Three Stories
from Cases in Bioethics

EDITED BY CAROL LEVINE

"AIN'T NOBODY GONNA CUT ON MY HEAD!"

A FIFTY-SIX-YEAR-OLD farmer, accompanied by his wife, consulted the Neurology Service of Veterans' Hospital because of memory difficulty. For two years the patient had been having increasing trouble with technical aspects of farming. More recently he had been talking about his brother George as if he were alive although he had died two years earlier. He gave his own age as 48 and the year as "1960, pause . . . er, no, 1970." Examination revealed that the patient walked with a wide-based gait (a standard sign of brain pathology) and decreased cerebral function but was otherwise normal. The patient had no difficulty with simple coin problems and could repeat six digits.

Pleading pressing business, the patient declined hospitalization to determine the cause of his decreasing cerebral function. His wife tried to persuade him to enter the hospital, but when the resident suggested that she might assume guardianship for her husband through court action she declined.

Six months later the patient's condition had worsened. Through the urging of the county agent the patient had leased most of his farmland to his neighbors and now did no work. His gait had become so wide-based that acquaintances mistakenly thought him inebriated. He urinated in his pants about once a week, and recently seemed not to care. He sat watching television all day, but never paid any attention to the program content.

Examination at this time showed an apparently alert man without speech difficulty but with considerable mental deterioration. The patient gave his age as thirty-eight, the year as 1949, the president as Eisenhower, and the location as a drug store in his home town. He failed to recognize the name Lyndon Johnson, but upon hearing the name John F. Kennedy he spontaneously volunteered knowledge of his assassination. The patient could not subtract 20 cents from a dollar but could name the number of nickels in a quarter. He could recite the months of the year and could upon request from his wife give fairly long quotations from the Bible.

The resident and the attending physician urged hospitalization. They told the patient they would evaluate him for treatable causes of mental deterioration and memory deficit. In view of his wide-based gait and urinary incontinence in association with dementia, it was likely he had occult hydrocephalus. It was explained that this disorder caused decreased mental abilities by interference with absorption of cerebrospinal fluid. The mental deterioration in these patients is partially (as in his case now) or completely (as in his case six months ago when first seen) reversible. The treatment is to place a plastic tube through the skull to drain the cerebrospinal fluid from the brain to the vascular system; this was explained to the patient with diagrams. The patient immediately rejected the surgery, summarizing his thoughts with these exact words: "Ain't nobody gonna cut on my head." The patient's wife again attempted to persuade the patient to accept hospitalization and, if tests confirmed the clinical impression, surgery. The attending physician argued to the wife that the patient did not have the mental competence to decide his own fate and the wife should become the patient's legal guardian through court action and force hospitalization. The wife politely but vigorously rejected this course of action, pointing out that in her family the husband made all important decisions.

The resident and the attending physician differed in opinions at this point. The resident thought the patient should be followed in the outpatient clinic until he perhaps changed his mind. The resident pointed out that though the patient had decreased mental abilities he still retained enough intelligence to decide his own fate. The attending physician wished for court action to make the patient the ward of one of his relatives or, if necessary, the temporary ward of the hospital, and to force hospitalization and therapy.

COMMENTARY

James M. Gustafson

The principal substantive moral issue in this case is the status of the right of the patient to determine his own bodily destiny. He refuses to consent to a procedure which is likely to relieve his disability, though apparently he understands in lay terms what is involved in the surgery. At his level of competence he is "informed," but he refuses to give "consent."

The principle of informed consent is based upon one moral assumption and upon one philosophical judgment. The moral assumption is that individuals have a right to refuse treatment even when in the judgment of others that treatment is in the patient's own best interests. A person has a right to determine his or her own destiny. The ground of this assumption is historically located in the libertarian tradition of Western culture; it stems from the same tradition that values civil liberties, that believes that the state exists properly only on the basis of the consent of the governed, and so forth. The philosophical justification for the individual's right to self-determination has been made in various ways: the right is "natural"; capacity for self-determination is what makes humans distinctive as a species and from this is derived both its value and the right; individual rights are conferred by God; excessive incursion on self-determination leads to repression and in turn to social unrest, and for this reason the right is to be protected.

