Prepare for a Sleep Study?

❑ **In preparation for the study**

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



Sample First-Then Board

❑ **Write a Social Story™**

- A Social Story™ is an individualized short story written to help a person with IDD understand expectations and social cues in a given situation. A parent or caregiver can write a personal story for the individual. For example, a Social Story™ for a sleep study might begin like this:

My name is John. I am 27 years old. Sometimes, adults 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 person is sleeping, he will ask for a sleep test. In a sleep test, a person like me will go to a hotel and go to sleep in the hotel bed. Mom or Dad or my support person may come too. I will wear special stickers on my body to monitor my body while I sleep. This is okay and does not hurt.
- Prepare the person by practicing applying sensors and stickers like those used in the study.
- Use a visual schedule (see example on back cover) to help prepare the person for each step of the study.



❑ **The day of the sleep study**

- Bring the person to the center after having dinner, a bath or shower, and possibly dressed in pajamas.
- Try to ensure the person is sleep deprived (wake him/her earlier than usual, make sure the person doesn't 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.
- A parent or another caregiver may stay overnight in the room with the person, if needed, while the sleep study is taking place.


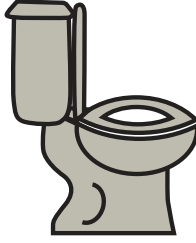


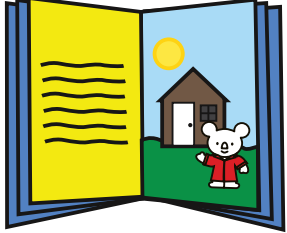
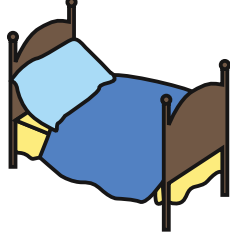
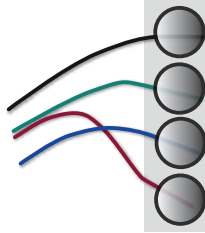

❑ **What will the steps of the sleep study be?**

- The person and his parent or caregiver will check in at the sleep center.
- The room looks like a regular hotel room. There is a video camera in the room so sleep technicians can see the person sleeping.
- The sleep technician will talk to the person about what to expect that night and answer any questions.
- The sleep technician will put sensors on the person, 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")
- 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

❑ **Other tips that may be helpful**

- Follow the person's regular bedtime routine as much as possible at the sleep study.
- Bring visuals if the person uses those at home or school.
- If the person uses a communication device or PECS, be sure to bring it.
- If the person uses a weighted blanket for anxiety, bring it.
- Bring items that are important for the person to have.
- Bring a nightlight and/or sound machine from home.
- Consider bringing a large nightshirt or nightgown to wear over bands and sensors.
- If the person has a behavior therapist, ask if it is possible for the therapist to come along to the sleep study.

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

Sample Bedtime Routine Visual Schedule

Resources

- Helping An Adult (and Family) Sleep Better**
 While this information is specifically for children, the tips may be useful for adults with IDD as well.
vkc.mc.vanderbilt.edu/assets/files/tipsheets/sleeptips.pdf
- National Institutes of Health Sleep Studies**
www.nhlbi.nih.gov/health-topics/sleep-studies
- Sleep and Health Education Program**
healthysleep.med.harvard.edu/portal/
- Vanderbilt Sleep Center**
www.vanderbilthealth.com/sleepcenter
- Visual Supports**
vkc.mc.vanderbilt.edu/assets/files/resources/visualsupportsd.pdf
- WebMD Sleep Disorders Health Center**
www.webmd.com/sleep-disorders/

This publication was originally developed and written as a guide for children 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 Adulthood Development, Professor of Neurology and Pediatrics, Director, Vanderbilt Sleep Disorders Division.

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