

Editors' Note and Prologue

AUTHORS: James M. Perrin, MD,^a and Daniel L. Coury, MD^b

^aDepartment of Pediatrics, Harvard Medical School, MassGeneral Hospital for Children, Boston, Massachusetts; and ^bDepartment of Pediatrics, Nationwide Children's Hospital, Ohio State University School of Medicine, Columbus, Ohio

ABBREVIATIONS

AIR-P—Autism Intervention Research Network on Physical Health

ATN—Autism Treatment Network

CAAI—Combating Autism Act Initiative

MCHB—Maternal Child Health Bureau

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Address correspondence to James M. Perrin, MD, Department of Pediatrics, Harvard Medical School, MassGeneral Hospital for Children, 100 Cambridge St #1542, Boston, MA 02114. E-mail: jperrin@partners.org

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After the Combating Autism Act of 2006, the Health Resources and Services Administration/Maternal Child Health Bureau (MCHB) in 2008 developed a program covering several research, guideline development, and training activities (the Combating Autism Act Initiative [CAAI]). Two autism intervention research networks received funding through this initiative, as did both Leadership Education in Neurodevelopmental and Related Disabilities and developmental/behavioral pediatrics training programs. MCHB also initiated several research projects in autism intervention through a request for proposals.

One of the research networks, the Autism Intervention Research Network on Physical Health (AIR-P), expanded on an already existing network, the Autism Treatment Network (ATN), which had initial (and continuing) infrastructure support from Autism Speaks. Overall activities of the AIR-P are described later in this supplement. This network also took on leadership in developing the current supplement, to describe a number of the activities of the MCHB initiative and findings from related research studies.

This supplement includes several sections, all related to the initiative. It brings together in one place a rich and diverse compilation of clinical research and practice improvement related to the care of children and youth with autism and related neurodevelopmental disorders. The supplement begins with an introduction from the MCHB describing the CAAI, followed by an article that describes the development of the larger of the research networks, the AIR-P. One of the components of the ATN is a patient data registry that allows analysis of a number of research questions about children and youth with autism. The next section of the supplement provides results from registry analyses in areas of psychotropic medication use; complementary and alternative medication use; sleep and behavior problems; and the associations of attention-deficit/hyperactivity disorder symptoms, adaptive functioning, and quality of life in children with autism.

A major activity of the CAAI has been the development of clinical practice guidelines based on best available current evidence. Three of these, covering constipation, insomnia, and medications for attention-deficit/hyperactivity symptoms, arise from the work of the ATN. A fourth, on nonmedical interventions, comes from the companion Autism Intervention Research Network on Behavioral Health. The statements, findings, conclusions, and recommendations in these guidelines are those of the author(s) and do not necessarily reflect the view of MCHB, Health Resources and Services Administration, the US Department of Health and Human Services, or Autism Speaks.

CAAI support has led to the initiation of more than 16 clinical research projects within the AIR-P, several recently completed or nearing completion. Reports from 3 of these, on insomnia interventions and nutritional status and iron status of children with autism spectrum disorders, are included in this supplement. A fourth article in this section reports on a consensus meeting from a full-day session at the 2009 meeting of the

North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition, supported by Autism Speaks, to develop a research agenda in the area of gastrointestinal disorders among children and youth with autism, an area of intense interest to parents.

The final set of articles arises from other research activities of the CAAI, other than those in the AIR-P. The first is a review of guidelines for nonmedical interventions arising from the behavioral health network. Two reports provide

early data from research projects supported by MCHB, along with an analysis of associations of immigrant status with autism and other neurodevelopmental disabilities carried out by MCHB investigators.

The supplement closes with an overview of promising next steps in autism intervention research: what topics to address, how new technologies may help speed research, and the role of networks in these efforts.

Together, these articles provide a broad look at issues that families face as they interact with the health care community and seek the best treatments available for their children with autism and related neurodevelopmental disorders. Our hope is that this issue will help inform the health care community and parents about the needs of children with autism and the evolving knowledge, practices, and guidelines that can ultimately improve the quality of health care that children and their families receive.

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