The Teaching of Bioethics in High Schools

Ruth Levy Guyer

Does the duty to preserve life include all life or only specific lives? Should babies born with mental or physical disabilities be prevented from living? If so, who should decide which disabilities are not acceptable? What roles do political realities, the equal protection clause of the 14th amendment, and religious and cultural attitudes play in how our society treats at-risk babies? What factors could or should be considered when resources are allocated for the babies' care?

These are a few of the questions that teachers in high schools are posing this year as their students study the plight of Baby Bollinger. The baby's fate was sealed long ago—Thanksgiving, 1915—but his five-day life nonetheless has strong relevance to topics addressed in contemporary high school science and social science classes. The story is one of five in the high school bioethics curriculum unit entitled BABIES developed at the Kennedy Group Home System Fails the Mentally Disabled

Julie Eddinger

In a recent series of articles covering the serious lack of care in Washington D.C.'s group homes for the mentally disabled, a Washington Post reporter found "more than 350 cases of abuse, neglect, molestation or stealing." The investigation covered group homes and day programs based on the records of four district agencies as well as the federal and D.C. courts. (WP, 3/14/99, A1). Washington Post staff writer, Katherine Boo, describes the lives and deaths of several mentally disabled adults:

Profoundly retarded, elderly Calvin Neilson was fatally scalded in a home owned by a prominent developer. An aide left him alone in an overheating shower about which city inspectors had repeatedly complained. (WP, 12/5/99, A1).

Reginald Lovette, 28, was strangled by his 250-pound roommate. For a year, his repeated pleas for protection had been disregarded by the convicted criminals who served

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Group Home System Fails the Mentally Disabled

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as his group home counselors. (WP, 12/5/99, A1).

In January 1997, Fred Brandenburg, 57, was "tranquilized in a staff mix-up, grew acutely ill and, surrounded by caretakers, slowly died without treatment." His body was cremated treatment." His body was cremated without an autopsy. His caretakers changed the records detailing his death keeping evidence of wrongdoing from the police. (WP, 12/5/99, A1).

The reporter states, "today in the name of the privacy and dignity of the retarded, top city officials say they can't publicly acknowledge that a man named Fred Brandenburg was ever in their care." (WP, 12/5/99, A1)

The cost of the taxpayer-funded system of care was $100,000 per person per year. Soon the District's system of group home care fell into the hands of individuals whose primary interest seemed to be profit. Some of the 150 District group home owners included a convicted embezzeler and night club owner who paid go-go dancers as "group home consultants"; a psychologist who billed the government for services that were never rendered, using the money for buying luxuries and making home improvements; and a wealthy racehorse owner who had his group home residents shovel manure at his farm for $5 per day.

Ten years ago, a federal lawsuit closed Forest Haven, an asylum in Laurel, Maryland, just outside of Washington because of the poor care it provided to its 1,110 mentally disabled residents. Those who had grown up at Forest Haven were then placed in privately operated group homes in the District of Columbia that were created to "provide sensitive, individualized care in homelike settings-care monitored by a large network of city and federal protectors." (WP, 3/14/99, A1) In addition to moving residents to group homes the city provided them with an annual, individualized plan for therapy in a day program; but management of the program was not carefully monitored. City officials gave the responsibility of managing the program of group home care to the Mental Retardation and Developmental Disabilities Administration, (MRDDA), a part of the District's Department of Human Services.

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After Ms. Boo's stories were published in the Washington Post, several changes occurred in group homes in the District. The D.C. mayor, Anthony A. Williams, ordered the evacuation of two homes where neglect and life threatening conditions had been ignored by city officials for years.

