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Journal of Clinical Sleep Medicine

http://dx.doi.org/10.5664/jcsm.2132

PRO: "Not Just Little Adults": AASM Should Require Pediatric Accreditation for Integrated Sleep Medicine Programs Serving Both Children (0-16 years) and Adults

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Recently, the leadership of the American Academy of Sleep Medicine has called for the development of innovative approaches to better enable the field to meet the challenges of anticipated changes in healthcare delivery, to weather the realities of the current economic climate and tightening cost-containment measures, and to ultimately shift the focus of clinical sleep medicine from an emphasis on diagnostic testing to a model of long-term disease management and improved health outcomes.1 A key element of the proposed "Integrated Sleep Management Delivery Model" involves the requirement for comprehensive sleep centers to obtain three levels of accreditation (AASM Accreditation of Sleep Center, AASM Accreditation of Out of Center Sleep Testing, and AASM Accreditation for Non-Medicare DME Suppliers). This is based on the premise that AASM Accreditation provides a necessary framework or "gold standard" for the delivery and integration of high quality sleep medicine services. In an accompanying recent editorial, Dr. Allan Pack also eloquently argues that in order for the American Academy of Sleep Medicine to "move our field to a new, patient-centered and outcomes-based delivery model," modifications in current accreditation standards are required, encompassing standardized definitions and improved metrics for assessing health outcomes, an emphasis on management of the full range of sleep disorders, and integration of behavioral sleep medicine services.²

While we applaud these developments and enthusiastically support our adult sleep medicine colleagues in moving forward with these important and timely efforts, the absence of any mention whatsoever of the need to establish accreditation standards for children or to develop a similarly comprehensive and integrated approach in the future to the treatment of children with sleep disorders is both striking and highly disappointing to those of us who care for these pediatric sleep patients and their families. On the one hand, the current lack of standardization for conducting pediatric sleep diagnostic services and providing comprehensive evaluation and treatment of pediatric sleep disorders in "mixed" adult and pediatric sleep centers greatly increases the risk of delivery of "second class" or substandard care for children, a situation which is clearly unacceptable. On the other hand, if future accreditation standards for the field of sleep medicine are truly to address the needs of all patients and incorporate a developmental "life cycle" perspective, then neglecting to include the fundamental, unique, and complex needs of children and families in the model is tantamount to a failure to achieve those goals.

Based on this assumption that a "double standard" in the clinical care of adult and pediatric sleep patients currently exists, we propose that the AASM should take the lead in rectifying the situation. We believe that including pediatric standards in the AASM accreditation of sleep centers as a means of achieving parity in the delivery of sleep medicine services is not only necessary and important, but urgent. The specific rationale for this proposal is outlined below:

1) Demand for pediatric sleep diagnostic services is likely to increase.

The AASM 2011 Practice Parameters on Respiratory Indications for PSG in Children³ recommends that all children undergoing adenotonsillectomy for sleep disordered breathing have a diagnostic sleep study to establish the diagnosis and determine severity. Currently, it is estimated that fewer than 10% of children have a sleep study prior to surgery. The practice parameters further recommend that repeat sleep studies be conducted in clinical situations in which residual SDB is likely to be present (e.g., obesity, severe baseline SDB, craniofacial anamolies); the percentage of high risk children currently undergoing postoperative PSG is not known, but likely to be similarly small. In addition, it is anticipated that increased awareness among pediatric healthcare providers of SDB and its potential consequences will result in increased demand.⁴ As more studies linking pediatric OSAS with adverse behavioral and cognitive outcomes are published and disseminated,5 mental health providers, educators, and parents are also likely to become more active in the referral process. Thus, the potential need for expansion of sleep diagnostic services to appropriately evaluate and treat SDB in children is substantial.

At the same time, we acknowledge that there is clearly a significant "service gap" posed by the relative lack of facilities around the country which provide specialized pediatric sleep medicine services, especially in non-academic and non-urban settings.⁶ Currently there are only 28 "titled" pediatric sleep centers accredited by the AASM, according to the 2012 AASM Roster of Accredited Sleep Centers. This results in a total of only 1.8% of all accredited sleep centers. Eighty-two percent of

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accredited sleep disorders centers report accepting children 13 years of age or older. Only 47% of all accredited centers report acceptance of patients 5 years of age or younger and less than one-third of centers will accept children less than 3 years of age.

2) At the same time, demand for in-lab testing in adults is likely to decrease.

As portable monitoring increasingly becomes the standard for adults with uncomplicated sleep apnea,1 sleep labs will face increasing competition for inpatients. Given the complexity of conducting sleep studies in children, it is not expected that home studies will also become the standard of care, at least in individuals under 12. The financial incentive for adult labs to study children has also increased due to the recent CPT Editorial Panel approval of increased reimbursement for pediatric sleep studies (age less than 6 years) (http://www.ama-assn.org/ resources/doc/cpt/summary-of-panel-actions-feb2012.pdf). While this change is an acknowledgment of such child-specific variables as the increased time and effort required to score and interpret pediatric studies and the need for a high sleep technologist to patient ratio (1:1) in many pediatric patients, it may have the unintended consequence of encouraging unequipped and ill-prepared adult facilities to market their services to the child population.

