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A NEW AGENDA AND A NEW ALLIANCE*

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I WELCOME this occasion to sort out some of my thoughts on having been vice president of the Temple University Health Sciences Center in Philadelphia, Pa. My colleagues there, I am sure, have their own second thoughts on the subject, but then we perceive and proceed from rather different biases. Education, research, and the care of patients are all in varying degrees the products and the processes of a university health-sciences center. Without them there is little reason to exist. Yet I am not a scholarly academician, nor have I high qualification for the rigors of research. And, admittedly, my years with the Public Health Service had done little to credit me as an outstanding clinician.

Perhaps this very lack of credentials in any one aspect of health sciences gave me the opportunity—and even the necessity—of focusing on the totality. The setting of goals, establishment of priorities, and allocation of resources *among* the three sectors was to become the arena for my adjudication; others would deal more competently with these issues *within* each of the sectors. I was to be, of course, *primus inter*

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pares, because of the increased complexities of arriving at and applying these decisions among different professional schools as well.

Such were my thoughts at the beginning of the 1960's. Had I addressed you then, I should have been pleased to share some firm conclusions. But at the beginning of the 1970's, I can only share with you some of the perplexing questions that evolved and over which I am still puzzling. If my comments are more anecdotal than analytical, they are intended to share with you some of the frustrations and joys of the recent past. As you may see, I have been most fortunate in my choice of a new career, for the asking of questions rather than the administration of conclusions is at the core of the work of a foundation.

As the decade of the 1960's unfolded many things happened to disrupt the rather placid sense of order within the closed system I had envisioned. Our nation launched a "war on poverty" at home and escalated a "war on aggression" abroad. Some moved to the city for the welfare of their children; others moved out of the city for the same reason. We saw published a new edition of *Webster's* unabridged, and saw it obsolesce as words gained new meaning, as "Negro" became "black" and black became beautiful; "slums" became "ghettos" but didn't become beautiful. Irrationality and inconsistency characterized much of our national behavior as we vowed to conquer "killer diseases" but voted less money to learn how; or as we preached the primacy of preventive care but rewarded only the system of curative care. Each of you might well add other complaints from your own catalog of grievances against the 1960's.

But most of these discrepancies are not new; they may have become more frequent, or more persistent, or even more systemic, but they are a continuation. It seems to me, however, that one set of occurrences was new, and that it set in motion the most profound sequence of changes in my experience. I refer to the concepts and issues of participation by consumers in the very affairs that, 10 years ago, I had seen as the sole prerogatives of professional office: setting goals, establishing priorities, and allocating resources.

Let me confess to a personal distaste for the expression "consumerism," which appears to be gaining in fashion. It seems to me too soon to formalize into a systematic "ism" such diffuse concerns, values, and uncertainties as the term connotes. Nor does the use of "consumerism" offer a helpful differentiation from Ralph Nader's campaigns, despite

their considerable merits. To counter the staleness of "professionalism" with the ambiguity of "consumerism" adds little clarity; in fact, it begs the real issues of who shall participate in what, to what extent, and under what terms.

In recent years at the Temple University Health Sciences Center I found the "who's" of consumers and the "how's" of participation to be as diverse as institutional goals themselves. Professional societies, academic institutions, industrial concerns, governmental agencies, and a host of others could be rather easily identified as "consumers" of much of our research. In truth, they had long since identified themselves and had developed sophisticated and persuasive ways of participating. Contract research is an obvious form of such participation in the setting of goals, the determination of priorities, and the allocation of resources.

The undergraduate medical student, of course, is readily identifiable as a consumer of educational services. While he has not yet developed the tools he is increasingly developing the rhetorical symbols of participation in decision making. Sit-ins, "confrontations," boycotts, etc., are becoming almost commonplace.

However, in order to simplify matters let me set aside any further discussion of the student as a consumer of our education services. I do this not because the subject is uninteresting or unimportant but rather because I wish to deal more centrally with the complexities of the consumption of health services.

If I must first legitimize this topic, let me do it quite simply: if my argument seems, in fact, simplistic, then so be it. Participation in decision making about the goals, priorities, and allocations for health services *must* be extended to the consumers of those services for reasons of justice and equity. Participation *should* be extended because it can demonstrably improve the quality of those decisions.

I do not here use the term "participation" in the sense of an organized communal ritual as we experience it in elections when, through voting, the citizen participates in government. Political scientists tell us that that form of participation is largely symbolic, since electoral choices have little to do with legislative and administrative choices.

A particularly astute observer of participation, Professor Murray Edelman, clarifies the subject further:

> Elections give people a chance to express discontents and enthusiasms, to enjoy a sense of involvement. This is participa-

tion in a ritual act, however; only in a minor degree is it participation in policy formation. Like all ritual, whether in primitive or modern societies, elections draw attention to common social ties and to the importance and apparent reasonableness of accepting the public policies that are adopted. Without some such device no polity can survive and retain the support or acquiescence of its members. The key point is, however, that elections could not serve this vital social function if the common belief in direct popular control over governmental policy through elections were to be widely questioned."*

And that is precisely the point, for a large and increasingly vocal minority is widely questioning the common belief in direct popular control. This kind of ritual and symbolic participation in government policy does not fulfill the vital social role for functionally disenfranchised residents of an inner city ghetto or for those in the by-passed wastelands of Appalachia.

