Solving Sleep Problems in Children With and Without Autism

STOP PLAYING

Musical Heds

Mary Lynch Barbera, PhD, RN, BCBA-D

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Solving Sleep Problems

This book is dedicated to solving sleep problems for children. While the strategies covered in this book were created specifically for children with autism, they will also work well -- if not better -- for all kids, even those without special needs. This is a good resource for parents who want to correct their child's sleep issues on their own, as well as for professionals who would like to use these strategies with their clients.

For more information and to sign up for a free online workshop visit: <u>MaryBarbera.com/workshop</u>



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Introduction

Sleep is a complicated issue, especially for children with special needs and autism. As you may have already experienced, many children on the spectrum have difficulties sleeping, especially sleeping through the night. Consequently, their families are equally sleep-de-prived.

In her book, *How to Get Your Child to Go to Sleep and Stay Asleep*, Dr. Kirsten Wirth reveals that sleep disorders are common in all children. In fact, 15% to 40% of typically developing children will have a sleep disorder at sometime in their life. The rate is much higher for children with special needs, who have sleep disorders at a rate of about 85%. So, if you're a parent out there with a child with autism who has sleep issues, you certainly are not alone.



My Family's Experience with Sleep

To begin, I'd like to share with you my own story of solving sleep problems in my house. I am a mom to two boys – Lucas and Spencer. Lucas was diagnosed with autism one day before his third birthday, after regressing at about 18 to 22 months of age. Spencer is 18 months younger than Lucas. They are both young adults now.



Lucas has had sleep problems since he was very young, beginning around the time of his regression. When he was first diagnosed with autism, the developmental pediatrician recommended melatonin (an over-the-counter supplement that can aid with sleep) to address his sleeping issues. He continued on melatonin for many years, but his sleep problems persisted in spite of it.

During the time Lucas was two to ten years old, most nights in our house looked like a game of musical beds. Lucas would take melatonin (an over-the-counter supplement that can aid with sleep) before bed, but often he would wake in the middle of the night anyway. Once awake, he would leave his bedroom, jump in bed with us, and go back to sleep. If we took him back to his bedroom, he would usually lay awake for hours.



Most nights we had to choose between staying awake and monitoring him to make sure he stayed in his own bed and was actually sleeping, or, allowing him to sleep in our bed where he would often fall asleep quickly. As a result, there was not a lot of quality sleep happening in our house.

Because I didn't work outside the home until the boys were about six or seven years old, I often took on the responsibility of managing Lucas' sleep problems so that my husband could be more rested for his shifts as an emergency physician.

During this time, when Lucas was about six years old, I became a Board Certified Behavior Analyst (BCBA). But even then, even with my education and experience, I was so sleep-deprived that I lacked the clarity and energy to objectively look at Lucas' sleep problems--at our family's sleep problems--in a way that would help me solve them.

In fact, when Lucas was about nine years old, I was writing my book, The Verbal Behavior Approach, and my husband said to me:

"Whatever you do, don't put any advice about sleep in your book because you are terrible at getting kids to sleep,"

and he was absolutely right. You won't find a single piece of advice about sleep in my book published in 2007, because I was not in a position to give it.

However, shortly after I finished the book, I had an experience that started me down the path towards becoming "better" at sleep. On a trip to Ohio to present a one-day workshop about my book, I had dinner with a fellow behavior analyst. I told her about Lucas, mostly about his language and behavior--the things I know well.

Then, she asked about sleep. I readily admitted that sleep had been a real challenge for us and that's why I hadn't included any material about it in the book. As it turns out, she was a BCBA who specialized in sleep. So, I told her a bit about Lucas' sleep patterns and how we'd been trying to address them. Needless to say, and not surprising to me, she didn't approve of our methods, or lack thereof.

Based on what I told her, she was able to make some concrete recommendations: don't let Lucas get into our bed; keep the door locked and walk him back to his room as soon as he tries to come in; don't allow him to have a TV in his room (even if it initially helped him fall asleep).

Here's what I did: I explained to Lucas that I was going to lock my bedroom door at night and that he needed to stay in his own bed through the night, and if he did, he would get a cookie treat in the morning.