One probable result of this situation of increased demand and enhanced incentives is that more adult sleep programs will consider expanding their services to include diagnosing and treating children. Recognizing this reality and acknowledging that pediatric sleep centers are currently inadequate in number and geographical distribution to meet the demands, we would argue that the need to establish clear standards for conducting and interpreting pediatric sleep diagnostic tests in non-pediatric settings now is imperative and that incorporation of those standards into accreditation requirements for mixed labs in the near future is mandatory.

3) Inappropriate or substandard pediatric sleep testing drives up healthcare costs.

In this era of tighter healthcare budgets, increasing scrutiny of health expenditures and uncertainty regarding the future of federal healthcare programs, any perceived unnecessary or wasteful spending for diagnostic procedures will be closely examined and challenged. We contend that pediatric sleep studies which are inappropriately conducted, interpreted, or scored by sleep medicine providers inadequately trained in pediatrics may result in excessive healthcare costs due to the need to repeat studies, delays in treatment, and unnecessary or over-treatment. Requiring specialized pediatric accreditation standards would substantially reduce this risk.

4) Conducting, scoring, and interpreting sleep studies in children require specialized training of both health care providers and technologists.

There are a myriad of specific and unique challenges to providing at the very least a minimum standard of diagnostic sleep services for children. First, both healthcare providers and technologists need to posses a knowledge base regarding pediatric respiratory pathophysiology and neurophysiology, normal developmental changes in sleep architecture and cognitive/motor/ language/social developmental milestones. Required technical skills in conducting and scoring pediatric sleep studies necessitate initial specialized training, ongoing education, and exposure to an adequate volume of patients. For example, most adult sleep labs have little experience with ETCO₂ monitoring, which is considered the standard of care in performing pediatric sleep studies. Sleep staging and respiratory scoring in children in particular, are quite different from those in adults (i.e., sleep architecture findings unique to children such as hypnogogic hypersynchrony, required duration of apneic/hypopneic events,). Moreover, implementation of specific diagnostic procedures such as the multiple sleep latency test, and therapeutic interventions such as PAP therapy in the child population, requires both specialized knowledge and technical expertise, as well as application of principles of behavioral sleep medicine.⁷

We would argue that many, if not most, sleep centers contemplating expanding their services to include children, as well as some "mixed" labs currently seeing children, do not currently have the knowledge, skill, and expertise to do so. There are a number of reasons for this situation. While ABMS sleep medicine fellowship trained physicians are required spend a minimum percentage of their training seeing children (40 pediatric sleep studies), this may not be sufficient to ensure adequate quality of care, especially for non-pediatric specialties. The relative dearth of specialized pediatric sleep centers available for training sleep medicine fellows also is likely to result in variability in amount and quality of exposure to pediatric sleep medicine across programs. Moreover, non-fellowship trained sleep physicians may have had minimal to no pediatric training. Finally, sleep technologists are not required to have any specific pediatric exposure or to learn appropriate skills during their training.

Therefore, we would propose that a minimum requirement for mandatory training in pediatric sleep medicine for physicians and other healthcare providers and sleep technicians/ technologists be developed and included in the AASM accreditation standards for all labs intending to study patients under the age of 16 years. Previously accredited labs would be required to meet these specialized pediatric accreditation standards, including demonstration of pediatric proficiency of technologists in data acquisition and scoring, at the time of re-accreditation.

5) Family-centered care is a mandatory component of pediatric sleep diagnostic and treatment services.

Conducting sleep studies in children requires specific accommodations to the physical space (sleeping accommodations for parents, cribs), to the emotional and physical needs of children across a range of ages and their caregivers, and the implementation of pediatric-specific procedures to insure comfort and safety.^{4,8-10} For example, lab hours may need to be extended to accommodate young patients, and age-appropriate toys and books need to be made available. Tours of the lab prior to the testing date should be offered and instructions regarding lab procedures should be sent in advance to families. Recognizing that caregivers are an integral component of pediatric care, sleep programs should have specific policies which provide family-centered and child-friendly care. This is currently not required for accreditation. We contend that minimum standards for the children in the sleep lab environment should be established and child-specific policies and procedures should be included in pediatric accreditation requirements.

6) Appropriate triaging of pediatric patients is fundamental to successful integration of pediatric sleep services.

While triaging by age is straightforward and feasible, appropriate screening mechanisms to exclude children with significant medical, psychiatric, and neurodevelopmental comorbidities, or children with severe sleep disorders are also needed. Inadequate screening potentially results in poor diagnostic yield and suboptimal care in these special populations and may pose situations which are safety threats. Thus, patient acceptance and referral procedures, and triage parameters and guidelines should be included in pediatric accreditation standards. However, recognizing that, at best, screening procedures are imperfect and that children may present to the sleep lab with unexpected medical, cognitive, or behavioral challenges, the sleep lab personnel, environment, and policies must be prepared to accommodate a wide range of clinical situations. Policies and procedures specific to caring for children with special needs should be included in accreditation standards.

