

***Children, Ethics, and Modern Medicine*, by Richard B. Miller, M.D. Bloomington, IN: Indiana University Press, 2003. 318 pp. Index.**

Richard Miller, who serves as director of the Poynter Center for the Study of Ethics and American Public Institutions at Indiana University–Bloomington, has written extensively in the areas of theological and philosophical ethics, on topics ranging from casuistry, bioethics, and just war to pacifism and humanitarian intervention. *Children, Ethics, and Modern Medicine* is the fruit of reflection on an interdisciplinary seminar on professional ethics and Miller's clinical "immersion" experience in medical settings in the Boston and Bloomington areas. This clinical experience provides the backdrop for many of the cases taken up in the text, which primarily involve the care of critically ill children. Miller weaves together a traditional principle-based approach to medical ethics with virtue ethics, casuistry, political philosophy, and rich narrative.

The book is organized into two sections. The first outlines the "moral contours" of pediatric ethics, using an "ethics-disant" approach. Chapter One begins with a provocative reflection on the scriptural narrative about the sacrifice of Isaac. This is a humbling beginning, as adults are reminded that they exercise responsibility for the children in their care with "fear and trembling." Chapter Two draws on the philosophy of John Rawls to outline the parental responsibility to care for children, as well as the particular duties of health-care professionals. These duties are carried out in the context that balances respect for family autonomy with respect for children's rights. Chapter Three outlines paternalism in pediatric contexts. Paternalism, often inappropriate with adult patients, can be incorporated into the pediatric paradigm. Chapter Four provides a detailed exploration of what it means for a proxy to "represent" a young patient's wishes and interests. An adult proxy must carefully consider the competence of the young patient and the patient's accessibility, needs, and desires to determine whether this particular patient requires a del-

egate, a representative, or a guardian. Chapter Five tackles the concept of basic interests and quality-of-life decisions in pediatric contexts. Miller continues to incorporate political philosophy but also brings in the insights of Richard McCormick to explore basic human goods in medical settings.

Miller joins those who fault the dominant paradigm in medical ethics for failing to account for the unique challenges facing children in medical contexts. Ethical reflection and health-care policy that place a strong emphasis on patient autonomy fail to recognize that many young patients do not exercise an adequate degree of self-determination. In the case of children, it is the parents and the family unit that enjoy autonomy, though this must be balanced with the medical interests of the child. Miller proposes a pediatric paradigm that centers around the "therapeutic alliance" between families, care providers, and the child patients, many of whom possess a degree of competence that often goes unrecognized. A functioning alliance is able to mediate between a presumption in favor of family autonomy, a commitment to beneficent practices, and respect for the patient's rights and desires.

Part Two of *Children, Ethics and Modern Medicine* takes up an "ethics-near" approach and addresses practical cases, reflecting on them in light of the pediatric paradigm. The chapters explore the ethical implications of the aggressive treatment of critically ill children, the freedom of children to refuse certain treatments on the basis of religious beliefs and claims of conscience, and the treatment of children whose families' cultural practices may not serve the medical interests of the children.

Chapter Six describes the case of Billy Richardson, who is characterized by his parents as "a fighter, doing God's will"—a phrase used as the subtitle of the chapter. This phrase succinctly captures Billy's situation: "technologically tethered, retaining fluids, on steroids, sedated, and four years old." Young Billy suffered from Hurler syndrome (formally known as gargoylism) and the many serious conditions that come with it—cardiac abnormalities, umbilical hernias, skeletal

deformities, and enlarged tongue, liver and spleen—among others. When Dr. Miller first met him, Billy was in intensive care following his second bone marrow transplant.

Forming a therapeutic alliance with his parents meant that health-care personnel needed to respond to the parents' particular religious beliefs about God's absolute sovereignty and Billy's role in God's plan. Aggressive treatment was seen by his parents as a way of protecting God's freedom to heal Billy; despite its increasing futility, they were reluctant to withdraw treatment, his mother said, because "we didn't want to prevent God from the possibility of a miracle" (155). Billy's role in God's plan, as she saw it, was as "an invitation for others to grow in neighbor-love." Billy's medical interests may also have been obscured by his parents' view of him as a fighter: "If he hadn't been so feisty, we might not have done this" (153). This view ironically involved thinking of Billy as someone in control of his own dying.

