

# Bureaucratizing Values

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Since the beginning of human experience, people have behaved as if freedom meant more to them than their lives. Yet, even more important to them has been the need to belong to a community, to be part of a fabric larger and more enduring than their fragile selves. This is why among the ancient Greeks to be banished was a punishment more severe than death. Only recently have we come to realize that many recipients of our human services have been punished by *both* banishment and loss of freedom in socially and often physically restrictive environments. As a result, uncounted commissions and agencies, bureaus and bureaucrats are today engaged in righting the wrong under the flag of the "least restrictive alternative."

I too have grieved for those we punished in the name of kindness; and I am glad that at last some of our official bureaus have taken human rights as an official concern. Yet the term "least restrictive alternative" is one I have misgivings about. Though better than outright banishment or imprisonment, it nevertheless implies an environment and conditions that I would not want for myself. So long as we speak of "least restrictive," we are speaking of "restrictive," and no "alternative" could be my "first choice." Certainly, we must work at minimizing the harm our society does, but in this chapter I would also like to look past this task to a society that maximizes good.

There is, however, a more immediate, less utopian concern I wish to explore in this chapter. The issue we confront in human services is one of very fundamental human values—freedom and community. Yet, our hopes and plans for securing these values for everyone are invested in government agencies and public laws, in an approach that codifies and mechanizes the "delivery" of values. In holding to our hopes we have seriously overestimated the power of bureaucracy. That is why, in the last

analysis, the concept of "least restrictive alternative" will remain, even in its most precise definition, no better than an exactly specified degree of banishment.

## Understanding Transitions

In the past 30 years, the mission of the mental retardation field has changed in crucial ways. In the 1950s, its purpose was to provide expertise and professional treatment to those afflicted with retardation. Then, our plea was to the nation, but our focus was clinical. To the extent that we addressed society at large, it was only to ask for support of our professional efforts—that is, to provide funding. Today, our primary work seems to be that of transforming not mentally retarded people but the society in which they live. Certainly we are still concerned with special applications of, for example, medicine and education, but the pivotal concerns of our field are now societal—gaining community acceptance of mentally retarded people, changing the attitudes of typical children toward handicapped children, securing for mentally retarded people the legal and human rights that the rest of us enjoy. Our major benchmark of this century was reached with the passage by Congress of Public Law 94-142, providing for the "least restrictive alternative." As reflected by this achievement, our activities have assumed a significant political thrust.

One of the characteristics of political activity is that it can seldom expect to succeed by openly seeking its final goal. A program must be presented, rather than as a totally realized whole, in politically feasible steps. This is necessary, in part, because society would repel any attempt at wholesale change—it must be urged and lured by small, often circuitous, steps toward the larger goal. But in still larger part, this is necessary because the goals of social change are invariably unclear. Not only is it difficult to specify what we would wish to happen, it is usually impossible to anticipate what the achievement of our wish would bring about in actual practice. History is replete with political visions turned to nightmare by success; and even "successful" social experiments more often than not turn out rather different from what their authors initially had set as their objectives. For example, today's "bad guys,"—those who wish to segregate special needs individuals—were our heroes of the 40s, the 50s, and the 60s, and could well be heroes again if society says it has had its fill of mainstreaming, normalization, and Public Law 94-142. And who knows, psychoanalysis could make a comeback, behavior modification could be declared unworkable, and the trains could again be made to run on time. Almost anything tried with enthusiasm works well for a while;

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then there are unexpected consequences, then disillusionment, then nothing seems to work.

Although our goals may be unclear, we know enough about them to specify some essential elements for the future we have in mind. Mentally retarded persons will have to have certain legal rights that have been denied them—public education, public standards of health care, a fair chance at economic self-support, and the incidental rewards of self-support. Because most of us do not have serious doubts that a society which grants these and other basic rights to everyone will be a better society, we do not worry about what that society will be like in detail. But it should be apparent to us that, although we need not worry, we *really do not* know what that society will be like—except that it will be different and that there will be many points of great strain for all of us in the change. Whatever the price may be, we are committed to pay it for the sake of a better world.

However, not only is the future obscure, the present as well is often hard to assess. The rights of handicapped people emerged as a social issue with a suddenness that revealed to us how unaware we had been of the social implications of labeling, institutional segregation, and devaluing stereotypes. Most of us would have acted quite differently 15 or 20 or 30 years ago if we had understood some of the side-effects of our programs. Thus, the political and social process (in which PL 94-142 is but one step) is a powerful thrust from a world we do not understand very well toward a world we cannot predict, and, quite probably, will not ever understand well.