7) Comprehensive clinical care, including followup care for pediatric sleep patients undergoing diagnostic procedures, and evaluation and management of children with the full range of sleep disorders is a necessary component of an integrated sleep medicine program.

Accreditation of "free-standing" sleep labs, without wraparound full-service clinical sleep medicine services, is no longer offered by the AASM. Furthermore, no accredited adult sleep lab would be allowed to limit their scope of services solely to testing for sleep disordered breathing. Similarly, accredited sleep labs which provide services to children should not only offer the full range of diagnostic testing and treatment procedures, but also make available the corresponding appropriate follow-up and comprehensive clinical care. Current lab accreditation standards stipulate that no more than 80% of patients referred for sleep testing be direct referrals; this means that at least 20% of pediatric sleep study patients should be accommodated and seen in an affiliated clinical sleep program before or after their sleep study.

A high percentage of children referred to sleep clinics have diagnoses other than sleep disordered breathing, which include behavioral insomnias, RLS/PLMD, partial arousal parasomnias, and circadian rhythm disturbances,¹¹ the evaluation and treatment of which may differ substantially from that for similar diagnostic entities in adults. Moreover, a substantial proportion (up to 40%) of children referred for overnight sleep studies for a suspicion of SDB have at least one, and frequently multiple, additional sleep diagnoses.¹² Therefore, a comprehensive evaluation for the range of sleep disorders is a necessary component of standards of care.

Finally, our field is rapidly moving to a conceptualization of sleep disorders as chronic health conditions frequently necessitating long-term care.¹ If anything, this paradigm shift is even more salient for children, for whom both the short- and long-term consequences of sleep disorders such as OSAS are often profound and wide-ranging. There is a substantial need for ongoing medical and psychosocial management of chronic sleep disorders in children and adolescents such as narcolepsy or delayed sleep phase disorder in order to prevent poor health and functional outcomes. Conversely, early identification and rapid treatment of sleep disorders such as SDB may result in significantly improved outcomes.^{5,13}

8) Adequate evaluation, treatment, and follow-up of pediatric sleep disorders, including sleep disordered breathing, may not be available in the community.

A number of studies have substantiated the observation that primary care pediatricians, medical subspecialists (neurology, pulmonary), and mental health practitioners caring for children are often poorly trained in the diagnosis and management of children with sleep disorders.^{14,15} Therefore, the assumption that pediatric providers in the community appropriately screen for and refer patients with sleep disorders may be erroneous, and reliance on these providers to subsequently appropriately manage children diagnosed with sleep disorders may be misguided. Therefore, accreditation standards should states that the provision of sleep diagnostic services for children must be accompanied by access to appropriate follow-up care.

9) Ultimately, failure to include special considerations for the pediatric population in planning for the future of sleep medicine would represent the loss of a major opportunity to improve the health of children and advance the field.

There is increasingly compelling evidence for the negative impact of an insufficient quantity and/or quality of sleep on children's physical and mental health, cognitive function, behavior, and academic success,16-20 consequences for which children from racial/ethnic minorities and those living in poverty may be at even higher risk.^{21,22} There are a large number of cross-sectional and prospective studies which have consistently shown associations between sleep problems and a host of adverse health outcomes in children and adolescents, including increased obesity risk,²³ higher rates of motor vehicle accidents²⁴ and accidental injuries,²⁵ adverse cardiovascular outcomes,26 and depression27 and suicidal ideation.28 By mandating accreditation standards for the delivery of sleep services for children, the AASM would be sending a clear message that the field acknowledges the profound impact that sleep disorders have on children's health and recognizes that optimal diagnosis and management of pediatric sleep disorders in the clinical setting represents a key strategy to reduce adverse outcomes. Adoption of pediatric accreditation standards would make practical, real and sustainable progress towards achieving those goals.

Finally, the future of sleep medicine will depend in large part upon the development of innovative approaches to care delivery such as telemedicine, the emergence and validation of new and existing sleep technologies, the development of more sophisticated diagnostic techniques such as biomarkers, and the incorporation into practice settings of tools like clinical registries to assess outcomes and quality of care.²⁹ In order for any of

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these innovations to be truly progressive and to ultimately have an impact on the health of all Americans, we would contend that the inclusion of the pediatric perspective is both necessary and timely.

CITATION

Owens J; Kothare S, Sheldon S. Pro: "Not just little adults": AASM should require pediatric accreditation for integrated sleep medicine programs serving both children (0-16 years) and adults. *J Clin Sleep Med* 2012;8(5):473-476.

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SUBMISSION & CORRESPONDENCE INFORMATION

Submitted for publication May, 2012 Submitted in final revised form May, 2012 Accepted for publication May, 2012

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DISCLOSURE STATEMENT

This was not an industry supported study. Dr. Owens has consulted for Takeda Pharmaceutical Company Limited, Purdue Pharma, UCB Pharma, Transcept Pharmaceuticals, Inc, and Shire and serves on the advisory boards of Purdue Pharma and Jazz Pharmaceuticals. Dr. Sheldon has received research support from KarmelSonix Ltd. and travel reimbursement from Cadwell Diagnostics. The other author has indicated no financial conflicts of interest.