On the first night of the intervention, he got out of bed three times, came over to our room and knocked. So, three times, I reminded him that he would get a cookie in the morning, brought him back to bed, went back in my bedroom, locked the door, went back to sleep. I also looked at the clock and then in the morning jotted down what time it was each time he came to my door, and noted that he did not engage in any challenging behavior when I escorted him back to his room.

On the second night, he woke up and came to my room twice.

On the third night, he came to my room once, and after that, he never came to my room again in the middle of the night.

After almost 10 years of struggling with sleep, these simple interventions corrected the sleep problems for us all in three nights!

As a Board Certified Behavior Analyst, of course I was thrilled that the intervention worked, but I was also kicking myself for having let it go on for almost 10 years. During those years, I knew there was a problem, and I knew I needed some sort of intervention, but I was so sleep-deprived that I couldn't make a real plan to address it.

Chances are, if you're reading this, you're feeling as frustrated and exhausted as I was back then.

Here's the good news: I not only solved Lucas' sleep problems, but I've gone on to help dozens of children learn to sleep. I created this ebook as a resource for parents to correct their own children's sleeping problems, and for other professionals to use with their clients who are struggling to get children to sleep through the night in their own beds.

Developing Your Sleep Intervention

If you work step-by-step through the following material, you will have a well planned intervention tailored to your child's or client's specific sleep issues. And, you can implement it right away.

I. The Assessment

If you are a parent reading this ebook in order to correct your child's sleep issues on your own, it's fair to say that you've already identified a problem related to sleep, and performing an assessment of your current struggles is unnecessary. However, for the professionals who are using this book to help other parents work with their children, you'll want to begin with an assessment. No matter the problem behavior you're facing, starting with assessment is always the first step as I teach in my online courses.

1) Assess the Motivation of the Parents to Tackle Sleep Issues

Start by assessing the parents. Here's the question you need to answer: "Are the parents struggling with sleep?"

Parents of children who aren't great sleepers by our definition, might not necessarily be struggling with sleep. A good example of this is a family I worked with from India. In Indian culture, it is quite common for children to co-sleep with their parents until an older age. These families are not struggling with sleep and they don't really want an intervention.

Another example would be of a family that is dealing with so many of their child's issues that addressing sleep might not be at the top of their list of priorities. This is why it's important to first assess the parent's motivation to change something about the child's sleep before assessing the child's sleep issues.

Once you've determined that the parents are struggling with the child's sleep problems and that they desire to change the child's sleep habits, you will then assess the child's sleep.

2) Assess the Child's Sleep Issues

Assess the child's sleep by interviewing the parents. For the readers who are parents, take the time to interview yourself and write down the responses. You will want answers to questions like:

- > Where does the child fall asleep?
- > Where does he sleep during the night?
- > Does he take naps?
- > What is his bedtime?
- > What does the entire bedtime routine look like?
 - -A snack?
 - -A bath?
 - -TV?

-Does the parent lay with the child in bed or sit on the floor?

- > Does the child share a bedroom with a sibling?
- > Does the child take medication before bed?
- > Does the child use a pacifier, special blanket or stuffed animal for sleep?
- Does the child use an iPad, listen to music, or do you need to go for a "Sleepy Drive" before bed?
- > How long does it usually take for the child to fall asleep?
- > How much sleep does the child end up getting?
 - -Naps: start time and end time
 - -Overnights: start time and end time
- > Does the child wake during the night?
 - -If so, what happens?
 - -Does he get into the parents' bed? Does he scream?
 - -Does he go to the gate or door?
 - -Does he run around his room, throw clothes, or play with toys?
 - -What does the room where the child sleeps look like? Is it safe?
 - -What exactly happens?

It's important to understand what the whole bedtime routine looks like because any one of these factors can impact the child's sleep. Often, parents are so sleep-deprived that they

will go to great lengths to get their kids to sleep -- things like, going on "Sleepy Drives" or laying on the floor next to the child's bed.