The serious philosophical judgment on which the principle of informed consent is based is that persons actually have a capacity to determine their own destinies. Every case of this sort opens the historic debate about "free will" if the case is carried beyond the immediate clinical circumstances.

This case can be analyzed on the basis of two questions which follow from the two paragraphs. 1) Are there *moral* grounds for exerting persuasive, or legal and coercive, measures to override this man's presumed right of self-determination? Do his obligations to his family and to the community (or, to make the point in a weaker way, do the interests of his family and the community) provide a sufficient basis for intervention without his consent? How one would answer this question would depend upon the status of the right of self-determination in relation to the claims of communities (his family, the neighbors, etc.) to limit and even override that right. 2) Are this man's capacities to judge rationally and to act in accordance with a rational judgment impaired by his illness to the extent that he cannot properly exercise his moral right to self-determination? Is he, to use the common term, really "competent?" Does his impairment provide "excusing conditions" so that just as he is not held accountable for his wide gait, so he is not accountable for his rejection of the proposed therapy? Given the assumption of "free will" in the consent procedure, can his will be judged to be "less free" than is necessary and sufficient to make a sound judgment? The attending physician could justify his "wish" for court action on the basis of either or both of the matters raised by these questions.

In this case I would argue in favor of the attending physician's "wish." My principal argument would be on the basis of the patient's limited capacities to exercise his right of self-determination. Note that an empirical judgment about those limits is involved. A hypothesis (and that is all it is) would be required to support the argument, namely, if this man's capacities were not so impaired he would consent to the surgery. Procedurally, I would support the steps taken in the report of the case; that is, first seeking voluntary consent of the patient, then of his family, and only as a last resort seeking a court order. I am prepared also, however, to argue that this man has obligations to his family and to the community that he ought to take into account in making his own judgment. His failure to consent is, it appears, costly to others; others are dependent upon him and, thus, also have a claim on him to consent to a procedure that would permit him to fulfill his duties to them. Procedurally, if such a line of argument failed to persuade him, and then his family, there would be a moral justification for court action. At the base of my conviction here is a significant qualification of the individual libertarian tradition in the direction of a more "social" view of persons and of duties and obligations of persons to other individuals and to communities.

COMMENTARY

Francis C. Pizzalli

At first blush, the attending physician presents a fairly convincing case for initiating state intrusion into the patient's brain. As the title of the case implies, the proffered therapy is fairly characterized as "brain surgery" and thus avoids categorization as "psychosurgery," replete with its politically value-laden premise of experimental treatment for the purpose of controlling socially deviant behavior. If, indeed, the preliminary diagnosis of occult hydrocephalus is sound, the operation would be tailored to rectify an accepted organic brain pathology. Though this entails the concomitant effect of controlling aberrant behavior (e.g., urinary maintenance and dementia), the presence of excess cerebrospinal fluid calls into play a well-defined medical/disease model which makes less persuasive the need to inquire into the motives of the physician as a check against the potential transmogrification of psychiatrists into thought-controllers.

If one were to accept the physician's evaluation of the mental incompetency of the patient, coerced institutionalization and treatment could be defended on a number of grounds. The procedure is relatively non-intrusive; to wit, it is a safe, non-experimental operation which involves no destruction of brain tissue and is intended to control behavior that ranks rather low on the continuum of volitional and autonomous functions. Not only is this intrusion minimal, but an array of humanitarian and utilitarian impulses militate for intervention. Does not the state have a moral obligation to the patient's former self to restore it? Or an obligation to construct a new self for the person, at which point he would be released to exercise his autonomy to its fullest potential? And would not this restoration to optimal functionality redound to the benefit of his family and community?

Even if we were to assume the patient's competency, the cost of overriding his competent judgment would be measured in terms of a single interference with personal autonomy at a particular time, presumably to be outweighed by the personal and social interest in a long-term increase in autonomy achieved by effective treatment.

