Behavioral Sleep Interventions

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Abbreviations

ADHD	Attention-deficit/hyperactivity disorder
ASD	Autism spectrum disorder
NDD	Neurodevelopmental disability/disabilities
REM	Rapid eye movement

Introduction

Children with neurodevelopmental disabilities (NDD) exhibit behavioral, emotional, cognitive, and sensory-motor difficulties which directly impact their sleep and patterns. Sleep problems such as trouble falling asleep, staying asleep, parasomnias, morning arousal, or early morning waking are commonly seen in children with NDD [1–7]. Disrupted sleep has been associated with intensified daytime behavioral and emotional difficulties. Furthermore, insufficient or inefficient sleep can further cause difficulties with performing activity of daily living.

Sleep problems in children with NDD likely have a behavioral and learning component that is perpetuated through throughout development [8]. While it is not known with certainty what initially causes these issues, abnormalities in circadian rhythms, disturbance in melatonin production, and abnormalities in other hormones or neurotransmitters may also be involved. Other factors involved could include increased sensory sensitivity and lack of bedtime routine. Such factors, individually or in combination, can lead to difficulty initiating and maintaining sleep.

Prior research has shown that behavioral interventions can successfully address sleep problems in typically developing children [9, 10]. Many of the same interventions are currently recommended to address the aforementioned sleep problems in children with NDD. For example, the Sleep Committee of the Autism Treatment Network recommends behavioral intervention as a first-line approach for treating insomnia in children with autism spectrum disorder (ASD) [11]. In terms of acceptability, research has found that parents of children with NDD rate behavioral treatment and melatonin, which is widely used for sleep, similarly [12]. Further, establishing more adaptive bedtime habits and routines have been effective in minimizing and reducing disruptive sleep problems [1, 7, 11]. The purpose of this chapter is to discuss behavioral sleep interventions to address problems falling asleep, problems staying asleep, and problems waking and remaining alert in the morning.

Case Vignette

Kyle is a 2-year-old male with a history of autism spectrum disorder and sleep disturbance. In addition to sleep concerns, Kyle has a history of feeding disorder and disruptive behavior, including tantrums and sibling-directed aggression. He has been receiving behavioral psychology services to address these feeding and behavior concerns. Kyle was referred to interdisciplinary Sleep Clinic given caregiver concern regarding his night wakings and inability to initiate sleep independently.

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Kyle's mother and grandmother attended the assessment, since both caregivers are involved with his bedtime routine. They reported following a consistent evening routine, which included watching a highly preferred television show before going upstairs for bed. Kyle has engaged in a tantrum every night when he transitions away from his television show, and it has sometimes taken a significant amount of time for him to calm. Kyle shares a room with his mother and sister due to a limited number of bedrooms in the home. Due to work schedules, on weeknights, Kyle's grandmother completes his bedtime routine and sleeps in the room with him overnight, while on weekends, his mother completes the routine and remains in the room. In order to fall asleep, Kyle needs a caregiver to rock him in a rocking chair for up to 30 min before being placed in his own bed. There is a nightlight on when Kyle falls asleep; however, it is turned off once his sister falls asleep. Kyle's mother reports trying a variety of prior interventions, such as singing, patting Kyle on the back instead of rocking him, and sitting with him on the floor instead of in the rocking chair; however, Kyle has not fallen asleep under any of these conditions.

Overnight, Kyle wakes frequently and comes to his caregiver's bed where he is able to initiate sleep immediately. If required to return to his own bed, Kyle requires rocking in order to reinitiate sleep, and latency to sleep onset is much longer. If Kyle wakes overnight and a caregiver is not present in the room, he sits on his mother's bed crying and screaming until a caregiver returns to the room to help with sleep reinitiation.

In the morning, Kyle wakes at a consistent time without difficulty. He also takes daily naps. When at home, Kyle must be rocked to fall asleep for a nap; however, at daycare his teachers are able to pat his back without rocking him to help him fall asleep.

Management and Evidence Base: Problems Falling Asleep

Sleep Hygiene

With many of our families, the starting point is to assess a child's sleep hygiene, or the consistent habits to help maximize sleep, because if a child has not established good sleep habits, it will be difficult to get therapeutic traction and see maximum benefit from other interventions [13]. The child's sleep schedule should be consistent throughout the week, with a set bedtime that is the same every night, even on weekends. Ideally, the child will be put to sleep when he is sleepy but not yet asleep, so that the skill of independent sleep initiation can be developed. The child should fall asleep consistently in the same place every night, since changes in environment can shape problematic sleep-onset associations and night wakings. The child's room should be dark, of a comfortable temperature, and free of distractions such as electronics and highly preferred toys, which may motivate or prolong wakings. To further help a child develop appropriate sleep associations, whenever possible, the child's room should be reserved only for sleeping. This means that the bed and bedroom should not be the place of time-outs, homework completion, or daytime play, as all of these activities can create competing associations that weaken the association between the bedroom and sleep. Many children with NDD are noise sensitive, so sound machines, background music, or white noise can be trialed when creating a comfortable sleep environment. However, our experience has been that some children will respond well to having extraneous background noise muffled, while others will find this additional auditory stimulation aversive.

During the daytime, a consistent wake time should be maintained, even on weekends and holidays. For many of our children and adolescents with early wake times for school, this recommendation can be quite challenging. Other recommendations to promote nighttime sleep include either avoiding daytime naps or adjusting their timing as developmentally appropriate, ensuring adequate light exposure during the day, engaging in physical activity before late afternoon, avoiding caffeine in the late afternoon and evening, and avoiding large meals before bedtime.

Addressing sleep hygiene as the sole intervention is unlikely to eliminate sleep problems [14]; however, it has been found to be a beneficial treatment component both for children with attention-deficit/hyperactivity disorder (ADHD) [15] and ASD [14, 16]. Therefore, it is typically most helpful as part of a comprehensive treatment package [14].

Bedtime Routine

Many children with NDD need additional external cues to signal that it is time to wind down and go to bed, as completing a consistent bedtime routine signals that bedtime and sleep are approaching [17]. The bedtime routine should begin approximately 20–30 min before bedtime and should include hygiene activities, such as brushing teeth and putting on pajamas, in addition to a relaxing activity (individualized to the child), such as singing songs or reading a book. The final step of the routine should always end in the child's bedroom. To help provide structure and enforce predictability, many children with NDD benefit from a picture schedule depicting the different steps of their bedtime routine [18].