Or, sometimes, parents sleep in their child's room because they worry that the child will wake up and leave the house, or start a fire, or they'll go down and raid the refrigerator or make a mess. Correcting the sleep issues, often involves relieving parents from taking these actions and giving them the peace of mind that their child is capable of sleeping without constant supervision.

A note about naps: As the child gets older, it's important to start eliminating naps or at least to limit the duration of any naps. Most experts say that the child should not be sleeping after 3:00 pm. If the child falls asleep at 3:00 and naps until 5:00, they are more likely to have problems falling asleep at 8:00 for their usual bedtime. If the child does nap, limit the naps to between 60 and 90 minutes, sometimes even shorter. And, be sure that naps are over by 3:00pm.

II. The Plan

Once your full assessment is complete, then it's time to make a plan.

The plan always involves the parents, or the main caretakers, who must also be willing and able to carry out the plan.

Otherwise, it just won't work.



Here are some ideas of recommendations that the plan might include:

- > Stop or decrease naps -- making sure naps are not too long in duration and that they end by 3:00pm at the very latest.
- > Avoid multi-vitamin supplements and caffeine in the afternoon and evening.
- Limit liquid intake after dinner, as well as limit spicy food, fatty food, or other things that might upset the child's stomach.
- > Wean from pacifiers and bottles. Take a look at my blog post on this topic.
- Establish the child's bedroom as a place for sleep not for running around the room, wrestling with the parent, tickling, watching TV, playing with an iPad, etc. If there is no
 - TV currently in the room, I highly recommend not putting one in the bedroom. -If, like Lucas, the child already has a TV in the room and it is working as a means to help the child fall asleep, you may want to consider leaving it there, at least temporarily. However, I strongly believe that iPads and other handheld devices should not be a part of any bedtime routine. The screen light is bad for sleep and you have no control over their access to it. At least with the TV, you can take the remote and you can have some control over the child's access to it.



Establishing a Bedtime Routine

If the parent's goal is to have the child sleep through the night in his own bed, which I believe should be the main goal for most children, create a plan to help improve the bedtime routine. This may include things like requiring that the child fall asleep and stay asleep in her own room.



Once the child is upstairs, or in the bathroom/bedroom area of the home, it's important to prevent them from returning to the family room or the kitchen for snacks or electronics. It might be necessary to obtain a gate for the child's room, the top of the stairs, and/or lock the parents' bedroom door as I did with Lucas.

Safety

Safety needs to be our number one priority -- the child needs to be safe alone in their bedroom for any plan to work.

It's important to make sure that the child cannot leave the house, cause injury to self or others, or cause property damage. That may mean taking all of the furniture out of the child's bedroom, bolting furniture to the wall, or leaving only a mattress on the floor until the child learns to sleep through the night. This may sound harsh, but sleep is important for both the parents and the child, so it's important to take steps that will make a difference.

Parents who sleep in their child's room, might also consider putting a cot or a trundle bed in the child's room as a temporary measure as they wean themselves out of the room.

I encourage parents not to get into the bed and lay down with the child at all (and if that is happening currently to stop this) because once parents establish themselves as part of the routine it's hard for them to remove themselves from it.

Sleep supplements

Parents who already have a good bedtime routine established, and have tried all of these recommendations, might consider checking with their doctor about melatonin, an over-the-counter supplement that can aid with sleep.

Decide on Reinforcement

The plan should also include reinforcement. Any time we teach a new or difficult skill to a child, we have to think about a plan for reinforcement. Don't forget to include the reinforcement as part of the bedtime routine checklist and be sure to state how and when the reinforcement will be delivered.

Different reinforcements work for different kids. Praise should always be given, but in addition, some edible treats, stickers, access to an electronic or tokens to save and cash in at the end of the week might also be needed. A special cookie in the morning worked well for Lucas, but for some, that might be too long of a delay. Remember to be consistent with the reinforcement.

As you build your task routines, remember that problem behaviors most often occur when reinforcement is too low and demands are too high. Finding the right balance of reinforcement and demands is critical to any ABA programming.