The medical staff respected the freedom of Billy's parents to choose aggressive treatment for their child even though he would not benefit from it. According to Miller, "respect for freedom provided the backdrop for Billy's body to become a battleground for multiple and contested interests, none of which guarded him from aggressive treatment or embraced the substantive value of his medical welfare" (151). Miller is not dismissive of religious values or the important role they can play in medical decision making, but not every religious conviction yields sound medical decisions, and some can "misguide" patients and their families. Billy's medical interests may have been obscured, for example, by his parents' view of his suffering as an opportunity for others to grow in compassion.

A major strength of the text is its attention to matters of religious and cultural differences between patients, families, and care providers. Cases involving Jehovah's Witnesses are often cited in the literature and are included in this study. In Chapter Eight, Miller also treats the case of a girl whose mother wanted her treatment to include several "new age" therapies. Although Miller sees the need for health-care professionals, who live in a

culture of their own, to respect cultural differences, he points out that it is irresponsible to allow untested treatments even for the sake of maintaining an alliance with the parents.

Another powerful story related by Miller is the case of Lia, a patient whose parents are Hmong immigrants to the United States. Although her parents sought medical help when their daughter presented with seizures and convulsions at three months of age, a lack of effective communication in their own language prevented them from adequately understanding her illness and her treatment regimen—and prevented medical personnel from responding to her parents' concerns. Lia's parents attributed her illness to her "vagrant soul," which would have to be recaptured. For this she would need the spiritual healing brought about by ritual sacrifices, or *neeb*. To her parents, the doctors "didn't understand about the soul." The parents opted for a "little medicine and a little *neeb*" (192). Lia survived a massive epileptic seizure at age four that left her in a persistent vegetative state, and against expectations she later survived the withdrawal of artificial life support. She was discharged from the hospital to be cared for with great affection at home.

Lia's case, with its many tragic twists and turns, allows Miller to address cultural differences, including questions about a child patient's quality of life:

The new problem, posed by Lia's persistent vegetative state, is not how to treat, but whether to treat in the event of a life-threatening event.... Are quality-of-life considerations potentially ethnocentric? Supposing [her parents] do want Lia to be kept alive, would house staff at [the hospital] be guilty of cultural prejudice if they refused to treat her? Would they be interpreted as saying "What the Hmong consider to be a life worthy of respect and treatment is not a life that we think deserves to be helped"? (197)

Miller writes about every case with respect, insight, and nuance—and without losing sight of the interests of the patients. Unless these interests are attended to in a meaningful way, language barriers, beliefs about what causes illness, and the use of

“nontraditional” remedies can place strains on the therapeutic alliance that put the their well-being at risk.

In a chapter on organ donation, Miller discusses the need to “properly marginalize” some forms of altruism with respect to unrelated and nondirected organ donors—specifically, to screen donations from strangers (201). Less clear in this chapter is how this need relates in particular to children and childhood. For example, Miller’s thoughts on organ donations between young siblings (or classmates or others) and the latitude that parents may or may not enjoy in consenting to these procedures would be a welcome addition to this section.

The cases move from the bedside to the conference room in a chapter on ethics committees. Examining the processes and policy outcomes of an ethics committee allows Miller to bring his critique to the institutional level. Again, he relies on case narrative to illustrate the issues at stake. The case under review involves obtaining consent for an autopsy in a pediatric context. Miller highlights both deliberative and nondeliberative approaches to the formation of a sound, ethical policy for obtaining the informed consent of parents.

Miller’s chapter on pediatric research does not focus on the history of abuses but rather looks at the parameters of such research and raises the alarm about research in the context of a market-driven industry. This is especially timely, given increasing awareness of the effects of market dynamics on the delivery of health care and the directions of promising research. An unintended consequence of protecting children from abuse in medical research is that not enough research is done on medications or procedures to determine their effectiveness and side effects in young patients:

Our culture appears to discriminate against children, leaving them more at risk than adults when it comes to drug safety and efficacy. In the words of one commentator, lack of information and proper labeling about the safety and efficacy of drugs have left children as “therapeutic orphans.” (242)

Unfortunately, the corrective to this situation has taken the form of financial incentives for pharmaceutical corporations. In exchange for doing more pediatric research, they receive extensions on lucrative patent agreements. Companies in turn promise test subjects financial reward for their participation. Miller discusses limits on the role that money can and should play in research and argues in favor of some research on pediatric patients on the grounds of “turn-taking, reciprocity, and fair play.” The principle of proportionality sets the limits that protect children from harm in this context.