Is there a decisive rebuttal to the physician's benevolent despotism? From a traditional legal perspective the case for involuntary commitment (i.e., enforced hospitalization) in this instance is rather weak. There is no mention of antisocial activities by the patient, which would warrant a finding of "dangerousness to others." To say that occasional urinary incontinence and mindless fixation upon the boob tube—behavioral traits found in many "normal" persons—constitute dangerousness to oneself reflects a most extreme paternalistic bias.

Even if the criteria for involuntary commitment are met, the case against intervention by no means falls. We cannot conclude that because an individual may no longer be competent to care for himself generally (e.g., due to memory deterioration), he is thereby incompetent to pass informed judgment upon such an intrusion as the proposed organic therapy. The notion of limited competency, besides having legal recognition, is rooted in the empirical observation that certain mental illnesses do not completely obliterate a person's ability to make decisions. While the patient may no longer recall dates and ages, it is hard to envision how memory deficit can totally discredit the capacity to understand the consequences of an operation, and to immediately summarize the resident's explanation and conclude with a refusal, as the patient has done. Even if we were to adopt the simplistic view that there is no competency where the refusal only occurred because of the mental deterioration, there is no evidence to indicate that the patient is other than strongly individualistic, and would not have decided likewise prior to the onset of deterioration. Moreover, the competent spouse's concurrence in his decision might be construed as evidence of agreement with his lifelong views on brain surgery.

To respond to the invocation of a classic Benthamite calculus that would override limited, albeit informed, judgment to refuse therapy, we might profitably view the case from a rule-utilitarian perspective. While it may be true in this particular case that only a minimally intrusive operation is needed to arrest mental deterioration and partially restore memory function, we should ask what the consequences would be of a practice of substituting the state's judgment for individual informed consent in order to achieve the incremental gain in utility involved in curing those who suffer from marginal mental impairment. Is it too far-fetched to conclude that the result would be a society in which democratic values of personal autonomy, freedom, and privacy would be subjugated to the ideal of state control over various kinds of behavior?

There is one final barrier to coerced surgery, assuming for the sake of argument that there are grounds for civil commitment and that the patient does not have the limited competency to give informed refusal to treatment. Shall the next-of-kin be designated as the proxy, with the power to give or withhold consent? To argue in the negative, because it is suspected the spouse will only rubber-stamp the incompetent's decision, conflicts with the legal presumption of identity of interests among kin. Likewise, to propose a third-party guardian who will rubber-stamp the physician's decision, on the ground that it will enhance the well-being of the patient and his family, arrogates to the physician the right to define that well-being, instead of allowing it to be defined within the privacy of the family.

In sum, only a highly paternalistic society could tolerate the intrusions upon autonomy and privacy that would flow from a practice of coercion in cases such as that at hand.

The Woman Who Died in a Box

One frigid January day Rebecca Smith, age sixty-one, was found dead of hypothermia in her makeshift home—a cardboard box covered by a rug—on a New York City street. The Red Cross had reported her unusual living arrangements to the police two weeks earlier. Social workers had visited her, offering food and help in moving to a city shelter. A mobile unit designed to help geriatric patients had approached her. A psychiatrist had visited her and declared her an "endangered adult," part of the procedure that would have allowed the authorities to hospitalize her under seventy-two-hour protective custody. But before the order could be carried out—the first time the city had attempted its implementation—Rebecca Smith died.

Before she joined the ranks of New York's homeless street people, Rebecca Smith had lived a rather different life. One of a family of thirteen children in Virginia, she had graduated from Hampton Institute as valedictorian. But she was hospitalized as a schizophrenic for ten years and underwent electroshock therapy. When she was released from the hospital, her daughter said, she was a changed woman.

In 1959 Mrs. Smith came to New York to live with her sister and then entered a mental hospital in Long Island. She was later released from the institution and decided to strike out on her own. That meant living on public assistance, taking Thorazine, and going to a medical clinic. In 1981 she failed to appear for recertification interviews with social workers and from then on—until her death—she lived on the streets.

