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This volume is impressive in its organization, readability, and coverage of a wide range of common and uncommon health conditions. The inclusion of practical, evidence-based medical, psychosocial, and academic interventions is especially useful. This is a highly valuable resource for practitioners, trainers, and students in school psychology and other educational professions.

—**Thomas J. Power, PhD, ABPP**, Professor, School Psychology in Pediatrics and Psychiatry, Children's Hospital of Philadelphia; Perelman School of Medicine at University of Pennsylvania, Philadelphia, PA, United States

This is not just another summary of facts: It is a sourcebook for providers and researchers to further explore topics some have never heard of before. This is what I consider a true contribution to the field of psychology.

—**Elaine Clark, PhD**, Professor, Educational Psychology, University of Utah, Salt Lake City, UT, United States; Fellow, American Psychological Association

The second edition of *Health-Related Disorders in Children and Adolescents* is an outstanding new volume and a worthy tribute to Dr. LeAdelle Phelps's classic text. The tone and focus of the book support the role of psychologists and educators in interdisciplinary coordination and consultation for children and adolescents with medical issues. Drs. Perfect, Riccio, and Bray have brilliantly modernized, reorganized, and updated an important text in pediatric school psychology.

—**Steven R. Shaw, PhD**, Associate Professor, Department of Educational and Counselling Psychology, McGill University, Montreal, QC, Canada

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## 1

## Introduction to the Second Edition

Michelle M. Perfect, Cynthia A. Riccio, and Melissa A. Bray

Although estimates vary, as many as one fourth of school-aged students experience some form of a health-related condition—the equivalent of over 15 million individuals under the age of 17 (Van Cleave et al., 2010). One possible explanation for these high rates has been the significant improvements in survival rates for children with chronic illnesses (American Academy of Pediatrics, 2016). By definition, a *health-related condition* occurs when there is a specific set of symptoms, with those symptoms persisting for 3 or more months (Katz et al., 2015). Most practitioners, regardless of their professional orientation, are familiar with disorders like attention-deficit/hyperactivity disorder (ADHD), Down syndrome, and other more frequently encountered health-related chronic conditions.

Over 20 years ago, the first edition of this book, *Health-Related Disorders in Children and Adolescents: A Guidebook for Understanding and Educating* (Phelps, 1998), was published, supplying vital empirical information about medical conditions that had been previously unavailable and providing practical information about how to support these students not only medically but also educationally and social–emotionally. This second edition focuses on disorders with less widespread research and information yet with a prevalence of at least one in 25,000 individuals. In many cases, these less researched conditions co-occur with ADHD or other emotional and behavioral disorders (Pan & Bölte, 2020). Moreover, it is important to note that additional syndromes or disorders may exist or have yet to be identified. Taken together, the conditions selected

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*Health-Related Disorders in Children and Adolescents: A Guidebook for Educators and Service Providers, Second Edition*, M. M. Perfect, C. A. Riccio, and M. A. Bray (Editors)  
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for inclusion demonstrate the similarities and differences across a range of disorders. With the updated organization and research included here, the second edition may prove helpful for psychologists, medical professionals, educational professionals, and others involved in behavioral health, as well as university training programs.

## **THE INTEGRATED COLLABORATIVE APPROACH**

As noted already, over the past 2 decades, innovative and effective medical treatments have led to increased survival rates, necessitating an updated resource that summarizes the prevailing issues related to health-related conditions, potential accommodations, and needed supports that would allow medically involved students to achieve success. At the same time, there has been growing awareness of the need for coordinated behavioral health services. The educational implications for children with health-related difficulties and the need for collaboration among parents and medical, behavioral health, and educational professionals have been known for some time (Harris, 2009; Power et al., 2003). Reauthorization of the Individuals With Disabilities Education Act (2004) with Other Health Impairment as a disability category cemented the mandate for thoughtful coordination of educational programming, including psychological services, for children with health conditions. Despite the frequency and mandates, however, empirical studies have continued to demonstrate that there are immense unmet needs for children with chronic conditions and their families. For the children, this educational–health care gap exists due to limitations of regulations governing education and lack of research to identify and support the appropriate educational services needed.

School psychologists and other mental health professionals in the schools are in a unique position to take the lead in orchestrating and coordinating school-based services for students. These professionals have knowledge of special education law as well as training and skills in consultation and collaboration among school-based professionals and parents. Although medical professionals have expertise in addressing medical issues, mental health professionals like school psychologists understand the complex nature of cognitive, academic, and psychosocial factors of children with health-related conditions (Root et al., 2016).

This second edition is intended to provide a synergy of scientific underpinnings and practical research-based suggestions. The editors recognize that the book is not exhaustive; not all health conditions are included, and prevalence may vary depending on developmental level. In order to accommodate the number of disorders, chapter content is targeted and specific to the goals of this text: to inform users of the most up-to-date information on symptoms, outcomes, and potential interventions.



