

# **Ethics in Child Health**

## **Principles and Cases in Neurodisability**

**Edited by Peter L. Rosenbaum, Gabriel M. Ronen,  
Eric Racine, Jennifer Johannesen  
and Bernard Dan**

2016  
Mac Keith Press

© 2016 Mac Keith Press

Managing Director: Ann-Marie Halligan

Production Manager/Commissioning Editor: Udoka Ohuonu

Project Management: Riverside Publishing Solutions Ltd

The views and opinions expressed herein are those of the author and do not necessarily represent those of the publisher.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the prior written consent of the copyright holder or the publisher.

First published in this edition in 2016 by Mac Keith Press

6 Market Road, London, N7 9PW

British Library Cataloguing-in-Publication data

A catalogue record for this book is available from the British Library

Cover design: Hannah Rogers

ISBN: 978-1-909962-63-7

Typeset by Riverside Publishing Solutions Ltd

Printed by Hobbs the Printers Ltd, Totton, Hampshire, UK

Mac Keith Press is supported by Scope.

# Contents

<i>Authors' Appointments</i>	xvii
<i>Foreword</i>	xxiii
<i>Acknowledgements</i>	xxv
<b>Introduction</b>	<b>1</b>
<b>SECTION A: SETTING THE STAGE: ATTUNING MORAL AND ETHICAL THINKING</b>	
<b>1 A parent's perspective on everyday ethics</b>	<b>7</b>
<i>Jennifer Johannesen</i>	
<p>The editors were very fortunate to engage as a co-editor Jennifer Johannesen, the parent of Owen (<i>No Ordinary Boy</i>), who was born with profound impairments and died at age 12 years. She offers insights, as someone with training in ethics, to share her personal experiences.</p> <p>Johannesen provides three vignettes she and her family experienced in their journey with Owen into the world of the clinician. Each story provides invaluable perspectives that reflect the good intentions of the healthcare providers and systems with which their family worked. At the same time, as she describes the actions of medical professionals, it becomes apparent that there were unrecognized implications and consequences to these encounters.</p>	
<b>2 Present-day health and neurodevelopmental disability</b>	<b>17</b>
<i>Peter L. Rosenbaum and Gabriel M. Ronen with contributions by Barbara J. Cunningham</i>	
<p>The co-editors address, among other themes, current insights and beliefs about children, families, disability issues, rights, policies and the conceptual and clinical underpinnings of work in childhood neurodisability. They reflect on how the current era has been enormously influenced by developments in, for example, public health (survival of children with impairments);</p>	

concepts about ‘health’ (such as the World Health Organization’s International Classification of Functioning, Health and Disability); and movements to enshrine the rights of children and the rights of people with disabilities in international conventions.

- 3 Can moral problems of everyday clinical practice ever be resolved?  
A proposal for integrative pragmatist approaches** 33  
*Eric Racine*

Co-editor Eric Racine is an ethicist with a major interest in child neurodisability. His informative, context-setting chapter was written as the book was being completed, and brings together a number of themes and approaches to ethical analysis. We believe that this chapter will help readers frame their understanding of the cases that populate the book as well as their own real-life professional encounters. It explains and discusses the importance and complexity of the methods by which ethical deliberation processes are engaged. While one chapter can scarcely do more than sketch the outlines of this multifaceted and evolving field, readers may well find themselves returning to this essay as they delve into individual chapters.

## SECTION B: EARLY DAYS, THE START OF THE DIFFERENT DEVELOPMENTAL JOURNEY

- 4 Prenatal consultation: ethical challenges and proposed solutions** 49  
*Jennifer Cobelli Kett, Hannah M. Tully and Dan Doherty*

A recurring theme in this book concerns the ways in which advances in modern technology challenge service providers and families to confront ‘new’ issues. For example, prenatal assessments provide ‘information’ at earlier and earlier stages of fetal development. Before the availability of our current early detection capacities, infants were usually first identified as having a developmental issue at birth or in infancy. Today, detection of impairment at a prenatal stage makes the level of uncertainty faced by counselors, and of course by families, proportionally greater. In this chapter Kett and colleagues present a clear interface between what can be considered ‘good clinical practice’ and what are emerging as the ethical imperatives that must explicitly guide these practices. In a pair of contrasting scenarios, they illustrate these issues and the ethical considerations that flow from them.

- 5 Evidence-based neonatal neurology: decision-making in conditions  
of medical uncertainty** 61  
*Isabelle Chouinard, Eric Racine and Pia Wintermark*

Despite scores of trials, the best ‘evidence’ for the management of a specific clinical dilemma is often lacking, although decisions still need to be made

and prognoses still need to be given in the individual situation. In the case scenario presented in this chapter, Chouinard and colleagues demonstrate the complexity of prognostication and end-of-life decision-making for newborn infants with an apparently very poor neurological prognosis, particularly when evidence is not clear and/or is conflicting. The case also highlights the type of evidence that weighs more heavily when there is biomedical uncertainty. The authors discuss both the limits of 'evidence' from best studies when such evidence is to be applied to the individual, and the reality that for many of the important questions that parents and practitioners face there is simply no good evidence available. This issue is also discussed in Chapter 6.

- 6 The importance of beliefs and relationships in the decision-making process** 75  
*Howard Needelman and David Sweeney*

In many clinical situations in the field of developmental impairment, knowledge of the facts may be limited or conflicting, and the decisions clouded by emotion, time pressures and alternate, often competing, views among the protagonists. Needelman and Sweeney bring these issues clearly into focus in this chapter, with a scenario covering the need to make decisions about the care and prognosis of a high-risk preterm neonate. By identifying the 'cast' and the 'roles' of the major players, the authors show us that this kind of drama unfolds without a pre-set script, and cannot be presented as a story that is 'typical' or formulaic. They remind us of the essentially personal nature of each story, and of the challenge and thus of the limitations of using 'the literature' appropriately in the specific case.