Could Rebecca Smith's death have been prevented? How far do society's obligations extend toward those who are in need but who refuse to conform? Does society have different obligations to intervene in protecting those it considers mentally ill?

COMMENTARY

Kim Hopper

On March 19 this year [1982], I joined a hundred others across from the White House in a memorial service for the homeless poor who had died on the streets of six American cities this winter. Forty crosses were driven into the ground of Lafayette Park, joining over 500 already in place, the reported toll of the last five years or so in eleven cities. As it happened, the name on the cross I carried, the name I shouted out in the bright sunshine that day, was Rebecca Smith.

Rebecca Smith's death has drawn much more attention than her life ever did; it has been the subject of two editorials in the *New York Times*, another in the *Washington Post*, and of several commentaries on local TV news. But listen for a moment to the words of Betty Higden in Dickens's *Our Mutual Friend:* "You pray that your Granny may have the strength enough left her at the last . . . to get up from the bed and run and hide herself, and sworn to death in a hole, sooner than fall into the hands of those Cruel Jacks we read of, that dodge and drive, and worry and weary, and scorn and shame, the decent poor" (cited by Steven Marcus, "Their Brothers' Keepers," 1978).

What little we know of Rebecca Smith's life suggests that she may well have read about, and directly encountered, "Cruel Jacks" in the course of her institutionalized life. Mental hospitals were forbidding places in the 1950s and 1960s, and patients often fared as badly there as the "decent poor" had a century earlier in England.

There is a danger in discussing Rebecca Smith's death—that it will be taken more than it should be, as emblematic of a general refusal of assistance on the part of the homeless. From there, it is a small step to reviving the stale myth that the legions of the homeless poor on our streets are there because they choose to be. The recent history of New York's sheltering efforts suggests otherwise.

Since the *Callahan v. Carey* suit[1] was filed in October 1979, more than 1700 new emergency shelter beds have been provided by New York City. All were filled this winter. An additional 175 homeless men and women avail themselves each night of the twenty-four-hour drop-in facilities at the Moravian Church and Olivieri Center. Dozens more found respite this past winter, courtesy of the churches and synagogues that opened their doors to the wandering poor. Did these people materialize out of thin air? Or, as appears to be the case, were most of them making their way wretchedly until a more decent option presented itself?

It is difficult to attribute the recent surge in the sheltered population to more rational behavior by the homeless. If anything, observers agree that recent recipients of shelter have more tenuous mental health than traditional clients of the public shelters. The decisive difference appears to be the range of options offered the homeless poor: as that range has increased, so has their demonstrated willingness to come in out of the cold. It takes some flexibility, a modicum of decency, and respect for the heightened sense of self-protection that life on the streets can breed. It takes patience—but that is all.

But exceptions do occur. We don't know exactly what Rebecca Smith was offered, or what she understood the offer to be. A lot of people tried, but there was neither world enough nor time. City attorneys waited until a Friday afternoon to file papers in court, assuring inattention for another two days. Does that imply misgivings about their own resolve? This was, after all, the maiden application of the Protective Services Law. The process has since been streamlined to minimize gratuitous delays. Thus, several people may subsequently have been spared death by exposure. Clearly, once the protection of due process is secured, it is a civil obligation to take emergency action to save from imminent death one who is unaware of the peril.

But in the unforgiving light of hindsight, more than "what should have been done" is illuminated. Private shelters are filled with wary, once-desperate men and women who formerly saw no alternative to the degradation and danger of the public shelters than to live apart from them and to die decently when that failed. Betty Higden would have been one:

> Comprehending that her strength was quitting her, and that the struggle of her life was almost ended, she could neither reason out the means of getting back to her protectors, nor even form the idea. The overmastering dread, and the proud stubborn resolution it engendered in her to die undegraded, were the two distinct impressions left in her failing mind.

Betty Higden's prayer—"to die undegraded"—was heard. She died, alone and unseen, by the roadside one night, the money to pay for her burial sewn into her gown. There is a defiant dignity in such a death, one that refuses to exonerate a society inured to her suffering. It was as if she had demanded, not justice at last, but injustice consistently applied. There were to be no eleventh hour "heroics," no final capitulation to the indignity of a pauper's death. This recognition, that even the desperately poor may prize self-respect above a forced and servile dependency, should arrest easy ruminations about "what should have been done."