Visual schedules can be constructed with photographs of the child completing each step of his routine, for greater personalization, or clip art/cartoon pictures can also be used (Fig. 28.1).

When working with children with NDD, it is important to remember that many may have restricted interests or atypical responses to common activities. Many children with NDD become activated by bath time or water play. For such a child, it may be important to move bathing to the morning or as early in the bedtime routine as possible (i.e., before dinner or as the first step in the routine) to provide ample time to wind down. Additionally, many caregivers of children with NDD identify that their child's only calming activities are electronic media or screen-based. This will require additional problem-solving and collaboration with the family to address ways to fade electronics usage at bedtime. Can electronics slowly be faded out of the routine by gradually decreasing the amount of time they are available to the child (i.e., 30 min faded to 25 min faded to 20 min etc. until eliminated)? If the child watches a specific show on the tablet, could he listen to the show instead of watching it on a screen? Can the content of the electronics be adjusted (i.e., transitioning from active games to more passive activities)? Can the brightness and, more specifically, blue light be dimmed on the tablet via tablet settings, app, or special blue light-blocking glasses? Once domains are identified where electronic usage can be adjusted, a structured plan can be created to gradually begin fading them out of the bedtime routine.

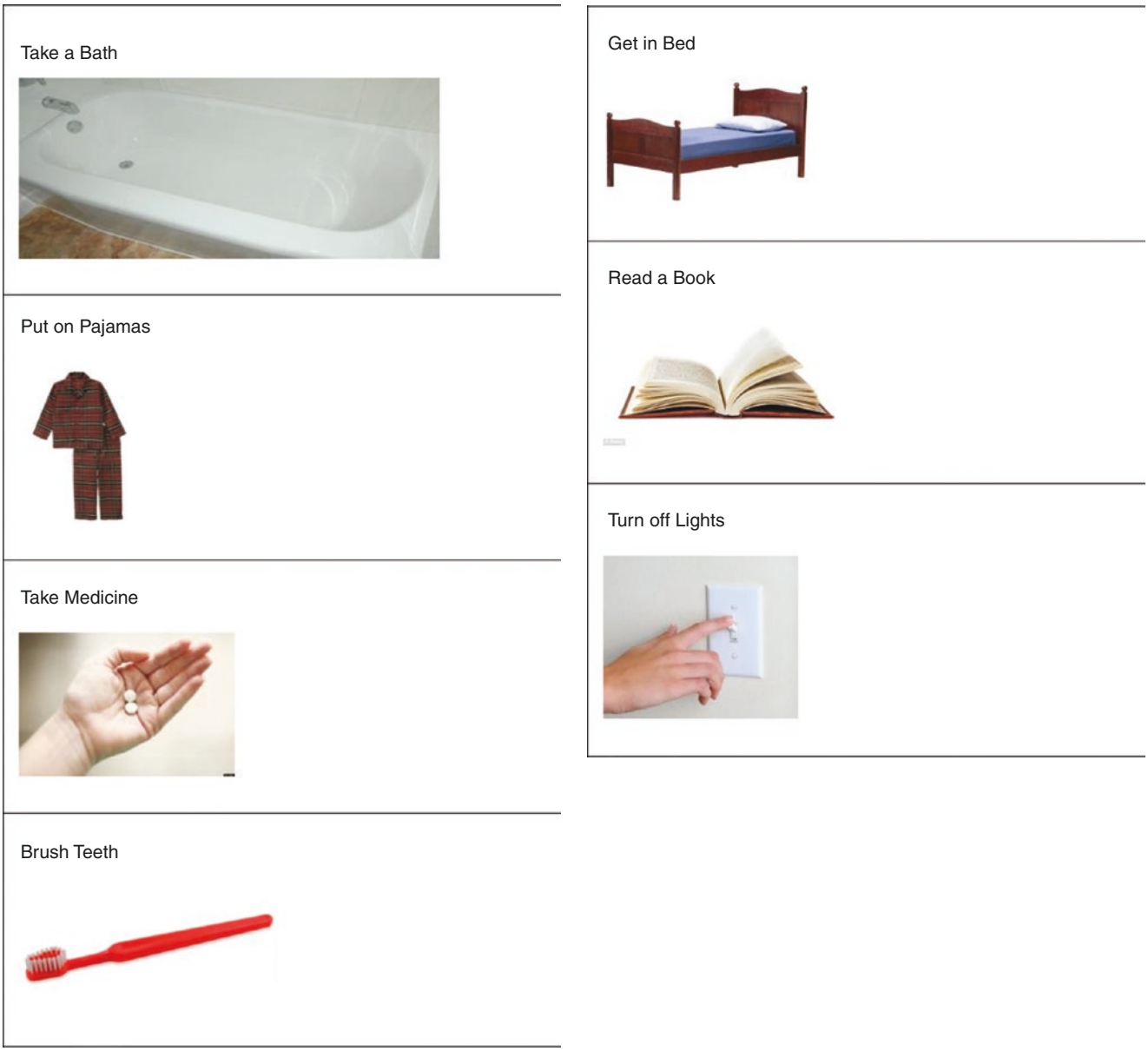

Fig. 28.1 Sample visual schedule for bedtime routine

Delay behaviors, such as refusals or stalling, interfere with completing a bedtime routine for many children. To address these behaviors, a reinforcement plan can be implemented to reward children for following the bedtime routine (i.e., brushing teeth, getting in bed, etc.). Prior to implementation, a reward (i.e., small prize, sticker, or preferred activity the next day) and goal criteria (i.e., number of completed steps, number of points needed, number of successful days) should be established. A structured bedtime routine paired with reinforcement has been found to be a beneficial treatment component for children with ADHD [19] and intellectual disability [20].

Another behavioral intervention that can address delay behavior at bedtime is called "beat the buzzer." During this intervention, a timer is set for a slightly shorter time than the bedtime routine is currently taking to complete (i.e., if the routine currently takes 45 min, initially set for 40 min). If the child completes his routine before the timer sounds, he is provided with a reward. If he does not complete the routine before the goal time, no reward is given. The time on the timer should be gradually adjusted a few minutes shorter each night, as long as the child is successfully meeting his goal in order to shape routine completion to a more preferable duration.

