

# CHAPTER 1

## **INTRODUCTION**

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In 2010, data from the national *Survey of Children with Special Health Care Needs* indicated that approximately 15% of children in the United States had special healthcare needs. With a population this large, it is likely that most pediatric healthcare professionals will have occasion to care for this population of children and their families in a variety of outpatient and inpatient settings in the community. Many clinicians, however, have limited experience with meeting the needs of children with disabilities and may feel uncomfortable with their care. Clinicians can significantly influence overall health and well-being by offering interventions that influence the well-being, levels of support, and stress levels of both children with disabilities and their parents. Taking a family approach is important not only for the adults but also because of the link between child well-being and parent well-being. Thus, the goal of this handbook is to provide a resource that is easily accessible to clinicians from a variety of disciplines, and that offers concrete, practical suggestions for caring for children with physical, sensory, developmental, communication, and social/emotional challenges. This text is likely to be of benefit to professionals from the fields of nursing, social work, physical therapy, occupational therapy, and speech therapy, among others. Although the primary focus of the handbook is on caring for children with disabilities in the United States, the organizing frameworks and major concepts presented in each chapter have cross-cultural relevance. We hope that this handbook will meet the needs of clinicians in practice. For this reason, the chapters are presented in an expanded outline format so that key material can be easily accessed, and each chapter offers suggested interventions that are highlighted.

The handbook is organized into three main content areas:

- Chapters 2 and 3 examine common features of a variety of physical, sensory, and developmental disabilities. Descriptions include etiologies, presenting signs and symptoms, prognosis, common therapies, and an introduction to roles of healthcare providers that are often a part of interprofessional teams caring for children with disabilities.
- Chapters 4 through 6 shift the focus away from recognizing and understanding a particular disability and toward specific interventions addressing differences common to children with a variety of special needs, including differences in community, mobility, and social/emotional status.
- Chapters 7 through 13 broaden the scope to inform clinicians about cross-cutting issues affecting children with disabilities in a variety of settings. We address the role of the family as client, legal and regulatory issues, theoretical bases for quality care, enhancement of the child's and family's quality of life, the role of public health and school nursing professionals, end-of-life care, care planning, and coordination of care.

We hope that by moving from a narrow focus on specifics to a broader perspective of the child and family in a variety of contexts that we are able to meet both immediate and longer-term needs of clinicians in practice. Throughout the handbook, the editor offers case examples from her practice as a pediatric nurse practitioner. One case in particular, from the editor's practice as a pediatric nurse practitioner with children with special needs, offers a number of promising practices for high-quality care of children with special needs and their families, as well as examples of challenges inherent in caring for this population. Exemplars of practice, such as this case, will be referenced throughout the remainder of the text.

- This is the story of Mia and her family. Mia is a five-year-old child with Down Syndrome who came into our outpatient pediatric clinic because of complaints of ear pain. Our staff was very familiar with Mia and very comfortable with her mother's knowledge about otitis media. I examined her, prescribed an antibiotic, and did the necessary teaching for safe administration. Although as pediatric primary care providers we often choose a "watch and wait" approach to treatment of otitis media in typically developing five-year-olds, children with Down Syndrome have some anatomical differences in the ear that put them at greater risk from complications related to otitis media.

What I did less well was to inquire about the family system, and how they were adjusting to her diagnosis of Down Syndrome and all that entails. This memory stays with me many years later, as I have a child with severe disabilities and those early years were devastating to our family. Still, probably due to "being too busy," I did not take the time to make sure all was well. The next time I saw the family in the clinic all was clearly *not* well. Even though Mia presented with a similar complaint, her ears were fine but her family was not. This time her father was with Mia and her mother, and there was noticeable tension in the room. After assuring the family that Mia's ears were not infected, I asked "how is everything else going?" At this point, Mia's mother burst into tears, her father grabbed her, and they walked out of the examination room. Mia's mother told me that they had just received a letter from their local public school that outlined Mia's special education setting for her kindergarten year that fall. Apparently (and unsurprisingly) Mia's mother had been receiving lots of support from other parents of children with disabilities, but her father had been more or less denying the diagnosis and talking about her future as if the Down Syndrome did not exist. The letter from the school system eroded his denial and he was very angry. At this point in the encounter, one of my colleagues played with Mia in the waiting room and I spent time listening to Mia's parents talk and grieve, helping them make plans to move on. I was able to make some referrals for counseling and support that they requested, as well as help them develop a plan for respite care so that they might strengthen their ties as a couple. If I had only done this on the previous visit, this visit might have been unnecessary.

Although the first encounter demonstrates the importance of understanding growth and developmental differences in order to provide appropriate health promotion and disease prevention education for Mia, as well as the important role of the family as the context for high-level wellness in the child, the second encounter demonstrates a higher level of care with the entire family as the client.