Rebecca Smith's is not a "right to die" case, anymore than Betty Higden's was. It is rather an object lesson in how comfortably we tolerate routine misery and how quickly we will pounce to sequester evidence of that fact.

Of course, there is an out. One could argue that others have found their way to refuge before death, that it needn't be shameful, and that were more decent shelter available, Rebecca Smith might not have had to die to force the issue. But to raise the question of intervention only at the hour of her death is seriously to cheapen the worth of her life.

COMMENTARY

Nicholas N. Kittrie

Despite my continuing concern for the excesses of the "therapeutic state"—which has permitted involuntary sterilization, lobotomies, electroshock, and indeterminate incarceration for those suffering from mental illness, while forbidding these procedures to be applied to convicted criminals—I believe that New York has failed in its duty toward Rebecca Smith. This conclusion follows from general principles of enlightened jurisprudence, which are applicable community-wide, regardless of the psychiatric status of Rebecca Smith or the mental illness laws of New York.

The balance between personal autonomy and communal responsibility is difficult to strike. Excessive stress on autonomy is likely to reinforce individualism, but also to introduce alienation and community disintegration. Emphasis on communal responsibility, on the other hand, while strengthening collective bonds, could result in paternalism and possibly even in authoritarian suppression. Different societies strike the balance differently. While American jurisprudence, in its commitment to liberty, has not usually articulated "Good Samaritan" laws for the community or individual citizens, both the Italian and French Penal Codes specify penalties for "any person who neglects to afford the necessary assistance" to a "person wounded or otherwise in danger."

One may doubt the desirability or effectiveness of decreeing that an individual citizen become a Good Samaritan under the penalty of criminal law or of interfering with an individual's voluntary exposure to danger—including motorcycle riding, smoking, or sky diving. Yet one can readily concede the importance of communal efforts on behalf of those who appear to be *involuntarily* stranded or in danger.

Rebecca Smith was exposed to evident, continuing, and increasing danger on the public streets of New York. Suppose she had stepped into the middle of oncoming traffic. Would the state agencies have felt the need for a complex and time-consuming procedure to remove her to safety? Would it have mattered whether or not she suffered from one mental illness or another, or from none? In a reasonably humanitarian, welfare-oriented society, at the moment of risk the state must step in, at least temporarily, to rescue those disabled from their own pursuit of "life, liberty and property." This rescue the state owes to its citizens regardless of color, creed, sex, fortune, or mental ability.

What if the citizen for a second time marches into the middle of the traffic, climbs onto the rooftop, or threatens to jump from the bridge? Even for a person who is sane, the state is expected to make a second rescue effort. Moreover, under common law such willful citizens could be charged with disturbing the peace, attempting suicide, or some other obscure legal violation, thus affording the state the justification for temporary restraint.

If minor sanctions are to be attached to deliberate, repeated risk takers, they should apply whether the risk takers are competent or incompetent. But I am strongly opposed to attaching a psychiatric label to people in order to permit greater intervention and control over their lives than over the community at large.

Rebecca Smith died before New York City authorities could implement her hospitalization under its new protective custody law. Yet for at least three decades, under special laws, the mentally ill, alcoholics, and drug addicts have been confined on the basis of psychiatric labels, without complying to the standards of "due process" and "probable cause" required under the criminal law. At the height of the therapeutic state, in the 1950s and 1960s, efforts were made to greatly and unduly broaden the insanity defense, as well as to altogether prohibit criminal sanctions against public drunkenness. But the late 1970s brought an antitherapeutic movement of similar extremity. While therapists of two decades ago called for voluntary and involuntary "treatment" of all deviants, today's therapeutic nihilists wish to totally abolish the insanity defense and to condemn to benign neglect those who require assistance.