- 7 Humanism in the practice of neurodevelopmental disability: examples of challenges and opportunities** 85  
*Garey Noritz*

Noritz's chapter provides reflections from an academically trained clinician working in both a hospital clinic and a community-based disability practice. While related situations are also reported and discussed by other authors (see, e.g. Chapter 4), it is Noritz's particular vantage point that allows him to raise these issues and consider them from the perspective of 'the community'. The author uses an ethical framework, language and thinking to provide context and opportunities for discussion of the challenges he describes so clearly and compellingly within this framework. As such, the chapter offers readers a way to think about the many common challenges we experience in our work in developmental disability – and to refract these issues through the lens of an ethical framework.

- 8 Truth with hope: ethical challenges in disclosing ‘bad’ diagnostic, prognostic and intervention information** 97  
*Iona Novak, Marelle Thornton, Cathy Morgan, Petra Karlsson, Hayley Smithers-Sheedy and Nadia Badawi*

Communicating bad news to parents and carers must be recognized as a process rather than a one-time event. When this process is done ineptly or insensitively it can add a considerable burden to the suffering experienced by families new to the ‘career’ of parents of a child with a chronic problem. In this sensitive and also practical chapter, Novak and colleagues discuss the communication of bad news by exploring the processes through an ethical framework, and present comments from several parents to illustrate the impact that this process can have. The authors then provide an evidence-based approach to sharing ‘bad news’, developed in the field of cancer care (the six steps of the SPIKES framework) as a guide to this challenging but essential step in building a relationship with families.

### 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** 111  
*Dinah S. Reddihough and Jane Tracy*

Reddihough and Tracy’s chapter tells the moving story of an adolescent and her family who come to the attention of clinical services for the first time when the young woman is 14 years old. The authors use this story to explore the issues associated with the process of engaging with an adolescent. They report on the challenges they experienced, the distress and upset they felt and the process of developing a relationship between the healthcare team and the family over a period of time. Rather than engaging child services, the clinical team took the time and effort to build a trusting rapport with the family that eventually led to a satisfactory resolution of many of the issues that could easily have been addressed punitively. Variations on this theme are also discussed in Chapter 18.

- 10 The importance of patients’ and families’ narratives: developing a philosophy of care to support patient/family goals** 123  
*Jean C. Kunz Stansbury and Scott Schwantes*

This chapter explores the intersection of medical capability and families’ personal narratives. The authors remind us of the essential responsibility to understand the perspectives and stories of the patients and their families. They present, analyze

and follow the story of a 15-year-old girl with cerebral palsy and her widowed mother across time and crises, outlining how the many people in this young woman's life worked together in this complex situation, and considered the potential benefits and costs of various courses of action. By applying a systematic process of case analysis and reflective practice the care team – including the family and their support – reached what appears to have been an appropriate decision for all concerned.

**11 The ethics of patient advocacy: bending the rules on behalf of patients** 133  
*Raymond Tervo and Paul J. Wojda*

There are clearly times when all health professionals – as advocates for children and families – face the dilemma about whether it is right to bend the truth on behalf of the people we serve. Tervo and Wojda have produced a fascinating chapter about the ethics of deception. They cite authorities, both ancient and contemporary, who have reflected on these issues in considerable philosophical detail. Their analysis is likely to support some readers' views and challenge others'.

**12 Responding to requests for novel/unproven alternative and complementary treatments** 143  
*Edward A. Hurvitz and Garey Noritz*

With the advent of two modern developments – the democratization of knowledge through the availability of the Internet, and the expectation of patient engagement in the management of their own conditions – there appears to be an acceleration of requests from consumers for service providers to know about, and perhaps to endorse and support, the use of 'complementary and alternative' therapies. In their desire to do the best for their children, parents are often susceptible to the lure of interventions that promise more than they can provide. Hurvitz and Noritz explore these issues thoughtfully and sensitively. They offer sensible and useful ways for service providers to consider the challenges of working openly and honestly with families. To illustrate their approach consideration is given to the challenges associated with a specific contemporary 'alternative' therapy that is growing in popularity and complexity.

**13 A miracle cure for neurological disability: balancing hype and hope for parents and patients in the absence of evidence-based recommendations** 153  
*Paul C. Mann, Russell P. Saneto and Sidney M. Gospe Jr.*

Parents of children and young people with complex and incurable neurodisabilities sometimes request support and endorsement from their

service providers for interventions that are outside the scope of conventional practice. In some circumstances these requests can generate considerable discomfort for the practitioners. Clinicians can be caught between wanting to respect parent/patient autonomy (in the service of family-centeredness), and being concerned about issues of safety, legality or probity of these alternative approaches. The more complex the child's issues and the less we have to offer from conventional management, the more ethically challenging the parents' demands might become. Mann, Saneto and Gospe explore a case scenario where medical marijuana is the perceived complementary and alternative medicine for a child with uncontrolled seizures.

## SECTION D: RESPECTING SOCIAL AND CULTURAL VALUES

### 14 Terminology in neurodevelopmental disability: is using stigmatizing language harmful? 161

*Lisa Samson-Fang*

It might seem unusual to include a chapter on language and terminology in a discussion of ethical issues in childhood disability. However, the way we talk reflects the way we think and at times clinicians may fail to think about the meaning and impact of our words. Drawing on an extensive personal narrative, Samson-Fang probes the use of words and explores issues of stereotyping and stigma – issues she believes should be front of mind for professionals working in neurodevelopmental disability.