Bedtime Fading

When children have trouble falling asleep once they get in bed, they often begin to associate being in bed with wakefulness, playtime, tantrums, or other daytime behaviors, as opposed to associating their beds with sleep. When a child does have a significantly delayed sleep onset, it is important to ask parents what happens when their child is put to bed at a later time. If the child still takes an extensive amount of time to fall asleep, even when put in bed later, then bedtime fading is not the best intervention to implement. If the parent is unsure what would happen, or reports that the child falls asleep more quickly with a delayed bedtime, then bedtime fading would be an appropriate intervention to trial. (When considering the appropriateness of bedtime fading, additional assessment for delayed sleep phase may also be necessary.)

Bedtime fading involves temporarily delaying the child's bedtime until approximately 20–30 min before he or she is currently falling asleep (i.e., temporarily making bedtime at 10:30 PM if the child currently is falling asleep at 11:00 PM). Problem-solving should be done with the family to identify quiet, non-electronic activities to engage the child during the time between the current bedtime and temporarily later bedtime. When the child consistently falls asleep with an appropriate latency to sleep onset (e.g., 20–30 min), then bedtime should be moved earlier by 15 min. This shaping process (incrementally earlier bedtime) should continue until the child is falling asleep within 20–30 min of his goal bedtime.

Caregivers may initially be hesitant to implement an intervention that delays bedtime for a child who is in need of more sleep. To increase their buy in, it will be important to explain the rationale for this approach. By temporarily delaying bedtime to close to the time the child is currently falling asleep, the amount of sleep the child is getting is not actually decreased, since he was consistently awake during this time anyway. Instead, the association between getting into bed and actually falling asleep soon after is being strengthened. Bedtime fading has previously been found to be an effective intervention for children with ASD [14, 21].

Extinction/"Cry-It-Out" Method

When families come to Sleep Clinic, they have often heard of extinction or the "cry-it-out" method. Many caregivers have tried unsuccessfully to implement this intervention and may fear that this will be the only recommendation given to address their child's delayed sleep onset. Extinction involves the caregiver putting the child in bed, leaving the room, and not returning despite any outbursts or distress the child may express. The goal of extinction is to "extinguish" the outbursts in order to teach the child that protests will neither delay bedtime nor increase bedtime interactions with their caregiver. By learning this, the child is supposed to also learn to fall asleep independently more quickly. Extinction has previously been found to be effective in a small sample of children and young adults with NDD, although parents found the procedure challenging to implement, especially during initial treatment stages [22].

As can be expected, this intervention can be very distressing for caregivers since they are not supposed to comfort their child during the initial stages [23]. When parents use this process, children often escalate their behaviors and protests to gain caregiver attention after being put in bed. Because of this escalation, called an extinction burst, the child may engage in unsafe or self-injurious behavior in an effort to get caregivers to intervene. For example, some children may become so distressed that they vomit or cry. This level of distress is not the goal of this intervention, and it may be unsafe for many children with NDD, medical conditions, or self-injurious behaviors to reach this level of physiological arousal and distress [24]. Furthermore, some children may continue to escalate their behavior to a level that cannot be safely ignored. If the caregiver intervenes and provides attention, they are unintentionally providing intermittent social reinforcement that will make the behavior more likely to occur in the future and likely to escalate quickly in intensity (i.e., "this got mom to intervene last time, so I'll try it again"). Incidentally, the same intermittent reinforcement

schedule will perpetuate delayed sleep onset and simply complicate the problem. Because of these concerns, a more gradual approach to extinction is typically recommended in our clinic for children with NDD.

Gradual Extinction with Caregiver Presence

Another common type of gradual extinction involves fading, or slowly removing, the physical presence of caregivers at bedtime. Similar to the "excuse me" drills described below, children should begin in their own bedrooms, as it is incredibly difficult to fade the child out of a caregiver's bedroom. Many children with NDD are accustomed to falling asleep with caregivers hugging them, rocking them, or providing some other form of deep pressure as they fall asleep. As a result of this apparent need to seek sensory input, children may be unable to fall asleep without these sensory-seeking behaviors.

The first step of fading parental presence at bedtime is determining the current whereabouts of the caregiver and level of physical contact between caregiver and child at bedtime. Is the caregiver in bed with the child? Are they physically touching? The initial step of fading should only be a minor change from current conditions: for example, if previously the caregiver and child have lain in bed together talking, a first step could be to have the room silent once in bed. If previously, the caregiver was in direct physical contact with the child, a first step would be to have the caregiver simply lie next to the child, not in physical contact. As the child tolerates each step in the fading process, he can progress to the next step until the caregiver is ultimately able to remove herself entirely from the child's room. Of note, this intervention involves a time commitment, and parents must remain consistent with implementation. In order to maintain consistency, caregivers should carefully choose when to implement this intervention because they will need physical stamina and emotional energy to follow through on this strategy. Therefore, this intervention should not begin during times of great stress, transitions, illness, or other demands on the caregiver's resources. To the extent possible, caregivers should choose a time when they are well rested and when social and emotional support is available from trustworthy family members or friends. Similar to "excuse me" drills, a reinforcement plan for "following the bedtime rules" can be beneficial. Table 28.1 depicts an example of a sample fading procedure.

Table 28.1 Fading gradual extinction with parental presence: sample fading process

Step 1	Have the caregiver stop verbal interactions with the child once in bed
Step 2	Have the caregiver discontinue active physical contact (back rub, hugging), instead placing a hand on the child
Step 3	Have the caregiver lie next to the child but not engage in physical contact
Step 4	Have the caregiver sit next to the child in bed instead of lying down
Step 5	Have the caregiver sit at the foot of the child's bed
Step 6	Have the caregiver sit in a chair right next to the bed, still within the child's line of vision
Step 7	Have the caregiver systematically move her chair further from the child's bed until she is seated in the doorway
Step 8	Once the caregiver's chair is outside of the doorway, have her begin to say goodnight at bedtime and then leave the room

"Excuse Me" Drills

More often, parents prefer to use a gradual extinction method, whereby they gradually fade, or decrease, the amount of time they are present as the child falls asleep. One type of gradual extinction intervention is "excuse me" drills. With any type of gradual extinction, it is easier to fade a caregiver from a child's room than the child from the caregiver's room, as the caregiver is far more motivated for change than the child. With "excuse me" drills, a caregiver completes the bedtime routine as usual and places the child in bed. When the child is in getting ready to fall asleep (e.g., in bed, quiet, head on pillow, controlled breathing), the caregiver will briefly excuse himself from the room for a reason plausible to the child (i.e., to use the bathroom, check on something in the kitchen, ask the other parent a question) before returning and completing the routine as usual. This approach is especially helpful for highly anxious children because each individual "drill" is a demonstration to the child that they are safe, the caregiver is not leaving indefinitely, and the caregiver can be relied upon to return to provide brief support, reassurance, and praise. Initially, the time-out of the room should be very brief (i.e., a matter of seconds or minutes) based on the child's level of anxiety and behavioral tolerance. The brevity of the caregiver's time outside of the room keeps the child's anxiety from escalating before the caregiver returns. Over time, as the child becomes accustomed to this procedure, the parent's time-out of the room can be gradually increased (i.e., 1 min, then 3 min, then 5 min, etc.). The child learns that the parent is reliably nearby and returns as promised. As the child is able to tolerate his caregiver's time outside the room, that amount of time will continue to be gradually increased until the child "accidentally" falls asleep before his caregiver's return. Once the child is able to regularly fall asleep while his caregiver is out of the room, caregivers can begin saying goodnight and leaving the room after putting the child in bed.

