Child Rights and Clinical Bioethics

historical reflections on modern medicine and ethics

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ABSTRACT Why might pediatric bioethicists in the United States reject the U.N. Convention on the Rights of the Child (CRC) as a framework for resolving ethical issues? The essays in this issue present arguments and counterarguments regarding the usefulness of the CRC in various clinical and research cases. But underlying this debate are two historical factors that help explain the seeming paradox of pediatric bioethicists' arguing against child's rights. First, the profession of clinical bioethics emerged in the 1970s as one component of modern medicine's focus on improving health through the application of technologically sophisticated treatments. The everyday work of U.S. bioethicists thus usually involves emerging technologies or practices in clinical or laboratory settings; the articles of the CRC, in contrast, seem better suited to addressing broad policy issues that affect the social determinants of health. Second, U.S. child health policy veered away from a more communitarian approach in the early 20th century for reasons of demography that were reinforced by ideology and concerns about immigration. The divide between clinical medicine and public health in the United States, as well as the relatively meager social safety net, are not based on a failure to recognize the rights of children. Indeed, there is some historical evidence to suggest that "rights language" has hindered progress on child health and well-being in the United States. In today's political climate, efforts to ensure that governments pledge to treat children in accordance with their status as human beings (a child right's perspective) are less likely

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to improve child health than robust advocacy on behalf of children's unique needs, especially as novel models of health-care financing emerge.

A reader confronting this collection of essays might wonder if something went awry in Jacksonville, Florida, in February 2014, when conference organizers gathered pediatric bioethicists and international child rights advocates to discuss the application of the U.N. Convention on the Rights of the Child (CRC) to the work of clinical bioethics in the United States. Surely a document proclaiming a worldwide consensus on child rights would strengthen the hand of ethicists advising clinicians and researchers who face difficult decisions. Yet the conference discussion—and resulting manuscripts—depict a deep divide: bioethicists largely rejected the notion that the CRC (or any other set of child rights) is a useful framework for answering ethically difficult questions in the clinical or research context. Furthermore, although generally supportive of the CRC, they did not seem to feel a special obligation, as bioethicists, to support its U.S. approval.

For the international and U.N.–based child rights advocates, the conference must have felt like a miniature reenactment of the ongoing failure of the United States to endorse the CRC. In the 1980s, U.S. representatives were deeply engaged in drafting the international document, and the specific articles of the CRC are consistent with U.S. law and tradition. Yet the United States remains the sole member of the United Nations not to ratify the CRC—20 years after agreeing in writing to consider ratification. In Jacksonville, child rights advocates were hoping to find allies in U.S. clinical bioethicists, yet instead found resistance regarding the usefulness of the CRC for pediatric bioethics. Further, U.S. bioethicists offered arguments about the importance of families in clinical decision-making that echoed the arguments of some of the political forces aligned against the U.S. ratification of the CRC.

In this essay, I explore two historical reasons why U.S. bioethicists might reject the CRC as a framework for resolving ethical issues in clinical and research settings. First, the profession of clinical bioethics emerged in the United States in the 1970s as one component of modern medicine's sharp focus on improving health through the application of technologically sophisticated treatments to individual patients. As such, most of the everyday work of bioethicists pertains to clinical and laboratory settings, and it often involves emerging technologies or practices; the social determinants of health—where the CRC might have had more traction—are more often viewed as the province of social workers, economists, sociologists, and "health services researchers" than medical bioethicists. Second, U.S. child health policy veered away from a more communitarian approach, common in Western Europe in the early 20th century, for reasons of demography that were—and continue to be—reinforced by ideology and by concerns about immigration. The divide between clinical medicine and public health in the United States, as well as the relatively meager social safety net, are not based on differing views

of the importance of children or their "rights." Ratifying the CRC is unlikely to improve health outcomes of children in the United States, and there is some historical evidence to suggest that "rights language" has in fact hindered progress on child health and well-being.

I conclude this essay with the (hopeful) observation that the long history of social medicine in the United States has gained traction in recent decades as we confront the limits and costs of curative medicine. It may be that accountable care organizations are able to achieve for child well-being what decades of exhorting the value of children—or ratification of the CRC—could not: attention to disease prevention and health promotion at a community level, and ultimately a reduction in health disparities.

