

# Ethical and Legal Issues in the Medical Care of Retarded Persons

by Philip R. Reilly

## Introduction

I vividly remember the first time I met a mentally retarded person. It was 1963 and I was newly enrolled as a junior in a small town high school in Massachusetts. It was autumn and I was tentatively making a new set of friends. A classmate invited me to his house after school, and I eagerly accepted. The back door gave way to a meticulously kept kitchen where a tall, thin, gray-haired woman was washing a few plates. How old his mother seemed compared to mine. We drifted into the living room, talking casually. Suddenly a heavy-set, short boy with an odd grin leaped at my friend. "This is my brother, Teddy," said my friend quietly, as he tried to extricate himself from a bear hug. "He's retarded."

Small waves of curiosity and fear washed through my mind. His small head, his protruding tongue, his obesity all disturbed me. Teddy plopped down and began watching the television. A few feet away I pretended to talk with my friend, but I was really studying his brother. Was he dangerous? Would he

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try to hug me? Should I try to talk to him? Gradually, other feelings gave way to sadness. I do not recall how long my visit lasted, but I know I cut it short, and felt a sense of freedom as I walked home.

Nearly twenty-seven years have passed (a fact that I grasp with difficulty), and I am now the director of an institution

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dedicated to helping mentally retarded persons and their families. My years working as both a physician and an attorney on behalf of people like Teddy have taught me a great deal about the problems faced by retarded persons in our society. Although I shall focus on ethical problems that arise in the medical arena, they are paradigmatic of other life concerns such as housing and employment.

The single most important ethical problem faced by physicians dedicated to helping the mentally retarded is to respect their right to be autonomous individuals. More specifically, care givers must realize that retarded persons have, albeit to a limited degree, the ability to learn and to make choices, and that they have the right to act in ways which are unwise or even foolish. For health care professionals who are dedicated to helping and protecting, this is hard enough. But it is especially difficult to respect retarded persons' autonomy while realizing that on occasion the right of a retarded person to behave autonomously should be restricted. The most challenging ethical and legal questions emerge in the debate over when it is appropriate to limit autonomy.

## Access to Medical Care

Depending on the nature of his or her disability, the problems faced by a retarded person in seeking access to medical care may be significant. For example, many infants with Down syndrome have undergone life-saving cardiac surgery. Yet I have seen a thoracic surgeon refuse to perform a thoracotomy on a 50-year-old retarded patient because he thought (incorrectly) that the man would not cooperate in his post-operative care, and therefore posed a higher than usual risk of dying from complications. The surgeon showed little concern about the consequences of **not** performing the thoracotomy.

Access problems also arise in less dramatic situations. A not uncommon problem in hospitalizing severely retarded persons is the hesitation of the nursing service to care for such persons. The

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usual concern is that because these patients either have serious disabilities in communicating their needs or may develop behavioral problems in an alien setting, they should be accompanied by special caregivers who know them and are better able to care for them. This, of course, is a very costly request. What is particularly troubling is that nursing services have frequently resisted assurances from direct care staff or families that the patient is unlikely to demand a special level of attention. Indeed, the opposite is sometimes the case.

This problem also surfaces in primary care medicine. Our society has largely ended the practice of segregating retarded people in isolated institutions, and we now offer them the chance to lead lives as close to normal as our own. In medicine this means, in part, that such a person should go to his doctor's office for a check-up or for evaluation of an intercurrent illness. Yet, I have had many retarded patients travel fifty or sixty miles to see me for a routine physical because no local doctor would see them. Why? The two most often stated concerns are: They will frighten other patients (as I was frightened long ago), and caring for them takes so much time that

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it disrupts the office schedule and inconveniences other patients. Although both concerns are real, it seems to me that the principle of beneficence demands that accommodations be made so that retarded persons can receive routine medical care. To those who argue that such individuals can receive excellent care at special facilities, I respond that our society has long recognized that the doctrine of "separate but equal" inevitably creates an unfair system.

There is a third concern that is more difficult to resolve. Many retarded adults (those 18 and over) are presumed competent (legally capable of acting in their own interests) and do not have legal guardians. A serious medical problem often challenges this presumption, and can result in harmful delays as care givers seek legal resolution. After a physician has become entangled in a few guardianship proceedings, he or she may shy away from future involvement with such patients.

Access to sophisticated medical care may be a much greater problem for older retarded persons with serious illnesses than for infants and children. While an infant with Down syndrome is usually considered a candidate for repair of a ventricular septal defect (a hole in the heart), a 50-year-old woman with Down syndrome is not a competitive candidate for a heart transplant. One famous example of the access issue is the *Saikewicz* case<sup>1</sup> in which the Massachusetts Supreme Court ultimately approved the decision **not** to provide complex and painful chemotherapy to an older retarded man with leukemia, even though the majority of non-retarded persons of similar age with the same illness chose to be treated. I doubt that the retarded patient's inability to understand or cooperate with the therapy, and the likelihood that he would be frightened and made ill by it, should control the decision to treat or not to treat. Since the majority of patients choose treatment and since it is, I think, a fiction to pretend that one is capable of ascertaining how a severely retarded person would choose if he could (the premise of the legal doctrine of "substituted judgment"), I would argue that we should err on the side of attempting to provide such persons with the same care the rest of us would most often choose.