I am confused by the reluctance of many to participate in health affairs. I am puzzled, and occasionally disturbed, by rhetorical flourishes such as "power to the people," which do nothing to clarify the nature of power or its relation to participation. And the circuitous rhetoric of "maximum feasible participation" does nothing more than restate the question. I suspect that there is such profound and, in fact, institutionalized alienation from these symbolic forms of participation, that merely coloring them black, or tan, or poor, will not suffice. Structural changes are called for in decision making, and these undoubtedly will have to deal centrally with issues of boundaries, institutional development, and professional rewards—in fact the changes will affect not just the superstructure but the infrastructure as well.

Let me disclaim, quickly, any profound knowledge of the ultimate outcome of the changes. I do not know the form which participation by consumers will take, nor can I yet see a clear resolution to the questions of representation: of whom, by whom, to whom. Experience has taught me, however, that only some form of joint participation can lead to the answers. I first began to realize this when my interest in consumers began to shift from that of a *supplicant* to that of a *consultant*.

Like many of my colleagues seated at the apex of a large health-

*Edelman, M.: *The Symbolic Uses of Politics*. Ill., Univ. Illinois Press, 1967, p. 3.

sciences complex I was duly impressed by the august majesty of my office. You can well imagine, then, the unpreparedness and frustration I felt when the tenor of petitions to me began to change—from humble "requests" to militant "demands." However, the real frustration, I learned, came not from the impoliteness of the demands but rather from my impotence. I had neither the mandate nor the power to honor their legitimate demands even if they had been cloaked in the cloth of humility. The problem was that many of these consumers—who were also the institution's neighbors—had interests in our Health Sciences Center that could not be contained by the role of the consumer.

I met with a group of community leaders one evening to discuss complaints about our emergency clinic. We never got around to this subject. Security for themselves and their children was uppermost in their minds. Everyone present had had some recent traumatic experience with gangs in North Philadelphia. One of the women present had a son in our hospital who had been shot by the members of a gang and would be permanently paralyzed from the waist down. Another woman complained that her children were afraid to go to school because they were molested either on the streets or within the school. The question of these women to me was: "What is the university going to do to correct this situation?" Then this small group of black consumers rated improved housing, education, and opportunities for jobs above health as more relevant to the needs of their neighborhood, and they expected us to assume an active role in meeting these needs.

On a similar occasion I attempted to engage the community-consumer group in a discussion of priorities for health services. One especially angry black mother stated, with not a little feeling, that recreational services and development of job skills for teen-agers in Philadelphia's ghetto were a high priority when measured by need. As often as she stated her proposition, I repeated mine: "such matters are not on the agenda for a health priorities committee." I hid behind the shield of tradition. The mother ended the argument with a simple statement from whose profundity I am still learning: "Then, man, you've got the wrong agenda."

The community of North Philadelphia is in many ways not unlike the communities of Morningside Heights or Newark. In each of these cases, not a small contributing cause to riot was the role of a large university as a consumer of land, municipal services, and privileges.

Resentment was profound and, may I add in retrospect, appropriate. We found, quite often though, that we had to give a higher priority to the demands of residents of the community before they would provide assistance to us. The priorities in question might require that we join them in appearing before the city council to support a proposed ordinance, to secure improved performance by the Department of Licensing and Inspection, or to oppose the granting of a license to a new bar for the neighborhood.

These were new and strange involvements for a university. We had become such a closed intellectual system of educators and scientists with fears, traditions, practices, values, and an insecurity that were not too different from that of the consumers except that we spoke a different language.

Difficult as this type of joint participation is, however, there is relatively little opposition to these matters of external territoriality. The neighborhood is often pleased with a clear system of trade-offs: the university gets land and the politicians are pleased. Professors are usually pleased because their internal territoriality has not been threatened. It is participation by consumers in the education, research, and function of caring for patients that raises the greatest fears and resistance.

I cannot dispel all your fears, but I should like to tell you of some of the gains to be made, apart from matters of equity or political posturing. Let me begin with some considerations in education. A great number of medical schools now have organized departments of community medicine. Not a few have begun to accept the fact that the community itself is properly both the place and the substance of the learning. The community of the consumers really holds the key to our success; without the participation of its members *as teachers*, neither we nor our students will learn. It is interesting to note that several schools are already hiring local residents as docents for small units of students. I have recently heard of a school in which local residents participate in the evaluation and formal grading of students. The old economic axiom that the consumer is not served until he thinks he has been served seems to have been actualized.