Neither extreme supplies even and civilized justice for America. Rebecca Smith's life should have been saved, even at the cost of a temporary loss of freedom. But the same conclusion should apply to all citizens similarly situated, regardless of their psychiatric diagnosis. The New York seventy-two-hour temporary custody law, designed exclusively for those allegedly mentally disabled, proved not only unjust, but also ineffective.

DECISIONS ON BEHALF OF THE INCOMPETENT

Sterilizing the Retarded Child

A retarded eleven-year-old girl from the city of Sheffield, England, had been booked to enter a hospital on May 4, 1975, for a sterilization operation. The girl, known as "D," suffers from Sotos Syndrome—also called cerebral giganticism—an unusual group of congenital abnormalities including epilepsy. Characteristics of the disease include large hands, feet, and skull; poor coordination; and endocrine problems of unknown etiology. Intelligence ranges from normal to severe retardation, with most mildly retarded. ("D" had a normal intelligence range, a fair academic standard, and the understanding of a nine- to nine-and-a-half-year-old.)

While authorities in the genetics of Sotos Syndrome are uncertain about its inheritability, they believe that it is not one disease but a heterogeneous group of disorders, and that it may be either a recessive trait or a new dominant mutation. Most cases of Sotos Syndrome have been sporadic, occurring equally in both sexes. Those afflicted do not seem to have a higher incidence of relatives affected than does the normal population, and the risk of genetic transmission is not known. There have been reports, however, of its occurrence among first cousins, identical twins, and between father and son.

"D's" father died in 1971, leaving the mother to raise the girl and two other daughters in very difficult circumstances. The mother, a part-time cleaner, is very hard-working, sincere, and devoted. The girl sleeps with her mother in one bed; their two-bedroom house has no toilet; and they live under conditions described as appalling.

In 1973 "D" was transferred to a school specializing in children's behavioral problems, a move reported to be a success. Her progress in education and behavior was evident. But by the time "D" reached puberty at the age of ten the mother had grown concerned, fearing her daughter might be seduced and have an abnormal baby, for which she would then have to care. She stated: "I don't think my daughter will ever be responsible enough to bring up a family. I don't think she will improve enough to look after children." However, "D" had not yet shown any interest in the opposite sex, and her opportunities for promiscuity were virtually nonexistent since her mother was always at her side.

Dr. Ronald Gordon, a consultant pediatrician at Sheffield Northern General Hospital who had taken an interest in the family, said that there was a risk that any child borne by "D" would be abnormal and that the girl's epilepsy might cause her to harm a child. He thought that she would always remain so substantially handicapped that she would be unable to care for herself or any children she might have. He maintained that his recommendation to operate was based on his clinical judgment; furthermore, he claimed that he and the gynecologist, Dr. Sheila Duncan, should be the sole judges of whether surgery should be performed, provided that there was parental consent. Dr. Gordon also asked the mother, who consented to the sterilization, to discuss the operation with her daughter.

Mrs. Margaret Dubberley, an educational psychologist at the school the girl attended, strongly opposed the operation and brought legal proceedings aimed at having the girl made a ward of the court. The headmaster at the girl's school believed it was unrealistic to be dogmatic about "D's" future, a view supported by some medical evidence. Mrs. Dubberley was further supported by the National Council for Civil Liberties and by a movement in the House of Commons opposing the operation.

COMMENTARY

LeRoy Walters

Before we examine the normative issues in "D's" case, it will be useful to analyze precisely what kind of sterilization is being proposed on her behalf. Since there is no evidence to indicate that the sterilization of "D" is medically required for the diagnosis or treatment of an existing illness or injury, the proposed sterilization can be categorized as *nontherapeutic.* A more complex question is the voluntariness of the proposed procedure. The surgery envisioned is clearly not compulsory, or involuntary, in the sense of being performed against the expressed wishes of the daughter. However, "D" is legally a minor and is probably not mentally competent to provide voluntary consent to the surgery on her own behalf. Perhaps a third category is required—nonvoluntary sterilization, or sterilization in the absence of the prospective sterilizee's consent or refusal. The proposed sterilization in "D's" case would seem to correspond most closely to this third category; that is, if performed, the sterilization would be nonvoluntary and would be authorized by the substituted judgment of the mother and the two physicians.

