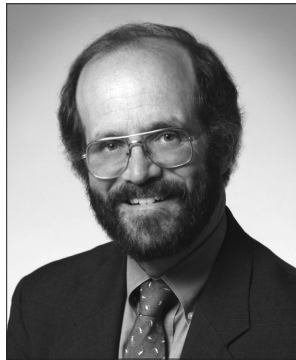




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Autism in Wisconsin—Is It Increasing, and What Can We Do About It?

Albee Messing, VMD, PhD; Robert N. Golden, MD

The Waisman Center, which has graced the University of Wisconsin's west campus for more than 50 years, is internationally renowned for research and clinical services related to developmental disabilities. Named after Harry Waisman, MD, PhD, a pediatrician and biochemist who in the 1940s through 1960s pioneered work in polio and metabolic disorders, the Center has a comprehensive mission that combines clinical service, education, outreach, and research spanning the entire continuum from molecular biology to social sciences. One of a nationwide network of 14 Intellectual and Disabilities Research Centers funded by the National Institutes of Health, the Waisman Center recently received renewal of its funding through 2021 following a rigorous competitive peer-review process.

The Center achieves its clinical mission through an active partnership with UW Health, and together we manage 14 clinics and treatment programs that provide care for patients from throughout Wisconsin and the United States.

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In this column, we highlight efforts related to autism and autism spectrum disorders (ASD). Waisman Center clinicians and researchers

Based on case findings throughout Wisconsin, he identified 280 children ages 3 through 12 years who met criteria for "infantile autism."

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have been committed to advancing our understanding of these disorders for many years. Recently, public interest has increased because of an apparent rapid rise in prevalence and the corresponding burdens faced by families as well as health care and education facilities. We consider 2 questions: Is the prevalence really increasing, and how can we help children and adults affected by autism and ASD?

Is the Prevalence of Autism Increasing?

One of the most notable trends in developmental disabilities in the past 2 decades has been the rising number of individuals diagnosed with autism. In 1970, Wisconsin psychiatrist Darold Treffert, MD, published the nation's first population-based study of the prevalence of autism.¹

This corresponded to a population prevalence of 3.1 per 10,000 children. Today, the prevalence of autism in Wisconsin and nationally is estimated to be more than 30 times higher than this, at greater than 1% of children.

To monitor the rise in autism and better understand its underlying causes, epidemiologists at the Waisman Center and the UW School of Medicine and Public Health's (SMPH) Department of Population Health Sciences have been working since 2003 with state partners, the Centers for Disease Control and Prevention in Atlanta, and other sites around the country. They have identified one clear explanation for the trend: the broadening of the concept of autism and its diagnostic criteria over time, to include a wider spectrum of impairments

in social communication and interaction with restricted and repetitive patterns of behavior. However, not all of the increase can be readily explained by the casting of a wider net of diagnostic criteria.

For example, between 2002 and 2012, a period in which there was no change in ASD diagnostic criteria, the prevalence among 8-year-old children in Wisconsin increased more than 2-fold, from 0.5% to 1.1%.² The rise in autism prevalence also is seen in school enrollment data. In Wisconsin, the number of children receiving special education services for autism in 2015 was 11,470—up from 20 in 1992, the first year autism was introduced as a disability category for special education. Factors contributing to the increased prevalence are complex and may include older parental age, longer interpregnancy intervals, exposure to unknown toxins, and genetic variants that will take years to understand.

How Can We Help Individuals and Families Affected by Autism and Autism Spectrum Disorders?

Although ASD is most often diagnosed in early childhood, the condition affects patients and families across the lifespan. Indeed, an ASD diagnosis has an enormous impact on patients, families, and educational, health care, and social service systems. ASD should be viewed as a major national issue. For 2015, the annual combined direct medical, nonmedical, and productivity costs were estimated to be \$268 billion, and the forecasted costs for 2025 will reach \$461 billion.³ If the prevalence of ASD continues to grow at its recent pace, related costs likely will far exceed those of diabetes and attention deficit hyperactivity disorder by 2025.

In response to the increased number of patients diagnosed with ASD and the related costs, UW Health and the Waisman Center recently partnered to develop a suite of treatment programs—the “Together” series—to provide care from diagnosis to young adulthood. The goals are to reduce the patients’ severity of symptoms and improve their cognitive and social skills, decrease family stressors, and, in turn, reduce the need for treatment and sup-

port as patients grow older. ASD treatment contributes to significant positive developmental changes for patients, including increases in IQ, lessening of ASD symptoms, and decreases in the amount of intervention needed at school age for patients who receive intensive early intervention.⁴

Our Starting Together Program, launched in 2016, highlights the value of early intervention for children ages 2 through 5. An in-clinic adaptation of the Early Start Denver Model (ESDM),⁵ the program utilizes evidence-based practices of Applied Behavior Analysis. Sessions are provided in clinic and preschool settings, with direct one-to-one teaching and group instruction during typical preschool activities and play. Education and coaching also are provided to each family, based on the ESDM. Our goal is to develop a collection of best practices that are suitable for implementation in community settings and that are more effective than current approaches.

Even with early intervention, challenges remain. Lifespan trajectory studies identified a critical period as young adults leave the high school setting (thus leaving mandated services) and enter a period of much less-structured lifestyles. After high school, these young adults plateau and often decline in their functional capacity. To intervene in this critical period, Waisman Center investigator Leann Smith developed a multifamily group psycho-education intervention, Transitioning Together, for adolescents with ASD and their families.⁶ Outcomes from this intervention include improvements in social interactions for youth with ASD and well-being for parents. The fully manualized intervention is now available at the Waisman Center and also in dozens of schools and clinics across Wisconsin and the United States as a result of outreach and training.

UW Health and the Waisman Center share a mission to improve the lives of patients with ASD and their families through superior interdisciplinary care. This partnership provides patients with access to exemplary, evidence-based ASD treatment services that lead to the best possible clinical outcomes. We hope our ASD treatment services will serve as a model for Wisconsin, the region, and beyond.

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