As you can imagine, this is a large topic to cover so if you would like to learn more about reducing problem behaviors, sign up for a free workshop here: www.MaryBarbera.com/ workshop

Establish a Leader

If at all possible, I do usually recommend that one parent or caretaker be in charge of the bedtime routine until it's well established. While it might be convenient, when parents take turns with the bedtime routine, it results in inconsistencies, which can be detrimental to the child's progress.

For example, if you usually have your son brush his teeth after putting his pajamas on in the bathroom but your husband doesn't know that and prompts him to brush his teeth before a shower then put his PJs on in his bedroom, this can throw the child off and could impact sleep. Here again, if both parents choose to participate in the bedtime routine, or if alternating is necessary, having a task list of the steps of the bedtime routine in order will help with consistency.

Here is a draft task list that I made as an example.

Child tasks:

- Sits on toilet
- > Takes bath (with assistance)
- > Gets PJs on in bathroom
- Brushes hair
- > Brushes teeth (with assistance)
- > Selects 3 books from shelf
- Gets in bed

Parent Tasks in Order:

- > Dims lamp, put night light on
- > Sits on side of bed and read 3 books
- > Turns on music lullaby CD
- Turns off lamp
- > Kisses goodnight, remind child of reinforcement
- > Puts up gate (or hop over gate)

The goal in this example is to get a four year-old to fall asleep and sleep through the night without the parent's support or prompting.

You'll see that I broke the list into things the child does and things the parents do.

Tasks for the child can include things like:

- "Sits on toilet, brushes teeth, takes a bath, brushes hair."
- > Or, "Gets PJs on, gets in bed."

Tasks for parents can include:

"Reads book, plays music, CD x1, turns off lights."

Here's an example task sheet:

| ame: A.K. | | | Age: | 4 | | |
|---|----------|--|--------------|----------------------------|--------------------|-----|
| support/promp | | and sleep th | nrough the | night w | ithout pare | ent |
| EY: I – Independently V – V T – Touch Cue PP- Pa | erbal | signed prompt Physical prompt | M – F – I | Modeled pr Full physica | ompt l guidance | |
| Task Analysis Steps: | 5/1 | | | | | |
| ^{1.} Sits on toilet | F | | | | | |
| ^{2.} Teeth/Bath/Hair | F | | | | | |
| ^{3.} PJs | F | | | | | |
| ^{4.} Gets in bed | I | | | | | |
| ⁵ Parent reads book | | | | | | |
| ^{6.} Music CD x 1 | | | | | | |
| ^{7.} Lights off | | | | | | |
| ^{8.} Falls asleep (time) | 40 | | | | | |
| If wakes, back to bed | | | | | | |
| 10. Falls back to sleep (time) | 20 | | | | | |
| Data recorded | × | | | | | |
| Time in bed Time asleep | to to to | e (if applicable wake time to m (trundle be | to | | s asleep | |

Task Analysis/Level of Prompting Data Sheet (10 steps)

Do's and Don't's for Establishing a Bedtime Routine

Here are some rules to keep in mind when planning the sleep routine.

- DO always make sure the routine ends with the child lying in his bed, and be sure that the child remains in bed until he falls asleep. If the parent needs to remain in the room, they should sit on the side of the bed, in a chair, on the floor, or lay on the cot so the child remains in bed. But keep in mind that this is a temporary measure--it's important to start phasing the parent out of the room.
- DO have a gate in place to prevent the child from leaving the room if the child does wake up during the night. Parents should also lock their bedroom doors and prevent access to other parts of the house. For younger children, who aren't toilet-trained, I usually recommend gating their room. For older children who may need to use the bathroom, I will instead gate the other parts of the house and lock my bedroom door.
- DO explain to the child that your door will be locked, and he needs to sleep in his own bed, and remind him of the reinforcement you have chosen.
- DON'T lay down with the child or allow the child into the parent's bed. Again, the parent can sit in a rocking chair, on the side of the child's bed or lay in a cot, anything that is needed initially to get the child to stay in their own bed until they fall asleep.
- > DO react calmly and consistently when the child wakes up during the night, cries, walks through the gate, knocks on your door, etc. You want to calmly walk him back to his room, saying things like, "Oh, you're awake. Let's get you back in your bed. Remember, if you sleep in your bed by yourself, you get a cookie (or sticker or IPAD time) in the morning. Goodnight." Only stay in the room briefly, unless, given the particular child's behavior, it's important for the parent to stay in the room until the child falls back asleep.

