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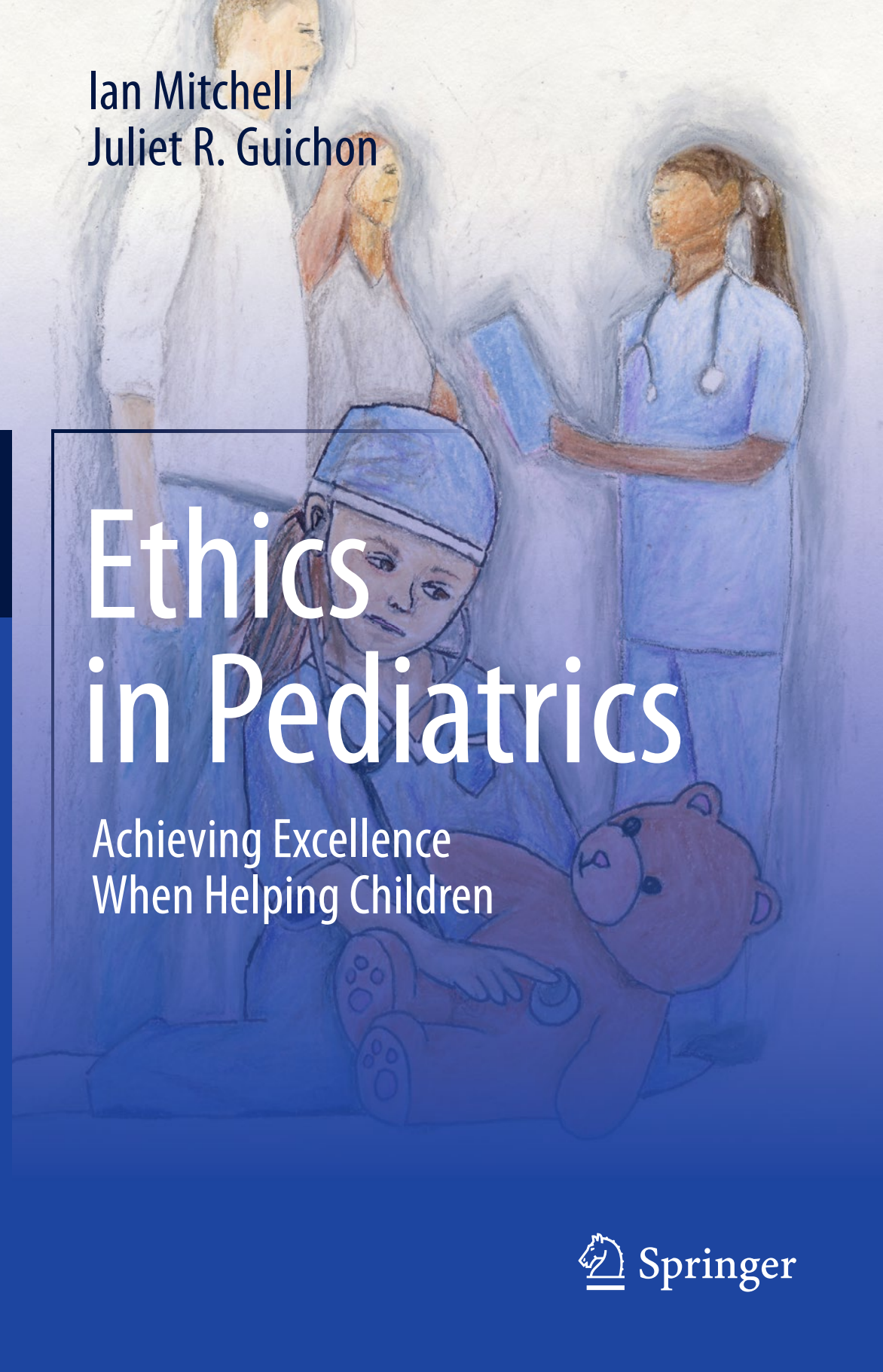

