
Preface

Children with special health care needs (CSHCN), including children with disabilities, represent approximately 20% of all children. They comprise a considerable extent of human variation, with their principal general distinguishing characteristic being that they need additional educational, health, medical, and assistive services so that they can live optimal lives. Whereas some of their conditions are severe, drastically limiting their potential, they are children, and we are committed to developing research and services that will help them to have happy, successful lives and to become leaders in our society.

In this book, 41 international experts on CSHCN have prepared chapters describing various aspects of disability policy, research, treatments, and interventions. The purpose of this handbook is to provide the many researchers, policy developers, consumer advocates, and families of CSHCN with resources to further their work. The topics are by no means exhaustive nor cover every type of disability or special health care need. Furthermore, the chapters are provided in no particular order of importance, although I have arranged them in a general flow of thematic areas, starting with policy, progressing through various conditions and contextual approaches for interventions, and concluding with special topics and the important emphasis on the medical home, the continuous, lifelong tracking of health and development that is critical for positive health outcomes of CSHCN, even for all of us.

Donna Petersen gets us started with an overview of CSHCN and public health policy in Chap. 1. In Chap. 2, Carol Page and Patricia Quattlebaum describe severe communication disorders and their treatment, conditions which affect many children but which may or may not attenuate with child development.

Andrew Martin follows in Chap. 3 with a comprehensive discussion of a major behavioral condition, Attention Deficit Hyperactivity Disorder (ADHD), which is increasing worldwide. Martin interweaves this discussion with intervention applications that involve the rich educational research literature on promoting children's positive psychological self-worth. Sunil Karande complements this chapter with a strong medical perspective on ADHD diagnosis and treatment in Chap. 4.

Ann I. Alriksson-Schmidt and Judy K. Thibadeau from CDC provide Chap. 5 on mobility limitations in CSHCN. Chaps. 6–9 address sensory

disabilities starting with Irma M. Munoz-Baell, Carlos Alvarez-Dardet, M. Teresa Ruiz, and Emilio Ferreiro-Lago, who present deaf education from a deaf culture advocacy perspective (Chap. 6). Jugnoo Rahi and Lola Solebo describe childhood eye disorders and visual impairment (Chap. 7), then Diane Whitaker and Elana Scheiner present specific approaches to evaluating infants and school children for visual disabilities (Chap. 8). Dental health often is overlooked for CSHCN, so Nancy J. Murray and Mary Anderson Hartley discuss oral health access issues for CSHCN in Chap. 9.

Tuberculosis often is overlooked among major, deadly diseases despite the facts that it kills more children than most other diseases combined and that approximately 30% of humans have been exposed to the bacterium. In Chap. 10, Elisabetta Walters, Elizabeth Lutge, and Robert P. Gie provide a sobering description of tuberculosis among children in southern Africa and issues involved in testing, diagnosing, and long-term treatment of the disease.

In Chap. 11, Yann Mikaeloff discusses diagnosis and treatments for CSHCN with multiple sclerosis. In Chap. 12, Jacquelyn Bertrand and Elizabeth Parra Dang from CDC provide a thorough overview of diagnosis and treatment issues for fetal alcohol spectrum disorders, which vary in extent but impact affected children for their entire lives.

Chapters 13–15 cover newborn screening for genetic, metabolic, and birth defect conditions. Bent Nørgaard Pedersen and David Michael Hougaard begin with a comprehensive discussion of newborn-screening programs and how laboratory tandem mass spectrometry and pediatrician follow-up visits can rapidly diagnosis and treat genetic and metabolic disorders following the heel stick blood test that is collected at birth for newborn infants in many countries. David Hollar discusses many of the various types of genetic and metabolic conditions in Chap. 14, most importantly listing resources for these conditions, including the very useful online Mendelian Inheritance in Man (OMIM[®]) website, initially developed by Dr. Viktor McKusick and currently updated daily by Johns Hopkins University and the United States National Library of Medicine National Center for Biotechnology Information. Hollar continues in Chap. 15 with birth defects screened by the National Birth Defects Prevention Network, and he provides an unusual fusion of psychological and biological development that serves as a basis for trying to understand the origins of many types of disabilities.

For studying CSHCN, Willi Horner-Johnson and Kathleen Newton (Chap. 16) describe several major databases with information on CSHCN that have been useful for studying public health and policy issues, with many of these databases being publicly available in a deidentified format by request. Jennifer L. Rowland covers an emerging important topic, secondary conditions in youth with disabilities (Chap. 17), secondary conditions being generally defined as physical and/or psychological conditions that arise due to the child's primary disability condition or due to others' misperceptions or environmental barriers to the primary disability.

In Chap. 18, Jo Ann Ford, Judson Workman, Navid Masoudi, Mary Huber, Theresa Mayer, and Karel Pancocha discuss risk factors faced by adolescents with disabilities, most notably substance abuse, and they provide a unique perspective on school-based prevention programming with their prevention

through alternative learning styles (PALS) curriculum. I had the privilege of working with this group and this curriculum during 2001–2003.

David Hollar and Arun Karpur describe proper approaches with examples for conducting research involving CSHCN, especially protecting study participants' rights and confidentiality, in Chap. 19. In Chap. 20, Chad A. Rose, Stephen Allison, and Cynthia G. Simpson discuss the critical topic of bullying, for which many CSHCN are victimized, and they evaluate various approaches to reduce risks for bullying.

Finishing the handbook, Renee M. Turchi and Marie Y. Mann emphasize the medical home concept and continuity of care for CSHCN and their families in order to have optimal health outcomes. Hollar concludes a brief Chap. 22 with a summary of major concepts from the chapters. We hope that you will find the information in this handbook useful for advocating positive health and life outcomes for CSHCN.

This handbook resulted from outstanding teamwork among an international group of coauthors, all experts on Children with Special Health Care Needs (CSHCN) within the overlapping fields of public health, education, and medicine. I thank each of them for sharing their expertise. I thank editors Khristine Queja and Diana Alkema at Springer for originally suggesting the idea for this handbook, editors Bill Tucker and Ian Marvinney for facilitating early implementation of the project, and Kathryn Hiler and Shreya Bhattacharya for proofing and final formatting of the handbook. Many thanks go to John Hattie, Dennis Moore, Sanjay Asrani, and numerous colleagues with the Disability and Maternal and Child Health Divisions of the American Public Health Association as well as Springer's *Maternal and Child Health Journal* for topic suggestions and recommendations of coauthors for the handbook. I express special gratitude to my family, Brooke, Paige, Virginia, and Roselyn, for their faith, patience, support, and interest in this project.

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