#### Consent and Refusal

The principle of autonomy suggests that an individual should be granted the benefit of the doubt as to his or her capacity to be educated about and con-

sent to or refuse a medical intervention. The principle of beneficence, however, suggests that a physician should try to influence a patient whom he believes is making an incorrect or dangerous choice. This creates the ethically troublesome situation in which retarded persons are likely to be regarded as having the capacity to consent to care when they assent (or acquiesce) to the physician's advice, but become the subject of guardianship proceedings when they refuse (often physically) to consent to care.

I am disturbed when the principle of autonomy serves as the basis for permitting mentally retarded people "to choose" an option that leads to suffering and death.

Consider a situation in which I have been involved on numerous occasions. An adult retarded patient needs a physical exam and some laboratory studies that require blood drawing. A family member or staff person from his residence accompanies him to my office. This usually friendly young man becomes physically violent when I attempt to draw the blood (expressing, no doubt, fantasies of flight that we all have as that tiny shaft of steel hones in on our arms). What are the therapeutic options? Cease the effort to draw blood? Clearly, he has communicated his refusal. Physically restrain him in order to collect what could be important information? The intent is surely beneficial, but it is illegal (a battery) and, I think, unethical as a denial of his autonomy. Seek a guardian so that I will have somebody with whom to reason, who may consent to my plan and agree to a medication order (in essence, provide me with a chemical restraint)? This option appears to respect the requirements of due process, but the result is almost certainly going to be what I want.

The way I resolve this dilemma is to ask myself, "How important is the diagnostic information I seek?" For example, when I acquiesce in a 40-year-old retarded woman's adamant refusal of a pelvic exam, I am in effect saying, "I accept your right to forego a test that would assess the one in 1,000 chance that you might now have cervical cancer." After all, millions of non-retarded women make the same choice

by simply not seeing their doctors. But consider the patient with a clear family history of rectal cancer and a recent episode of rectal bleeding who refuses a rectal exam. That I **cannot** accept. For **me**, this is the point where beneficence outweighs autonomy. At the very least I will ask a probate court (through the guardianship process) to appoint a temporary limited medical guardian to weigh the need for this and other tests.

Perhaps the most challenging variation of this problem arises when a retarded person refuses (whether by limited reasoning and words or by physical resistance) life-saving therapy. Consider for example a 45-year-old, otherwise healthy, retarded woman with a large breast lump that is highly likely to be cancer. When informed of the need for a surgical procedure, she refuses, and is unyielding even to repeated warnings that she could die in a few years. My response is to ask a judge to determine if she has the capacity to choose. If he decides "yes" we must respect her choice. Although I acknowledge a non-retarded woman's right to refuse surgery, I accept it grudgingly. But I am deeply troubled when the principle of autonomy is extended to permit retarded persons "to choose" a course that leads to suffering and death.

#### Sexual and Procreative Rights

For physicians dedicated to caring for retarded persons, the task of helping them in matters of sexual expression, contraception, and procreation raises a number of ethical issues. These are complicated by the fact that earlier in this century approximately 60,000 institutionalized retarded persons were involuntarily sterilized. The reality of AIDS and other sexually transmitted diseases poses additional concerns.

Perhaps the most common issue in this arena arises when parents ask the physician to sterilize an adolescent retarded daughter whom they fear will be (or in fact has been) seduced or raped, or has voluntarily become sexually active. Each case has its own nuances. Typically, the patient is moderately retarded, lives at home and travels to a workshop, has at best a primitive understanding of human reproduction and little ability to grasp the possible consequences of her normal sexual drives.

Over the years this problem has been resolved in different ways. Until the mid-1960s the most likely course was to sterilize the young woman (who was often told she needed an appendectomy). We now know that such deception is not uncommon in medical

practice.<sup>3</sup> In the 1970s there was a radical shift in physicians' willingness to accede to parental requests for sterilization. It became routine to submit the matter to probate court, a process that included having a guardian *ad litem* appointed for the young woman to assure an independent evaluation of her circumstances. Even the courts were often reluctant to act, and for a time it became so difficult to obtain a sterilization that some commentators began to argue that retarded persons were being deprived of their right to safe, permanent contraception. Then, sparked by a thoughtful decision of the New Jersey Supreme Court,<sup>3</sup> the probate courts began to articulate and implement criteria for judging such cases.

