

# Preface

This book exists for two primary reasons: (1) the incredible pressures on educators to address children’s medical issues in school settings and (2) the rapid pace of news and information delivery, which often occurs despite safeguards to ensure credibility and verifiability. Educators are charged with making policies, differentiating instruction, providing educational accommodations, managing the physical plant, providing special education services, collaborating with families, and working with the community in response to children’s medical, physical, and psychological issues. However, educators often have little training, support, or information to address these important issues. When faced with a medical question, many people (including us) turn to the Internet. Although much information from the Internet is high quality, much is not. Peer-reviewed scientific papers are often given the same weight in search engine results as advertisements for the latest snake oil. Information about medical issues is (1) presented in esoteric medical science journals with little relevance to schooling, (2) included as part of an encyclopedic but cursory overview of many topics, or (3) summarized and simplified on Web sites with questionable accuracy and oversight. We developed this book to give support and information to educators based on a critical review of scientific research that is credible, in depth, and practical.

*Genetic and Acquired Disorders* is the second book in a three-volume series entitled *Current Topics and Interventions for Educators*. This series presents detailed reviews of recent scientific research on a variety of topics in pediatrics that are most relevant to schools today. *Current Topics and Interventions for Educators* is intended to provide not only detailed scientific information on pediatric issues but also glossaries of key medical terms, educational strategies, case studies, handouts for teachers and parents, and discussion questions. Readers are presented with critical reviews of scientific medical research, including discussion of controversial issues. The authors of each chapter have completed scholarly reviews of the extant research and carefully considered the quality of research design, methodology, and sampling in determining what can be considered empirically valid conclusions versus conclusions based on hyperbole, conjecture, or myth. We believe that this information will help educators address the pediatric issues that affect schoolchildren and be better equipped to discuss these issues with parents, staff, and medical teams.

This book originated from a regular feature in the National Association of School Psychologists (NASP) publication *Communiqué* called “Pediatric

# 1

# Advances in Health Care and Medical Science

*Presenting New Challenges for Schools*

*Paul C. McCabe and Steven R. Shaw*

**T**he last several decades have seen tremendous progress in the medical science, research, and technologies that can be used to prevent and fight childhood disease. As a result, children born with or who acquire a medical disorder or disease are much more likely to survive the condition and live longer, healthier lives. However, a greater chance for survival does not come without complications. Although children with serious medical conditions may survive, they often experience physiological, psychological, and emotional effects secondary to the medical condition and/or the treatment. Many of these effects continue into adulthood. In addition, changes in the way medical treatments are administered have increasingly emphasized outpatient care and de-emphasized inpatient stays, in part due to advanced technologies and medications that make this possible. Therefore, most, if not all, treatment may be administered on an outpatient basis. This paradigm shift places an increased burden on families to oversee the child's treatment and follow-up, as well as on educators, who must coordinate home instruction or make necessary preparations for the child's re-entry to the classroom. It is important to examine how

# 3

## Rare Chromosomal Disorders\*

*Shohreh M. Rezazadeh and Steven R. Shaw*

Austin is a 5-year-old boy who is entering kindergarten. He is a happy child, but he has a number of unusual behaviors. When he plays with his favorite toys, he shakes and turns them. He frequently giggles, but for no obvious reason. Austin seldom interacts with other children except to provoke a response. He enjoys positive (laughter) and negative (crying) reactions from his peers. For example, sometimes he grabs a toy out of his sister's hands, not because he wants to play with it but because his sister becomes agitated and screams at him. Austin usually just drops the toy on the floor as he runs away giggling. He becomes preoccupied with various toys and repeats the same activity many times each day. His repetitive behaviors, such as playing with spinning objects and moving his fingers across his line of vision, can absorb his attention completely. He has received a diagnosis of autism and fragile X syndrome.

Because of Austin's behavior and social and cognitive issues, an Individualized Education Plan (IEP) has been developed by his teachers, therapists, and parents. His IEP has extensive treatment plans for attention problems, mood swings, tantrums, and hyperactivity. At this point, he has not experienced many mood swings or tantrums (although he has thrown some tantrums). Yet mood swings and tantrums are very common in children who have autism and fragile X syndrome.

Angela is a 9-year-old girl diagnosed with Williams syndrome. In addition to a number of health issues, such as cardiac issues and early puberty, she shows a distinctive facial appearance, an "elfin face." Angela also has moderate intellectual disabilities. She is overly and, sometimes, inappropriately friendly with both

\*Adapted from Shaw, S. R. (2003). Rare chromosomal disorders. *Communiqué*, 32(4), 37–39. Copyright by the National Association of School Psychologists, Bethesda, MD. Use is by permission of the publisher. [www.nasponline.org](http://www.nasponline.org)

the twins to a specialized school. She does not want to separate the twins, as they are close, but she feels that Trevor will excel if placed in the regular school environment. She is also exploring the option of medication to control Ethan's aggressive behavior.