### 15 Everyday ethics in Rwanda: perspectives on hope, fatigue, death and regrowth 169

*Emily Esmaili and Christian Ntizimira*

In this sensitive and deeply personal chapter, the authors describe the complexities and ethical challenges faced by healthcare workers in an under-resourced community with a horrific history that rocked their country and the world only 20 years ago. While the resource limitations in Rwanda make the clinical practice of child healthcare very difficult, the chapter reflects particularly on the personal and ethical dilemmas experienced by healthcare professionals, including the threat of burnout. The authors discuss the potential for professionals to withdraw into fatalism and to lose the humanism that drew them to the healthcare field in the first place.

### 16 When expectations diverge: addressing our cultural differences differently 177

*Laura S. Funkhouser with contributions by Suzanne Linett*

Many of the families we meet have come to our communities from cultures in which 'disability' carries meaning quite different from our understanding.

As a result, cultural clashes can arise and be daunting for everyone. This chapter discusses the story of a young teenager with significant impairments, whose family's values and actions contrasted with those the care team were recommending as important. These differences created tensions for everyone involved with the young lady's care. Funkhouser and Linett offer a thoughtful analysis of the approaches to these differences, in which good clinical practice includes listening, trying to understand and being attuned to others' realities. They also point out how important it is to maintain contact with families facing these kinds of predicaments, especially when situations change and what might have been difficult might become feasible. The issues discussed here have echoes of those discussed in Chapter 9 and Chapter 18.

**17 Service provision for hard-to-reach families: what are our responsibilities?** 193

*Michelle Phoenix*

Ethical challenges can emerge when clinical policies within an agency with decision-making responsibility – such as a community-based facility or government-run program – appear to conflict with the best intentions of the front-line service providers. Phoenix addresses these issues in a compelling story of the conflict created for her and her colleagues when a standard policy about families' missed appointments came up against the clinicians' awareness of and sensitivity to the stresses on a family that accounted for this apparent delinquency. The clinicians were caught in a dilemma that led to a no-win situation – at least for the immediate issue – and caused discomfort for most of the players.

**18 The obligation to report child abuse/neglect is more complex than it seems** 203

*Lucyna M. Lach and Rachel Birnbaum*

In most jurisdictions, professionals who work in child health have a legal responsibility to report suspected child abuse. This mandate can abut against the advocacy roles we fulfill in working with families of children with neurodisabilities as we lean towards 'tolerating' and 'understanding' parental behaviors or attitudes that would not otherwise be considered acceptable. We may also believe that by reporting a family to child welfare authorities we risk doing more harm than good for the child and family. In this chapter, Lach and Birnbaum address this issue in the context of social work teaching and practice, with discipline-specific frameworks and principles. Similar themes are identified in Chapter 9, though the language may be somewhat different.

- 19 The dilemmas for siblings of children with disabilities: personal reflections on ethical challenges** 215  
*Peter Blasco*

In this chapter, Blasco explores the issues of an able-bodied, but possibly troubled, sibling of a child with significant impairments who is the focus of the clinical attention. In recognizing the sibling's issues he explores the conflicts inherent in deciding the clinicians' roles and responsibilities to the patient and their family; the importance to the child of a family's well-being; the limits of our time and resources with which to address the sibling issues; and the potential for intervention to appear to overstep the narrow bounds of our clinical mandate. In the next chapter, Reddihough and Davis show how the same challenges arise when working with the parents of children with impairments.

- 20 Paying attention to parental mental health: is this our responsibility?** 223  
*Dinah S. Reddihough and Elise Davis*

It is increasingly recognized that the physical and mental health of parents raising children with complex needs is at substantially greater risk than the health of comparable parents of well children. For these reasons it is essential that professionals learn to be able both to identify parental distress and to help parents receive support for their own social and mental health issues as part of a family-centered care program. In the scenario that runs through this chapter the authors illustrate how, without specific attention to parental and family well-being, issues can fester and negatively affect everyone in the family.

## SECTION E: THERAPIES, REHABILITATION AND INTERVENTIONS

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

Therapists are often on the front lines of service provision for children and young people with neurodisabilities. In this role they can be caught between the competing views, philosophies and practical realities of families, young people with impairments, community colleagues and of course the service systems within which they work. In this chapter, Woo and her colleagues discuss three scenarios, each of which poses ethical as well as 'political' dilemmas. They use the Occupational Therapy Code of Ethics and Ethics Standards from the American Occupational Therapy Association (AOTA), and the Code of Ethics for the Physical Therapist from the American Physical Therapy Association (APTA) to analyse the scenarios. In the cases presented here, the authors could have

arrived at a variety of alternative solutions that were reasonable and defensible, and equally valid.

**22 Can't you just do therapy? When there is disagreement about discharge from therapy** 249

*Janey McGeary Farber and Harriet Fain-Tvedt*

In their compelling vignette, the authors present a story that illustrates the potential ethical dilemmas associated with continuing to provide therapy for a 15-year-old with significant impairment for whom functional improvement is an illusory goal, but for whom hard-to-measure comfort care may be achievable at a cost. They identify both the professional guidelines by which they are constrained and the human dilemmas faced by the family of the young woman whose story is the focus of the chapter, as well as the expectations of the community-based physician seeking to advocate for their patient. They describe the approach they took to reconcile these disparate needs.