Of extreme importance is the fact that caregivers must be mindful of the time they are out of the room, and they must always return to the child's room following the designated "excuse me" period. This gradual approach attempts to set children up for success by teaching children that (1) they are

capable of falling asleep without a caregiver present and (2) their caregiver is reliable and will return/be there the next morning if they are not present at sleep onset. Depending on the child's level of cognitive functioning, a reinforcement plan for following "bedtime rules" (i.e., staying in bed while the caregiver is not in the room) may add additional incentive for compliance. To maximize success with this intervention, it is important that caregivers not become impatient, overly confident, or distracted when implementing this strategy, thus extending their time-out of the room more quickly than the child is able to tolerate. Doing so may cause the child to become even more anxious or distressed.

Insomnia/Stimulus Control

When children have difficulty sleeping, they often begin associating being in their bed with being awake, watching videos, or playtime. This weakens the association between their bed and sleep. Because of this, it is important to talk to families about stimulus control and reserving the bed, and ideally the bedroom, for sleep. In order to be successful, stimulus control will need to occur both during the day and at night.

During the daytime, children should not be completing homework, playing, or watching television in bed. The goal is to associate the bedroom, and especially the bed, with sleep and no other activities. This is particularly important with respect to electronics in bed, which can be activating rather than calming to the brain. Electronics should be removed entirely from the bedroom, if possible, or at least turned off and removed from the bed an hour before bedtime. Also, at bedtime, the bedroom should not have highly stimulating toys as the presence of these items provides distractions from sleep. Ideally, the child should be allowed only quiet, relaxing, comforting items in bed. Additionally, whenever possible, the bedroom should not be used for time-out or other punishment because it can create anxious or aversive associations with the space, thereby making it more difficult to fall asleep at night.

Overnight, additional efforts need to be made to promote the association between sleep associations and being in bed. For example, in an effort to decrease "clock watching" and anxiety about being awake too long, clocks should be removed from the bedroom or turned away from the child's line of vision. For many children with NDD who obsess on specific times on the clock, pictorial clocks depicting colors (red/green) or images (sun/moon) to cue them as to when they are allowed to wake up may be helpful. For children who have the comprehension and maturity to do so, if they have been in bed and unable to fall asleep for what feels like 20–30 min, they should get out of bed and engage in a quiet, non-electronic activity for approximately 30 min before returning to bed and again attempting to sleep. This process (i.e., alternating effort to sleep with quiet out-of-bed activity) should continue until a child is able to initiate sleep.

Case Vignette: Behavioral Interventions to Address Problems Falling Asleep

As a starting point, education was provided by Sleep Clinic to Kyle's caregivers regarding sleep hygiene, the need for a consistent sleep environment, and the need to address independent sleep onset. Problem-solving was done with caregivers given Kyle's tantrums and avoidance behavior associated with transitioning from watching television to beginning his bedtime routine, as this made it difficult for him to calm at bedtime. It was recommended that all electronics, including television, be discontinued 30 min–1 h prior to bedtime. Instead, they were to be moved earlier in the evening so Kyle did not miss his opportunity to engage in these preferred activities and so that any tantrums associated with those transitions would not occur at bedtime. Additionally, caregivers were encouraged to provide verbal warnings that the transition to bedtime was about to occur. If Kyle had a tantrum during the transition, caregivers were encouraged to continue with the planned routine while using differential attention (i.e., ignoring the tantrum and providing praise and verbal interactions once he was quiet and cooperative).

Potential ways to improve consistency in Kyle's sleep environment overnight were also discussed with caregivers. Caregivers acknowledged that at the time, providing Kyle with his own bedroom or having a consistent caregiver present in the room was not an option. Additionally, because of space limitations, a caregiver would need to remain in the room while Kyle fell asleep in order to complete his sister's bedtime routine with her. Because of this, clinicians and family brainstormed together to identify areas where the family could be consistent. First, to maintain a consistent sleep environment, it was recommended that his nightlight remain on overnight instead of being turned off at time of sleep onset. Second, the family said they could consistently provide Kyle with a large body pillow in his bed to simulate the presence of a caregiver.

Caregivers expressed some concern regarding the potential for an extinction burst (escalation in disruptive behaviors at bedtime) since these changes would significantly change Kyle's current, preferred bedtime routine. Because of this, caregivers were encouraged to focus on consistently implementing these bedtime changes prior to receiving additional behavioral sleep recommendations. They felt this was a manageable plan.

Management and Evidence Base: Problems Staying Asleep

Every sleep-deprived parent knows that getting a child to sleep through the night is just as important as getting that child to fall asleep. Night wakings are a common problem in children and toddlers that persists in up to half, even though physiologically, they should be able to sleep through the night [25]. Approximately one-third of children have recurring difficulty with reinitiating sleep, primarily because they are unable to do so independently [26, 27]. Children who have not learned to fall asleep initially without parental presence and intervention are unlikely to be able to return to sleep independently after a night waking.

Sleep cycles or rhythms alternate between non-rapid eye movement (REM) and REM stage sleep throughout the night about every 1–1.5 h. It is normal for brief arousals or wakings to occur at the end of each sleep cycle. In healthy, typically developing children, these arousals occur multiple times per night and are immediately followed by efficient reinitiation of sleep with little or no conscious awareness that awakening has occurred [25, 28]. Problems staying asleep may occur when some other physiological or environmental event disrupts the efficient return to sleep after what would otherwise have been a brief nighttime arousal. For example, noise from another room, light from a TV, or an uncomfortable room temperature can provide enough stimulation for the child to become more fully awake after an arousal and then have difficulty reinitiating sleep. If the child has fallen asleep with a parent present, he or she will naturally expect that parent to be present on awakening. As a result, the child will cry or call out for the parent, or get up and go looking for the parent, often getting into the parents' bed. Similarly, internal stimuli such as hunger, thirst, anxiety, or pain may disrupt the child's ability to go back to sleep, leading to distress and seeking parental attention and assistance overnight.