III. The Data



Once the plan is developed and implemented, it's important for the parents to take some data. I recommend parents keep notes on a calendar that is reserved for this data only. This way you'll be able to jot down notes about nap time (start and end time, time to bed, the time child fell asleep, night time wakes, etc). Parents should record when and if the child wakes, what he does while awake, when he goes back to bed, whether he receives melatonin, and at what dosage, etc. This kind of data is easy to collect and analyze, and it allows both professionals and parents to make informed decisions.

Using data to make adjustments in the bedtime routine is key for success. Professionals might visit clients weekly or every other week to help parents adjust the bedtime routine -- i.e., moving bedtimes, adjusting reinforcement, fading parent out of room before the child falls asleep, etc. Professionals can also help parents identify parts of that routine might be counter productive.

For example, watching TV right before bed might not be ok for all children. For those children, turning the TV off sooner might be an easy fix instead of starting a prescription

medication or upping the melatonin dosage.

Here is an example of data collected on a former client who was not sleeping in her own bed through the night:

IV. Be Consistent

Whether you're a parent, or a professional helping a parent, keep in mind that the goal is to get the child sleeping through the night in their own bed. Remain committed to that goal, adjust as necessary along the way, and before too long the entire household will be sleeping better.

I played "musical beds" for about 8 years before I solved Lucas' sleep problems. My hope is that this short ebook helps your client or child with or without autism get better sleep starting tonight.

Additional Resources

Over the years, I have relied on the following books, and recommend them as additional resources:

Sleep Better!, by Dr. Mark Durand. First edition: 1999. Second edition: 2013.

I consider this to be the best, most classic book for sleep that I know of.

Sleep Difficulties and Autism Spectrum Disorders, by Kenneth J. Aitken First published: 2012.

This book takes a comprehensive look at sleep in regards to children and autism. It includes an analysis of the research that has been done in this area, and is comprehensive and helpful. This book differs from the first edition of Dr. Durand's book in that it includes information about proven medicine-based and non-pharmacological interventions--for example, the use of melatonin--available to address sleeping issue.

How to Get Your Child to Go to Sleep and Stay Asleep, by Dr. Kirsten Wirth First published: 2014.

This book, a recent discovery of mine, was written by a behavior analyst. It is not specifically for children with special needs, and includes a lot of advice for typically developing children along with her own children.

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Age:

Task/Goal/SD_____

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|----------------------|-------|---|-------------------------------|---|---|--|---|--|
| | Dates | | | | | | | |
| Task Analysis Steps: | | | | | | | _ | |
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| Notes: | | | | | | | | |

Task Analysis/Level of Prompting Data Sheet (10 steps)



Mary Barbera, PhD, RN, BCBAD fell into the autism world in 1999 when her first-born son, Lucas, was diagnosed with autism one day before his 3rd birthday. Mary quickly transformed from overwhelmed parent to Lucas' advocate and therapist.

In 2003, Mary became a Board Certified Behavior Analyst (BCBA) and began working in schools and homes with hundreds of children with

autism. In 2007, Mary published her first best selling book: *The Verbal Behavior Approach: How to Teach Children with Autism and Related Disorders*. Her book is endorsed by many professionals in the autism field as well as parents and is now available in several languages.

In 2011, Mary earned a PhD in Leadership and, since then has been systematizing her methods for working with children with autism and has focused most of her time on training and empowering others around the world. In 2015, she launched Autism ABA Help: Online Training for Professionals and "Gung-Ho" Parents, and Turn Autism Around for Toddlers Course in 2016 which has already reached participants from over 90 different countries.

In 2021, Mary published her second book, *Turn Autism Around: An Action Guide for Parents of Young Children with Early Signs of Autism* with the foreword written by Dr. Temple Grandin. This book empowers and helps parents turn things around for young children with language and social delays, or who have difficulty with excessive tantrums, sleeping, eating a variety of foods and potty training.

Visit MaryBarbera.com/workshop for more info.