**23 Concurrent therapy in pediatric neurorehabilitation** 259

*Marilyn Wright, Sandra Gaik and Kathleen Dekker*

When children and young people have chronic conditions or are in situations in which therapies provide at best partial 'success', families may choose to adopt additional therapies in the community. These may be pursued outside the conventional community-based public services their child is attending. This can create challenges, conflicts and ethical dilemmas for professionals. Wright and her colleagues provide and work through a decision-making framework that can help service providers approach dilemmas like these in a thoughtful and organized way.

**24 Ethical considerations regarding surgical treatment of severe scoliosis in children with cerebral palsy** 271

*M. Wade Shrader*

In our work with children with complex needs, the greater the level of uncertainty about a course of action (as discussed, e.g. in Chapters 5 and 6), the more challenging the issues become and the greater the chance of conflict, distress and dissatisfaction. This chapter illustrates these challenges clearly as the author considers the process of family and clinical team weighing the options for high-risk scoliosis corrective surgery in a teenager with severe impairments. The author presents the issues as they might be experienced by the child, the family and the healthcare team. The child and family's prior experience of surgeries and the intensive care unit weigh heavily on them, while the healthcare team must face the reality of the limitations of being 'evidence-based' when the facts are simply unavailable to guide their advice to families.

## 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*

This chapter poses the provocative question about whether our Western focus on the value of an individual's autonomy might at times clash with our uncertainty about an individual's capacity for independent thought and action. This in turn raises questions about parental (or other proxy) decision-making, and the potential for clashes between professionals' values and perceptions of the limited 'personhood' of people with significant impairments, in contrast to the values that parents might hold even in the face of their child's severe impairments. Clarke's account of the story of Charlie, a significantly impaired adolescent, brings together and contrasts the notions of 'quality of life' (an essentially personal 'existential' perspective) and 'value of a life' (judged from the outside and often considered to be very low in people with significant functional challenges).

### 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*

The fact that we often have the technological capacity to extend life can easily create considerable discomfort for practitioners as well as families, and can be the focal point for conflicts both between families and service providers, and more broadly within the health and social care teams. In their analysis of two cases, Newman and Zurbrugg discuss the impact of these challenges as they might concern the child, the family, the service providers and their teams, and the broader society in which these dramas play out. These dilemmas expose people's personal values, and bring into focus universal values such as those enshrined in United Nations' conventions on the rights of children and of disabled persons. (These issues are also addressed in Chapter 5.)

### 27 Discussing sudden unexpected death in newly diagnosed epilepsy 303

*James J. Reese Jr. and Phillip L. Pearl*

Reese and Pearl raise and explore the complexity of discussing sudden unexpected death in epilepsy (SUDEP). What makes this issue so unusual are features such as the variability of the risks of the condition from one form of epilepsy to another, the variable degrees of uncertainty in even beginning to try to predict it, and the potential to create considerable distress and perhaps suffering in people faced with this rare but obviously catastrophic event. The authors build their approach

to these challenges using a combination of descriptive and research-based literature and a thoughtful analysis of the ethical as well as clinical considerations that can be brought to bear in the specific clinical situation.

- 28 Ethical challenges of diagnosing fetal alcohol spectrum disorder: when diagnosis has sociopolitical consequences** 311  
*Ilona Autti-Rämö*

This chapter raises fascinating issues related to both the politics and ethical implications of certain diagnoses, in this case the challenges associated with a diagnosis of fetal alcohol spectrum disorder. It covers a wide range of implications of this diagnosis, including the moral and ethical responsibilities of professionals in some jurisdictions to make and report the diagnosis; the responsibility to the young persons themselves when they are old enough to ask about their condition; and of course the responsibilities to the family to deal honestly with what remains in many places a stigmatizing label for both the child and the mother.

## 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*

One of the dilemmas associated with 21st-century Western medicine is the possibility to engage in interventions that in earlier times might not even have been imagined, and were in any case usually technically impossible. Samaan considers this dilemma in the context of the possibility to manipulate physical and pubertal growth in a young person with significant permanent functional limitations. Whose needs and wishes are being served, and to whom are we as professionals accountable? Drawing on the highly publicized story of Ashley, a child in Seattle, USA, he explores the considerations that can and should be brought to bear on whether this ‘treatment’ is indicated, appropriate and ethical.

- 30 Independence in adulthood: ethical challenges in providing transitional care for young people with neurodevelopmental impairments** 335  
*Jan Willem Gorter and Barbara E. Gibson*

Whereas typically developing young people have opportunities to take risks, make their own decisions, and learn from life, many young people with impairments have limited possibilities to do this, and can be thought of as being ‘deprived’.

Gorter and Gibson apply ethical frameworks and processes to explore the many, often complex, challenges associated with our work as service providers striving to support the individuation of young people toward autonomy and seamless healthcare transition. They reflect on the possibility that some of our well-intentioned goals and activities may in fact be counter-productive. They also identify the very real challenges posed by environmental limitations and barriers that can interfere with even the best-laid plans for transition.

**31 Conservatorship in emerging adults: ethical and legal considerations** 349

*Henry G. Chambers*

Chambers, a pediatric orthopedic surgeon and parent of a young man with complex needs, brings to readers' attention the legal dimensions (often challenges) that may arise as young people enter the 'adult' world and continue to require support from family or other designated caregivers.

**Epilogue: Looking back to the future** 353

*Bernard Dan*

The final chapter of the book, by co-editor Bernard Dan, provides a thoughtful summative reflection of the issues the book has covered, and how readers might use these issues as a basis for discussion and consideration of future situations and action. This integration was done after a full reading of all the chapters. It offers an important perspective on the ways that people may consider the integration of the themes, issues, analyses and ideas of how to achieve potential resolutions of the many dilemmas described by the authors whose work appears in this book. The chapter also identifies challenges on the road ahead, and encourages all of us to keep reflecting and communication about the issues that this book addresses.