This is certainly not to say we should not continue that thrust. In the real world, the “facts” are never all in, and analyses and understandings are always imperfect. This is why action has to be based on judgment rather than deduction and why there is often so much disagreement among people who share similar goals: Their *judgments* of what should be the next step toward the goal can vary widely. But though we all know these things—that our understanding is imperfect, that the consequences of what we passionately advocate today may be unanticipated or even undesirable tomorrow—nevertheless, we must act as though there were no doubt about what we do. The success of any program of social reform depends too much on decisiveness and confidence to permit the awareness of our human condition to dampen it. Thus, PL 94-142 has its enthusiastic advocates not because the law is “the” answer, but because it is perceived to be an important step in the right direction. Those who feel that the next urgent order of business is to create jobs for handicapped adults have their eyes on the immediate benefits to the economic and social status of handicapped people rather than on global eco-

nomie factors. Obviously, these and other programs have merit. Each nudges us closer to a good society. But equally obviously, each of them is in a sense irrelevant to what we want as a goal. PL 94-142 is quite clearly a transitional device; no one could suppose that its reimbursements, incentives, and formulas should constitute a lasting form of justice for all citizens. Like affirmative action, it can be justified, if at all, only as a part of the remedy, not as a state of health. And providing jobs for handicapped people is also important as a step, but hardly begins to address the factors that have heretofore oppressed mentally retarded people. At this time, when the mentally retarded are excluded almost entirely from job opportunities, we are justified in demanding the creation of those opportunities. Yet in the long run, this demand will have to be reconciled with the fact of widespread unemployment in society as a whole, and even with our nation's uncertain fortune in the economy of the world.

It would be foolish of me to offer solutions to such complicated and long-range problems. But neither can I bring myself to concentrate solely on the daily business of our current programs. Just like those we were enthusiastically “promoting” 20 years ago, these programs too will probably contain new prejudices and misunderstandings. We should begin to look for them and clarify them now, before they become too firmly established in our thinking, our practice, and even in our laws—that is, before they become a new set of intransigent institutions for us to evacuate.

The temptation is to take the easy way and to discuss the various ingredients of PL 94-142: individual educational plan, mainstreaming, zero reject, and of course the topic of the day, least restrictive alternative. The problem with these terms and others like them is that, at present, they are little more than shibboleths and slogans. We simply do not have an adequate understanding of what they mean. That may be a harsh conclusion but there are not many people around who would deny that there are lots of different definitions for each of these concepts, some of them in conflict with one another. So I will take the hard road—for me the easy way out—which is to get to ideas that go beyond the current law or, indeed, beyond the issue of the handicapped themselves. If we are going to offer mentally retarded people the freedoms and benefits of our society, we should look at what it is we have to offer. To protect people in spite of themselves is sometimes to protect them from living. To avoid potential dangers is sometimes to avoid life. Even for the retarded—possibly especially for the retarded—the rule should not be to reduce risk taking. Rather, it should be to encourage certain reasonable risk taking. Risk taking is unavoidable for those who would develop well. To legally prohibit virtually any potential hazard is also to inhibit one's opportunity



to mature. As educators, we must be committed to the belief that people can learn and mature in their judgment and that, when all is said and done, this is the only protection from the dangers of life.

### **What Is a Least Restrictive Environment?**

What is going on in the United States? How free are we? Never mind the mentally retarded—how free are you? Let us take a look at a few aspects of life in the United States today. The Talmudists have the luxury—indeed, the divine responsibility—to read word by word, letter by letter, and to compare a tiny mark to an even tinier mark. Because they no longer have legal power over the people, they can be legalists of the narrowest variety. Contrast them with the founding fathers of this country who needed a Supreme Court to interpret the law in the context of the times. To appreciate the concept of “least restrictiveness” requires, I think, an overview of a couple of society’s institutions and not the Talmudist’s, nor the scientist’s nor the compulsive’s special talents. That is, I think that “least restrictiveness” should be understood as a whole and not by its parts. Of course, the catch is that the concept is too complex to be understood that way. And, of course, there is too much to know about all of those institutions to get it all down here. But you live in our society as well as I do, and you know what is happening as well as I do. Consequently, these remarks are intended to do no more than to make us want to think about what we already know.

First of all, it seems to be as true today as it was when Calvin Coolidge said it years ago, that “the business of America is business.” That is why we need stock exchanges and antitrust laws. That is why we need law schools, corporations, and Madison Avenue, and much of what is on television, and much of what is on people’s minds. That is why General Electric claims “Progress is our most important product,” though nobody believes them. And it is in the name of business that DuPont can bellow from today to doomsday that chemistry makes better things for better living, but nobody will believe DuPont. Because it is good for business, Nestlé’s can get away with promoting in Third World countries powdered milk that may be as lethal to babies there as uncontrolled asbestos plants are here.