## **ORGANIZATION AND STRUCTURE OF THE CHAPTERS**

The etiology of health conditions varies widely but typically involves disruption or dysfunction in one or more body systems. Body systems can be categorized as involving (a) the blood, cardiovascular system, and circulatory system; (b) the respiratory system; (c) the central nervous system; (d) the musculoskeletal system, focusing on bone and muscle; (e) the digestive system; and (f) the endocrine and reproductive systems. In addition, some disorders are best classified by mixed or multiple systems. Where possible, this text organizes disorders on the basis of the primary system or systems involved, with a number of disorders grouped as multiple system disorders. A brief introductory chapter about the body system(s) and a global understanding across the disorders is provided at the beginning of each part, with the following chapters listed alphabetically. All chapters have a similar structure: Etiology; Prevalence and Incidence; Symptoms; Outcomes, organized by Medical, Cognitive/Academic, and Social–Emotional and Behavioral; Interventions, organized by Medical Management, Cognitive/Academic, and Social–Emotional and Behavioral; Conclusion; Resources; and References.

### **Genetic Etiology**

Health-related disorders may be attributable to heritability and genetics such that the presence of the disorder is evident across family members and generations, with specific genes identified. Genes are found in DNA, and for many disorders, atypical series on specific locations on a given specific gene or genes give rise to the disorders. When multiple genes and locations are involved, the extent to which atypical patterns are present determines the symptom presentation and the body system(s) affected. Throughout this text, authors present a summary of information about what is known for each condition or group of disorders regarding genetics and mechanisms that could lead to genetic alteration.

### **Symptom Presentation**

Taken together, the body system(s) involved and the variation in underlying genetic contribution give rise to a range of symptoms. Depending on the disorder, the identification of the problem and subsequent identification of causes may occur as early as in utero, at birth, in early childhood, at school age, or later, depending on when the disorder and its effects manifest. Where there is a positive family history, genetic testing may be done along with routine blood testing at birth. The initial effects and symptom manifestation may affect attainment of even very early developmental milestones or may become more apparent over age. Most often, the disorder or disease manifests before or when the child begins school, leading to identification of the disorder (Bai et al., 2017).

**Anticipated Outcomes**

Medical outcomes are featured in each chapter for readers to understand the prognosis and health implications of the health conditions. At the same time, cognitive ability and acquisition of academic skills, as well as social–emotional development, may be compromised as the disorder manifests. As children enter school, considering implications for medical, cognitive/academic, and social–emotional factors in a coordinated fashion becomes critical. What is known about cognitive and academic outcomes associated with the disorder is highlighted. Similarly, anticipated social–emotional and behavioral issues associated with the disorder are discussed. Reviewed together, the extent of synergy across medical, cognitive/academic, and social–emotional and behavioral outcomes becomes evident. This speaks to the need for those involved in treating and supporting children with chronic disorders, regardless of their primary professional responsibility, to consider all child-specific facets, as well as the family system.

**School-Based Interventions**

Within each chapter, evidence-based interventions from a medical, behavioral health, and educational perspective are offered with the caveat that what works best will need to be individually determined as part of each child's medical treatment and educational planning. Medical management may or may not be extensive. Moreover, physical symptoms and medical needs often change over the course of development. Similarly, as the child progresses through school, curricular demands and expectations for independent function shift. Finally, the social and behavioral demands and pressures change. Most importantly, the medical status, cognitive/academic challenges and successes, and social and behavioral difficulties interact, rather than occurring in isolation. Thus, the use of a team approach is emerging as a preferred model, involving service providers from all contexts related to the child. This team includes medical practitioners, educators, and mental health professionals, such as nurses, special and regular education teachers, and psychologists. It also includes consideration of the family context. The child is not the only individual affected by the health-related condition; the family system is challenged as well. Family support is important to the outcomes for these children and can include parent training so that the family system may be empowered to build on strengths and assets.

**Summary and Resources**

Each disorder-focused chapter ends with a summary paragraph, highlighting the most salient information provided within the chapter. In some cases, the conclusion also identifies areas of additional research. To facilitate further study of the conditions of interest, authors were asked to provide resources that may

provide further detail or be appropriate for sharing with parents and other professionals working with that child.

## CALL TO ACTION

As mentioned, a significant gap persists between professionals who work with children with chronic health disorders (e.g., medical staff, educators, mental health professionals). Many health care settings have only recently begun to incorporate behavioral health as an integrated service; fewer use an interdisciplinary team that includes school-based staff. Within educational settings, there are already established teams aligned with special education or the Americans With Disabilities Act. The coordination of services to integrate health care and educational teams is a common component across chapters in this text. Bidirectional flow and communication are needed to meet the medical, educational, and social and behavioral needs of children with health-related disorders. Hopefully, as you use this text, you will be energized to work toward a more integrated and collaborative approach to identification, goal determination, intervention and accommodations, and progress monitoring. A more detailed discussion of coordinated care across disorders is provided in Chapter 2 by Forman et al.

## RESOURCES

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