In April, 1999, the head of the Department of Human Services, Jearline Williams, ordered the removal of several D.C. officials who had known about the life-threatening conditions and neglect in D.C. group homes for at least five years. In May, 1999, Denise Braxtonbrown-Smith, a psychologist who operated a day care program, was indicted for allegedly misusing medicaid funds

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intended for the mentally disabled. Several months later, Arnett C. Smith, chief of the MRDDA, who helped Braxtonbrown-Smith set up her company and oversaw her assignments, was indicted on charges that he accepted more than $25,000 in illegal gratuities from her. (WP, 11/6/99, B1). Yet, even with these changes, neglect and abuse of the mentally disabled continued. In July, 1999, Patrick Dutch, 41, a blind, mentally disabled man died of heat exhaustion when he was forgotten by his caretakers and left in a van for seven hours in 99 degree heat. After the Washington Post ran a story about Dutch’s death, Mayor Williams stated, “We have a sacred trust to ensure the well-being of our most vulnerable clients.” Mayor Williams promised, “There will be radical changes starting now to ensure that those still in the group homes are safe. This will never happen again.” (WP, 7/13/99, A1)

For the past ten years, many mentally disabled adults living in D.C.’s group homes have suffered in silence. Have they now been given a voice through these investigations?

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Institute of Ethics. Each story is entangled in ethical, medical, legal, and social dilemmas.

High school courses that focus on facts and single-answer questions do little to prepare students for dealing with real-life problems for which, typically, there are no absolutely right answers. In contrast, bioethics case studies are ideal, because they give students practice analyzing dilemmas and making decisions. Some students initially react to the stories with strong statements of what "ought" to be done. But, when they stop pontificating and start listening to their classmates' ideas and opinions, real learning begins. They discover that opinions other than their own are valid. They see firsthand the importance of working toward consensus, and, if necessary, agreeing to disagree. They realize that actual dilemmas always crosscut disciplines—medicine, law, science, culture, technology, economics, and so on. The school day may be broken into discrete subjects but real-life problems are not.

The BABIES stories raise the important question of who should speak for the members of society who literally cannot speak for themselves, and this feeds into the more general question of who should be involved in any medical-ethics decision. In today's high-tech medical arena, no one can escape eventually becoming a "player" in a bioethical dilemma.

Baby Bollinger's Story

Baby Bollinger was one of a number of babies whom the "black stork," Harry Haiselden, determined should die. Haiselden, a surgeon in Chicago, convinced the baby's parents to choose death for their son rather than to embark on a series of operations that might repair some of his deformities. Haiselden told the Bollingers that, in addition to the physical problems—the baby's head was attached directly to his shoulders, he had one ear, his face listed to one side, his ribs were deformed, his chest seemed to have caved in, some organs were severely malformed—he would likely "be an imbecile and possibly criminal." He was, in Haiselden's opinion, a "defective" whose life was not worth saving.

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Haiselden oversaw the deaths of a number of babies besides Baby Bollinger. At first, he simply let the babies die, but later he engineered the deaths with injections of narcotics. He made no effort to cover up what he was doing. In fact, he wrote newspaper articles, gave lectures, and invited reporters to the hospital to gawk at the babies. Haiselden championed both euthanasia and eugenics.

In an article that he wrote for the New York Medical Journal in 1915 (102:1132-1134), his biases surfaced: "It was not a pink, full blooded baby that would invite attention, but a thin deformed little one, from which the uninitiated would turn away...I did not kill the baby; nature killed him. Nature saw her terrible mis-take and remedied it."

Haiselden had supporters who thought, as he did, that society would be better off without "defective" members. He also had opponents. Chicago's Commissioner of Health wrote in the Journal of the American Medical Association (LXV(23):2025, 1915) that "while it is true that mental and physical defectives have been a burden on society...who can say that the love and care bestowed on these defectives have not enriched the minds and hearts of those who have worked with and for these unfortunates, so that in the end the world is repaid..."

In 1916, Haiselden stepped over the line in the opinions of many of his colleagues. He wrote a screenplay—The Black Stork—about his euthanasia practices, and he actually starred in

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the film, portraying himself. He was soon ousted from the Chicago Medical Activities Society. The story of his is recounted by Martin Pernick in the 1996 book The Black Stork (Oxford University Press, NY) (See box for more information).