It seems impossible to conjure up the march of American business without its accompaniment of nonsense and outright hazard. Our system and its freedoms have been designed to foster the creation of wealth and power, not to control them when they are used or pursued irresponsibly. That is why Ralph Nader is now inevitable and necessary, though terribly wrong. He is incontestably right that “they” are bastards. “They” could not be anything else because the profit motive and the free market

are utterly indifferent to human values—unless those values affect sales. However, Nader is mistaken when he suggests that what “they” are doing, from price-fixing to manufacturing gas tanks that explode, represents some sort of aberration that could be corrected without attacking the business of America at its heart. And Nader is quite wrong in his avalanche of proposed laws for us to control the bastards. The effect of those regulations is likely to be as destructive as “their” lawlessness. We betray the human race and, in the final accounting, the individual as well, when we deny that the world must necessarily be a dangerous place. Most of us would pay high prices for our freedom; I am claiming now that Nader wants to exact a higher price for my safety than I am willing to pay.

American business has given us the possibility of the four-day work week and the two-home and three-car family at the same time that it has given us the choice of destroying either our health or our freedoms. Seizing upon the wonders of American technology, big business has made us free, but within narrower confines than ever before. It has given us the time to pursue virtually any hobby or interest we have, but it has also enticed us to sit in drugged stupors watching a lighted box. In America, only the truly brave, strong-willed, innovative person can exploit the genius of the American system and reject the damaging side-effects that accompany progress and that make us less well off than our grandparents.

Why is it so difficult for a parent to gain permission to teach a child at home or to help the teacher teach the child in school? Schools seem to be unnecessarily restrictive. Most parents once accepted it as their parental responsibility to teach their young. Even while schools have become necessary, there remain important things for parents to teach. But today parents are excluded from sharing that responsibility. Of course, teachers are not what they used to be, but that is not my point—they never were what they used to be. What I am getting at is that almost everybody today has the time and the potential competence to teach something to somebody. One would think that most people would enjoy the opportunity to teach if they could believe in themselves sufficiently to enter into such activity. Teaching could be like jury duty. But if it were like jury duty practically everyone would ask to be excused. Most people would feel they had nothing to teach. Today even teachers ask to be excused. They too have nothing to teach, except in their areas of specialization. Everybody seems to have excuses when it comes to teaching something outside of his or her narrow ranges of interest and preparation. All of this is another way of saying that, with the exception of a few “genuine” teachers, virtually everybody in America lives in a very restricted intellectual environment. Furthermore, virtually everyone seems to be content with this situation.

Things could be different. A friend of mine insists that a person should



learn the names of trees in his neighborhood, that when he walks to work it is good to be able to distinguish the sycamore maple from the sycamore. It helps one know better where one is going, and even why. This friend of mine also keeps bees. He knows what most of us forget, that bees are absolutely essential for our lives to continue, and that in no sense are they in competition with humans. As we shoo bees away, we shoo life away. There are millions and millions of potentially excellent teachers around, people who could interest us in trees, and bees, and aerodynamics, or how the body works, how to make a kite, or bait a hook. And yet, in spite of this knowledge, our "best minds" have come to the conclusion that the only people who may teach must be certified and degreed. There is more to this problem before us than what is the least restrictive environment for the mentally retarded.

There was once a time—admittedly a dangerous time—when learning and living were not governed by certification and regulation and legislation. It was the time when our idea of freedom started its development toward its present shape. From "Sweet Land of Liberty" to "Born Free," from Tchaikovsky to Tin Pan Alley, we have been sung to, entranced, and bombarded with cannons in the name of liberty. If musicians today thought like lawyers and spoke like legislators, they would serenade us in the names of least restrictive environment, zero reject, and mainstreaming. And if the prophets and the psalmists had thought like bureaucrats, they too would have told stories about zero reject rather than about strangers in the land of Canaan. But what was once one—religion and the law—is now, by law, separate. And so what was once the predominating influence, our religion, today predominates only on Sunday, and even then for a minority of our society. Today, the law prevails over all beings and institutions, over religion itself, and our freedom must live between its lines.

The law is concerned with who is and who is not restricted. There are forced restrictions and voluntary restrictions. There are those restricted by prejudice, those restricted by regulations. In our "let-it-all-hang-out" culture today, least is best. The Puritans, on the other hand, thought differently. The mode today is that the less restriction the better, the mode today is concerned more with the body than with the soul. Today, the mode is about what we do rather than about what we think. It seems that most people today would be satisfied with being physically unrestricted though mentally enchained. So today, what looks like an almost completely unrestricted, free, unfettered, unhampered, "doing-your-own-thing" society is, in another view, a culture that works by rote response and by communication through intermediaries. It may be fair to say that ours is at once the most unrestricted and restricted society ever created. *So what is a least restrictive environment?*

### Privileged Extensions of Freedom

Least restrictive alternatives cannot be understood out of the context of the particular culture under examination. Whether an environment is restricted or free depends on where that environment is, who is in it, and how we look at it. Certainly, the least restrictive alternative in Nazi Germany was not at all the same as the least restrictive alternative in the present-day United States. And the least restrictive alternative in the United States of 1800 was not at all the same as the least restrictive alternative in the United States today.