Today it is clear that a parent or guardian's power does **not** extend to authorizing a sterilization. The court must approve the process and it will do so only if it is in the patient's **best interests**. The criteria used in weighing a sterilization include the following: the patient's understanding of human reproduction and contraception, the likelihood that she could successfully use non-surgical contraceptive methods, her interest in having children, her ability to act as a responsible parent, her health and the impact of various contraceptive methods upon it, her age, whether she is sexually active, and past experiences with contraception. Although the courts prefer not to approve sterilization petitions, their reluctance is tempered by the knowledge that pregnancy raises even more difficult questions.

When a severely retarded woman becomes pregnant, a physician may be asked either to deliver prenatal care or to terminate the pregnancy. In the latter case the court will almost certainly be involved. An effort is made to ascertain the patient's interest in parenthood and her capacity to parent, the relative risks of pregnancy and pregnancy termination to her health, and the health of the fetus. Here too the court proceeds with a best-interests analysis. Although outcomes vary, when a guardian requests a pregnancy termination it is usually granted, out of concern for the health of the woman and her likely inability to understand her pregnancy.

#### **Anti-Psychotic Medication**

Roughly one-fifth of all institutionalized retarded persons regularly receive anti-psychotic medication (the so-called "chemical restraint"). Although this number is high, it represents a steady decline in usage since the 1970s. The staff who care for retarded persons with behavioral problems must repeatedly

ask themselves whether the medication is really needed. By law in Massachusetts, care givers must hold monthly meetings to review the treatment of each patient on anti-psychotics. Where possible, behavioral modification programs are developed and data are collected by a psychologist. The goal is to keep the abnormal behaviors under control while reducing or eliminating the use of anti-psychotics. In this process one can often discern a clash of two ideologies: the behaviorist versus the neuro-psychopharmacologist. While both seek to eliminate the need for medication, one is much more optimistic than the other.

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### **Especially complicated ethical dilemmas surface when we provide care for retarded people in matters of sexuality, contraception, and procreation.**

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Short term use of anti-psychotics also poses complex ethical issues. The governing test here is whether the patient is "dangerous to himself or to others." However, this is a vague criterion often shaped by forces as remote as the state budget or the availability of back-up staff when someone calls in sick. As studies of prescription drug use in nursing homes suggest,<sup>4</sup> there is a tendency to write medication orders to assist overburdened staff who are trying to manage the program. The prescribing physician must ask whether the medication is clearly indicated. Overuse of medication in effect warehouses patients, whereas failure to order appropriate medication may actually endanger a patient or some third party.

#### **End-of-Life Care**

Another difficult judgment involves offering older retarded persons two options now being chosen by many non-retarded persons: (1) Should we voluntarily limit the use of extraordinary life-saving measures? (2) If a chronic, terminal illness occurs, is there an appropriate point when we can justifiably limit routine procedures and allow the person to die at home? A few years ago I was involved in the case of an 87-year-old retarded woman with advanced ovarian cancer whose home was a large state institution. She had no living family and the people closest to her were the staff in her building. In Tillie's case there was no meaningful therapy; she needed comfort

measures and friendly faces in a familiar setting.

The process by which the staff agreed to care for Tillie at home was quite moving. Although there was unanimous agreement in principle that it was the right course of action, many staff persons were afraid of acting illegally; others were afraid to care for a dying person. After communicating with Tillie and deciding that she really did prefer to stay at home, the staff held several meetings to share their worries. Physicians, clergy, lawyers, and social workers participated. The guardian who was appointed for Tillie ultimately approved the plan to provide comfort care only. Over a period of several months the woman gradually declined. She died in her room, her home for twenty years, surrounded by friends at her side.

Such stories inevitably raise the question, "To what extent are living wills appropriate for mentally retarded persons?" These documents, now recognized by many states, permit one to broadly control medical intervention at the end of life. Although the right of a guardian to create such a document is not clear, the principle of normalization suggests that retarded persons should not be denied any option available to you and me. I think retarded persons should have the right to make living wills, but given the importance of the document I would argue that it should be reviewed by a court before it is implemented.

Justice Cardozo, the author of many influential legal opinions, once wrote (in a case that is among the earliest on the law of informed consent) that "every human being of adult years and sound mind has a right to determine what shall be done with his body."<sup>5</sup> Seventy-five years have elapsed, and it is my view that we should now recognize an ethical obligation to help persons who are retarded to exercise this right in as wide an arena as possible.

1. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E. 2d 417 (1977).

2. D.H. Novack, et. al. "Physicians' Attitudes Toward Using Deception to Resolve Difficult Ethical Problems." *Journal of the American Medical Association* 261 (1989), pp. 2980-2985.

3. *In the Matter of Grady*, 426 N.E. 2d 467 (1981).

4. M. Beers, et. al. "Psychoactive Medication Use in Intermediate-Care Facility Residents." *Journal of the American Medical Association* 260 (1988), pp. 3016-3020.

5. *Schloendorff v. Society of New York Hospitals*, 105 N.E. 92 (1914).