# Ethics in Pediatrics

## Achieving Excellence When Helping Children

Springer

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ISBN 978-3-030-22616-9 ISBN 978-3-030-22617-6 (eBook)
https://doi.org/10.1007/978-3-030-22617-6



This Springer imprint is published by the registered company Springer Nature Switzerland AG.
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

*For all students and trainees over decades who have asked questions and challenged me to give meaningful answers.*
*Ian Mitchell*

*For Mary-Claire, and with love for Raymond-Laurent and Sophie-Charlotte.*
*Juliet R. Guichon*

# Preface

Pediatrics developed as a medical specialty in the late nineteenth century. In the latter part of the twentieth century and the first part of the twenty-first century, we have seen remarkable enhancement of child health around the world. Such advance has resulted mainly from a rise in economic well-being, in addition to improved hygiene, nutrition, and vaccination. These positive changes have been due also to improvements in pediatric care.

Such improvements include a wide range of new technologies and diagnostic tests and many new drugs including the latest biological agents. At the same time, pediatrics has changed considerably, as has all of medicine. The specialty has welcomed women, who are likely to be in the majority in the near future. In most places in North America and Europe, the specialty has become more welcoming of people who are gay, lesbian, bisexual, trans, queer, or other. The working arrangements of pediatricians have also changed, with the rise in subspecialists, and the general restriction in the time physicians, including pediatricians, will devote to their practice.

Despite the enormous changes, we continue to see trainee pediatricians who are committed to excellence in their care of children.

It is in that context that we developed this book. Two bioethicists with different, but complementary, backgrounds have written this work. The first, IM, is trained in pediatrics and has worked both in Europe and North America. He has been involved in ethics education and scholarship for about a quarter of a century and has a higher degree in Bioethics. The other author, JRG, has lived in four nations and has a background in law and legal scholarship. They have taught collaboratively and participate jointly in research projects and advocacy. They challenge one another and aim to ensure clarity in the ethical ideas articulated and advanced here.

The ethical practice of pediatrics is changing, just as pediatric practice constantly changes and as the pediatric work force changes. We understand pediatrics to be a triadic specialty, with the focus on the child, a general deference to the role of parents in decision-making (or the child, if sufficiently mature), and a definite role for the pediatrician. The process has been described as joint decision-making. We would emphasize that the deference to parental decision-making is never absolute.

Recently, one of us (IM) entered the hospital cafeteria and with tray in hand approached the seating area. As he passed two colleagues seated at a table, he saw that they were engaged in animated discussion and might even have been arguing with one another. He decided to nod politely and to move along to another table with different colleagues. As he went past the two colleagues, he heard one of them say to the other, "The problem with your group is that you allow issues of morals and ethics to get in the way of medical decision making." This is one instance when the colleague was not confronted at the time. It did not seem that a hospital cafeteria was the right place. Later, a meeting with the colleague was sought, and the view that issues of morals and ethics are involved in every action physicians take was advanced. That colleague was not convinced, but the interaction was an impetus to complete this book!

The content of the book is based on continuing contact with trainees and colleagues in pediatrics, the anxieties and concerns they express to us, and our own observations on pediatric practice. Such exchanges have informed personal choices of what is important to address, therefore, the content of this book. We have arranged the contents in five parts. Part I gives the background to pediatrics, including comments on boundary issues and how to obtain help when confronted with ethics issues. Part II addresses consent and confidentiality. We have called Part III "Everyday Issues," dealing with prenatal and pregnancy issues, child abuse, children with medical complexity, and advocacy. We also include in Part III a section "Misunderstandings and Disagreements" that offers help in a variety of perplexing situations. Part IV has topics that we regard as important, but do not fit neatly into other chapters, such as responding to errors, research, teenagers, and cost. Finally, Part V is our view of the topics that will be sources of anxiety and concern in the near future.

The book is not and cannot be comprehensive; it does offer information on most of the ethical problems that physicians in pediatrics, at any level of experience, will encounter.