Within the context of any setting, moreover, we find privileged extensions of freedom, the unchallenged special considerations that certain people or groups enjoy. Certainly, Nixon not only wanted the privileges awarded to the president of the United States, but he took for himself privileges that earlier office holders did not have. Certainly, a Rockefeller, a United States senator, a "super star," and other individuals and groups (such as priests and rabbis) enjoy special privileges. Such privileges as those that are the right of clergy and celebrities are not what we have in mind when we advocate the least restrictive alternative for mentally retarded people, but they are part of the context in which our definition will have to work.

On leave once from my university responsibilities in order to direct a new Division of Mental Retardation in a State Department of Mental Health, it was my responsibility to oversee all of the state's institutional programs for the mentally retarded, which were many, as well as their community programs, which at that time consisted of a handful of nursery school classes. Soon after assuming this position, I visited one of the state schools and, accompanied by the superintendent, toured the entire facility. It was payday and people were queued up at the cashier. Off to the side was a large table on which were piled hundreds of dozens of eggs. As the workers left the cashier's cage, many of them stopped at the egg stand and purchased one or more boxes of eggs from a man who seemed to be very familiar with the situation. I went over to ask him how much the jumbo eggs cost. "Twenty cents a dozen," was the reply. I identified myself and expressed surprise that the state was selling its eggs in this manner and at such a low price. He informed me that these were not the state's eggs, but his. He also informed me that he was the manager of the state school's farm and that the chickens who laid these eggs were his chickens. After probing, I learned that the state indeed owned thousands of chickens, but so did he. I also learned that this man had the unusual ability to know for sure which were the state's chickens and which were his. And he repeated that these, indeed, were his eggs, laid by his chickens.



Anyone who can look at a field of thousands of chickens and know which are his and, furthermore, know for sure that his chickens would not eat the state's feed, is indeed a special person. But I think it is not coincidental to find such special people, who enjoy omnipotent characteristics and unusual privileges, in places where most of the other people are exempt from virtually all privilege. And certainly, a home for the mentally retarded is just the place for a bright state employee to learn to be better than most other people; not only better, but different, possessed with rare powers.

People lust for privileges, for more than their share. Why a person wants more than he or she deserves is perhaps mainly due to a rotten memory. People who do not remember that they are going to die seem to engage in more than their share of silly business as they take more than their share of the common wealth. Perhaps the most prominent recent example of forgetful and silly greed is Nixon. Why would he buy a million dollar house here and another one there, while all the time he had a big free White House in Washington and a free camp in Maryland?

There are infinite anomalies in our thinking and not thinking about death, perhaps because we tend to think about death only in terms of human beings. We assume animals are not concerned with their impending deaths. But it is the human being who is anomalous and not death. As everyone really knows, death is the most invariant of phenomena, one to which there is no less restrictive alternative. But how do the mentally retarded think about death? They do, of course, but do *we* remember that they do? It seems that it is difficult enough to remember our own deaths, much less whether the mentally retarded remember theirs. Of course, we think a lot about what will happen when we go, and what will happen to Billy or Mary, our retarded son or daughter. Or that Billy is one of God's innocents and will therefore surely go to heaven. But do we ever think about whether Billy thinks about his death? Of course not! In the same way that we do not think (or is it care?) about what our pet canary thinks about his death, it is difficult for us to think that retarded people have the same thoughts and worries that we have. As a matter of fact, in all the years I have been in this work, I have found but one article in the literature that deals with this question; and that 40-year-old report restricts itself to the mildly retarded, those who are most nearly like the rest of us.

What does death have to do with privileged extensions of freedom? Maybe almost everything. The privileged "need" a million dollar estate to counteract the often dim but always disquieting knowledge of their fate. Mentally retarded people are not even thought about as people who know they are going to die. As an extension of this attitude, little atten-

tion is paid to what else the mentally retarded may be thinking about, what they may like to have in terms of the world's extras. After all, *we* deserve that car, that cruise, that cashmere, that special privilege. *We* have something to worry about. Not the retards! They get life's subsistence rations, not merely because they have not earned more, but because they will not appreciate more, and because they will not suffer the way we suffer during our mortal lives. They do not need diversions to make them forget their mortality.

Well, it may not be true. Mentally retarded people may know an awful lot more than we think they know. The mentally retarded person may know more about the underprivileged than almost anyone around, even those who live in the ghetto. They are experts on the most restrictive environment. The mentally retarded person and Mr. Nixon should write the definitive book on the least restrictive environment. They represent the range and the expertise.

