Ethics in Child Health
Principles and Cases in Neurodisability

Edited by
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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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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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