Medicine and Bioethics in the 20th Century

Historians of medicine seeking to explain current phenomena often begin their story in the late 19th century, when many institutions and clinical practices took their modern form. Hospitals and medical schools may have existed for centuries, but by 1900 a modern doctor would find much that is familiar: medical education predicated on the in-depth study of pathology, biochemistry, and physiology, followed by clinical apprenticeships in hospitals with full-time faculty; hospitals as a place where patients would go to get curative medical treatment, rather than as a refuge where poor and isolated people went to die. By the early 20th century, surgeons routinely used anesthesia and aseptic techniques to offer welcome relief of diseased organs, rather than the 19th-century practice of cutting off a limb in a last-ditch effort to save a life. Specialty medical practice proliferated among many urban and academic physicians, and nursing became a well-defined health profession. The American Medical Association (AMA) emerged in the early 20th century as a formidable political force at the state and national levels, and the prestige if not salaries of physicians rose precipitously in the aftermath of medical education reforms and state licensing laws (Starr 1982).

In the decades around 1900, laboratory science became the foundation of clinical medicine, even if the promise of science was greater than its actual effect on curing disease. Antibiotics, vaccines, and most current medical therapies did not become part of routine clinical practice until the 1950s and 1960s. But by the early 20th century, there was a consensus that laboratory science offered a powerful way of understanding and addressing disease. Centuries of belief in the balance of "humors" (blood, saliva, black bile, and yellow bile) as the best explanation for health and illness had given way to germ theory. In the late 19th century, scientists such as Robert Koch and Louis Pasteur demonstrated how microorganisms could explain infectious disease; Pasteur in particular was widely celebrated in the media for offering the potential to protect people—and animals—from deadly epidemics. The story of scientist as hero is perhaps best captured in the Pulitzer

Prize–winning novel *Arrowsmith* (Lewis 1925). Sinclair Lewis tells the story of young Martin Arrowsmith and his journey as a physician. Each stage of his career—apprentice to a local physician, attendance at a modern medical school, general physician in a small town, public health staff in a medium-sized city, medical specialist at a Mayo Clinic–like practice, and finally, scientist at a metropolitan basic science institution—encapsulates stages in the history of medical practice in the United States from the mid-19th to early 20th centuries. At each step of his career, Martin learns that the pursuit of "pure laboratory science" is the key to personal happiness, and the reader discovers how the scientist is replacing the cleric, businessman, and politician as trusted community leader (Rosenberg 1963).

Moreover, Americans' experience with polio in the 20th century affirmed their faith in science and medical technology. Polio was a particularly dreaded disease because it started as a simple febrile illness, and then in seemingly random cases would progress to complete paralysis and sometimes death. The most severe cases did not follow the typical epidemiological contours of poverty and race/ethnicity: middle-class white families were most likely to be affected, which helped make polio a national emergency. In the 1930s and '40s, the response was a sophisticated distribution network of "iron lungs" to patients who needed them the most. The hope was that the large box that provided negative pressure around a body to keep lungs opening and closing would suffice until the paralysis receded. In the 1940s and '50s, a coordinated effort of government and private philanthropy (the March of Dimes) to invest in laboratory science led to the Salk and Sabine vaccines, which eliminated the yearly epidemics almost immediately. From this experience, Americans learned two lessons: it is possible to provide technically sophisticated medical care to everyone who needs it, and scientific research could indeed provide miracles—like ending the polio epidemic (Rothman 1997; Smith 1990).

The trend in the United States of relying on laboratory science and treatment of individual patients as the keys to improving health accelerated through the 20th century. Today, the U.S. health-care system focuses extraordinary resources on the sickest patients, with little incentive for promoting health or preventing disease. Medical students spend their first two years relearning laboratory sciences that many studied as undergraduates; virtually no time is devoted to understanding human behavior, using systems engineering to improve the quality of care, or learning how to address social determinants of health. Residency and fellowship training occurs primarily in hospitals, where training cannot help but reinforce the idea that health care should focus on the patient at the bedside. While a 19th-century physician was often expected to provide expertise in public health matters, today most physicians see what happens outside the hospital or medical office as someone else's responsibility (Brandt and Gardner 2000). Historian Charles Rosenberg (1979) has characterized this transformation of medical practice as "inward vision, outward glance." To picture this, imagine you are standing inside a critical care unit of an urban academic medical center. You marvel at the

truly remarkable power of modern medicine. Then look out the window (if there is one) and see the surrounding neighborhood. There you will likely see how poverty and neglect lead to the highest levels of morbidity and mortality. Although most physicians and other health professionals standing next to you would acknowledge the impact of social determinants of health, they would maintain that their professional responsibility is to the patient at the bedside.