*Index*

359

# Authors' Appointments

**Ilona Autti-Rämö**

Medical Director, Insurance Medicine Unit, The Social Insurance Institute, Health Benefits, Helsinki; Adjunct Professor, Department of Child Neurology, University of Helsinki, Finland

**Nadia Badawi**

Chair of Cerebral Palsy, Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney; Grace Centre for Newborn Care, Children's Hospital at Westmead, Discipline of Child and Adolescent Health, The University of Sydney, Australia

**Rachel Birnbaum**

Professor, Cross-Appointed with Childhood Studies (Interdisciplinary Programs) & Social Work, King's University College, Western, Ontario, Canada

**Peter Blasco**

Director, Neurodevelopmental Programs, Institutue on Development and Disability, Oregon Health and Science University, Portland, Oregon, USA

**Henry G. Chambers**

Professor of Clinical Orthopedic Surgery, University of California, San Diego, USA

**Isabelle Chouinard**

Medical Student, University of Calgary Alberta; PhD Candidate, Université de Montréal, Quebec, Canada

**Michael A. Clarke**

Consultant Paediatric Neurologist, Leeds Teaching Hospitals NHS Trust, UK

**Barbara J. Cunningham**

PhD Candidate, School of Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada

**Bernard Dan**

Professor of Neuroscience, Université libre de Bruxelles (ULB), Brussels; Director of Rehabilitation, Rehabilitation Hospital Inkendaal, Vlezenbeek, Belgium

**Elise Davis**

Associate Director, Jack Brockhoff Child Health and Wellbeing Program, Melbourne School of Population and Global Health, The University of Melbourne, Australia

**Kathleen Dekker**

Speech-Language Pathology Profession Lead, Developmental Paediatrics and Rehabilitation, McMaster Children's Hospital, Hamilton, Ontario, Canada

**Dan Doherty**

Associate Professor, Department of Pediatrics, University of Washington, USA

**Emily Esmaili**

Graduate Student (Candidate for M.A. in Bioethics and Science Policy), Department of Science and Society, Duke University, Durham, North Carolina; Pediatrician, Lincoln Community Health Center, Durham, North Carolina, USA

**Harriet Fain-Tvedt**

Chief, Medical Therapy Program, County of Orange-California Children's Services, USA

**Janey McGeary Farber**

Pediatric Physical Therapist; Supervisor, Inpatient Therapies, Gillette Children's Speciality Healthcare, Minnesota, USA

**Laura S. Funkhouser**

Assistant Clinical Professor, Department of Pediatrics, School of Medicine, Loma Linda University, California, USA

**Sandra Gaik**

Occupational Therapy Profession Lead, Developmental Paediatrics and Rehabilitation, McMaster Children's Hospital; Assistant Clinical Professor (Adjunct), Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada

**Barbara E. Gibson**

Senior Scientist, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario; Associate Professor, Department of Physical Therapy, University of Toronto, Ontario, Canada

**Jan Willem Gorter**

Professor of Paediatrics, McMaster University, Hamilton, Ontario, Canada

**Sidney M. Gospe, Jr**

Herman and Faye Sarkowsky Endowed Chair; Professor, Neurology and Pediatrics; Head, Division of Pediatric Neurology, University of Washington; Head, Division of Neurology, Seattle Children's Hospital, Washington, USA

**Edward A. Hurvitz**

Professor and Chair, Department of Physical Medicine and Rehabilitation, University of Michigan, USA

**Jennifer Johannesen**

Author and Patient Advocate, Toronto, Ontario, Canada

**Petra Karlsson**

Research Fellow, Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney, Australia

**Jennifer Cobelli Kett**

Pediatric Palliative Care Physician, Mary Bridge Children's Hospital, Tacoma, Washington, USA

**Lucyna M. Lach**

Associate Professor, School of Social Work, McGill University, Montreal, Quebec, Canada

**Suzanne Linett**

Licensed Occupational Therapist, Private Practice, USA

**Paul C. Mann**

Assistant Professor of Pediatrics, Division of Neonatology, University of Washington; Faculty Member, Treuman Katz Center for Pediatric Bioethics, Seattle Children's Hospital, Washington, USA

**Cathy Morgan**

Research Fellow, Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney, Australia

**Howard Needelman**

Associate Professor of Pediatrics, Munroe Meyer Institute, University of Nebraska Medical Center, Omaha, Nebraska, USA

**Christopher J. Newman**

Consultant, Senior Lecturer, Paediatric Neurology and Neurorehabilitation Unit, Lausanne University Hospital, Switzerland

**Garey Noritz**

Associate Professor of Pediatrics, Nationwide Children's Hospital and The Ohio State University, USA

**Iona Novak**

Professor, Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney, Australia

**Christian Ntizimira**

Palliative Care Expert and Educator, Advocacy and Research Division, Rwanda Palliative Care and Hospice Organisation, Kigali, Rwanda

**Phillip L. Pearl**

Director of Epilepsy and Clinical Neurophysiology, Boston Children's Hospital; William G. Lennox Chair and Professor of Neurology, Harvard Medical School, Boston, Massachusetts, USA

**Michelle Phoenix**

PhD Candidate, School of Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada

**Eric Racine**

Director, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM); Full Research Professor, IRCM; Associate Director, Academic Affairs, IRCM; Associate Research Professor, Department of Medicine, Université de Montréal; Adjunct Professor, Department of Neurology and Neurosurgery, McGill University; Affiliate Member, Department of Medicine, Division of Experimental Medicine, and Biomedical Ethics Unit, McGill University, Montreal, Quebec, Canada