We believe that this book is relevant to all who are involved in pediatrics, whatever their level of training or specific role. There is material for the beginner and also many sections that will provoke thought in those more experienced. We have addressed a myriad of ethical issues and have identified areas in which ethical concepts are evolving.

Calgary, AB, Canada

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# Acknowledgments

The authors thank Springer Nature for agreeing to publish this work and for the support they have received from Floor Oosting, Executive Editor, Applied Ethics, Social Sciences and Humanities, and Christopher Wilby, Assistant Editor, Applied Ethics. Monica Ruff checked and collated references and abbreviations with meticulous care. Pediatric residents, Drs. Jody Platt, Simone Kortbeek, and Rubeeta Gill, gave invaluable help in developing the proposal, reviewing medical accuracy in our stories, and ensuring we were aware of the ethical concerns facing today's trainees. Dr. Kathryn Kenny helped us understand some of the nuances in reproduction and obstetrics. Dr. Julie Lauzon patiently explained some of the current complexities of genetics. Drs. Candice Bjornson and Kirsten Ebbert pointed out some issues to be included. Of course, despite the excellent help, errors might have crept in; if so, then the authors bear full responsibility. The cover illustration is by Jennifer Caldwell. Jennifer is a teenager who has a talent for art. She has had many contacts with Alberta Children's Hospital. Jennifer enjoys life and her art.

Ian Mitchell is grateful for the unwavering support of Anne, his late wife, throughout his career and the patience of his sons and daughters-in-law, David and Meredith, Neil, and Shonna. Inspiration comes from the "Mitchell cousins," Jordan, Ryan, Alexander, and Isabel.

Juliet Guichon thanks pediatricians for welcoming in their midst a scholar trained in law. She is grateful to her husband, Alain Verbeke, for his remarkable example and loving support, to her children, Raymond-Laurent, Mary-Claire, and Sophie-Charlotte, for their cheerful tolerance and the inspiration they offer daily, and to Editha Clemente for making many good things possible.

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# About the Authors

**Ian Mitchell** received his medical education in Edinburgh, Scotland where he also had training in pediatrics, pediatric lung disease, and pediatric critical care. He has been involved in bioethics for over 30 years and earned a graduate degree in Bioethics from the Medical College of Wisconsin. Dr. Mitchell has held leadership positions in bioethics at local and national levels including serving as Director, Office of Medical Bioethics; Faculty of Medicine, University of Calgary; and President, Canadian Bioethics Society. He has been a Member of the Canadian Medical Association Committee on Ethics, the Bioethics Committee, Canadian Paediatric Society and the Canadian TriCouncil Panel on Research Ethics. He has held bioethics educational positions including Chair, Undergraduate Teaching in Bioethics; Course Lead, Introduction to Bioethics for University of Calgary Residents; and Co-Chair, Ethics and Professionalism, Pediatric Residents, Alberta Children's Hospital. Dr. Mitchell has published extensively in pediatrics and bioethics, with approximately 200 peer-reviewed articles, editorials and invited articles, book chapters, and books. He has received many awards for ethics teaching and other awards including the Community Service Award for work with parents whose child has died of sudden infant death syndrome, Faculty Association, University of Calgary, 2011; Vic Chernick Award for outstanding contributions to Pediatric Respirology in Canada, Assembly of Canadian Paediatric Respirologists, 2012; and Canadian Medical Association, Dr. William Marsden Award in Medical Ethics, 2013, which is awarded to individuals who have demonstrated exemplary leadership, commitment, and dedication to the cause of advancing and promoting excellence in the field of medical ethics in Canada; for that award, he was cited as using "insight, innovation and fearlessness…". The Canadian Bioethics Society, in 2015, bestowed on him the Distinguished Service Award.

