THE HANDBOOK OF CHILD LIFE

Second Edition

THE HANDBOOK OF CHILD LIFE

A Guide for Pediatric Psychosocial Care

Edited by

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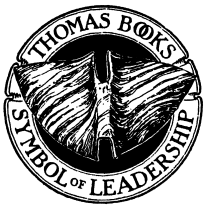

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To my family
Lynn, Brenna, and Haley

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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.

I wrote the preceding paragraph of this introduction a decade ago for the First Edition of *The Handbook of Child Life*. Much has changed over that period of years, yet much remains the same. Children and families in healthcare settings and beyond continue to face challenges through their daily encounters. As the research covered in Chapter 3 indicates, despite our best efforts to provide quality, sensitive psychosocial care to children and their families, they remain vulnerable (though not inevitably so!) to lingering aftereffects. This may be due, in part, to continuing changes in the delivery of healthcare services, administered at a rapid pace, assisted by remarkable technological advancements. As a result, children and families may pass through healthcare environments quickly and return to the home and community where follow-up care continues. While the reduction of time spent away from home is a goal of sensitive care, it must be accompanied by necessary information and supports to foster optimal levels of wellness–physically and emotionally.

There have been changes in technology, changes in the funding of healthcare for our children (with far too many still denied access to afford-

able care), and changes in the responses healthcare organizations and providers have made to adjust to this new medical landscape. Part of what has remained constant over time is the willingness and capacity of child life specialists to adapt, to grow and to accept the challenge of providing excellent psychosocial care in the face of changing circumstances. But, child life has also changed over the past decade in many very important ways, enhancing its educational requirements, branching out into new areas, incorporating technology into clinical work, accessing information to make deliberate, informed decisions about practice following an evidence-based model. As the profession of child life has changed, so has its leading professional organization. When work began on this revision, we had the Child Life Council (CLC). With an eye to the increased professionalism of the field, and a wish to communicate directly to others the nature of the organization, CLC became the Association of Child Life Professionals (ACLP). This change has been incorporated into the text, with references to CLC made in historic contexts and as the publisher of key works cited in reference lists, and to ACLP as we move into the future.

The goal of this revised edition is to help prepare child life specialists to deliver the highest level of care to children and families in the context of these changing realities. The challenge to authors of the text has been to review their original work and provide updates reflecting new knowledge and practice. I am grateful to each of the authors who accepted this challenge with dedication and perseverance. Each chapter has been substantially revised, based not only on updated information and adaptations in practice, but also based on the helpful feedback we received in response to the original work. Authors of several chapters invited additional colleagues, new to this project, to join their work. We are pleased to welcome Katherine Bennett, Eileen Clark, Toni Crowell-Petrungaro, Chantal LeBlanc, Toni Millar, and Sheila Palm to our team. Particular thanks go to Janet Cross, who agreed to join the team preparing Chapter 6, "Patient- and Family-Centered Care," taking the lead role on revision of this chapter, as well as on Chapter 10, "Program Administration and Leadership." To further reflect the changing circumstances of child life today, especially growth into newer areas requiring entrepreneurial skills, two additional chapters have been incorporated: Chapter 11, "One-Person Child Life Programs" by Teresa Schoell, and Chapter 17, "Child Life in the Community and in Other Non-Traditional Roles" by Missi Hicks and Kathleen McCue.

As I am grateful to each of the authors for the work they have done preparing this manuscript, they in turn would like to acknowledge individuals who contributed their insights, knowledge and critiques in the preparation of the text. This includes Elizabeth Anderson, Benjamin Broxterman,

Carol Goetz Buck, Lisa A. Ciarrocca, Kelli Ferguson, Carol Fisher, Julie Albright Gottfried, Dena Henson, Joanne Hochu, Meghan Kelly, Amber Lafferty, Allie Leidy, Ivana Man, Susan Marchant, Emily Murray, Kelly Pulford, Anita Pumphrey, Laila Ramji, Kelly Raymond, Rose Resler, Matthew C. Schoell, Kate Shamszad, Hailey Simpson, Maryl Sommer, Kathy Suzuki, Emily Synnott, Gina Fortunato Tampio, Belinda Thayn, Shani Thornton, Elizabeth Welch, Leslie Marnett Welch, and Cora Welsh.

Finally, each of the authors of the text recognizes that child life is, and always has been, a community–one through which we share, collaborate, learn from and inspire each other. As we prepared this text, we were aware of the legacy we have been given by those who preceded us in the field, but are sadly no longer with us. I, for example, am ever grateful to my mentor, colleague and friend, Gene Stanford, who helped me to appreciate the power of reaching out to others through writing. The authors of this text were, as a group, saddened by the loss of our dear co-author and colleague, LeeAnn Derbyshire Fenn, who died during the preparation of this book. The authors, therefore, would like to acknowledge and celebrate the influence of the individuals noted below who have inspired our lives in child life!