Physicians in the United States have also taken a laissez-faire approach to bioethics. It is true that ethics has long been part of medicine—witness the Hippocratic Oath—and that U.S. physicians and their professional societies have embraced codes of conduct. For example, the AMA Code of Ethics was written as part of the founding of the association in 1847. Such public statements suggested norms of physician behavior; they were also intended to enhance public perceptions of medicine and to demarcate boundaries of the profession. In general, such codes were not legally binding, however, and through the late 20th century, organized medicine in the United States approached ethical issues by insisting that the professionalism of individuals was sufficient to protect patients and distribute resources. In contrast, European medical societies negotiated rules to govern transformative technologies such as ventilators and dialysis machines. Revelations of lapses in research ethics and the rise of the civil rights movement in the 1960s and '70s eroded faith in established medicine in the United States. By the 1970s, there was a legitimate role for an outsider—someone not trained in health professions—to help with the most difficult ethical decisions, and bioethicists stepped in to fill the void left by physicians (Baker 2013; Rothman 1991).

Timing matters. Bioethics emerged as a profession long after medicine had become focused on cure at the bedside. The questions most relevant in medicine and science in the 1970s (and since then) included lack of consent and outright deception, as in the Tuskegee syphilis experiments; patient (and family) autonomy at the end of life; definitions of brain death and implications for transplanting organs; the potential of genetic manipulation to create a new eugenics; and the distribution of limited and expensive treatments, such as kidney dialysis. The list is not so different now, though the abilities of scientists and physicians to alter the course of nature have increased. Professional bioethicists continue to focus on the questions that trouble clinicians and families at the bedside, vex researchers and their regulators, and—not inappropriately—cover the institutional costs of employing bioethicists. As such, bioethicists' work reflects broader priorities and trends in medicine and science. Many clinical bioethicists are funded through hospitals and universities, for example, so their work focuses on clinical and research questions. Broader research funding for ethics is available through organizations such as the National Institutes of Health (NIH), but such grants typically focus on ethical concerns regarding whole genome sequencing and similar topics.

The CRC was created, on the other hand, to codify international agreement on how children should be protected and nurtured as they grow into adulthood.

The document was not designed as a tool to address thorny issues of clinical or research ethics. The essays by U.S. bioethicists in this volume reveal a variety of reasons why the CRC is not a useful framework to solve the ethical challenges they face in their professional work. This should not be viewed as a failure of the CRC, but rather a reflection of how bioethicists' daily work mirrors broader trends in U.S. medicine and science. Bioethicists need intellectual tools to disentangle thorny issues that often involve conflicting "rights," and a longer list of such rights does not seem helpful.

Child Health and Policy in Europe and North America, ca. 1900

One ongoing theme of the 2014 Jacksonville conference was this: surely U.S. bioethicists, as scholars interested in the ethical issues related to children in health-care settings, should be the first to point out that the distribution of resources in the United States is unfair, that children are innocent, and that all deserve an equal chance in life. The United States spends more on health care per capita than any other nation, yet population health metrics for children and adults are typically well below those of other industrialized nations. Who can defend the fact that, in a rich country like the United States, millions of children live in poverty, with substandard housing, inadequate diets, and basic material deprivation? Quality of education, health, recreation, and safety are all closely correlated with income, maternal education, and neighborhood. Why don't bioethicists condemn a nation that puts children first, rhetorically, yet allows children who live in poverty to have such dismal outcomes? The first answer, described above, is that many bioethicists do—though not necessarily because they work as clinical bioethicists.

A second answer, from a historian's point of view, is that ratifying the CRC is unlikely to address the more fundamental issues leading to relatively poor health of U.S. children. Indeed, emphasis on child rights might be part of the problem: U.S. laws designed to protect child rights have sometimes led to worse outcomes for children. To understand these issues, it is helpful to briefly review the historical reasons why the United States, at least compared to Europe, has such a fragile commitment to providing all children with proper nutrition, safe homes, health neighborhoods, and high quality health care.

Child health became a "problem"—and the focus of concerted effort—relatively late in modern history. In the late 1800s in Europe and the United States, healthy children came to be seen as critical to the well-being of emerging nation-states. Wars were won or lost and economies rendered productive or sluggish according to the health of a nation's young men. Both politicians and medical scholars believed that the health of a population required attending to the health of babies, because infants and children eventually became adults. Similarly, women's health was critical because conditions of pregnancy influenced the infant; healthy mothers bore and raised healthy children.

In this historical context, the infant mortality rate (IMR) took on symbolic meaning as a measure of public health and community well-being. The IMR was well above 100 deaths per 1,000 live births in most communities, and infant diarrhea was responsible for almost half of the deaths. Public health efforts to improve the milk supply led to "clean milk depots" and eventually Pasteurization of the milk supply. Pediatrics emerged as a specialty clinical practice, in part because of pediatricians' scientific advice on how best to feed—and protect—infants and young children (Brosco 1999; Meckel 1990).