**Juliet Guichon** is an Associate Professor at the University of Calgary's Cumming School of Medicine in Calgary, Canada. Her work focuses on bioethics issues particularly as they relate to law, journalism, and sometimes religion. She has authored academic articles, presented at academic conferences, and was Senior Editor of the book entitled *The Right to Know One's Origins: Assisted Human Reproduction and*

*the Best Interests of Children (Brussels: ASP*). A grant Recipient and award-winning Lecturer and Seminar Leader, Dr. Guichon is a frequent Contributor to public debate and has founded six child health advocacy groups. She has been invited by the Canadian House of Commons and Senate to testify in public hearings on health matters and is the Recipient of the Canadian Medical Association Medal of Honor and the Canadian Public Health Association's National Public Health Hero Award. A graduate of Yale University, she earned two law degrees at Oxford University where she was a Commonwealth Scholar and a doctoral degree in law at the University of Toronto where she was elected Don of Hall of Massey College. She was called to the Bar of Ontario. A native of Calgary, Canada, she has taught at the Universities of Toronto and Brussels.

# Abbreviations

| | |
|---|---|
| AAP | American Academy of Pediatrics |
| AAPHR | American Association of Physicians for Human Rights |
| ACMG | American College of Medical Genetics and Genomics |
| ADHD | Attention Deficit Hyperactivity Disorder |
| AE | Adverse Event |
| AIDS | Acquired Immunodeficiency Syndrome |
| AMA | American Medical Association |
| ART | Assisted Reproductive Technology |
| ASR | Acute Stress Response |
| BPD | Bronchopulmonary Dysplasia |
| CADTH | Canadian Agency for Drugs and Technologies in Health |
| CAM | Complementary and Alternative Medicine |
| CCC | Child-Centered Care |
| CCCs | Complex Chronic Conditions |
| CDC | Centers for Disease Control (United States) |
| CEC | Clinical Ethics Committee |
| CF | Cystic Fibrosis |
| CFSPID | CF Screen-Positive Inconclusive Diagnosis |
| CMC | Child with Medical Complexity |
| CMPA | Canadian Medical Protective Association |
| COI | Conflicts of Interests |
| CP | Cerebral Palsy |
| CPAP | Continuous Positive Airway Pressure |
| CPR | Cardiopulmonary Resuscitation |
| CSP | Child Standardized Patient |
| CT | Computed Tomography |
| DCDD | Donation after the Circulatory Determination of Death |
| DTC | Direct to Consumer |
| ECC | Early Childhood Caries |
| ED | Emergency Department |
| EEG | Electroencephalogram |

| | |
|---|---|
| ENT | Ears, Nose, Throat |
| ETS | Environmental Tobacco Smoke |
| FCC | Parents- and Family-Centered Care |
| FFM | Five-Factor Model |
| FGC | Female Genital Cutting |
| GDP | Gross Domestic Product |
| HATH | Heterosexual Attitudes Toward Homosexuality |
| HEEADSSS | Home, Education/Employment, Eating, peer group Activities, Drugs, Sexuality, Suicide/Depression, Safety |
| HIV | Human Immunodeficiency Virus |
| HPV | Human Papillomavirus |
| ICU | Intensive Care Unit |
| IM | Ian Mitchell |
| IOM | Institute of Medicine (United States) |
| IRB | Institutional Review Board |
| IV | Intravenous |
| IVF | In Vitro Fertilization |
| JRG | Juliet R. Guichon |
| LGBTQ+ | Gay, Lesbian, Bisexual, Trans, Queer, or Questioning |
| LSMT | Life-Sustaining Medical Treatment |
| MAID | Medical Assistance in Dying |
| MCC | Medically Complex Child |
| MGA | Male Genital Alteration |
| MRI | Magnetic Resonance Imaging |
| MRP | Most Responsible Physician |
| NBS | Newborn Screening |
| NHMRC | National Health and Medical Research Council (Australia) |
| NHS | National Health Service (UK) |
| NICE | National Institute for Health and Care Excellence (UK) |
| NICU | Neonatal Intensive Care Unit |
| NIPT | Non-Invasive Prenatal Testing |
| NIS | Nationwide Inpatient Sample (USA) |
| NSPCC | National Society for the Protection of Children (UK) |
| OCAP | Ownership, Control, Access, and Possession |
| OECD | Organization for Economic Cooperation and Development |
| OSCE | Objective Structured Clinical Examination |
| PaCT | Palliative Care Team |
| PCC | Patient Centered Care |
| PDSA | Plan-Do-Study-Act |
| PGD | Preimplantation Genetic Diagnosis |
| PICU | Pediatric Intensive Care Unit |
| PKU | Phenylketonuria |
| PTSD | Post-Traumatic Stress Disorder |
| QALYS | Quality Adjusted Life Years |
| QI | Quality Improvement |

