

# Editors' Note and Prologue

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We are delighted to introduce the second supplement to *Pediatrics* on “Health Care for Children and Youth With Autism and Other Neurodevelopmental Disorders.” The first supplement appeared in 2012. Since then, research in care and new practice arrangements have grown dramatically, and this new supplement provides good evidence of that growth in a varied compendium of studies and reports. The Autism Intervention Research Network on Physical Health has led the development of both of these supplements, with support from the Health Resources and Services Administration and its Maternal and Child Health Bureau through the Combating Autism Initiative (see Park et al in this supplement). Infrastructure investments such as the Autism Intervention Research Network on Physical Health (see Perrin et al in this supplement) and the Developmental-Behavioral Pediatrics Network (DBPNet) (see Hansen et al in this supplement) provide the framework for collaboration among colleagues across institutions, the sharing of ideas and resources, and the review and assessment of existing practices. We provide below an overview of the articles in this supplement issue. Importantly, together they document the efforts of large numbers of investigators in many institutions, active collaborations that would not have occurred without the major investments of the federal government in the research network, as well as the growing numbers of committed clinicians working to improve care for children and youth with autism spectrum disorder (ASD) and other neurodevelopmental conditions and their families.

All but 1 of the 14 articles in this supplement are authored by teams of researchers representing multiple medical centers, universities, and other organizations. Research grant support has facilitated both the leveraging of existing databases to generate and test hypotheses about ASD services, treatments, and needs as well as projects that gather and analyze original data to address novel questions and assess new interventions. Eight articles in this supplement report on analyses

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**POTENTIAL CONFLICT OF INTEREST:** Dr Zwaigenbaum has received grant funding from the Canadian Institutes of Health Research, NeuroDevNet, the Women’s and Children’s Health Research Institute, and SynaptDx and has a grant under review by the Azreieli Foundation and Brain Canada; and Dr Erickson Warfield has indicated she has no potential conflicts of interest to disclose.

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of secondary data sources and literature reviews, and 6 describe original data collection. Of the 8 secondary analyses, the National Survey of Children with Special Health Care Needs and the Autism Speaks Autism Treatment Network (ATN) registry were the basis for the analyses in 5 articles. Together, the articles in this supplement reflect state-of-the-art knowledge in 4 specific areas: (1) understanding ASD and its diagnosis, (2) frequently accompanying symptoms, (3) recommendations for clinical care, and (4) interventions and services for ASD and other neurodevelopmental disorders. We briefly review the articles in these 4 areas and offer recommendations for future work.

This supplement includes 2 evidence-based recommendations for the assessment and management of anxiety and problem behaviors, among the most common mental health challenges in patients with ASD. Consistent with a care model emphasizing coordination across the various levels of the health system, these recommendations are targeted at primary care physicians, with referral to specialty services when symptoms are more complex or do not respond to initial treatment recommendations. Vasa et al<sup>1</sup> propose a multistep process for the assessment and management of anxiety symptoms, informed by a previous systematic review published by some of the authors.<sup>2</sup> They acknowledge the complexity of assessing for comorbid anxiety (eg, overlapping diagnostic features with ASD, compromised reporting of emotions) and provide a thoughtful framework that emphasizes the importance of multiple informants across settings and acknowledges the complex interplay between self-regulation, emotional-behavioral symptoms, and physical health issues. McGuire et al<sup>3</sup> outline a practice pathway for irritability and problem behaviors, highlighting

the importance of individualized assessment and treatment planning that takes into account the child's communication level, psychosocial stressors, current management approach (including inadvertent reinforcement of negative behaviors), and any underlying medical and mental health conditions. Their recommendations are informed by the systematic review and meta-analysis of the effectiveness (and side effects) of psychopharmacological treatments by Fung et al,<sup>4</sup> also in this issue.