Miller concludes the book with a reflection titled “On Liberal Care.” While families enjoy some autonomy in the raising of children, the medical needs of some children require compromising parental wishes. For Miller, “families must be caring and just.” While children thrive in families that are “loving and equitable,” their well-being is a profoundly social responsibility (274). The many institutions of social life share the obligation to advocate for and protect children and young people.

Other urgent issues affecting children and young people—such as global public health concerns, the just distribution of health-care resources among children, and issues concerning access to and confidentiality in matters of reproductive health, sexually transmitted diseases, and substance abuse treatment—do not enjoy sustained discussion in the book. However, Miller’s reflection on children’s competence, his insights with regard to respecting cultural differences, and his attention to the influence of institutions (medical, familial, religious, legal, corporate, and governmental) on the well-being of children will surely be of interest to researchers working in these areas.

Children, Ethics, and Modern Medicine is suitable for scholars of philosophical and theological ethics and health-care professionals (at the bedside and in the boardroom), and would be a fruitful addition to graduate courses in medical ethics. In its entirety, it may be too challenging for all but advanced undergraduate courses, although the case narratives could provide the context for discus-

sion in more introductory courses. Miller has provided a creative and stimulating resource for discussion among those committed to serving and promoting the health and well-being of children.

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***Jesuit Health Sciences and the Promotion of Justice: An Invitation to a Discussion*, by Jos W. M. Welie and Judith Lee Kissell, eds. Milwaukee, WI: Marquette University Press, 2004. 265 pp. Bibliography. Index.**

More than one hundred health science degree programs are offered by Jesuit institutions of higher education worldwide. Jos Welie and Judith Lee Kissell, both of the Creighton University Center for Health Policy and Ethics in Omaha, Nebraska, have compiled nineteen essays which address the question of how these programs can respond to the overall vision of the Society of Jesus as expressed by its recent documents from General Congregations—that is, the “service of faith, of which the promotion of justice is an absolute requirement.”¹

One of the contributions is an address by the General Superior of the Society of Jesus, Fr. Peter-Hans Kolvenbach, S.J., to representatives of the twenty-eight Jesuit universities and colleges of the United States who met at Santa Clara University in 2000 for a conference on “Commitment to Justice in Jesuit Higher Education.” Fr. Kolvenbach declares that

the measure of Jesuit universities is not what our students do but who they be-

come and the adult Christian responsibility they will exercise in the future towards their neighbor and their world.

Fr. Kolvenbach gives as a warrant for this *diakonia fidei* (service of faith) and the promotion of justice a citation from the 1971 World Synod of Catholic Bishops:

Action on behalf of justice and participation in the transformation of the world fully appear to us as a constitutive dimension of the preaching of the Gospel or, in other words, of the Church’s mission for the redemption of the human race and its liberation from every oppressive situation.²

Kolvenbach lauds the U.S. Jesuit institutions of higher learning for their offering of service learning experiences, where students experience firsthand the lot of the poor and the marginalized and graduate with a “well-educated solidarity.” He exhorts faculty to ask themselves “Where and with whom is my heart?” and to become, in the words of Pope John Paul II, “masters of life and moral commitment”³ (62–63).

An essay by Fr. Thomas Massaro, S.J., of Weston Jesuit School of Theology in Cambridge, Massachusetts, gives theological foundations of an option for the poor and their effect on the early choices of ministry of St. Ignatius and the other first Jesuits. Even the first Jesuit school for teaching non-Jesuits, founded in 1548 in Messina, Sicily, served as a venue where rich and poor could mingle—especially as tuition was free! Massaro jumps to the end of the twentieth century and the experience of the Jesuits and their co-workers at the Universidad Centroamericana José Simeón Cañas (the UCA) in San Salvador, El Salvador. Founded in 1965, this university was organized specifically to addresses issues of poverty, human rights, and unjust social structures in that country so

¹ Society of Jesus, “Our Mission Today: The Service of Faith and the Promotion of Justice,” Decree 4 of the Thirty-second General Congregation of the Society of Jesus (December 2, 1974–March 7, 1975), n. 2.

² World Synod of Catholic Bishops, “Justice in the World” (1971), n. 6.

³ John Paul II, Address to the Faculty of Medicine of the Catholic University of the Sacred Heart (June 28, 1984).