**Dinah S. Reddihough**

Paediatrician, Royal Children's Hospital, Melbourne; Honorary Professorial Fellow, The University of Melbourne; Group Leader, Developmental Disability & Rehabilitation Research, Murdoch Childrens Research Institute, Melbourne, Australia

**James J. Reese, Jr**

Assistant Professor of Neurology, University of New Mexico, Albuquerque, New Mexico, USA

**Gabriel M. Ronen**

Professor of Paediatrics, McMaster University, Hamilton, Ontario, Canada

**Peter L. Rosenbaum**

Professor of Paediatrics, McMaster University, Hamilton, Ontario, Canada

**Elizabeth Russel**

Research and Program Outcomes Coordinator, California Children's Services, Medical Therapy Program, Children's Medical Services, Department of Public Health, County of Los Angeles, California, USA

**M. Constantine Samaan**

Assistant Professor, Department of Pediatrics, McMaster University, Hamilton, Ontario, Canada

**Lisa Samson-Fang**

Pediatrician, Intermountain Medical Group, Salt Lake City, Utah, USA

**Russell P. Saneto**

Professor of Neurology and Adjunct Professor of Pediatrics, University of Washington; Attending Physician, Division of Neurology, Seattle Children's Hospital, Washington, USA

**Scott Schwantes**

Associate Medical Director of Pediatrics, Gillette Children's Specialty Healthcare, Minnesota; Associate Professor, University of Minnesota, USA

**Eunice Shen**

Physical Therapy Education Coordinator, California Children's Services, Medical Therapy Program, Children's Medical Services, Department of Public Health, County of Los Angeles, California, USA

**M. Wade Shrader**

Professor and Chief, Pediatric Orthopedic Surgery, Children's of Mississippi, University of Mississippi Medical Center, USA

**Hayley Smithers-Sheedy**

Research Fellow, Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney, Australia

**Jean C. Kunz Stansbury**

Certified Pediatric Nurse Practitioner, Gillette Children's Speciality Healthcare, Minnesota, USA

**David Sweeney**

Staff Chaplain and Ethics Consultation Service, Nebraska Medicine, Omaha, Nebraska, USA

**Raymond Tervo**

Professor of Pediatrics, Mayo Clinic, Minnesota, USA

**Marelle Thornton**

Former President of the Board and Parent, Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney, Australia

**Jane Tracy**

Director, Centre for Developmental Disability Health Victoria, Monash Health, Clayton, Victoria; Adjunct Associate Professor, Living with Disability Research Centre, LaTrobe University, Bundoora, Victoria; Adjunct Senior Lecturer, School of Primary Health Care, Faculty of Medicine Nursing and Health Sciences, Monash University, Victoria, Australia

**Hannah M. Tully**

Acting Assistant Professor, Division of Pediatric Neurology, Department of Neurology, University of Washington, USA

**Pia Wintermark**

Assistant Professor of Pediatrics, McGill University, Montreal, Quebec, Canada

**Paul J. Wojda**

Associate Professor, Theology Department, University of St. Thomas, Minnesota, USA

**Lora Woo**

Occupational Therapy Education Coordinator, California Children's Services, Medical Therapy Program, Children's Medical Services, Department of Public Health, County of Los Angeles, California, USA

**Marilyn Wright**

Physical Therapy Profession Lead, Developmental Paediatrics and Rehabilitation, McMaster Children's Hospital; Assistant Clinical Professor, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada

**Eric B. Zurbrugg**

Affiliated Staff (Neuroscience), Children's Healthcare of Atlanta, Georgia, USA

# 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.

**Dr Karen Horridge**  
Disability Paediatrician, Sunderland, UK  
Chair, British Academy of Childhood Disability

# Acknowledgements

Creating a book like this on ethics can only be done as a collaborative effort among many people – and indeed there are many contributors to whom we owe a great debt. Without the enthusiasm and dedication of everyone involved in this project, this book would be very different, if it existed at all!

It will be obvious that we owe a huge debt of gratitude to all the people who contributed to this project. These include members of the American Academy for Cerebral Palsy and Developmental Medicine, the British Academy of Childhood Disability, the European Academy of Childhood Disability, the International Cerebral Palsy Society, Child-Neuro E-Mail List for Child Neurologists and HemiHelp, UK who responded to our survey. People who influenced the creation of this book include both those whose work appears within these covers, and the colleagues who offered us suggestions, potential topics, and drafts of work that did not quite ‘fit’ the mandate we established with increasing clarity as the process unfolded. Everyone who has written for this book has had the courage and honesty to expose themselves – their thinking and reflections – and to share issues they have actually experienced within the world of child health. As will be recognized, many of these issues may at times be discussed among colleagues, but they are much less often presented publicly with such clarity and openness in this thoughtful and humanistic way.

We want to thank our colleagues at Mac Keith Press for their confidence in us as this project unfolded, and for their unwavering support and wise counsel. They allowed us to fly into a new territory, to exercise our collective skills, and to engage colleagues around the world in this effort. They offered feedback, advice and perspectives on so many aspects of the book – from how best to frame the issues to approaches to

## Acknowledgements

promoting it across the world. Their extensive experience in this 'world' of creating books taught us a great deal.