Seven supplement articles provide new insights into ASD-related interventions and services. One article describes a year-long access improvement project that reduced the number of patients with ASD waiting for follow-up appointments and reduced delays to new diagnosis in 2 different sites.<sup>5</sup> Kuhlthau et al<sup>6</sup> surveyed caregivers of youth with ASD regarding health care transition services. Although families who received health care transition services were generally satisfied, overall rates of service receipt were quite low, and those who were not provided with services generally desired them. Lindgren et al<sup>7</sup> asked whether challenging behavior in young children with autism and other developmental disabilities can be treated successfully at lower cost by using telehealth to train parents to implement applied behavior analysis procedures. Their findings indicate that parents can use applied behavior analysis procedures successfully whether treatment is directed by behavior consultants in-person or via remote video coaching. Another study documented racial and ethnic differences in perceived need for 46 services that children with ASD and their families frequently use.<sup>8</sup> Importantly, caregivers' perceptions may affect how they prioritize and seek care, independent of their child's specific needs. Thomas et al<sup>9</sup> examined health insurance ratings

from parents raising children with autism and child expenditures to explore how these measures align. They found a mismatch between parent ratings of insurance adequacy, child expenditures, and relative financial burden. Finally, 2 articles address the unique service needs of children with ASD in the context of acute health care. Broder-Fingert et al<sup>10</sup> created and implemented an autism-specific care plan to help improve the hospital experience for patients with ASD. This study indicated that autism-specific care plans are both feasible and hold promise to improve the experience of care for children with ASD and their families in the hospital setting. Nicholas et al<sup>11</sup> carried out focus groups among key stakeholders (parents, frontline clinicians, and administrative decision-makers) to learn more about ways to improve the emergency department experiences of children with ASD. Participants recommended strategies to better accommodate emergency department services to children with ASD (eg, sensory environment), manage wait time, engage with families, and build capacity among health care providers and the health system more broadly.

Four articles shed further light on correlates and current practice with respect to medical and mental health comorbidities in ASD. Malow et al<sup>12,13</sup> extended previous analyses of the ATN registry, to describe how estimates of the frequency of sleep problems in children with ASD vary by ascertainment method. Parents reported higher rates relative to clinician-reported diagnoses, although medications may be prescribed even in the absence of a documented diagnosis. Greenlee et al<sup>14</sup> found that a history of depression in children with ASD, as reported by parents, was more common with greater chronological age (reaching 20% in those aged 13–17 years), higher cognitive level, and in those

with an Asperger disorder diagnosis. Depression was also associated with higher rates of seizure disorders and gastrointestinal problems, as well as other somatic complaints. High rates of medical and mental health, as well as neurodevelopmental, comorbidities were also highlighted by a survey of developmental and behavioral pediatricians comprising a national research network (DBPNet) in the United States, as reported by Hansen et al.<sup>15</sup> Finally Ezell et al<sup>16</sup> described patterns of comorbidity among children with ASD who had been adopted. Compared with other children with ASD, the adopted group had more severe parent-reported behavior and sleep problems and were more commonly prescribed psychotropic medication, emphasizing the complexity of the care needs of this population.

Collectively, the articles in this supplement offer considerable insights to help inform child- and family-centered care for the ASD population across a range of health care contexts, addressing service delivery needs related to core symptoms and comorbidities. The practice recommendations and novel findings relevant to clinical practice can support primary care practitioners in their efforts to provide a medical home for children with ASD and foster holistic and coordinated care over time.<sup>17</sup> Follow-up studies are needed to track the implementation of these recommendations and their impact on child and family well-being and quality of life.

This body of work also reflects the multifaceted nature of ASD and the importance of addressing the range of physical and emotional health challenges associated with the disorder. By drawing from rich databases such as the ATN clinical registry, the supplement findings reflect the experiences of a broad range of children with ASD, although with the caveat that ethnic and

economic diversity may not be fully represented. Of the 8 studies in which it was appropriate to describe individual characteristics, 7 reported that the vast majority of the sample was composed of individuals described as white/Caucasian (race) and non-Hispanic (ethnicity). In addition, only 5 studies reported some measure of socioeconomic status (income or education), and 3 of these studies had samples with high incomes or education relative to national averages. Innovative programs such as ECHO Autism (see Perrin et al in this supplement) hold promise for reaching a broader population of children with ASD and their families.

Finally, the studies in this supplement covered the age continuum from infancy to the transition to adulthood, although most data presented were cross-sectional. Future longitudinal analyses should generate further insights into the developmental course of ASD and provide opportunities to examine the impact of variation in clinical practice (including specific interventions) on trajectories of core symptoms and comorbidities. We hope the work reported here will stimulate many other investigators to collaborate to improve care for children with ASD and related neurodevelopmental disorders.

#### ABBREVIATIONS

ASD: autism spectrum disorder  
 ATN: Autism Speaks Autism Treatment Network

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## Editors' Note and Prologue

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