THE HANDBOOK OF CHILD LIFE

THE HANDBOOK OF CHILD LIFE

A Guide for Pediatric Psychosocial Care

Edited by

RICHARD H. THOMPSON, PH.D.

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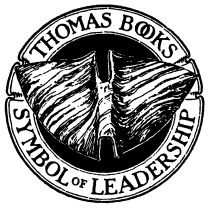

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TO MY FAMILY

LYNN, BRENNA, AND HALEY

INTRODUCTION

It has been said that the moral test of a society is how it treats its most vulnerable citizens. Those who enter the field of child life daily encounter those in our society who are among the most vulnerable . . . vulnerable because of their age and their ways of interpreting the world, vulnerable because of their physical circumstances, vulnerable because of the unfamiliar they encounter, vulnerable at times because of additional barriers such as language, poverty or prejudice. Yet, the child life specialist understands that each individual, despite the vulnerabilities he or she may bring to an encounter, also brings strength and resiliency. The task of the child life specialist is to build upon those strengths to minimize individual vulnerability and maximize the growth of the individual. The goal of this text is to assist in this process, drawing upon the expertise of leading figures in the field to help provide child life specialists, and other allied health professionals, with the knowledge and skills they will need to accomplish this important task.

This text was conceived several years ago through a conversation with Doctor Peggy Powers, my faculty colleague at the time at Wheelock College. We began with an outline of topics we felt would address the most important aspects of the practice of child life, a list that was modified more than once in the subsequent years. We then set about contacting our respected friends and colleagues in the field of child life, asking them to contribute a chapter and, in most cases, pairing them with one or more additional authors with whom they may or may not have already had a working relationship. Having assigned the topic for each, we gave them the further guidelines that the book be geared toward an audience beyond the introductory level, that it include information on the state of the art in the given area, and that, wherever possible, it demonstrated application of the content in practice through case studies.

We are grateful to each of the authors for the collaborative spirit with which they approached this project, for care with which they prepared their chapters, and for their patience with the editing process. On behalf of the authors, I would also to acknowledge the many, many individuals who have contributed to the preparation of this book through their reading and review

of the text, through their support of the process and in many other ways too numerous to list. I am certain the list is incomplete, but it includes Patricia Azarnoff, Peg Belson, Pat Collins, Donna Doerr, Della Ferguson, Laurie Fraga, Evelyn Hausslein, Muriel Hirt, Mary Ann Janda, Stephanie Kirylych, Jill Koss, Erin Munn, Michele O'Neill, Sheila Palm, Stefi Rubin, Renee Ruggiero, Rebecca Smith, Bev Stone, Gina Tampio (nee Fortunato), and Richard Wayne.

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Chapter 1

THE STORY OF CHILD LIFE

SUSAN POND WOJTASIK AND CLAIRE WHITE

INTRODUCTION

Discovering the story of childhood and the social and environmental conditions contributing to the health and illness of children is a challenging enterprise. Children are given scant space in the historical record. The modern reader is understandably puzzled and distressed by the indifference, indeed the harshness, with which children have been treated in earlier times. Today, knowledge of children's needs, and efforts to meet those needs, are taken quite seriously. Child life has played, and is continuing to play, a significant role in this new benevolence toward children, especially children in hospitals and other healthcare settings.

The history of how we became a people knowledgeable about and sympathetic to the complexity of childhood, in particular with respect to issues of health and disease, covers a very brief time span. Although theories of the contribution of microbes to the spread of disease and studies leading to improved infant nutrition occurred in the eighteenth century, a specific focus on children's health in the United States did not take hold until the mid-nineteenth century when the first children's hospital began caring for patients in Philadelphia (Brodie, 1986). Some years later scientific interest in the causes and cure of diseases in children, as well as interest in their general welfare, led to the academic institution of pediatric medicine. Nursing schools and social welfare agencies also have their roots in the middle to late nineteenth century and were agents of change in promoting the well-being of children (Dancis, 1972; Brodie, 1986; Colón, 1999).

The Industrial Revolution, which caused the migration of thousands of families from rural areas in this country and thousands more from abroad, caused a crisis in the cities. Men, women and children were paid small wages for long hours of work. Families lived in hovels without access to clean food or water and without even a semblance of sanitation. Disease epidemics were common, and large numbers of babies succumbed to the lethal "summer diarrhea" every year (Colón, 1999).

In the midst of this misery, philanthropists and professionals responded with investigations and programs to help children live and grow. As a deeper understanding of the nature of childhood was probed by professionals interested in the development of intelligence, emotional response, and social relationships, the care of children came to

include these elements as well. These aspects of child development have engaged the energies of child life specialists since the early decades of the twentieth century.

"THEY PLAY WITH YOU HERE"

The story of child life begins in the early twentieth century when large numbers of children began to be hospitalized. Children were understandably terrified at being in an unfamiliar place where many children cried and where everyone was a stranger. The children were there, of course, for their own good, for the treatment of illness or accident that would restore them to health.