When assessing any sleep problems in children, poor sleep hygiene must always be considered. However, if sleep hygiene is established such that the child has a consistent sleep schedule, an appropriate sleep environment, minimal or no stimulant consumption (caffeine or other), and developmentally appropriate napping or appropriately outgrown daytime sleep, yet night wakings occur regularly, the evaluation is not over, and further assessment is warranted.

Sleep-Onset Associations

Whenever a child has consistent night wakings, the source of concern may actually be with the way the child is falling asleep, as opposed to the waking itself. A common reason for recurrent night wakings is a sleep-onset association. Sleep-onset associations refer to the conditions under which we fall asleep and the expectation that how we fall asleep is how we will be awaken: for example, an association that a certain person (e.g., caregiver), activity (e.g., watching television), or environmental cue (e.g., living room sofa) is necessary to fall asleep or to reinitiate sleep. When children only fall asleep while being held or rocked by a caregiver, hearing a bedtime story, or watching TV or cuddling in bed with caregivers, they not only have difficulty falling asleep independently but also may not be able to reinitiate sleep after night wakings without parental intervention. These children have not learned to soothe themselves. When they briefly awaken during the night – and multiple brief spontaneous arousals are a normal part of sleep – to encounter environmental conditions different from those under which they fell asleep (i.e., parent not present; in a different bed and/or room; TV, nightlight, and music turned off; darkened room), they fully wake instead of quickly returning to sleep. When the child awakens with the expectation that these comforting things will be present, only to find the room quiet, dark, and minus the caregiver, he becomes distressed and begins calling out, crying, or searching for his caregiver in an effort to recreate his sleep-onset association to reinitiate sleep. At some point in development, all children, including those with NDD, need to learn healthy and independent sleep-onset associations.

Caregivers can facilitate this process by encouraging good sleep hygiene and a consistent evening and bedtime routine. One important step is to ensure that the child's bedroom environment is the same at bedtime as it will be when child has inevitable brief arousals/wakings during the night. The condition of the room, bed, lighting, temperature, and any ambient noise (music, white noise) should established at bedtime, kept constant during the night, and kept consistent across nights. The child should get in his bed when sleepy but not yet asleep. The child should not fall asleep somewhere other than where he is expected to sleep all night (e.g., caregiver's bed, on couch in front of TV, in the car, etc.) and then be carried to bed asleep, because when he awakens, he will be disoriented by the transition he doesn't remember making. The child should be encouraged to fall asleep independently to lessen the sleep-onset association with caregivers. Extinction or gradual extinction, such as "excuse me" drills or gradual extinction with caregiver presence (both previously discussed in this chapter), are interventions that can be used to encourage this change. It will help to have the child become accustomed to specific environmental stimuli that can be consistently present during the night. Comfort items that can be associated with falling asleep could be a favorite blanket, pillow, stuffed animal, quiet musical toy, or lullaby songs set to play throughout the night. Many times overnight wakings decrease once children are able to initiate

sleep independently at the beginning of the night; however, if necessary, an abbreviated version of "excuse me" drills or graduated extinction with caregiver presence can be implemented with night wakings until the child is able to awaken during the night, tolerate finding himself alone in bed, and reinitiate sleep without parental intervention.

Night Wakings

When children cannot reinitiate sleep without parental intervention, parents may fall back on survival strategies such as co-sleeping, permitting nocturnal eating and drinking, and allowing prolonged interactions with children overnight. Use of these potentially dysfunctional coping mechanisms becomes even more likely with children who have a NDD, such as autism, and/or chronic medical conditions. Most commonly, night wakings are maintained because of sleep-onset associations that children have developed. Sleep-onset associations are the conditions that have become necessary for the child to self-soothe and reinitiate sleep. These associations may involve being held, fed, rocked, sung to, or otherwise soothed by a familiar caregiver [9, 28, 31].

When deciding how to respond to a child's night wakings, first, one must determine if there is something motivating the child to be awake overnight while the rest of the house is sleeping. Is he accessing electronics? Is she able to play (uninterrupted) with a preferred toy? Is he engaging in self-stimulatory behavior? Is she engaging in a preferred or compulsive ritual that caregivers usually limit? If caregivers are able to identify that a child may be waking overnight to engage in preferred activities, then problem-solving will need to be done to find a way to restrict access to these things. For example, can Wi-Fi be turned off or restricted after bedtime? Can parents remove and secure the computer keyboard, video game controller, cable cord, or remote control (while leaving much larger televisions or computers in their typical places) when they go to bed at night? Can the preferred toys complete a bedtime routine of their own, such as being put into a plastic container and taken to the caregivers' room to restrict overnight access? Can a reinforcement plan be implemented to reward the child for adhering to these restrictions?

Also, is the child motivated by special interactions or individualized attention from a caregiver during night wakings? When night wakings are frequent and prolonged, details of the parent-child interactions and the child's behavior should be closely considered. Is the child receiving a significant amount of attention from their caregiver that is otherwise not available during the daytime? Is the child waking in order to see a parent who comes home late after an evening or night shift at work? Is the child waking overnight in an effort to receive extra comfort, snuggles, or preferred activities from their caregiver? Is he hoping to gain access to his caregiver's bed? The goal is always to help the child to learn to self-soothe and fall asleep (or reinitiate sleep) efficiently without excessive dependence on a caregiver [25, 28, 30]. Therefore, if overnight parent-child interactions are reinforcing the child's wakings, both daytime and overnight intervention will need to occur. First, caregivers will need to ensure that they are reserving time every day to engage in quality, child-led activities with their son or daughter. We have recommended at least 15 min daily. This reserved individualized time, sometimes called "special time," teaches the child that he does not need to wake overnight in order to spend time with his caregiver. Second, the quality of overnight caregiver-child interactions needs to be addressed. Verbal exchanges and physical contact should be minimal, and all activities should be boring rather than highly preferred. This shift in interaction teaches the child that preferred kinds of attention and activities with a caregiver are only available during the day, thereby weakening the reinforcing nature of overnight wakings.