### Loopholes

Perhaps the most important point I want to make is that the issues and solutions in our field can appear clear and simple only as long as we wear the blinders of specialization. It is not hard to think we know exactly what a least restrictive environment is if we think of it as a contrast to a dreary, segregated, and educationally counterproductive special class. It is even easier to think we know what it means in contrast to the locked back ward of an antiquated institution. Yet, life does not derive its meaning or dignity from contrasts; people do not remain cheerful from being told that things could be, or used to be, worse. Although in the end we may be unable to articulate precise definitions, we must try to provide mentally retarded people with opportunities that are not merely better but good. It should be a sobering reminder to us that when the pioneers in our field undertook this task, despite the greatest good will and thoughtful deliberation, their efforts led to the development of modern institutional settings. In offering enormous benefits, their work led to the loss of everything important to their beneficiaries.

If the line between love and hate is at times indistinct, the line between privilege and restriction may at times be nonexistent. How can we distinguish between people who are very rich and people in the most restrictive institutions? To be provided with all possible services, to have them at hand and receive them free is to enjoy enormous privilege. The very rich can have tutors instruct them or their children in their own homes. So can the mentally retarded—although their homes are called state schools. The very rich and the mentally retarded have swimming



pools, parks, playgrounds on the premises where they live; doctors make house calls; paid staff cook meals, wash clothes, clean and straighten up their rooms.

And the difference between the very rich and the mentally retarded is not to be found in the attitudes of the public. Both are viewed in stereotyped, often dehumanizing, ways by "typical" members of society. They are frequently assumed to be unable and unwilling to perform meaningful work. They are assumed to prefer to be "with their own kind," apart from general society. Members of neither group are supposed to have an understanding of "real life" sufficient to make them independent and viable members of society. And finally, both the very rich and the mentally retarded are often regarded as unpredictable and potentially dangerous.

Of course in making these comparisons, which could be extended even further, I am not uncertain about which structure is the mansion and which is the state school. I have constructed the ridiculous parallel only in order to point out that, in practice, we distinguish between the conditions of wealth and mental retardation not on the basis of the objective criteria—in which they are similar—but by means of an intuitive grasp of countless unspecified subtleties. Precise criteria only work in these matters when we know the conclusion ahead of time. We know that despite the restrictiveness of the trappings of wealth, the life of the wealthy is the freest possible; and that despite the privileges of institutionalized life, the life of the mentally retarded is restricted to the point of extinction.

In the past, when policy was guided by the supposedly dangerous mechanism of judgment, this intuitive understanding of differences was enough. Today, because we have grown impatient with our history of cruelly mistaken judgments, our policy must be in the precise and objective form of a federal law. So, what *is* a restrictive environment today?

### Quasi-Legal Practices

Part of the reason we are now in need of legal definitions for the field is that so much of what has been reprehensible in the past has been quasi-legal. I am no lawyer, and a good lawyer would surely discuss this less clumsily than I am about to, but most good lawyers probably do not know as much about the quasi-legal practices in the field of mental retardation as I do. So you will have to settle for the inevitable trade-off. Discussing quasi-anything usually requires one to walk a fine line. While there may not be a law or regulation allowing a given practice, there does not seem to be very much precedent forbidding it. Or conversely, while there may not be something on the books forbidding a practice, it does

not seem to be in good taste. Some examples of quasi-legal practices in the field of mental retardation must certainly include the continued approval of sterilization, inmate employment without compensation, and assignment of the recently deceased as medical school cadavers.

For many years, I have written about all of this and more. Indeed, I have spent the last 20 years cataloging virtually every type of legal, illegal, and quasi-legal abuse perpetrated on the mentally retarded. I have described the work of the cadaver committee in a New England city, sterilization practices at various state schools; the pulling of teeth of inmates who bite themselves or others; the pulling of plugs at distinguished medical centers; other premature or strange deaths, even stranger autopsy investigations; peonage in its almost infinite forms; a severe spastic choking to death on a whole hard boiled egg; a severely retarded bed patient nearly bleeding to death after his groin was ripped open by an assailant in the night and he was not seen by a doctor until morning infirmary call; inmates involuntarily volunteered for dangerous experiments at Ivy League medical schools; children raped by older inmates; and older inmates brutalized by marauding adolescents. And of course, although many of these atrocities could have been classified as illegal and the perpetrators could have been prosecuted, they hardly ever were; there is hardly a disruption of institutional routine when such situations occur.

I rummaged through my files, but there seemed nothing new to say about quasi-legal practices. Yet, I knew that I must say something. The very idea of "least restrictive environment" was born out of a history of quasi-legal practices applied to people. I then went to my diary, which is used, if anything, as a last resort. I knew exactly what I was looking for, the raw notes and description that provided the background for a book I started alone in late 1975 and, luckily for me, finished in 1978 with Andrejs Ozolins and Joe McNally.

Now I have read all of those pages and I want to tell you about Sophie, who was a resident of the state school for the retarded and died at a local hospital, and may have died of neglect. To this day, the only consequence of Sophie's quasi-legal demise was the withdrawal of medical services to the state school by the group of physicians in the community who had then been serving that place. There have been other inadequately explained deaths since Sophie's, and there have been other medical groups attending residents of the state school.