Poverty was a bigger problem than milk. A high IMR was associated with limited maternal education, substandard housing, general overcrowding and heat, poor sewage disposal, and faulty child-rearing habits. These problems were caused not by a simple lack of money, most reformers argued, but by defects in intelligence and moral character, especially of mothers. Visiting nurses and physicians therefore gave advice on infant care and home hygiene. Mothers learned how to protect the baby from diseases conveyed by their dirty hands, transmitted through impure milk, or carried by flies and other insect vectors. "Baby Weeks," "Better Baby Contests," and a flood of public health literature told mothers, among other things, that a fat baby was a healthy baby.

Some reformers argued that education alone was not enough. Many mothers had to work long hours and could not attend to their children; fathers could not afford homes in clean neighborhoods; and families with barely enough money for food and clothing could not afford a doctor. The disagreement over how to reduce the IMR mirrored a longstanding controversy over how to alleviate poverty in general. Most Americans agreed that for reasons of religion, morality, or self-interest, society had an obligation to improve the lives of the poor. However, there was also a persistent sense that the poor had only themselves to blame and that providing alms simply created dependence and perpetuated poverty. In the late 19th and early 20th centuries, Americans generally held that hard-working but low-income families deserved help, especially when the father died, fell ill, or lost his job. Such assistance was usually temporary, however, since philanthropists did not want to rob the poor of their will to work (Katz 1983).

One result of this ambivalence towards poverty is the country's relatively small scale of public child health. Although child welfare movements in European nations paid similar attention to the poor, and displayed similar ambivalence towards welfare, nations such as France and England created government programs that offered financial assistance and direct medical care to all mothers and children, regardless of income (Dwork 1987; Klaus 1993). Because their goal was future military and economic strength, European nations provided government benefits as a just entitlement to all citizens, not as a charitable donation to the poor. Britain's School Medical Service and the 1918 Maternity and Child Welfare Act, for example, demonstrated that nation's commitment to its citizens regardless of socioeconomic status. Today, most European nations provide a host of government services to all mothers and children as part of national plans to ensure child health.

Although the rhetoric of American leaders was similar to their European counterparts in the early 1900s, there was never sufficient urgency to pass national or state legislation guaranteeing the health of all mothers and children. This is partly because European nations faced a declining birth rate and shortage of healthy bodies, while the United States was flooded with immigrants. The influx of men and women willing to work in factories and sweatshops meant that America did not face the fundamental demographic problem of European nations—a population declining in numbers. Historians have noted several reasons for America's decision not to pass comprehensive health legislation in the early 1900s, including opposition by physicians, viability of workplace alternatives, and the decentralized nature of American politics (Murray 2007; Numbers 1982). However, the underlying difference in demographics contributed greatly to the differences between Europe and the United States. As a consequence, American child health policy focused on the problems of poverty and unfit mothers, and government and voluntary interventions were defined as a form of charity. Child health was primarily viewed as a private responsibility, with a limited role for local, state, and federal government (Brosco 2012).

This public-private split regarding child well-being persists today. For example, contrast the meager support that Medicaid and income-support programs provide to families living in poverty with the relatively stable and substantial political and financial support for Medicare and Social Security. It is hard to imagine that U.S. ratification of an international treaty asserting child rights would move public opinion or political debate towards a more communitarian approach to child well-being. Indeed, legal scholar Eric Posner (2014) has argued that rights treaties have provided relatively little benefit to the people that they are supposed to help. He catalogues the international advance of codified rights over the last 50 years and notes that passage of specific treaties seems to have little correlation with treatment of specific groups (for example, some nations that have ratified the CRC also sanction child labor).

In the United States, the prospects for the CRC helping children might even be dimmer. Historian Linda Gordon (2008) has argued that "child-first" laws and policies have been in place in the United States since the 1800s, yet may have led to unintended harm to children. The problem, according to Gordon, is that the stronger the drive to protect "innocent" children, the greater the likelihood to judge parents, especially mothers, as unfit. After a career dedicated to understanding the U.S. history of the child welfare system, family violence, birth control, and custody and immigration law, Gordon concludes that well-meaning reformers frequently erred when they prioritized children over their families. For example, the first large national welfare program, Aid to Families with Dependent Children, was created in the 1930s as part of the Social Security Act. However, many children lost or never received benefits because of their mothers' behavior: children needed "full-time" mothers, reformers believed, so there were strictly en-

forced limits on how much mothers could work, how they spent money, and how they maintained a "suitable" household. The penalty for breaking such rules was the end of financial benefits to the children (and the family). In similar attempts to "protect" children, state child welfare systems too often removed children from their mothers and placed them in inadequate foster homes. In each case, Gordon documents how women of color, immigrants, and others with relatively minimal social or political power were especially vulnerable to being judged inadequate, thus harming the children that a "child's rights" approach was designed to protect. Gordon concludes that both U.S. law and rhetoric have been strongly "pro-child" for at least 100 years, but that has not seemed to improve outcomes for children, at least relative to international comparisons.