## INTRODUCTION

Autism is a heritable, complex neurodevelopmental disorder characterized by distinct impairments in the areas of social interaction, speech development, and range of interests and activities. Autism is the most severe manifestation of a broad spectrum of disorders known as autism spectrum disorders (ASD) that share these essential features but vary in their degree of severity and/or age of onset. Within this spectrum, there are currently five official diagnoses:

1. *Autistic disorder*: Characterized by deficits before the age of 3 years in social interaction and communication (e.g., spoken language), accompanied by repetitive patterns of behavior, interests, and activities.
2. *Asperger's disorder*: Presents with similar but milder symptoms as seen in autistic disorder but without a language delay or cognitive impairment.
3. *Pervasive developmental disorder—not otherwise specified (PDD-NOS)*: Symptoms do not meet the criteria for autistic disorder because of late age at onset or atypical symptoms. Symptoms include impairment in the development of social interaction with either a deficit in communication skills or repetitive patterns of behavior, interests, and activities.
4. *Rett disorder*: Normal development occurs for the first 5 months after birth, followed by deceleration of head growth, loss of learned hand skills, loss of social engagement, poorly coordinated body movements, and severely impaired language development. This genetic disorder only presents in females.
5. *Childhood disintegrative disorder*: Characterized by normal development for at least the first 2 years after birth, followed by a loss of learned skills (before age 10 years) in language, social skills or adaptive behavior, bowel or bladder control, play, and/or motor skills.

Autism is recognized as the most common neurodevelopmental disorder, with estimates ranging from 1 in 100 to 1 in 300 children diagnosed with an autism spectrum disorder (CDC, 2009; Fombonne, 2003). Researchers believe that autism may have many genetic and nongenetic causes. In some instances, autism is a feature of an identifiable genetic condition; however, often no specific cause can be determined. During the past few decades, scientists have made significant breakthroughs in understanding the genetics of autism. Through newly developed technologies, researchers are now focusing on specific chromosomal regions that may contain autism-related genes. Recognizing autism spectrum disorders as a

Some research indicates that a person's current asthma status is associated with the condition's psychosocial impact. For example, Halterman and colleagues (2006) found that greater asthma severity is associated with higher likelihood of behavioral difficulties. Other studies have found that it is not severity but rather variables such as the general health of the child or parent and family functioning that better explain differences in psychological functioning and HRQOL (Calam, Gregg, & Goodman, 2005). Although it is apparent that parent and family factors are related to HRQOL in pediatric asthma, the specific mechanisms are unclear. It is possible that these variables affect HRQOL and other asthma outcomes through asthma management strategies practiced at home (e.g., adherence to medication regimens; Klinnert, McQuaid, & Gavin, 1997) and/or through psychophysiological pathways (Wright, Rodriguez, & Cohen, 1998).

## IMPLICATIONS FOR EDUCATORS

Given the high prevalence of pediatric asthma, educators are likely to encounter students with this condition on a regular basis. Collaboration among families, schools, medical professionals, and students themselves is vital to effective asthma management. Educators not only need to be aware of students' individual asthma symptoms but also knowledgeable regarding other factors that can impact the course and progression of the illness. These include severity level, subtypes, and patterns of symptoms (e.g., seasonal variations). In addition, school professionals can make valuable contributions when it comes to assessing the impact of asthma on students' everyday functioning and quality of life. This can be done through the use of surveys, such as the Adolescent and Child Health and Illness Profiles (Starfield et al., 1995), or through semistructured interviews. In assessing HRQOL, clinicians and educators should obtain a comprehensive picture of functioning that takes into account additional risk factors (e.g., poverty, low availability of appropriate health care), as well as student and family strengths and resources. Results from such assessments can be used by educational teams to gauge the impact of asthma on different areas of school functioning and to develop appropriate accommodations and interventions.

Educators must be competent in determining and providing appropriate services, accommodations, and interventions for students with asthma. It is essential to consider each student individually and not use a cookie-cutter approach. Each student with asthma should have an individual asthma action plan that specifies his or her symptoms and management. Due to possible side effects, students who take medication on a regular basis may require specific school-based accommodations, such as medication monitoring. Those with severe asthma may be eligible for a classification of "other health impaired" and receive special education and related services. Students with less severe asthma may be eligible for accommodations under Section 504, since their disease constitutes a physical impairment that significantly limits one or more major life activities. More recently, research and clinical practice have highlighted links between pediatric asthma and obesity (Figuroa-Muñoz, Chinn, & Rona, 2001). Due to the challenges posed by the combination of these conditions, it is important for school clinicians to collaborate with teachers and families to