I am sure that somebody somewhere in America today has just seen an inmate die needlessly, or has just learned that a medical group is withdrawing its favors from the state's bughouse, or has just attended a meeting where promises were made to finally fix up the state school, or is



right now reading in the evening paper that the state has finally found a way to serve the residential needs of the mentally retarded. But the deaths continue, nearly unnoticed and sufficiently legal. I am not surprised. If everything about Sophie's life was legal, why should not everything about her death be legal?

What follows was written at the time it happened in late 1975.

This has been a strange week, very strange indeed. My mind wanders to thoughts about last evening's meeting of our Advocacy Board. I could kick myself for getting so angry, for showing my anger. Why can't these good people realize, as I realize, that case-by-case advocacy will consume us, will play into the hands of those who want to maintain the status quo or regress further toward a segregated and bureaucratized society? We "win" victory after victory on behalf of this family or that one—no mean achievements—and I am not knocking those accomplishments. However, while we win those skirmishes, the city breaks ground for a new segregated facility, this one to contain the so-called "trainables." Case by case, we advocate for children and their families. Some we win, some we lose; the record is fairly impressive. But, we are losing too many; too many children are still denied educations; too many people sit in back rooms receiving little or nothing of society's interest or services; too many are in locked institutions, not because they must be locked up but, rather, because there is no other "place" to be, because the (only) "place" was created for them. The debate wore me out, driving me eventually to leave the meeting, not because of my anger—though I was angry—but because I was weary, and wanted to go home, and remove those stale clothes and drive out of my head the morbid thoughts of practical people.

Indeed, it has been a strange week. I forced myself to think about Sophie, but not to cheer myself up. Last Monday was scheduled to be a low-keyed, routine day. Nobody knew very much earlier than Monday—therefore nobody told me—that Sophie was to be buried on Monday. And, even had they known it would happen that she needed to be buried on Monday, nobody would have suspected earlier that I would have been asked to attend the funeral, or that I would have accepted the invitation had the offer come. You see, the very first time I ever laid eyes on Sophie was this past Monday at the Garfield Funeral Home. I saw her, but she didn't see me.

Sophie was a resident at the State Developmental Center, near the State School, near the Asylum for Idiots. She had been there for many, many years, leading what I was told was an uneventful and unhappy life. She became ill, very ill, so ill that she was removed to the Community General Hospital. There she died, approximately one week later.

What was interesting about all this, quite inflammatory in this community, concerned the allegation that Sophie did not die of natural causes. There were charges, confused and contradictory but strong charges, that—as we have lately learned to say—the plugs were pulled. Sophie was euthanized; she was rewarded

with a dignified death. A big cheer for Death With Dignity, and the Happy Angel that supervises it all. Rejoice, some told us. Sophie has left this vale of misery to an eternal peace and happiness that she did not find on earth. So we gathered together at the funeral home, the priest gave his blessings and read from the Scriptures, some said their Hail Mary's or Hail whatevers, we signed the guest book—guests!—and went on our own ways.

The Death With Dignity Society, and there is one here, should be pleased. The crazy thing about it all is that, in the Cosmos, there may be some explanation for all of this; and, it would not surprise me if such an explanation agreed with the death wishers. Yet, there is also something evil here, something that would tell a human being that it is time for her to die; but if we were in your shoes, sister, we would live! It's best that you die now, first because you're sick. If you were not sick, we would not kill you. Yet, not only are you sick, you are old (is 63 really that old) and, not only are you sick and old, you are defective. Sickness, we sometimes tolerate if it's not too much sickness. And, even the defectives need not be marked early on, especially, with the Terrible Decree. But, Sophie, even you must agree that you gave us no choice. Being sick, old, and defective necessarily must strip you of the rights other people have guaranteed to them. Don't blame us, Sophie, this is all your fault. Besides, you'll be happier up there than down here. It's all over for you, and we have yet to face the terror that is now behind you. What we have done for you is the stuff that causes ordinary people to become true humanitarians.

It is the day after Sophie's funeral. It is 8:00 P.M., then 9, then the hour approaches midnight. We are in Room 407 of the County Courthouse. The County Legislative Commission to Investigate Mental Health and Mental Retardation is holding its last formal hearing prior to its report to the citizens. I am a member of the Commission and, just before termination of the long evening's discussions, I ask the superintendent of the State Developmental Center to reflect upon the future: "In the best of all possible worlds, what do you envision for the Developmental Center in ten years?"

He responded: "In ten years things will not be very much different than they are today. Can I speculate about the world in 50 years?"

"Will the people wait 50 years? There are people who desperately need help, not even in 10 years, tomorrow," I said.