Conclusion

As a historian and pediatrician who writes about clinical bioethics and social medicine, I often feel out of place, and the Jacksonville conference was no exception. I don't quite fit with the clinical pediatric bioethicists, many of whom trained in philosophy, nor am I a full-fledged member of the child rights world, which includes scholars trained in law, medicine, and epidemiology. As an outsider, I found the debates illuminating and fascinating; respectful and intelligent disagreement can produce deeper understanding than easy compromise. While the essays assembled in this volume testify to the value of debate, they also represent a classic example of two groups talking past each other, despite underlying agreement and support of the values espoused in the CRC. (Although no formal vote was taken, I'm confident that nearly all present would have agreed that the United States should ratify the CRC.)

The gross disparities in child health in the United States stem from persistent social and economic inequity and from a health-care system that is ill-designed to address the social determinants of illness and health. History teaches us that appeals to the rights of children in the United States are unlikely to address these fundamental problems. There is hope, though, that the nation's health-care system is slowly beginning to use population health science in an outcome-based approach that rewards health promotion, disease prevention, and positive results from treatment of acute and chronic health conditions. Much of this is driven by the high costs of health care borne by governments and businesses; economic forces may lead to reductions in health disparities in a way that the language of child rights cannot. As accountable care organizations proliferate, pediatric bioethicists and child rights advocates can work together to remind policy-makers of children's unique social, developmental, and health-care needs.

References

Baker, Robert. 2013. *Before Bioethics: A History of American Medical Ethics from the Colonial Period to the Bioethics Revolution*. New York: Oxford University Press.

Brandt, Allen, and Martha Gardner. 2000. "Antagonism and Accommodation: Interpreting the Relationship between Public Health and Medicine in the United States during the 20th Century." *Am J Public Health* 90 (5): 707–15.

Brosco, Jeffrey. 1999. "The Early History of the Infant Mortality Rate in America: 'A Reflection Upon the Past and a Prophecy of the Future.'" *Pediatrics* 103 (2): 478–85.

Brosco, Jeffrey. 2012. "Navigating the Future Through the Past: The Enduring Historical Legacy of Federal Children's Health Programs in the United States." *Am J Public Health* 102 (10): 1848–57.

Dwork, Deborah. 1987. *War Is Good for Babies and Other Young Children: A History of the Infant and Child Welfare Movement in England, 1898–1918*. London: Tavistock.

Gordon, Linda. 2008. "The Perils of Innocence, or What's Wrong with Putting Children First." *J Hist Child Youth* 1 (3): 331–50.

Katz, Michael. 1983. *Poverty and Policy in American History: Studies in Social Discontinuity*. New York: Academic Press.

Klaus, Alisa. 1993. *Every Child a Lion: The Origins of Maternal and Infant Health Policy in the United States and France, 1890–1920*. Ithaca, NY: Cornell University Press.

Lewis, Sinclair. 1925. *Arrowsmith*. New York: Harcourt Brace.

Meckel, Richard A. 1990. *Save the Babies: American Public Health Reform and the Prevention of Infant Mortality.* Baltimore: Johns Hopkins University Press.

Murray, John E. 2007. *Origins of American Health Insurance: A History of Industrial Sickness Funds.* New Haven: Yale University Press.

Numbers, Ronald L. 1982. *Compulsory Health Insurance: The Continuing American Debate*. Contributions in Medical History. Westport, CT: Greenwood Press.

Posner, Eric A. 2014. *The Twilight of Human Rights Law.* New York: Oxford University Press.

Rosenberg, Charles E. 1963. "Martin Arrowsmith: The Scientist as Hero." *Am Q* 15: 447–58.

Rosenberg, Charles E. 1979. "Inward Vision Outward Glance: The Shaping of the American Hospital, 1880–1914." *Bull Hist Med* 53 (3): 346–91.

Rothman, David J. 1991. *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. Piscataway, NJ: Transaction.

Rothman, David J. 1997. *Beginnings Count: The Technological Imperative in American Health Care*. New York: Oxford University Press.

Smith, Jane S. 1990. *Patenting the Sun: Polio and the Salk Vaccine*. New York: William Morrow.

Starr, Paul. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.