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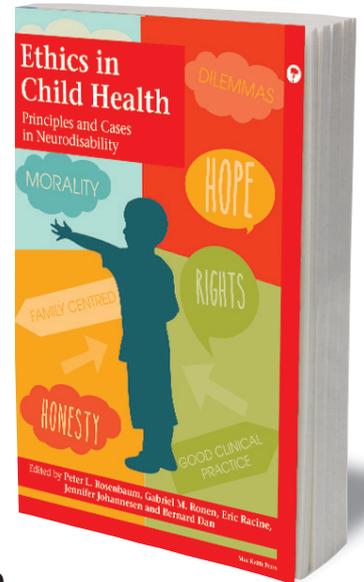


Ethics in Child Health

Principles and Cases in Neurodisability

Edited by

**Peter L Rosenbaum, Gabriel M Ronen,
Eric Racine, Jennifer Johannesen, & Bernard Dan**



Have you ever

- Disagreed with colleagues over a proposed course of treatment for a child?
- Considered ways to 'bump' a child up on a waiting list to speed up their assessment?
- Wondered how to deal with a family that repeatedly fails to keep clinical appointments?

From the Foreword

"This is a must-have book for everyone who works in the field of clinical childhood disability. There is something for all clinicians, therapists, nurses, and doctors whether in training or established in clinical practice for many years. This book 'works' because it is full of real stories of the situations we will all recognise from our own practice, written and edited by internationally renowned and respected clinicians and others with direct experience, who share their 'workings out' of the ethical issues discussed."

Dr Karen Horridge, Chair, British Academy of Childhood Disability

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Contents

Introduction	1
SECTION A: SETTING THE STAGE: ATTUNING MORAL AND ETHICAL THINKING	
1 A parent's perspective on everyday ethics <i>Jennifer Johannesen</i>	7
2 Present-day health and neurodevelopmental disability <i>Peter L. Rosenbaum and Gabriel M. Ronen with contributions by Barbara J. Cunningham</i>	17
3 Can moral problems of everyday clinical practice ever be resolved? A proposal for integrative pragmatist approaches <i>Eric Racine</i>	33
SECTION B: EARLY DAYS, THE START OF THE DIFFERENT DEVELOPMENTAL JOURNEY	
4 Prenatal consultation: ethical challenges and proposed solutions <i>Jennifer Cobelli Kett, Hannah M. Tully and Dan Doherty</i>	49
5 Evidence-based neonatal neurology: decision-making in conditions of medical uncertainty <i>Isabelle Chouinard, Eric Racine and Pia Wintermark</i>	61
6 The importance of beliefs and relationships in the decision-making process <i>Howard Needelman and David Sweeney</i>	75
7 Humanism in the practice of neurodevelopmental disability: examples of challenges and opportunities <i>Garey Noritz</i>	85
8 Truth with hope: ethical challenges in disclosing 'bad' diagnostic, prognostic and intervention information <i>Iona Novak, Marelle Thornton, Cathy Morgan, Petra Karlsson, Hayley Smithers-Sheedy and Nadia Badawi</i>	97
SECTION C: ETHICAL ISSUES IN ADDRESSING FAMILIES' PRIORITIES	
9 Different perspectives, different priorities: using a strengths-based approach to gain trust and find common ground <i>Dinah S. Reddihough and Jane Tracy</i>	111

10 The importance of patients' and families' narratives: developing a philosophy of care to support patient/family goals	123
<i>Jean C. Kunz Stansbury and Scott Schwantes</i>	
11 The ethics of patient advocacy: bending the rules on behalf of patients	133
<i>Raymond Tervo and Paul J. Wojda</i>	
12 Responding to requests for novel/unproven alternative and complementary treatments	143
<i>Edward A. Hurvitz and Garey Noritz</i>	
13 A miracle cure for neurological disability: balancing hype and hope for parents and patients in the absence of evidence-based recommendations	153
<i>Paul C. Mann, Russell P. Saneto and Sidney M. Gospe Jr.</i>	

SECTION D: RESPECTING SOCIAL AND CULTURAL VALUES

14 Terminology in neurodevelopmental disability: is using stigmatizing language harmful?	161
<i>Lisa Samson-Fang</i>	
15 Everyday ethics in Rwanda: perspectives on hope, fatigue, death and regrowth	169
<i>Emily Esmaili and Christian Ntizimira</i>	
16 When expectations diverge: addressing our cultural differences differently	177
<i>Laura S. Funkhouser with contributions by Suzanne Linett</i>	
17 Service provision for hard-to-reach families: what are our responsibilities?	193
<i>Michelle Phoenix</i>	
18 The obligation to report child abuse/neglect is more complex than it seems	203
<i>Lucyna M. Lach and Rachel Birnbaum</i>	
19 The dilemmas for siblings of children with disabilities: personal reflections on ethical challenges	215
<i>Peter Blasco</i>	
20 Paying attention to parental mental health: is this our responsibility?	223
<i>Dinah S. Reddihough and Elise Davis</i>	