"Don't misunderstand me. If I had my way," he replied, "we would evacuate the Developmental Center in 10 years, five years, or sooner if we could. We would give it to the State, or to your university to use as a dormitory, or for some other educational purpose."

I do not misunderstand. I am embarrassed for him. I think about those times six years ago when it might not have been too late to stop the construction of this \$25,000,000 monstrosity. I attempt to avoid remembering the pleadings and arguments, even the threats we made, anything to block construction of the new State School. I remember too much.



Quite early the next morning, I am back in my office . . . The phone rings. It's the Executive Director of the President's Committee on Mental Retardation. Not any president's committee, *The President's!* Would I do a study for them! Would I visit the institutions that continue to defy extinction? Would I expose the rottenness, the abuse, the mismanagement, the inhuman treatment?

"Sure" I reply, "what else do I have to do? As a matter of fact, I was just thinking about those problems today. I'll study these state schools for you. I hope you don't think I've been sitting by this phone all morning waiting for you to call, though. You just happened to catch me in, between assignments, so to speak. Between life and death. You caught me just as I was beginning to believe that Sophie was the lucky one."

I have been arguing that, as Robert Frost might have said if he had been a poet of the human service industry. Something there is that doesn't love a definition. No sooner do we build a row of definitions—definitions of restrictiveness or abuse, freedom or dignity—than it begins to crumble into loopholes, exceptions, and quasi-legal rubble. I have been trying to show that this is not so much because we do not build good definitions, but because life simply will not be captured in definitions.

Yet even as I describe our failure to define things better, even as I read my notes on Sophie whose life slipped away over the edge of a definition of human rights, I too have to agree that we need better definitions. Perhaps, to burden Robert Frost a little more: Good definitions make good neighbors. And though they fall down in the winter of our inattentiveness, each spring we must build them anew, as though they would stay.

### Variations on the Definition of Restrictiveness

All of those who have tried have had difficulty defining restrictiveness. Consequently, I need not preface my suggestions with any elaborate disclaimer: I too will not provide the definitive statement. But for whatever it is worth, I think about a "restrictive environment" as one in which, if placed there him or herself, the superintendent of a state mental institution would feel insulted and threatened. Conversely, I think about a "least restrictive environment" as one in which, if placed there, the inmate of a state mental hospital would sense that he or she was now living somewhere that is quite different from, and much more pleasant than, the hospital. Certainly, these definitions will not escape the need for revision. And certainly, they only shape our thinking for purposes of developing a continuum. But in some situations, they may offer useful analogies, and analogies may be the strongest definitions we can get.

Suppose "least restrictive environment" were understood to mean

"what I demand as rights," and suppose "restrictiveness" were understood as "that which is contemptible and inhumane"; would not the mentally retarded and the mentally ill and the elderly and other modern-day pariahs be better represented than they are now? If we thought about restrictiveness in terms of the Golden Rule, would we be defining small institutions as relatively less restrictive and, consequently, more acceptable? If we remembered the Golden Rule—"Do unto others as you would have them do unto you"—would we need to remember all of this folderol about per capita floor space, staff/patient ratios, standards for state and federal reimbursements, or accreditation?

A big deal is made about the technical aspects of environments for the unwanted because, first, people do not want to admit they are dealing with the unwanted and, secondly, people do not want to put themselves in the same category as these unwanted. I know that no loving child or parent could ever easily place a parent or child in one of our traditional state institutions, be it designated most restrictive or least restrictive. I also know that the term "least restrictive environment" ought to be reserved for places that, by definition, fall outside of the state's traditional mental institutions. A truly least restrictive environment would have nothing to do with state departments of mental health or with clients placed in their facilities *because* of mental incapacitation. In the world of mental health and mental retardation, people live either in large institutions or small institutions. People who are caught in the mental health—mental retardation net, by definition should not be thought of as living in a least restrictive environment.

I can envision many variations of the definition of restrictiveness. How can we be satisfied with one-dimensional definitions? Is that really what science is all about? Or is it really what blind professionalism is all about? I am dissatisfied with the official definitions, so dissatisfied that I am unable even to note them here for the record.

Maybe it is my idiosyncrasy, but I think I would better understand the situation a person is in if I knew how many mistakes he or she was entitled to make before being yanked from the game. Robert Frost defined my idea of the least restrictive life very satisfactorily when he wrote in "Two Tramps in Mudtime":

But yield who will to their separation,  
My object in living is to unite  
My avocation and my vocation  
As my two eyes make one in sight.

To be yanked after one mistake or two might occur in a terribly restrictive situation. And to be in a position in which one's job and interests



are integrated, in which one wants to do what one has to do is an example of what a least restrictive environment might be.