| | |
|---|---|
| RCPCH | Royal College of Paediatrics and Child Health (UK) |
| REB | Research Ethics Board |
| SDM | Shared Decision-Making |
| SIDS | Sudden Infant Death Syndrome |
| sJIA | systemic Juvenile Idiopathic Arthritis |
| SMA | Spinal Muscular Atrophy |
| SP | Standardized Patient |
| STD | Sexually Transmitted Disease |
| WGS | Whole-Genome Sequencing |
| WHO | World Health Organization |
| YCHW | Youth Community Health Worker |

# Part I
# Background to Pediatrics

# Chapter 1
# What Is My Medical Specialty All About?


**Key Points Concerning Pediatrics**

- Pediatrics is a division of medicine related to the life and health of children
  - It concerns individuals from birth to adulthood, typically 18 years.
  - Pediatricians have additional training in the discipline after graduating in medicine and might have even more training related to a subdivision of pediatrics.
  - Pediatrics encompasses many activities from prevention, direct clinical care in many settings, research and education.
  - Pediatrics may take place in remote communities, large cities, academic medical centers, laboratories and even in international settings.
- Pediatrics aims to ensure that, when children become adults, they are as healthy as possible.
- Much of pediatrics is triadic – child patient, guardian and physician.
- Decisions focus on the best interest of the child patient.
- Pediatricians see children as whole persons, including understanding their environment (family-centred care).
- Pediatricians are compassionate and committed to working in a team-based setting, focusing on positive relationships.

## 1.1 Introduction

This chapter offers a background to pediatrics and describes features of the discipline, essential qualities of pediatricians, and a description of the pediatrician's role. The chapter will address the pediatrician's roles in the interaction with the child and various interactions with the parents, who are often the decision makers about medical care of their child. The topic of patient and family-centered care will be addressed in more detail later in the chapter. Other topics considered in this chapter include



I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_1

developing an understanding of how parents might see us, and describing and commenting on similarities and differences in how pediatricians treat mothers, fathers and other guardians. The chapter's key points illustrate the broad nature of pediatrics and the wide variation in activities involved.

This chapter can be described as a "philosophy of pediatrics". This phrase is used with some trepidation because it might cause pediatricians, with their predominantly scientific training, to be anxious that we are moving into esoteric knowledge unfamiliar to them. On the contrary, this chapter merely considers what pediatrics is about. By "a philosophy of pediatrics" we adopt Pellegrino's understanding: a "critical reflection on the matter" of pediatrics; dealing with the ideas, and background presuppositions that are specific to pediatrics (Pellegrino 2001). This notion entails understanding that the clinical encounter in pediatrics is about the "good" of the patient where "good" means combining a devotion to healing of the child in a manner based on recognizing and respecting the "wholeness" of the child. In other words, a philosophy of pediatrics is not a daunting idea. Discussing the philosophy of pediatrics is just one way to describe the ideas that underlie pediatrics; these ideas will be described here in a friendly fashion.