RICHARD H. THOMPSON

IN MEMORIAM

- Kris Angoff
- Mary Barkey
- Peg Belson
- Rosemary Bolig
- T. Berry Brazelton
- Mary McLeod Brooks
- Joan Chan
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- Madeline Petrillo
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- BJ Seabury
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THE HANDBOOK OF CHILD LIFE

Chapter 1

THE STORY OF CHILD LIFE

Susan Pond Wojtasik and Claire M. White

INTRODUCTION

A Brief History of Childhood

Consideration of the lives of children and the meaning of childhood were incidental or absent in the history of Western civilization until Phillipe Aries, a French medievalist, published *Centuries of Childhood: A Social History of Family Life,* in 1962. Perhaps a cause of this disinterest was the ephemeral nature of children, their vulnerabilities, their fragile lives before the modern era. Childbirth and infancy were perilous in the human story until modern times, and Aries's rendering of the nursery lives of children is harrowing. Complications at birth, family poverty leading to neglect or abandonment, inadequate or inappropriate food, accidents and poor hygiene were common factors in infant mortality. A myriad of infectious diseases that afflicted all ages and had no cure were especially devastating in the early months and years of life. Available records indicate that one in every three babies did not survive the first year of life, and thereafter one in six died before the age of five (Lancy, 2015).

Aries wrote his book with a purpose. He argued that medieval children who survived the nursery period were simply incorporated into the ribaldry, games and work of the adult world. It seemed to Aries that an important part of childhood was missing: those years that Freud would call "latency," between the end of life in the nursery and the beginning of what we would now call adolescence. These are the years that the seventeenth century intelligentsia saw as time for filling the blank slates of youthful minds with experiences that would make them free and reasonable men. Girls, it should be

noted, might benefit incidentally from this philosophy, but service to the needs of men continued to be the role of women in society at that time. In this era of enlightenment, childhood began to enjoy a status in the human story that would increase in the late eighteenth and early nineteenth centuries when children were thought to possess a primal innocence that could be instructive to adults and needed to be protected and cherished. Despite serious flaws in his work, Aries remains a foundational figure in historical studies of childhood. His *Centuries of Childhood* provoked an awakening of interest that has ushered in a stream of scholarship that both challenges and elaborates on his work (Colon, 1999; Heywood, 2001; Cunningham, 2005; Lancy, 2015).

In contemporary western culture, according to the anthropologist David Lancy, attention has shifted from focus on the needs of societies' oldest members to those of the child. Yet despite this apparent shift, we still do not serve children well, with nearly half the children under eighteen in the United States living in families in or near poverty (National Center for Children in Poverty, Columbia University: 2014)

Child life is a profession that draws on the insights of history, sociology, anthropology and psychology to serve children and families in many critical stress points in their lives, but especially when they are ill, injured or disabled and encounter the hosts of caregivers and institutions that collaborate to make them well. Children and their families can become overwhelmed by the task of understanding and navigating the healthcare environment. It is the job of child life professionals to provide care and guidance in these negotiations, to serve as culture brokers, interpreters of the healthcare apparatus to family and child and the child to medical professionals.

The Health and Welfare of Children in the Modern Era

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 in 1855 (Brodie, 1986). At about the same time 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; Colon, 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 often without even a semblance of sanitation. Disease epidemics were common, and large numbers of babies succumbed to the lethal "summer diarrhea" every year (Colon, 1999).

In the midst of this misery, philanthropists, health professionals and politicians responded with investigations and programs to ameliorate the damages poverty causes to the developing child. But it was not until 1938 that the Fair Standards Act set limits on the age at which children could be employed (14) and the number of hours per day they could work (10). There were limits to this law. Children of any age could be required to work without restrictions if employed by their parents or parent substitutes.

The United Nations Declaration of Human Rights in 1948 encouraged laws that considered the best interests of the child in custody proceedings and other legal procedures. As a deeper understanding of the nature of childhood was probed by professionals interested in the development of intelligence, emotional response, and social relationships, considerations of children's welfare included these elements. 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"

Play is a truly universal trait of childhood.
David F. Lancy

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.

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!"

Ultimately in the hospital setting the preponderance of opinion about play was on the side of the child, and programs of play and education were introduced into pediatric hospital care as early as the 1920s (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, and 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 systematically 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 means of coping, a means of healing.