Finally, it is important to assess whether overnight wakings occur at a consistent time. If spontaneous wakings appear to be consistently happening at the same time of night, scheduled night wakings (discussed in detail below in the Parasomnias section) could be trialed. Just as with parasomnias, scheduled wakings can be tried 30 min prior to the typical spontaneous overnight waking time.

Parasomnias

Children may exhibit non-REM parasomnias, including sleepwalking, sleep talking, or sleep (night) terrors, episodes of sudden arousal from slow-wave sleep accompanied by autonomic and behavioral evidence of intense fear, agitation, or confusion. Parasomnias typically occur in the earlier part of the night, with no child recall of the events in the morning. In contrast, they are quite memorable for and troubling to parents, who may believe the child is having a nightmare. During a non-REM parasomnia, in contrast to a nightmare, children are likely to avoid comfort rather than seek it. Therefore, caregivers should not attempt to awaken the child, as this may prolong the episode. Instead, the caregiver should supervise the child to ensure safety and gently guide the child back to bed. From a safety perspective, if a child engages in sleepwalking, care should also be taken to ensure that the child's floor stays clear (to minimize injury) and door locks or alarms should be utilized on windows and doors to ensure the child cannot leave the home – especially for children who have eloped from their homes during sleep.

If parasomnias occur during a consistent window of time every night, then scheduled night wakings may be beneficial. Scheduled night wakings involve purposely waking the child

approximately 30 min before the parasomnia typically occurs. These scheduled wakings should be brief, basically just enough for the child to stir, and need not escalate to full wakings, conversations, or other extended interactions. Scheduled night wakings should be trialed for a couple of weeks before skipping a few nights to see if parasomnias have resolved. If parasomnias do not recur when scheduled wakings stop, scheduled wakings can be discontinued and reinitiated in the future if needed. If parasomnias recur, scheduled wakings can be trialed for another week (to see if parasomnias resolve) before discontinuing this intervention. Research has found that scheduled wakings can be an effective intervention for addressing sleep terrors in children with ASD [29].

Nightmares

In the case of night wakings that are less frequent, occur episodically during the latter part of the night when REM sleep is more likely, and involve the child being distressed and recalling frightening or confusing dreams, nightmares are likely. Nightmares are simply frightening dreams that result in awakening from sleep followed by the child being upset and seeking comfort. All children have bad dreams on occasion. Up to 24% of typically developing children have severe and recurrent nightmares, which awaken them and which they recall. Between 2 and 5 years of age, about 20% of typically developing children have significant nightmares and between 6 and 10 years up to 41% [25, 28]. While data at this level of detail are largely unavailable for children with NDD, there is no reason to believe children with NDD have any fewer nightmares, and given their increased risk of having sleep problems in general, they may even have more frequent nightmares. However, many children with NDD lack the communicative ability to describe these experiences to their caregivers. On the other hand, it should be recognized that not all children who report having nightmares actually had them. On those occasions when the child has received comfort and reassurance from a caregiver during a reported nightmare, he may have learned that these reports are a reliable way both to get the caregiver to allow him out of his room and also to gain more access to interactions with adults. Thus, saying "I had a bad dream" can become a learned behavior for a child hoping to bend the typical overnight rules.

Sleep professionals generally do not analyze dreams, but it is sometimes revealing to ask about nightmare content. If the themes are suspiciously the same across time, this may suggest the child has learned to report on these themes as a guaranteed way to get nighttime comfort and attention. However, if reported dreams involve excessive fears of death, injury, or harm to family members, an underlying anxiety disorder may be presenting as a sleep disturbance, and the child should be evaluated by a behavioral health professional for such a condition.

When children have nightmares, they may fear going back to sleep and may begin to avoid or resist going to bed. Initial interventions for nightmares involve briefly comforting the child, reassuring the child that she or he is safe, redirecting the child back to bed, and then prompting use of coping strategies to facilitate reinitiation of sleep (i.e., encouraging the child to "be brave," repeat positive self-statements, listen to quiet music or comforting stories, or practice imagery or deep breathing). Children, who have experienced significant stress or trauma, have anxiety disorders or sleep deprivation, or take medication that may alter their amount of REM sleep are at greater risk for increased REM sleep (i.e., "REM rebound"), which increases the risk of nightmares. Children with NDD and comorbid anxiety or depression may be trialed on anxiolytic or antidepressant medications. Some of these medications can suppress REM sleep, but if discontinued abruptly may lead to a REM rebound effect [10]. Therefore, any intervention that can reduce these risk factors is likely to decrease the frequency of nightmares [25]. For a child with particularly distressing nightmares who has adequate cognitive and verbal abilities, a referral for nightmare imagery modification rehearsal with a psychologist or cognitive-behavioral therapist on an outpatient basis could be appropriate. Imagery modification involves helping the child to use his or her imagination to counter or replace frightening images experienced during a nightmare. One such strategy is helping the child to learn to imagine a more positive ending to a dream (e.g., a superhero appears to help the child defeat the monster; the child asks the troll why he is being mean, then the troll says he is sorry and starts being nice to everyone). Children can also be asked to rehearse the dream by drawing these more positive outcomes.

Additionally, it is important to keep in mind that children with NDD may become anxious and have nightmares about images, characters, television shows, and video games that may not frighten their typically developing peers. Because of this, it may initially be challenging for caregivers to identify the source of fear, and once it is identified, special attention will need to be given to monitoring and restricting the child's daytime access to that content.

Case Vignette: Behavioral Interventions to Address Problems Staying Asleep

As a second step to address Kyle's sleep difficulties, it was decided that caregivers would begin addressing the manner in which Kyle was falling asleep. Education was provided regarding sleep-onset associations as the likely reason why Kyle was unable to independently initiate sleep and why he was seeking out caregivers

during night wakings in an effort to reinitiate sleep. Given the family's prior attempts to fade their presence at bedtime, problem-solving was done to identify a gradual way to implement this change.

Caregivers identified that they would likely be most consistent implementing gradual extinction with parental presence in an effort to address Kyle's sleep-onset association disorder. Given the family's interest in no longer rocking Kyle to sleep, we all agreed this would be their goal. As a beginning step, it was recommended that they began rocking Kyle in their laps on his bed as a way to fade out the rocking chair. Once they were able to successfully make this transition while maintaining a 30 min latency to sleep onset, caregivers were encouraged to begin placing Kyle on the bed instead of their laps while rocking him from side to side. Once this step was achieved, caregivers were encouraged to place Kyle in bed and pat his back until he fell asleep, similar to the current approach at daycare.