Under what conditions can nontherapeutic, nonvoluntary sterilization be morally justified? I would like to suggest three formal requirements which should be applied to this and similar cases. First, there should be *just cause,* or a sufficiently weighty reason, for the proposed sterilization. A just cause is required because sterilization in the absence of consent constitutes a significant invasion of the body and a rather massive intrusion into the sphere of reproductive privacy that has recently been recognized by Anglo-American law. The second requirement is that sterilization should be a *last resort,* since it is generally irreversible and since equally effective, reversible contraceptive techniques are available—for example, the pill. The third formal requirement is *due process,* or an adequate procedure for representing the interests and protecting the rights of all parties concerned.

The proposed sterilization of "D" satisfies none of these formal requirements. First, there is no just cause for the sterilization of "D." It is not clear whether sterilization was recommended by the mother and the pediatrician primarily for the benefit of "D" herself, for the benefit of her mother and sisters, or for the benefit of a child which might potentially be conceived and born to "D." (Another logical possibility, not mentioned in this case, would be sterilization for the benefit of society as a whole.) However, no convincing arguments are presented to support any of these possible justifications. The evidence concerning the probabilty of "D's" producing handicapped children is inconclusive at best. In addition, the prognosis for "D's" own intellectual development is uncertain. It is at least possible that with the aid of continued special education she will one day be able to make informed decisions concerning her reproductive capacities.

Second, the proposed sterilization of "D" is clearly not a last resort. In the case report there is no evidence to indicate that reversible contraceptive techniques were either considered or tried. Until such alternatives have been demonstrated to be infeasible, consideration of an irreversible surgical procedure is premature.

Third, the proposal to sterilize "D" also fails to satisfy the due process requirement. Quite possibly the physicians and the mother based their decision primarily on the best interest of the child, as they perceived that interest. However, the "clinical judgment" of the physicians extended far beyond the bounds of the medically indicated. Even the mother, whose response in very difficult circumstances is understandable, did not sufficiently consider the rights of her child. In cases where the performance of an irreversible, nontherapeutic procedure on a child is contemplated, due process seems to require either the appointment of a guardian for the child or formal approval by an independent review committee. This at least seems to be the view of the U. S. Department of Health, Education and Welfare (as expressed in the sterilization restrictions published in the *Federal Register,* February 6, 1974) and the British Department of Health and Social Security, as outlined in a discussion paper, "Sterilization of Children under 16 Years of Age" (cited in the *British Medical Journal,* November 8, 1975 p. 356).

It is easy to forget that the momentary act of nonvoluntary sterilization has lifetime consequences for the person undergoing the procedure. A sociological study by G. Sabagh and R. B. Edgerton in *Eugenics Quarterly* (December 1962) reported that, of forty retarded persons who had been sterilized prior to their release from the institution, many understood "the meaning and implications of sterilization" and 68 percent "disapproved of the sterilization procedure which they had undergone."

In sum, the proposed sterilization of "D" in this case fails to fulfill the requirements of just cause, last resort, and due process. The preferable alternative would be to employ nonpermanent contraceptive techniques as necesary, in the hope that one day "D" will attain sufficient intellectual maturity to make her own reproductive decisions.

COMMENTARY

Willard Gaylin

When analyzed in terms of the specific data presented in this case, a court decision to prevent irreversible surgery seems reasonable enough; and that is, in fact, what took place. The child is, after all, still young; the nature of the mental impairment is still unclear; the degree of retardation (and possible maturation that can be expected) has yet to be defined. There will be a time for a reevaluation when the facts of her destiny become clearer.

The actual response the court's decision elicited, however, was not what one would expect for a prudential compromise, but more like that which is accorded a victory of the forces of good over those of evil. The applause in Britain and elsewhere was as unanimous and hearty as though Tinkerbell's life depended on it. One suspects that it was not the eleven-year-old girl and her future that were being judged, but a cliché. For years sterilization of the mentally retarded has been an issue fraught with emotion. The ominous implications of genetic engineering, cast in the shadow of the recent Nazi past, make the problem too easy by evoking an instinctive and intuitive response to the connotation of the words employed rather than their explicit meaning. Here was an issue that managed to unite educational psychologists, the medical establishment, the civil libertarians, and the House of Commons on one side—with only the unfortunate girl's mother in opposition. Any moral issue in biomedicine these days that commands such unanimity warrants a reexamination.

