CN Reviews

Readers are invited to contact T. Kushner at kushnertk@gmail.com regarding books they would like to see reviewed or books they are interested in reviewing.

Ethics in Child Health: Principles and Cases in Neurodisability, by Peter L. Rosenbaum, Gabriel M. Ronen, Bernard Dan, Jennifer Johannesen, and Eric Racine. London: MacKeith Press Publisher; 2016. 369 pp.

Challenges in clinical ethics typically arise when one or more of three instances occur in practice: (1) technological innovation enables novel diagnostic or therapeutic advances, (2) a vulnerable population is encountered, or (3) conflict arises among value systems or interests held by the parties involved in care. All three of these instances are often at play currently in our efforts to provide care to individuals, especially children, with neurodevelopmental disabilities.

Multiple transformations have occurred in society and the practice of medicine that task the healthcare provider, actively impacting the goal of ethical practice. These include: altered conceptualizations of health and disability and their determinants, moral and legal recognition of the rights of the disabled, an emerging emphasis on quality of life and subjective well-being in treatment decisions, an abandonment of patriarchal models of service delivery for one that is patient and family centered, societal perspectives (i.e., resource allocation) that may override individual imperatives, and the increasing diversity of patient populations and providers that bring different value systems, often rooted in religious and cultural narratives and—at first glance—seemingly irreconcilable, to bear on a particular situation.

Attempting to inform our ethical practice and approach to individuals with “neurodisabilty” is the raison d’etre for the recently published (2016) multiauthored text entitled *Ethics in Child Health: Principles and Cases in Neurodisability*. The editors, whose considerable personal experience brings an immediate relevance to the contents, include a parent/advocate, a developmental pediatrician, two child neurologists, and a neuroethicist.

Rather than providing “answers” to ethical challenges (an impossibility given the uniqueness of any clinical situation), the authors of this text seek to provide the practitioner with the means of situating ethical practice within the context of good clinical practice. This begins with explicitly recognizing that ethical issues occur in a way that merit detailed elucidation, reflection, and discussion among the partners involved in healthcare so that consensus can be reached, and consequently, conflict and harm can be avoided.

This pragmatism in an approach to clinical ethics is merited, and indeed welcomed, by those on the front lines of

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healthcare, especially those providing care to "doubly vulnerable" individuals with neurodisability. Vulnerability in this class is imparted by the lack of both full autonomy and the capacity to decide for themselves what is in their own best interests.

This text is organized by chapters that reflect the common journey of the individual with a neurodisability from diagnosis to adulthood, organized by broad themes encapsulating issues related to diagnosis, family context, social and cultural values, treatment and intervention, and an emerging partial independence and autonomy that deserves to be acknowledged and respected. A particular strength is the grounding of each chapter in well-written clinical scenarios that ground the subsequent discussion. The overly theoretical is avoided, and what is presented instead is an iterative approach whereby progress is sought through an identification of the issues, reflection, and bringing forth the participants' own prior experience.

Specific issues addressed in this text largely cluster around the challenges of clear truthful communication in difficult situations (e.g., prenatal diagnosis, prognostication), reconciling differing expectations (e.g., expectations of cure, alternative and complimentary therapies, critical illness), conflicting perspectives (e.g., cultural differences grounded in religious belief), resource allocation (e.g., disability care in low- resource settings), and implementing actions that have ramifications beyond the family unit (e.g., identifying fetal alcohol spectrum disorders, dealing with noncompliance, deception). The authors' primary goal appears to be to enable the reader to identify ethical quandary and conflict, then to identify the points of view of relevant agents to a particular situation, and then to provide a self-directed mechanism to reflect and move forward in a consensual nonconflictual way. The net result that can be anticipated is removing the need to refer to outside mediation (e.g., ethics committee, legal authorities) to effect resolution.

It cannot be expected that "answers" will be found in these pages to the ethical problems that vex us, but rather that we will become sensitized to increasingly recognizing that questions do exist that will cause us to pause. I foresee that the best use of this text will be to use individual chapters as a forum for learners and teachers in a healthcare milieu to frame interdisciplinary rounds. The clinical scenarios could be presented, prompting discussion guided by focusing on the points highlighted by the accompanying authors' text. In such a setting, participants may become aware of issues and points of view that they had not previously considered. This substantive experience would then be incorporated into their own future individualized iterative approach. In this way, this text would serve as a useful concrete prompt to informing and ameliorating ethical "best practice." If this does occur, then this text would have achieved its goal well, and would be a welcomed addition to the literature.

——Michael Shevell