Peter Rosenbaum and Gabriel Ronen also offer very special thanks to our three co-editors. All of us read, commented on and edited every chapter, but these three colleagues offered unique perspectives to expand the scope of this book. Jennifer Johannesen (Chapter 1) is a parent, a gifted communicator and an articulate writer, who shared her personal stories and insights in a way none of the clinical editors could ever do. Eric Racine's experience as an academically trained ethicist enabled him with his pragmatic approach to offer wise insights to our authors and fellow editors as their chapters evolved. His understanding of the clinical situations and dilemmas that are shared herein provided him the material around which to craft Chapter 3. Finally, after the chapters had been accepted, edited and assembled in the order in which they appear, Bernard Dan wrote the Epilogue. Like Jennifer's parental views and Eric's ethicist perspectives, Bernard's chapter provides a summative overview and ideas for how to move forward with the essential responsibilities to address the singularities of our patients' and families' issues with compassion, humility and humanity.

To all of these people, we and our readers owe a special thanks.

**PLR and GMR**

## Chapter 3

Eric Racine acknowledges funding from an FRQ-S senior researcher career award and support from NeuroDevNet. Thanks go to Natalie Zizzo for comments on a previous version of this chapter and to Roxanne Caron and Simon Rousseau-Lesage for editorial assistance.

# Introduction

Peter L. Rosenbaum and Gabriel M. Ronen

## As a health professional, has this ever happened to you?

- *A family repeatedly fails to keep clinic appointments. Institutional policy indicates that they should be discharged from the program as 'hard to serve'. However, you are uncomfortable with this plan as you sense that there may be extenuating circumstances.*
- *A family demands extra therapy for their child, when the evidence (or the available resources) make this an 'unreasonable' request.*
- *Members of a family disagree with one another about a recommended approach to a clinical management issue, making further action difficult.*
- *Professionals working with a child and family disagree amongst themselves about a proposed course of action.*
- *Your center has a long waiting list, so a family of a 1-year-old with a suspected health or developmental problem will have to wait many months for assessment, and perhaps longer for intervention services.*
- *Professionals often are in a position to need to deliver 'bad news' to a family, and are unsure what the best processes should be.*
- *There are frequently times when people may feel that treatment becomes ineffectual. It is not clear how decisions about this situation should be decided.*
- *You are aware of issues and challenges like the ideas above, and wonder whether there are ethical approaches and algorithms that can help in complex decision-making.*

These brief questions are offered as but a few examples of what we all recognize as everyday realities experienced by healthcare providers in the field of child health, including childhood neurodevelopmental disability. Such challenges are very common, and each can provoke in service providers a mixture of anger, frustration, confusion, fatigue and a wish that there were easy answers to these predicaments experienced by families and by us! We all value and embrace the duty to care that our fields expect of us, but also identify frequent misalignments between that duty and the many complex realities of resources – families’ and ours – such as time, human capital, community supports and the many layers of decision-making trajectories that can interfere with best – and ethical – services. Although we value, endorse and try our best to apply principles of ‘evidence-based medicine’ and to practice within a ‘family-centered service’ philosophy, neither of these important approaches explicitly provides guidance on how to address the issues outlined above.

This book has been developed with and written by people from a wide range of disciplines and populations who are in the forefront of childhood neurodisability. The goal is to present and discuss case scenarios that describe quotidian clinical issues and challenges, in order to consider them through the lens of ethical principles and practices.<sup>1</sup> We hope to encourage colleagues across the child health spectrum to add ethical perspectives and reflections to the clinical, administrative, fiscal, ‘evidence-based medicine’ and ‘family-centered service’ frameworks by which such problems are usually discussed and managed. The book aims to offer to clinicians and other professionals a set of guiding principles that overlap with and complement principles of ‘best practice’ and practical clinical wisdom.

### Goals of the book

- To identify and discuss briefly a number of ethical challenges that arise in everyday practice and are part of the fabric of clinical and policy-making practice in all areas of child health practice. This will allow us to shine a light on the ethical dimensions of issues that we, and others, have often either not recognized, or have ignored, or have been unsure how to address.
- To offer pragmatic principles, frameworks and approaches that underlie sound ethical thinking and practice, and that we hope readers will find useful in their respective spheres of practice and influence.
- To provide approaches to the formulation and analysis of ethical questions in our field.

---

<sup>1</sup> The cases presented and discussed in this book represent real people, insofar as the authors are telling stories of their experiences, but all the children and families depicted have been anonymized.

- To explore the intersections between good clinical practice, morality and ethics.
- To help professionals to develop practical ethical thinking that can also be shared with learners.
- To offer the book as a primer for students in the field.

This book is *not* meant to be

- A text on medical ethics
- A recipe book or formula for resolving ethical dilemmas
- A book of ‘answers’
- A comprehensive resource for every possible issue or dilemma that can arise in our field
- A philosophical or theoretical treatise
- An account of the ethics of human research
- A compilation of monodisciplinary ethics perspectives

### Background: the history of this book

For many years the editorial leadership of Mac Keith Press has been discussing its keen interest to publish a book on the broad topic of ‘ethics in childhood neurodisability’. There has never been a shortage of issues with which to explore what we have identified as a wide range of realities in everyday practice. Rather, the challenge for this book was how to settle on an approach, situated within clinical practice, that expands upon the focus commonly placed on these complex issues in child health while taking into account the literature from pragmatic ethicists and philosophers. We hope to illustrate with this book that there are myriad challenging issues in *all* aspects of child health – including but of course not limited to neurodevelopmental disability – that call for ethical reflection, ultimately aimed at improving the nature and quality of practice in the whole field. Thus we hope readers will see that the issues presented and discussed are relevant to all clinical child health services.