What is needed is some understanding of the value of sterilization in the mentally retarded. An automatic negative response is not warranted; and the reason is precisely the one sometimes relied upon by opponents of sterilization—that we now recognize the mentally retarded as a broad spectrum of individuals who, while limited in their capacity for certain functions of the healthy mature adult, are not limited in all.

One of the great disadvantages of IQ as the measurement of retardation is that it forces us to see the retarded of all ages as children. We describe them as "having the mentality of a six-year-old." No mentally retarded individual has the mentality of a six-, eight-, twelve- or fourteen-year-old. A six year-year-old is a learner par excellence, with unbounded intellectual curiosity, and a potential for mastery of new material that a thirty-six-year-old would envy. He is, however, immature, childish, and incapable of making the decisions which his profound intelligence might imply. A thirty-six-year-old with severe retardation to a point where he can neither read, write, count, tell time, nor follow street directions, can still be a mature adult in a host of ways beyond the capacity of the six-year-old. The price we make the retarded pay for their incapacity in one area is the sacrifice of capacity in certain other areas which could be compensatory if allowed to develop.

Because we cast mentally retarded adults as children we are appalled, for example, at the thought of their having a sexual or even a social life. Deprived of the joy and privilege of parenthood, for which they may have no capacity, they are punished further by being denied the privilege and pleasure of affection, tenderness, romance, and sexual contact for which they may indeed have a capacity.

A mentally retarded individual ought not be given the responsibility of raising a child, and indeed a mentally retarded woman could be terrified of the changes in her body which pregnancy would produce. Sterilization could allow for the kind of innovation in social living lacking at most facilities for the mentally retarded. There is no reason why community living, even a family-type living, that involved affection, tenderness, and sexuality could not be a fundamental part of their lives and partly compensate for their lack of ordinary intellectual pleasures. Instead we punitively add one deprivation onto the other.

Sterilization is, after all, simply a word. There is nothing in the procedure itself that is innately evil. We allow sterilization when its benefits for the individual outweigh its costs. It is a legitimate procedure, offensive to some for religious reasons but not to others. In this matter society ought to respect the individual conscience and the individual value.

When, as with the retarded, the concepts necessary for intelligent decision making are beyond a person's intellectual grasp, we would be wise to leave the power of the delegated autonomy in the hands of the family. If that is abused all sorts of legal mechanisms exist for rectification. What state right warrants intrusion into the decision making? If it is established (first by the family, then if there is suspicion of abuse, by courts), that the mental retardation is of a degree that precludes the role of parent, the young woman will be deprived only of the "privilege" of conception and, presumably, abortion. She will gain, however, new freedoms, and her parents will gain peace of mind.

The incursion into the powers of the family by the state, here as in other places, is often cast in the noble language of rights. What is really at issue in many arguments about "fetal rights," "infant rights," and so on is in reality the relocation of delegated autonomy and power from one institution—the family—to another—the state. Too often the kind of government intervention we have been seeing in these difficult cases, where right and wrong are too finely balanced for comfort or coincidence in any decision, represents arrogance rather than compassion. It is unseemly and demeans the state, for more often than not the state is acting not *in loco parentis* but simply as Nosey Parker.

If "D's" incapacities to be a mother are still evidenced when she is fifteen years of age, she, through the agents of her care, that is, her family, ought to have the right to exercise the privilege of sterilization.

Note

1. This class action suit successfully argued that conditions in the public shelters for men were so dangerous, dirty, and degrading as to constitute a genuine deterrent to their use by homeless men. It was settled in August 1981 by means of a negotiated consent decree that not only recognized a legal right to shelter but also established certain qualitative standards that public shelters must henceforth meet.