There was, however, no way for the children to comprehend this. They often faced empty days in which there was nothing to do but wait for the next dreaded examination or treatment. The children were so obviously miserable that in some instances recommendations were made to institute a program of activities to engage the children's interest when they were admitted and while they waited in their cribs for what would happen next.

Some critics of non-medical activities for children argued that a child sick enough to be in the hospital was too sick to play. Surely the hospital, the place where grave illnesses and impending death were the very reasons for being there, was no place for frivolity, for games, for laughter. But children need play like they need air to breathe, no matter what their circumstances.

Play is fundamental to the very structure and meaning of childhood. This is true even in the most onerous of circumstances, perhaps especially in times of great distress. Frank McCourt (1996), in his memoir *Angela's Ashes*, describes his childhood as miserable, immersed in poverty, neglect, the death of siblings, drunkenness, living conditions of almost unimaginable squalor. He was furious at it. Yet when he and his brothers played at romps and adventures he could say with unbridled enthusiasm, "We had a grand time!"

The preponderance of opinion was ultimately on the side of the child, and programs of play and education were introduced into pediatric hospital care as early as the 1920's (Rutkowski, 1986). Play leaders taught volunteers and nursing students how to communicate with children primarily through play, helped children understand the strange ways of the hospital and the people who work there, and prepared children for what was going to happen to them in their own hospital stay. These play leaders, with their volunteers and students, helped normalize the hospital experience.

There was a sense of urgency in this work based on an understanding that childhood is a time of such rapid development that not a day should go by without attention to the basic imperative to grow. As was noted in an article appearing in 1937:

> Children come to us at a formative period. They are developing rapidly, each day brings vast changes in them. We can do dreadful things to a child during even a twenty-four-hour stay, and we can change his entire outlook on life for better or worse during an eight-months' stay in a hospital. Any program of patient's care naturally begins with excellent medical and nursing care. In addition to that we must safeguard him in every way, physically and mentally. His day should approach the day of a normal child as nearly as is possible under the circumstances. (Smith, 1937, p.1)

By 1950 ten hospitals in the United States and Canada had implemented play programs on their children's wards (Rutkowski, 1986). The stage was set to address systemat-

ically the multiple emotional insults experienced by children when they are hospitalized. New scientific discoveries and methods of treatment continually change the face of pediatric medicine, and child life practice has developed to meet the changing needs of sick children. Preparation for medical encounters, supporting family centered care, pain management, coping with grief and loss are as fundamental to child life practice today as is play. Nevertheless, play continues as a central experience in the hospital lives of children. It is a mode of healing.

Play liberates laughter. It blows up and deflates, builds up and knocks down. It takes bits of this and that and makes a new thing. It imitates life and elaborates on it. It can be quite earnest and intense when a child is laboring to come to grips with something important, or it can be as flippant and irreverent as a thumb of the nose.

We value play in the hospital not only for the sheer fun of it, but also for the opportunities it affords for "playing out" emotionally laden hospital experiences in order to come to terms with them. This playing out is analogous to the work we adults do when we think through a problem, play with an idea, imagine a series of scenarios before taking action. It is with this kind of play that we create who we are and who we will become.

THE GROUND WE STAND ON

Humanizing healthcare for children was passionately embraced by its practitioners, but the success of such a revolutionary undertaking depended on validation of its presuppositions by others. Without the scientific enquiries and the advocacy for children's health and well-being by the relatively new division of medicine called "pediatrics," a stable context for child life programs could not exist. The development of interest in the behavioral aspects of pediatrics opened the way for making hospitalization a more child-friendly experience (Bakwin, 1941; Spitz, 1945). The insights of early to mid-twentieth century developmentalists and child psychologists provided a firm theoretical rationale for child life practice (Erikson, 1963; Winnecott, 1964; Piaget & Inhelder, 1969; Bowlby, 1982), and the structure of the multidisciplinary organization that came to be known as the Association for the Care of Children's Health added the impact of many voices from nursing, social work, pediatric medicine and psychiatry to help sustain and focus the ongoing work of child life specialists (Brooks, 1975).

Pediatrics: Developmental Medicine

In the late nineteenth century a sufficient body of knowledge existed about the health maintenance and the diseases of children for a new division of medical practice devoted exclusively to the care of infants and children to be established. Pediatrics in the United States has a very short history indeed, beginning, officially, when Abraham Jacobi, M.D., became the first Professor of Pediatrics in 1870 at Columbia University in New York City. Although Jacobi remained a general practitioner all his life, he had an unusual interest in and knowledge of the diseases of children and was a great advocate in the field of children's health. His interests were not limited to the diagnosis and treatment of disease but were wide-ranging, taking on issues of proper nutrition, preventive care, and the social aspects of illness. He began a tradition of concern for children's health that has had a profound and enduring effect on the well-being of children (Abt, 1965; Dancis, 1972; Colón, 1999).

In the first half of the twentieth century, city hospitals were filled with children sick