



Ian Mitchell
Juliet R. Guichon

Ethics in Pediatrics

Achieving Excellence
When Helping Children

 Springer

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*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.

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Juliet R. Guichon

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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 Respiriology in Canada, Assembly of Canadian Paediatric Respiriologists, 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