To address overnight wakings, caregivers were encouraged to consistently return Kyle to his bed every time he attempted to join them in bed. During these wakings, it was recommended that caregivers engage in soothing behavior (i.e., rocking, caregiver presence) consistent with what they were providing at bedtime to promote Kyle's sleep reinitiation. The possibility of seeing an extinction burst while caregivers implemented these changes was discussed.

Management and Evidence Base: Waking and Daytime Sleepiness

Dysregulated or fragmented sleep, including early morning awakening, daytime napping, delayed sleep onset, advanced sleep onset, and/or frequent nighttime awakenings, may perpetuate excessive daytime tiredness and irritability. Sleep promotion practices are usually aimed at influencing sleep onset, but for those with neurodevelopmental disabilities, early morning risings, difficulties waking, and increased daytime fatigue as potentially manifested in napping may be equally important.

Early Morning

Early morning waking is common in children with advanced sleep-onset patterns, discussed elsewhere in this book. If a child is going to bed too early, this may be the most obvious cause for rising early in the morning. One method to assist with shifting the sleep pattern is trying to shift bedtime later. It is recommended that moving or fading bedtime/sleep onset later be done in 15 min increments every couple of days, to prevent the child from being overtired. Another important aspect to assist with minimizing early morning arousal involves ensuring the bedroom is sleep-friendly, including a comfortable temperature (less than 75°) [10] and room-darkening curtains or blinds. At the same time, family should open curtains or blinds for bright natural light to encourage wakefulness during periods that sleep should not occur. Some children benefit from use of a white noise machine or soft calming music to assist with muffling the sounds of pre-dawn garbage trucks, eager birds, or other external environmental noise that may interfere with the sleep environment.

Difficulty Waking

Children and adolescents who sleep for what appears to be an acceptable amount of time throughout the night but do not feel rested the next day may be slow to start in the morning or may present with excessive daytime fatigue. Difficulties with rising in the morning can be associated with numerous psychosocial and environmental factors, including staying up too late, poor-quality sleep during the night, developmentally inappropriate early school start times, school avoidance, stressful life events, psychosocial functioning, medication side effects, and irregular sleep-wake schedules. Other common causes involve sleep-disordered breathing (e.g., sleep apnea) or other medical difficulties (e.g., seizures). Important to note, children may not display obvious excessive sleepiness during the day but may instead seem more irritable, hyperactive, or inattentive [28]. These effects may be even more pronounced in children or adolescents with NDD.

Scheduling sleep and wake in children, including the duration of daytime naps and bedtimes, needs to take into account developmental, health, social, cultural, and economic considerations, as well the individual needs of families [13]. Every attempt should be made to both maintain sleep/wake regularity. For example, there should not be more than an hour's difference in bedtimes and wake times between weeknights and weekends. Even if a child goes to sleep late, the recommendation is to keep the morning routine and the morning wake time the same, or at least not more than 1 h later than the normal wake time. Although it may appear more humane to allow the child to "sleep in" and catch up on sleep, a regular wake time will prevent the sleep schedule from veering further off-schedule, as can happen when the child who sleeps in subsequently stays up later and later. Consistent sleep-wake schedules may be particularly important for children with NDD, because they are uniquely vulnerable to both sleep and circadian rhythm disruptions [13].

When children continue to have difficulty waking despite attempts to regulate their sleep schedules, caregivers may need to be creative in how they wake their child. Maximum light exposure should be provided (both natural daylight and artificial lighting), ideally slightly before the child's necessary wake time, to help promote wakefulness. Caregivers can also use the child's preferred items, such as

favorite music, television shows, or breakfast items, to motivate the child to wake. Finally, reinforcement programs can be used to reward the child for waking in a timely manner.

Morning routines can further benefit children who have difficulties waking in the morning. A structured morning schedule that is predictable, consistent, and expected can help ease transitions and start the day on a positive note. As with bedtime, it may be helpful to have a visual/picture schedule to assist with step-by-step guidance so that the child knows what happens next. Predictable morning routines tend to be most successful not only when a consistent arousal time is identified but also when the consistent routine (e.g., opening blinds, washing face, brushing teeth, brushing hair, etc.) is adhered to every day, including holidays and weekends.

Napping

Early morning wakings may also occur if a child naps too long or too frequently during the day. Adjusting nap times or gradually shortening nap times may also create sleep pressure and assist with consolidating sleep overnight. Nap patterns are usually established in infancy and often revolve around feeding schedules. Napping becomes less essential as a child becomes older; however, while napping continues, it is important to keep nap times on a regular schedule, waking significantly before the evening hours so as not to interfere with sleep onset at bedtime. Additionally, it is helpful to leverage napping in the association with sleep and bed; naps should be in the child's bedroom and bed whenever possible.

Children who are older and have outgrown the need for a daytime nap should avoid napping unless there is some circumstantial change (e.g., illness, medical condition) or an extremely early wake time for school (e.g., to accommodate a lengthy bus ride). In specific, certain children with NDD may require extra naps or longer nocturnal sleep than their typically developing counterparts. Some fatigue more easily and may fall asleep inappropriately several hours before their regular bedtimes. If this is the case, every effort should be taken to ensure that naps occur as early in the afternoon as possible and are restricted to 20–30 min.

Case Vignette: 3-Month Follow-Up

At Kyle's 3-month follow-up visit, caregivers reported significant improvements in sleep after following recommendations from the previous clinic appointment. Caregivers noted that tantrums at bedtime decreased. Additionally, after following the fading plan, caregivers no longer needed to rock Kyle in order for him to fall asleep, and he had been falling asleep within 15 min. He continued to wake overnight but was able to reinitiate sleep more quickly in his own bed. Furthermore, Kyle started falling asleep independently for naps.

Based on the family's success with prior behavioral sleep recommendations, ways to further improve independent sleep onset were discussed. Once Kyle was in bed, it was recommended that family start using "excuse me" drills to begin slowly and systematically increasing Kyle's opportunity to fall asleep independently. Caregivers were praised for their hard work and dedication to consistently implementing prior recommendations.