In the matter of participation by consumers in services for the care of patients we have become sensitized by the high drama of Lincoln Hospital, or by the sit-ins at Temple's own Mental Health Center

while I was still there. I do not wish to minimize the significance of these incidents, nor could I conscientiously condone the tactics of fear and intimidation. Yet even from these disruptive and often chaotic experiences there are things to be learned. The disenchanted and disenfranchised consumers in North Philadelphia have made me hear—sometimes deafeningly—the voices of those who are themselves fearful and intimidated.

What I think I have heard them say, or at least most of them, is that *control* over the issues of health services is not the goal: meaningful access to useful services is. I suspect that the rhetoric of *control* is more indicative of past inability to influence and improve than it is an explicit attempt to control or destroy.

If it has taken inflammatory rhetoric to help us face the irrationalities of our programs and priorities, then clearly the fault is ours. We are at long last now being forced to join in accomplishing some of the very goals we have long advocated. I think that for the first time we are not just preaching early prenatal care, for example. We are beginning, under pressure from consumers and with their help, to make such care possible.

If participation by consumers in health services is heated, and if participation in education is becoming so, what of research? Probably the most sacrosanct preserve of professional protectionism has been the area of research. Not only did my immediate position as an administrative officer in the precincts of academia give me a responsibility to honor the independence of the researcher; my years with the Public Health Service also convinced me of the rightness of separating the freedom of research from the pressures of economics and politics. I need not belabor this point before *this* audience, for it is a heartfelt piece of our professional catechism. Nevertheless, in these days even catechisms are questioned and analyzed. Even the most sacred of beliefs are subjected to the spirit of *aggiornamento*. Sometimes this new updating has been uncomfortable for us but I think the consumer will be heard. A recent article by Doctor Robert B. Scott states the case simply and eloquently.* Our national health-care research priorities, Doctor Scott reasons, have little to do with prevalence, incidence, or other rational factors. Our expenditure of moneys, both public and private, on muscular dystrophy, he notes, is at a new case rate of 120 times that

*Scott, R. B.: Health care priority and sickle cell anemia. *J.A.M.A.* *214*:731-34, 1970.

for sickle cell anemia. It is certainly not merely a matter of coincidence that a long-term illness that affects one birth in 500 blacks and is all but unknown among whites, has never claimed a rational share of our professional research expenditures in time, personnel, or money. I am somewhat embarrassed to have to confess that I am shocked and surprised by this figure; the black consumer is exasperated but not surprised—he knew it all along. Why did it not occur to me to ask?

Conclusion

There is a growing demand in all aspects of life for fuller and more responsible accounting of decision makers to their constituencies. In an urban university's health-science center, this matter of accountability has particular urgency. Such a center serves many constituencies: students, faculty, patients, and neighbors. Each group, in its own way, is demanding an accounting from those who set priorities, allocate resources, implement programs, and evaluate and reward performance. The nature and styles of effecting such demands and protests vary, of course, even as they do on the national scene. But the intent of this new concern for accountability, this new agenda, is clear: the time of *credat emptor* has become one of *caveat emptor*. Simply because we profess from a position of presumed wisdom, we are not necessarily believed; our constituencies exert a new caution. They are demanding to be heard and to be heeded. They want a new alliance, a new partnership. From all sides, the pressures are mounting for exercising accountability through direct participation.

In this involvement it is important that we try to understand and not merely manipulate. Our neighbors already are highly suspicious, skeptical, and distrustful. Our credibility with them is not very great. It is true that finding real leadership in such a group is like picking up a handful of sand. One of our most effective leaders was a taxi driver; another was a funeral director. They are not always right, but we forget sometimes they have the same right to be wrong as do we.

Although there are logical reasons for this new partnership, what the university does is not always so clear and logical. We are uncomfortable with this new member of the team. We do not always understand his language, his hostility, his biases, or his fears. Neither does he understand the fears and insecurities within a university group. It has always interested me that often the faculty members who advocate

social change and external involvement are the very ones who resist any change to their own internal arrangements and security.

This new alliance will be an uneasy, timorous one for all. Understanding, effectiveness, and a degree of trust will require maturing for at least 10 years. We should be aware that the process will be frustrating and often more costly in time and money than if the institution continued to make all of the decisions. There is no quick or easy solution.

There are some factors we should understand and accept as we proceed. For example, there is no community body or organization that is truly representative. This is not surprising if one looks at a faculty senate or a student council. The membership of the community organization does bring with it a better understanding than the provider has, of the values, attitudes, fears, and hostilities of the larger group. The organization serves as an open and usually stormy forum where some of these long-standing tensions and frustrations can be exposed, a mental purging process. If together all can survive this an improved understanding and a basis for constructive joint action will have begun.

We have a new agenda, a new ball game. We are required to play the game a little differently. If we are to attack vigorously and with perceptiveness the outcries against the rising costs of care, demands for new systems of health care, and a rash of legislative proposals for national health insurance, it will be to the advantage of the American people if we can have a forum where providers, consumers, payers, and representatives of both public and private sectors can discuss, analyze, and prepare programs in a spirit of freedom, understanding, and a high degree of trust.

In the final analysis, such constructive and objective participation will preserve the freedoms we all value so highly, as well as our enlightened independence and self interest.