SECTION E: THERAPIES, REHABILITATION AND INTERVENTIONS

21 Tensions regarding the processes associated with decision-making about intervention	233
<i>Lora Woo, Eunice Shen and Elizabeth Russel</i>	

- 22 **Can't you just do therapy? When there is disagreement about discharge from therapy** 249
Janey McGeary Farber and Harriet Fain-Tvedt
- 23 **Concurrent therapy in pediatric neurorehabilitation** 259
Marilyn Wright, Sandra Gaik and Kathleen Dekker
- 24 **Ethical considerations regarding surgical treatment of severe scoliosis in children with cerebral palsy** 271
M. Wade Shrader

SECTION F: ETHICAL ISSUES IN SPECIFIC CONDITIONS AND CONTEXTS

- 25 **Considering best interest, quality of life, autonomy and personhood in the intensive care unit** 279
Michael A. Clarke
- 26 **How much is too much care? Interventions and life support in children with profound impairments and life-threatening conditions** 291
Christopher J. Newman and Eric B. Zurbrugg
- 27 **Discussing sudden unexpected death in newly diagnosed epilepsy** 303
James J. Reese Jr. and Phillip L. Pearl
- 28 **Ethical challenges of diagnosing fetal alcohol spectrum disorder: when diagnosis has sociopolitical consequences** 311
Ilona Autti-Rämö

SECTION G: EMERGING INDEPENDENCE AND PREPARING FOR ADULTHOOD

- 29 **Growth and pubertal manipulation in children with neurodisabilities: what are the ethical implications?** 323
M. Constantine Samaan
- 30 **Independence in adulthood: ethical challenges in providing transitional care for young people with neurodevelopmental impairments** 335
Jan Willem Gorter and Barbara E. Gibson
- 31 **Conservatorship in emerging adults: ethical and legal considerations** 349
Henry G. Chambers
- Epilogue: Looking back to the future** 353
Bernard Dan

Foreword

Considering ethical issues is fundamental to the 'art' of clinical practice, complementing the 'science' of making diagnoses and understanding body structure and functions. Clinicians must apply to ethical consideration their knowledge, informed by the best possible evidence, their experience, intuition, integrity, clinical judgement and compassion. They must share in decision-making with children, young people and their families about aspects of individual healthcare. They must also share with healthcare provider organisations and funders how health services can be most efficiently and effectively designed. This book provides insight into how a structured approach to the application of ethical theory can underpin sound clinical practice. Many of the ethical dilemmas presented have more than one 'right' answer; the expert discussions in each chapter help the reader to understand the range of possible ethical arguments and considerations, so that when they face a similar scenario themselves they can adopt a structured approach to arriving at the best conclusion for the unique situations of their patients.

Opening with the family perspective, the reader is immediately drawn in and cannot help reflecting on the stories shared and how these relate to their own experience. The context is then set, with an account of how the conceptual framework of disability has evolved over time and how the rights of disabled people have come to be better protected in law. The language and frameworks of ethical theory are then explained. The book follows the developmental journey on a timeline from early days, through sharing difficult new information, to many examples and perspectives on a range of ethical issues. A person-centred/family-centred approach runs as a thread through the book, emphasising how ethical issues are best considered in partnership, underpinned by excellent communication between professionals and families with a shared understanding

of the issues. Careful consideration is given to the ethical issues arising from the language we use to describe conditions and situations, to variations in ethical issues that arise due to differences in geography or culture and the ethical challenges in the field of safeguarding and child protection. There are clearly indexed separate sections for those wanting to home in on ethical issues relating to specific conditions, different therapies or interventions. The developmental journey continues to adulthood, with issues associated with emerging independence and preparing for adulthood explored in the book's final section.

The editors and authors have together made a hugely important contribution to the childhood disability literature here, with a volume that will sit comfortably on the shelves of practicing clinicians and clinicians in training, nurses, therapists, and policy makers across the globe. It is a book with great potential to change practices for the better, encouraging reflection and improvement in ethical considerations and decision-making. These aspects of 'art' within our clinical practice don't always get the time and attention they deserve in our continuing professional development, but are vital if we are to effectively apply our scientific knowledge in a way that leads to the best outcomes for disabled children, young people and their families.

This, therefore, is a must-have book for everyone who works in the field of clinical childhood disability. There is something for all clinicians, nurses, doctors and therapists, whether in training or established in clinical practice for many years. It 'works' because it is full of real stories of the situations we will all recognise from our own practice, written and edited by internationally renowned and respected clinicians and others with direct experience, who share their 'workings out' of the ethical issues discussed.

I highly commend this book and warmly thank the editors and authors for sharing their wealth of experience with such honesty and compassion.

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