People working in our fields are motivated by caring about, and empathy toward, young people with chronic health conditions and their families. Thus, as we began to consider the nature of a book on ethics in neurodisability, we also often came up against the reality that what a clinical audience would regard as ‘ethical’ practice abuts against – in fact overlaps considerably with – ‘good clinical practice’. It is our impression that although we expect clinical practice to be ‘ethical’, and assume that we behave ethically, we rarely explicitly identify clinical or management issues as requiring an ethical discussion, let

alone consult with an ethicist or ethics committee. One challenge for the authors – and perhaps for readers as well – has been to recognize these overlaps, the borderland areas, and the distinctiveness of each set of concerns. In this book, many of the issues that have an ethical dimension can also be seen to reflect effective, empathic, person- and family-centered clinical practice and advocacy. Readers can judge for themselves whether these distinctions are clear and helpful, or indeed whether they are even necessary. It has been our perception that everyday ethical issues can to some extent be contrasted to ‘media hype ethics’, that is, attention to the complex, highly controversial situations surfacing in clinical practice, and on which bioethics scholarship tends to focus much of its attention. Interactions with ethicists and ethics committees often involve dramatic situations associated with conflicting views and values.

After considerable discussion among the editors, and in collaboration with the Press, surveys were undertaken with members of the organisations listed in the Acknowledgments. From these surveys we were able to solicit the experiences and ideas of a large number of colleagues, whose scenarios and discussions contributed much of the material for this book. We have assembled a connected series of reflective interdisciplinary essays that address issues and challenges experienced in common practice by clinicians and clinical teams, within the perspective that we may think of colloquially as ‘ethics at the coalface’ or ‘in the trenches’.

### **What do we mean by the ethical dimensions of neurodevelopmental disability?**

Mac Keith Press focuses its academic attention on the broad area of neurodevelopmental medicine. For this reason, the material presented in this book has been solicited from health professionals who work in this area of child health. It is important, therefore, to offer a brief contextual background.

There are a number of implications of the contemporary concepts about children and neurodevelopmental disability, described in Chapter 2, that have ethical dimensions that we have explored in this book. We believe that these fundamental shifts in how childhood disability is thought about, assessed and managed should lead to major changes in the field of childhood neurodisability. These changes include, among many, the language of ‘disability’, the importance of child and family development, the roles and engagement of families as partners with professionals in the Internet age, and the formal recognition of the rights of children and the rights of people with impairments. Among the challenges for the field are how to work ethically within the constraints and regulations of existing systems; how the services and activities of health professionals should be delivered; and what is implied by changes to the organization and provision

of services regarding what we do and how we do it. Into this mix fall the ethical dimensions to which this book turns its attention.

Even apparently ordinary interactions and navigation of relationships between professionals and families of children with chronic health conditions (or with the young people themselves) require a thoughtful understanding that potentially everything we do, or do not do, can/does have an ethical dimension. This may be a statement of the obvious, insofar as ethical frameworks should inform all human interaction. Professionals have responsibilities at multiple levels in these relationships, and an awareness of special aspects of vulnerability specifically related to the inherent asymmetry of such relationships. In addition, what we have in mind here are some of the particular complexities of clinical practice when such activities involve populations who have traditionally been marginalized, whose voices have been muted, and whose value to the broader community has been questioned.

Furthermore, in a book meant to be useful to readers around the world, we have been pleased to secure contributions from a wide range of colleagues addressing clinical and ethical matters in ways we believe will be enlightening for everyone. To address these issues in the full light of contemporary thinking requires that these issues be discussed openly – a goal of this book.

## The purposes of this book

Given this background about the changing climate of childhood disability and the recognition that ethical dilemmas potentially inhabit every corner of the field, our goal with this book is to explore the interface between good clinical practice and ethical practice, and bring to life some of the ethical issues professionals experience in the field. To do so we have tried to articulate how we see the ethical dimensions of all aspects of clinical practice, and equally to reflect on how ethical principles should inform the further development, structure, concepts and content of the field. We hope to encourage people to consider issues of daily clinical life in the context of the perspectives that our authors have contributed to the continuing development and refinement of the world of neurodisability and the care of children with chronic health conditions. As an outcome of the book, we hope to promote a shared (or at the very least enriched) vision of how we can identify and address ethical issues – including how we can potentially prevent them from doing harm or creating problems – by developing partnerships with families and young people with impairments, and with colleagues, and of course with ethicists!

It is the hope of the editors and publishers of this book that in addition to its exploration of 'everyday' ethical issues and dilemmas in our field, the book will provide material for use as an educational resource. We imagine chapters of the book becoming the

focus of discussion in book or journal clubs, and in programs for inter-professional education and collaboration, as a way to bring to light (and to formal consciousness) the kinds of issues our authors have identified and discussed. In fact, these discussions could broaden the ethical arena to include alternative approaches for both the analysis and any potential resolution of dilemmas.

To this end, we have identified three or four ‘Themes for Discussion’ at the end of most chapter. These issues are in no way meant to be anything more than examples of the kinds of topics we believe should provide continuing opportunities for dialog and discussion. In this way the book may provide educational material and become the kick-off point for conversations among professionals at every stage of their experience, and hopefully also between professionals and program managers, funders and policy-makers. If this happens, the book will have served one of its key purposes.

As with so many of the issues and questions identified in this essay, and in this book, there is rarely a clear answer. There is also usually more than a single ethical aspect to a clinical scenario. The reader will recognize that there is an apparent overlap in some of the clinical scenarios (e.g. those that unfold in the ICU or in rehabilitation settings). However, the subsequent discussions emphasize different ethical aspects. We believe that it is worth asking rhetorically whether, by framing these common clinical challenges within an ethical as well as a service delivery context, we might provoke more, and more serious, discussion of the need to bring these issues forward and resolve them more effectively than is often done.