Taking Sleep Difficulties Seriously in Children With Neurodevelopmental Disorders and ASD

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In this month's issue of *Pediatrics*, the large-scale epidemiological study by Reynolds et al[1] finds that close to one half of 2- to 5-year-old children with autism spectrum disorder (ASD) or a neurodevelopmental disorder (NDD) with some autistic features have significant sleep difficulties. In addition, >1 in 4 children with other NDDs or delays, as well as otherwise healthy children, also have sleep problems.[1,2] These sleep difficulties have significant negative consequences, such as exacerbating the social communication deficits in ASD and increasing repetitive and restrictive behaviors.[3] They contribute to behaviors such as aggression and self-injury[4] and often make life more difficult for the entire family. Pediatricians and nurse practitioners in primary care and more specialized health care providers such as developmental-behavioral pediatricians, child neurologists, psychologists, behavior analysts, and social workers often, but not always, hear from caregivers about these sleep difficulties. Yet, on the basis of the data presented here and elsewhere, whatever is being done currently is not working.[5]

The good news is that the sleep difficulties experienced by children with ASD and other NDDs are not different from those of typical children, and they can be treated in ways that do not, in most cases, require extraordinary medical intervention. However, in ASD and other NDDs there are a greater number of different kinds of common sleep problems within an individual child, and a greater number of factors likely contribute to these difficulties within the child and family.[1] This means that simple interventions proposed without regard for the specific needs of the child and family are less likely to be effective.[6,7] Multiple interventions for different aspects of sleep (whether creating successful bedtime routines, getting the child to actually sleep, or minimizing night waking and middle-of-the-night cosleeping), and in some cases relevant gastrointestinal or respiratory issues, may have to occur simultaneously.[1]

So, what can be done within the context of busy clinical practices, particularly when health providers have many other responsibilities, and when reimbursement levels for sleep counseling can be low? Researchers in a recent Delphi Behavioral Health Group review proposed 131 recommendations about sleep, 84 of which were judged to be relevant to 4 groups of children with different NDDs or delays, and none of which were judged to be of low importance.[8] Published studies describe effective behavioral interventions for improving sleep onset and decreasing night waking as taking from 5 to 15 weeks with 30-minute sessions of parental training.[9–11] Thus, although the bulk of the actual work is done by caregivers, these interventions take time to design and monitor. Caregivers must identify the behaviors they need to address in their children and themselves, consider

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DOI: https://doi.org/10.1542/peds.2018-2629

Accepted for publication Dec 3, 2018

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

FINANCIAL DISCLOSURE: The author has indicated she has no financial relationships relevant to this article to disclose.

FUNDING: Supported by R01 HD081199 and SFARI 1336363.

POTENTIAL CONFLICT OF INTEREST: Dr Lord has received royalties for diagnostic instruments that were used in this study; royalties were donated to a not-for-profit agency.

COMPANION PAPER: A companion to this article can be found online at www.pediatrics.org/cgi/doi/10.1542/peds.2018-0492.

To cite: Lord C. Taking Sleep Difficulties Seriously in Children With Neurodevelopmental Disorders and ASD. *Pediatrics*. 2019;143(3):e20182629

what they are capable of doing within the family environment and when they can do this, and be helped to regroup and try new strategies if first attempts are not successful.

Again, the good news is that there are a variety of approaches that can be used with the resources available in different health settings and communities. Individual and group caregiver–oriented programs have been shown to have similar results[12]; there is great hope for newly modified e-health programs that are specifically developed for children with NDDs (eg, Better Nights, Better Days for Children with Neurodevelopmental Disorders[8]). Successful behavioral programs include bedtime fading, teaching healthy sleep practices, and increasing a child's physical activity during the day.[7,11,13] The point is that someone (whether the primary care physician, nurse practitioner, psychologist, or social worker) needs to ask the family about sleep to make sure that difficulties are not going unattended. There also needs to be follow-up, such as making weekly appointments for several months to monitor and provide guidance to a family, running a sleep group for families of preschoolers with some additional time for the parents of children with NDDs, or supervising participation in an e-health online program.

In addition, numerous studies have now shown that melatonin improves sleep initiation and duration for many children.[5,14] However, that is not enough, as is indicated by the number of families in the current study whose children were already taking melatonin and continued to have significant sleep problems.[1] Thus, it is recommended that families try behavioral programs before trials with melatonin. Other medications have had less consistent results.[14,15] Particularly for younger children (age ≤5 years) with mild obstructive sleep apnea, adenotonsillectomies may also be effective.[16–18]

Overall, the charge is for pediatricians and health care providers who see children with ASD or other NDDs to make sure that sleep is discussed with families and, if there are difficulties, to move beyond brief advice to either carrying out systematic interventions themselves or referring families to get appropriate help. In most cases, this help does not have to come from sleep experts, but does require dedicated time and effort using the now-growing base of evidence about effective interventions.

ACKNOWLEDGMENTS

Thanks to Dr Susan Hyman for her quick and thoughtful comments and to Marcella Sanchez for the kind help with references.

ABBREVIATIONS

ASD: autism spectrum disorder
NDD: neurodevelopmental disorder

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Pediatrics 2019;143;
DOI: 10.1542/peds.2018-2629 originally published online February 11, 2019;

PEDIATRICS®
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Pediatrics 2019;143;
DOI: 10.1542/peds.2018-2629 originally published online February 11, 2019;