We will also describe the many changes in society that have affected the practice of pediatrics. One example is that many new mothers are in their late 30s or early 40s and might already have established careers. For many mothers, care of the child is extremely important, but is an activity that they wish to balance with other activities. Many of these mothers with active careers are, themselves, pediatricians. Pediatrics now has a majority of women, and many individuals who no longer hide the fact that they are lesbian, gay, bi-sexual, trans, queer or other. In other words, changes in society affect the kind of person we interact with, and the kind of people we are.

## 1.2 Introductory Story: Emily

*Emily always did well at school. Her friends and family noticed that she was always trying to help others and suggested that she apply to medical school when she completed her science degree.*

*In her teen years, Emily's very close friend, Louise, developed leukemia. Louise had a difficult time with chemotherapy, and later had a stem cell transplant. However, the end result was excellent, and Louise was also at university, studying music.*

*Emily visited Louise frequently when she was in hospital and spent time with her when they were both at home. Emily found staff including the pediatricians in the pediatric oncology unit to be friendly and helpful, and thought this field of medicine might be one in which she would like to participate.*

*Emily is now halfway through medical school and has had electives in pediatrics. In her electives, she has seen pediatricians working in hospital as generalists and as subspecialists and has also seen pediatricians working in a community practice. She is certain she wants to be a pediatrician but is uncertain whether she wants to be a generalist or specialist, and in what kind of settings she would like to work – whether in a hospital, a private office or a community clinic.*

*Emily meets her mentor in medical school, a pediatrician, someone well aware of her career ambitions. Emily asks, "What is pediatrics about anyway?"*

## 1.3 Who Are Pediatricians? What Is Pediatrics?

### *1.3.1 Who Are Pediatricians?*

A pediatrician is defined by the age of the patient for whom he or she cares. Yet the age limit of pediatricians' patients is not strictly determined. The pediatrician might be concerned with prenatal activities, including the family background and genetics. The definition of "child" as being humans aged 0–18 years, takes the upper age limit from a World Health Organization (WHO) (2013) statement on the rights of the child. The statement mentions that some countries might have an age limit that is lower. In the United States, the age limit is higher: the association of United States pediatricians, the American Academy of Pediatrics (AAP) (Hardin et al. 2017), indicates that pediatrics continues until the age of 21 years. In some jurisdictions, pediatricians provide primary care that is the first point of medical contact for a child patient. In others, pediatricians who provide clinical care, might do so almost entirely as consultants, that is, they receive patients only once they have been referred by other medical practitioners.

Pediatricians, whether trainees or people who have been in practice for years, tend to develop a personal narrative of themselves in relationship to pediatrics. Creating this narrative necessarily involves developing an understanding of the discipline. The description of pediatrics offered here is based on an exploration of the literature, some knowledge of the history of pediatrics; both are blended with personal experiences that have shaped the career of one of the authors. The personal experiences have occurred during many interactions with parents and children, with colleagues and with mentors (Mitchell 2015). New entrants to pediatrics will likely have similar experiences. Pediatrician's personalities are formed by contact with children experiencing illness and with their families; these encounters offer great opportunities for personal growth. To quote from Mitchell (2015) above, from children, "I've learned how to rise above adversity; from their parents, I've learned that silence can be better than speech."

### *1.3.2 What Is a Pediatrician and What Is Pediatrics About?*

A different, but very closely related question is, "What is a pediatrician?" The American Academy of Pediatrics defines "a pediatrician" as "a physician who is concerned primarily with the health, welfare, and development of children and is uniquely qualified for these endeavors by virtue of interest and initial training." (Committee on Pediatric Workforce 2015). The article expects the pediatrician to have wide interests, and states, "Because the child's welfare is heavily dependent on the home and family, the pediatrician supports efforts to create a nurturing environment."

Aspiring pediatricians like Emily need some idea of the scope of pediatrics as they begin to develop their personal narratives as pediatricians. Emily also needs to know the scope of the discipline and the skills and experience practitioners need to face novel and challenging situations.