Baby Bollinger in the Classroom

The "hooks" for integrating Baby Bollinger's story into different classes vary. No one knows what caused his deformities—candidates include gene mutations, aberrant fetal development, and Mrs. Bollinger's bout with typhoid early in her pregnancy. Thus, biology teachers are introducing the story into genetics, anatomy, embryology, and health and disease classes, where it sparks discussions of advanced technologies and the opportunities and problems they present, differences between active and passive euthanasia, relations of doctors and patients, and the challenges of genetic engineering. In history, anthropology, and psychology courses, the story ties in with numerous themes and topics—nativism (who are the authentic Americans?), infanticide, eugenics, xenophobia, euthanasia. Turf questions arise in government, economics, and ethics courses: when should the good of society take precedence over the good of the individual, where do medicine and the law collide, when should the doctor's choices trump those of the patient or parents, what is just? Most generally, the story serves any class as a springboard for teaching civility, because it illustrates the power of language and its potential for destructiveness. (The baby was called "a monster" and "a defective.") Where teachers from several disciplines work together, the broadest and richest discussions result. The other cases in the BABIES unit deal with prematurity, siamese twins, anencephaly, and a baby in a persistent vegetative state. All of the stories in the BABIES unit teach students strategies for thinking, communicating, and listening. One teacher says that, after several days of discussion about Baby Bollinger, he asks his students this question: "If you knew that your baby would be born this way, what would you do?" He wants them to learn about themselves and their beliefs. He wants them to discover what resources—themselves, doctors, their religion, friends—they will rely on when, inevitably, they are confronted with their own bioethical dilemmas.

For more information about the High School Bioethics Curriculum Project, contact RLG at the Kennedy Institute of Ethics at Georgetown University at 202-687-8099 or RLG@aol.com.

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Pernick's The Black Stork

The Bollinger case, the 1915 events that are the basis of the teaching discussed in Ruth Guyer's account beginning on page 1 of this issue of the Newsletter, is presented in the thoroughly researched 1996 study by University of Michigan medical historian Martin S. Pernick. Its full title is The Black Stork: Eugenics and the Death of “Defective” Babies in American Medicine and Motion Pictures Since 1915. Pernick based his research on newly-discovered sources including long-lost motion pictures such as the one bearing the same title. The book traces the twentieth-century history of cultural attitudes about “defective” and “unfit” infants showing the links between this case and the movements for eugenics and euthanasia of the disabled. The book ends with comparisons of attitudes in Haiselden’s time with the Baby Doe cases of the 1980s, the practices of Jack Kevorkian, and the Human Genome Project. The book is published by Oxford University Press. It has recently appeared in paperback ($24.95).
New Journal Addresses Religion and Disability

A new academic publication, the *Journal of Religion, Disability & Health*, provides "an interfaith, interdisciplinary forum that will reflect and support the growing dialogue between religious/spiritual perspectives and clinical/scientific perspectives in supporting people with disabilities and their families."

Its co-editors are William C. Gaventa, MDiv Coordinator, Community and Congregational Supports, The Elizabeth M. Boggs Center on Developmental Disabilities, The University Affiliated Program of New Jersey, University of Medicine and Dentistry of New Jersey; and David L. Coulter, MD, Associate Professor of Pediatrics and Neurology and Director of Pediatric Neurology, Boston University School of Medicine, Massachusetts. They say they "hope to provide an equal place 'at the table' for the voices of people with disabilities and their families as they encounter and address services and supports in the world of faith and health.

Among the subjects the journal plans to address are the ethical, moral, and spiritual issues raised by people with disabilities in health and rehabilitation services including the move away from a medical model of care and supports. Subscription rates (per volume) are $50 (for individuals), $95 (for institutions), and $125.00, for libraries in the U.S.; $65, $124.00, and $163 for Canada, and $70, $133, $175 elsewhere.

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Communities of Moral Inquiry Involving those with Retardation

A recent article in the *Journal of Religion, Disability & Health* addresses the notion of moral community among the interdisciplinary care giving team in facilities serving those with disabilities. The article is authored by Roger K. Peters, D.Min, Director of Pastoral Services at Selinsgrove Center in Selinsgrove, Pa. He is the past president of the Religion Division of the American Association on Mental Retardation.

Drawing on the word of contemporary communitarian authors writing in bioethics such as Alasdair MacIntyre and Daniel Callahan, Peters, who has chaired his organization's ethics committee, appeals for the use of the moral community, including persons with mental disabilities, for decision-making. See "Toward Creating Communities of Moral Inquiry: An Interdisciplinary Opportunity." *Journal of Religion, Disability & Health* 3 (No. 2, 1999):37-45.
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