Areas of Uncertainty and Future Directions

While extensive research has been conducted on empirically supported behavioral sleep interventions for typically developing children [9], limited quality research has been published on the efficacy of these interventions in children with NDD [11, 24, 31]. Even fewer studies have been conducted on adolescents with NDD [32]. Likely some of this lack of research is due to the heterogeneity of sleep problems in a sample of children with NDD, making it difficult to implement standardized interventions across a sample. Additionally, children with NDD may present with a wide variety of behavioral and sensory concerns, further necessitating the individualization of interventions and making standardization of care challenging. Because of this need for individualization, the majority of studies of behavioral sleep interventions for children with NDD to date have been case studies or case series [8, 32], limiting the generalizability of findings.

When larger-scale studies have been conducted, findings are often variable regarding the intervention's success at addressing sleep concerns in children with NDD [11, 32–34]. In considering this difference in rates of success compared to typically developing peers, it could be hypothesized that comorbid behavioral or medical concerns or other unique characteristics of children with NDD could all play roles. However, there is currently no empirical evidence to say why these differences occur. Additional research is needed given the uncertainty of how well behavioral sleep interventions generalize to children with NDD, both as a group and studied in terms of specific diagnoses, and whether modifications to these interventions may be needed to improve their efficacy [e.g., 14, 31, 33].

Guidelines/Take-Home Tips

1. Addressing sleep hygiene is always a good starting point [13].
2. Individualization of interventions is key [8]. Behavioral sleep recommendations must be adapted not only to the child's individual sleep problems but also the factors maintaining them [35, 36].

Table 28.2 Summary application of behavioral sleep interventions

	Sleep initiation	Sleep maintenance	Parasomnias	Waking/morning
Sleep hygiene	X	X	–	X
Routines	X	–	–	X
Bedtime fading	X	–	–	–
Extinction	X	X	–	–
"Excuse me" drills	X	X	–	–
Graduated extinction with caregiver presence	X	X	–	–
Stimulus control	X	X	–	X
Scheduled waking	–	X	X	–
Reinforcement	X	X	–	X

3. When making recommendations, clinicians must be mindful that families of children with NDD often have many demands placed on them and their time. Because of this, paired with disrupted caregiver sleep, feasibility and caregiver satisfaction must be taken into account when suggesting interventions.
4. Behavioral concerns or medical conditions may also limit the implementation of any interventions that may lead to extinction burst or sudden escalation in behavior. Families may view behavioral interventions using gradual approaches as easier and more acceptable than interventions requiring abrupt change [24].
5. Given the multifaceted nature of sleep problems in children with NDD, no single approach is likely to show results, and multiple interventions including a variety of the previously mentioned behavioral interventions will likely be required to see the full treatment benefit (e.g., [32, 37, 38]). Table 28.2 provides a brief summary on when the application of strategies described in this chapter will be most helpful.
6. Consistency is key. Sleep problems likely developed over time and, because of this, may only resolve over time. Consistent implementation of behavioral recommendations over time is therefore required for success. Because of this, many families find it beneficial to work with an outpatient behavioral therapist or psychologist in order to receive ongoing support and help with problem-solving during intervention implementation.
7. Implementing behavioral sleep interventions with children with NDD is challenging, and the first try is not always successful. A multidisciplinary approach, incorporating both behavioral and medical, will likely improve chances of success.

Conclusions and Final Recommendations

Children with NDD exhibit behavioral, emotional, cognitive, and sensory-motor difficulties that impact their bedtime and wake-time behavior and sleep patterns. Problems with initiation of sleep, sleep associations, night wakings, parasomnias, early morning waking, difficulty waking, and daytime sleepiness are commonly seen in children with NDD impacting their daytime behavioral adjustment and emotional functioning. Abnormalities in circadian rhythms and disturbance in production of melatonin or other hormones or neurotransmitters may be physiologic contributors. Increased sensory sensitivity and lack of bedtime routine can also play roles.

Clearly more research is needed on the factors that individually or in combination can lead to difficulty initiating, reinitiating, maintaining, and awaking from sleep, as well as factors affecting ability to stay awake during the day. Whatever may be the origins of sleep disturbances in children with NDD, there is a preliminary body of research and growing clinical experience demonstrating that behavioral interventions can be helpful alone, or in combination with medical interventions, for treating sleep problems in children with NDD. Many of these interventions are modified versions of interventions that have been empirically validated with typically developing children. Large-scale research on interventions validated specifically for children and adolescents with NDD is sparse and still in its infancy. This is an important gap in the literature in light of the fact that individuals with NDD are at increased risk for medical, behavioral, and sleep problems. While improving sleep hygiene can greatly improve sleep patterns, it is typically not sufficient to solve all sleep problems, particularly for many children with NDD. Furthermore, children with NDD may have restricted interests or atypical responses to common forms of stimulation and activities. Therefore, careful and ongoing collaboration by medical and behavioral health-care staff with caregivers is required to address these additional challenges. The cumulative body of clinical experience known to medical, behavioral, and other health-care professionals has much to offer families toward solving behavioral sleep problems. Compiling this information in a useful format has been a major goal of this chapter.

One important conclusion from the available literature is that children do not automatically fall asleep in healthy ways. Healthy bedtime behavior and sleep patterns must be learned. Due to their unique risks, challenges, sensory, motor, and

behavioral characteristics, children with NDD may require more assistance from caregivers with this learning process. For these reasons, families with children having NDD may need to progress through a process of recognizing that a problem exists, identifying barriers to healthy sleep patterns, brainstorming and testing potential solutions, evaluating preliminary results, and fine-tuning efforts until they are successful. For a sleep-deprived caregiver, who may have other children to care for, this can be a daunting process. The sleep health of all children, especially those with NDD, should be monitored by primary care physicians to allow for early identification, caregiver guidance, and, when indicated, referral for specialized behavioral services to address sleep difficulties as early and efficiently as possible, before years of maladaptive sleep-related behavior patterns and caregiver-child interactions develop. Families often benefit from the assistance of a behavioral psychologist or therapist to support, encourage, and guide them through this process because it can take weeks or months to achieve sleep goals. Whatever environmental or behavior changes are to be implemented by caregivers, it is vital that they have to support and encourage to be consistent and to persist long enough for the child to have the opportunity to learn to behave differently. Unfortunately, all too often, exhausted caregivers become frustrated that changes do not occur immediately and abandon their efforts. It is also important to help them recognize problematic behavioral and sleep patterns early, as early intervention may prevent more complex behavioral sleep problems. Recommended intervention strategies may need to continue and remain consistent as the child develops since managing sleep in a child with NDD is often a long-term project. Therefore, it is important to help prepare caregivers for the ongoing job of helping their child develop healthy sleep patterns.

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