Emily has lots of other questions. Do pediatricians really enjoy what they do? Is their role challenging? Can she be the best possible pediatrician she might be? Emily particularly enjoys hiking and would like to have her own family one-day. Will there be time for other activities? Make no mistake, Emily, like almost every aspiring pediatrician, will not be satisfied with mediocrity or by just "getting by" in her chosen career. Nor will she want to neglect her own children or her enjoyment of life. She will want to be sure all are possible.

What will we say to Emily? You might see her question, "What is pediatrics about anyway*?"* as odd. Let's try to work out this out. A dictionary describes pediatrics as, "A branch of medicine dealing with the development, care, and diseases of children" (www.merriam-webster.com). The American Academy of Pediatrics offers more detail about pediatrics by defining it as:

> A specialty of medical science concerned with the physical, mental, and social health of children from birth to young adulthood. Pediatric care encompasses a broad spectrum of health services ranging from preventive health care to the diagnosis and treatment of acute and chronic diseases. (Committee on Pediatric Workforce 2015)

This description helps us quite a lot, but another way to answer the question, "What is pediatrics about?", is to examine its aims. An ethics think tank, the Hastings Center, explored the goals of all medical disciplines, including pediatrics (Allert et al. 1996). The resulting report concluded that the goals of medicine included prevention and health promotion, relief of pain and suffering, caring and curing, and when death was unavoidable, ensuring it was peaceful. (We will return to the notion of accepting that death occurs in children and the duties of ensuring that it is peaceful in Chap. 4 Consent, Chap. 8 Medical Complexity and Chap. 10 End of Life.)

Let's reframe these goals for pediatrics:

- The prevention of disease and injury from birth and throughout childhood.
- The promotion of normal development and achieving a healthy adulthood.
- The relief of pain and suffering caused by injury and illness.
- Helping siblings and parents as well as helping sick children.

- Caring for suffering children and curing them where possible.
- When death in childhood is unavoidable, ensuring that it is pain free and peaceful.

But how will Emily see things? Emily will have developed some opinions of her own, based on visiting her friend in hospital. She might also have some views developed from portrayal of healthcare in the media. Regarding pediatrics, news reports are frequently about a "miracle cure" or a very tragic death of a child. Pediatrics *per se* is rarely depicted in TV dramas, though children are often portrayed. Unfortunately, TV dramas tend to depict "high adrenaline" situations, often with the need for cardio-pulmonary resuscitation (CPR), unrealistically ignoring basic rules of medical practice. TV dramas also tend to place the physician at the center of every activity, disregarding the large number of team members essential to modern medicine. If you have ever watched these TV dramas, then you will know that romance is common, and intimate affairs frequent. As an aside, children are usually portrayed as just another patient and are depicted in the same setting as adults. Yet children should be seen by physicians and other healthcare team members in settings designed around their needs, whether in-patients in hospital, a specialized clinic, or a physician's office.

There will be more in this chapter about the role of parents, and the various relationships between pediatrician and parents; in the meantime, we will describe some other aspects of pediatrics.

## 1.4 Brief History of Pediatrics

Children have received healthcare from physicians from time immemorial and are mentioned in medical texts since the era of Hippocrates. Yet the role of a physician specializing in the care of children is a very recent development. Specialist doctors for children arose largely in the middle and late parts of the nineteenth century; pediatrics has developed further throughout the twentieth and into the twenty-first century.

Around the time pediatrics emerged (mid-to late nineteenth century), children's hospitals were being developed. Although there were buildings described as children's hospital just before this time, those institutions were usually for the general care of abandoned children rather than devoted to the care of ill and sick children. After 1850, it was becoming obvious that the diseases suffered by children were different from diseases suffered by adults and that treatment of children required a different approach. Even when children had the same condition seen in adults, the details were often very different.

At about the same time, the pathological basis of disease was being studied, leading to a reinterpretation of clinical medicine (and pediatrics). Moreover, physiology was developing as a field of study relevant to human disease. These three elements – children's hospitals, pathology, and physiology – were important to the initiation of pediatrics.