Why is it that artists seem to describe life so much better than the rest of us? Then why is it that the rest of us do not turn more to artists to explain what we are unable to explain for ourselves? It has not always been this way. In the old days, artists rendered reality in a descriptive manner, from Victorian painters who described street urchins and fallen women, to Dickens who wrote about them, to journalists who reported it all. Artists were once society's definers. What got in the way were the universities and their professors, and the professionals they eventually trained, and the disciples of the professionals, the gullible public. Unnecessary science became a mischievous nuisance.

The discourse sounds more conspiratorial and menacing than I want it to be. To be sure, professionalism in America was not created to close out the artist and to do in the consumer. To be sure, the country had its fill of barber surgeons, patent medicines laced with dope; and not only quack doctors and quack patients, but quack ministers, teachers, and scientists. Abraham Flexner had a point to make just as Ralph Nader had virtually the same point to make half a century later. Flexner's point was that amateurs were running things, and it was time for professionals to become organized and monitor the world. Nader's point is that we had better beware of the professionals who are greedy louts running things for their own benefit. Abraham Flexner once saw the enemy embedded within the suspicion, the prejudice, and ignorance of the 19th century. Ralph Nader sees the enemy embedded within the firm pillars of status and respectability created out of the Flexner Revolution. And while it is not difficult to find many among us today who see the shortsightedness of Flexner's vision, there are too few here who see the catastrophe of Nader's "revolution." Flexner created a professionalized society. Nader seems to want to overcome that evil by a bureaucratized society, one to be controlled by the people to be sure but, nevertheless, people who would weigh everything, test everything, define everything, and be suspicious of everything. Possibly, at this time what is needed more than either Flexner or Nader is a good poet who would give us some hints on how to live better with each other. Maybe we once needed Flexner. Maybe we needed Nader when he came along. But I will take Frost.

## Conclusion

In the real world, people die for their freedoms. In the field of mental retardation, they hold conventions or invite each other to conferences. In the real world, people learn from each other, help each other, and protect

each other. In the field of mental retardation, one must be licensed to teach, certified to treat, and commissioned to protect. That which is considered to be good about the real world naturally unfolds. That which is considered to be good about the field of mental retardation is professionally controlled. What is least restrictive about the real world derives from thousands of years of human discourse under such diverse leaders as Attila and Lincoln, Pharaoh and Moses, George III and George Washington, Martin Luther and Martin Luther King. What is most restrictive about the world of mental retardation derives from 200 years of professional interest in the pathology rather than in the universality of people. Professionals have created much of the need to do something about the problem of too-restrictive environments forced upon the mentally retarded. We have created or have been much of the problem, and now we seem anxious to do something about our unholy work. Indeed, we must do something, but less to rescue the mentally retarded than to redeem ourselves; less to obtain their freedoms than to establish ours; less because they need us than because we need them.

When I was a little boy, I would jump out of bed most mornings barely able to wait for what lay ahead. And there were days when I could not sleep because of eagerness to push aside the darkness to reach a time when people were allowed to take advantage of all the wonders there. Frost said he had "a lover's quarrel with the world." I did not know about Frost then, and I surely did not know the world on those terms. But I too have had an affair with the world, with the air and the birds, but also with the movement of people on hot steamy sidewalks, and even with the institutions, with everything we think of as life. From the start, I felt lucky to be born and to live as a free person. I never had to learn what it is to be alone in an alien land. I never had to know what it is to be without advocates, what it means to need advocates. I never needed protection against my brothers. I never needed protection against my government. I never needed protection against God. What harm befell me, I usually did to myself. What grief occurred was the grief done to any fragile human being, usually more by accident than by design. Thank God I was born free and now live free. But I am very sad that not everyone shares such good fortune.

We have listened to neither the inner heart nor the call for the common good, not to God nor fellow man. We have made swords into guns. We will believe only the poets who confirm what we have believed. We want to believe that literal fences do indeed make good neighbors, and that tough attitudes characterize practical and wise men of the world. Our faith is more in ourselves than in mankind, but little in ourselves. We have created an unnecessarily restricted society. To free ourselves, we



must free the old, the weak, and the handicapped because, in truth, they *are* us. Yet we resist that kind of world. Our problem is not one of merely defining what represents the least restrictive environment in an unjust society, but rather one of changing that society for everyone. This is not a local or professional issue, but a world issue. We should stop confusing ourselves. We should try to better understand that we are not dealing here only with the problem of the mentally retarded, but with our common problem, the problem of facing our lives as if they will end, and in believing in the hereafter as if it might be there.

Perhaps the reason I kept returning to poets in this paper, the reason I believe they can give us better guidance in life than bureaucrats or scientists, is that when we read poetry we *know* that we are dealing with metaphors, analogies, ways of thinking—rather than lists of facts. Surely there can be no doubt that if the Golden Rule were a federal regulation, it would become meaningless and useless. Emerson nailed down one part of our common problem when he said: "All our science lacks is a human side." A serious part of our common problem is that too much of humanism has gone scientific. And too much of our science makes it easier to banish our brothers and sisters from our lives.