

VOLUNTEER SERVICES IN THE DECADE OF THE SEVENTIES by

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At the very beginning of my remarks, I feel I must say that I found the suggested title of my remarks, "Volunteer Services in the Decade of the Seventies," quite beyond me. The whole human services field is changing so rapidly that I find it extremely difficult to think of projecting what anyone will be doing in this field ten years from now. It is almost like being asked to predict what the role of the State mental hospital will be in the seventies. I think the only safe prediction is that it is not going to be what it is today. However, just as it is clear that change is upon us, like it or not, it is even more clear that our opportunities for bringing about change in a desired direction and at an accelerated pace are greater than they have ever been before. Consequently, most of my remarks will concern themselves with the climate of this change and its implications.

As I started to think about the various developing trends in mental health and mental retardation programs and their implications for volunteer services, I became increasingly bothered by the term "volunteer services." The term implies a worker performing a service without pay of a type for which ordinarily he would be paid, i.e., he is volunteering his services for free. Although this will undoubtedly always remain a source of much needed help in all of our services and programs, i.e., the extension of manpower resources in direct service programs through the integration of non-paid workers with paid workers, as our programs change rapidly, increasingly we see an ever more critical role for the citizen to participate in these programs, not as an extension of the manpower of the service agency, but rather fulfilling a unique and different role that can only be filled by a non-employee of the program. I would like to suggest that perhaps in some of our programs in the not too distant future we might be thinking of Citizen Participation Programs, rather than Volunteer Services Programs, to borrow from a model that NIMH is apparently already following. This may seem to be nit-picking, but I believe the implications of the differences between these two terms will become more apparent as I attempt to explore very briefly with you only a few of the developing changes and trends that have

implications for the services for which you are responsible. I trust you will pardon me if many of my remarks are couched in terms of what we see here in Pennsylvania, since I am sure this is not too much different from that going on elsewhere.

In Pennsylvania, as elsewhere, there is a strong commitment to increased active citizen participation in the shaping and development of programs. As we have moved to develop local responsibility for services to the mentally ill and mentally retarded, we have built into these organizational patterns the requirements for as much citizen participation as we can anticipate. The nature of this participation is quite different from the past role of the citizen in voluntary agency affairs.

Just as we now say freely that the mental health of a community is too important to leave to the professional "mental healthers," we are also saying that participation on citizen boards can no longer be left to the so called "professional board member."

One of our commitments to the changing times is that programs must be responsive to the needs of those whom they purport to serve; the people being served must become equal partners with those providing the service. If this commitment is tied to another commitment of the changing times, i.e., services should be developed to serve a limited population base to make possible a service that is attuned to the needs of that population and reflective of the ways of life of that population, it becomes apparent that we must find ways of involving a whole new body of citizens in policy formation, one which has never been involved before. This is a role for most of these citizens that is a completely new one to them. As many of our programs have already found out, this increased participation from a body of citizens, never before able to participate in any meaningful way, is fraught with many difficulties and dangers.

It is going to call for the best of our efforts in leadership, training, and knowledge of community to insure that this participation becomes a productive one rather than a destructive one. The potential for destruction has developed in many instances already. However, we have no choice. If our mental health programs of the future are to live up to their much touted promises, they must find ways of achieving this kind of citizen participation. I believe the evidence is already in. Just as we could not leave the development of volunteer services in our institutions to happenstance—or to the interests of staff to bring in volunteers—or to outside voluntary agencies to develop such programs—but rather had to come to look on volunteer services as needing the deliberate, planned, program development and administration as any other service in the institution, so can we not leave to happenstance the kind of citizen participation that is so critical to our developing community programs—the interests of voluntary agencies—or what have you—but rather we must move rapidly and vigorously to develop this service as we would any other service. That is to say, citizen participation is as critical to the functioning of a program as psychiatric services, social services, or any other service.

Even greater implications are present for the direct service rendering role of the volunteer. Throughout the country there is almost an explosive nature to the development of services at the local community level. The success of these programs will mean not only fewer of the mentally ill or mentally retarded being treated in institutions, but also that large numbers of those chronically disabled from mental illness or mental retardation will be maintained in the community rather than in institutions. This trend will be compounded especially by certain concepts that are strongly influencing program development throughout the country. Among these is the strong civil liberties movement with the increasing emphasis on the right of everyone to maintaining his freedom within the community as long as he is not a threat to the community.

A parallel development is the firm conviction of many who are responsible for program development that the need for residential care does not of necessity require institutional care. A residence can often be provided within the community, with the other elements needed for a comprehensive program coming from the extra-residential resources of the community. In other words, the total community becomes, in a sense, the institution.

The promise is tremendous. We are going to make sure that the mentally disabled are able to live and function as members of the community—not excluded from it and shuttled off to some isolated institution.

But the promise is filled with dangers. We can already see the worst influences of the back wards of our institutions being transferred to the community, in sub-standard rooming houses housing the mentally disabled in a way of life not much above the vegetative. Patients become as easily lost, forgotten, and isolated in the community as they did in the institution. The name of the game may change, community living rather than institutional living, but the game and its results may still be the same as far as the patient is concerned. It is apparent that, if we are not just to transplant the mistakes of institutional care to community care, vigorous action is necessary. Have no doubt about it: care of the mentally disabled in the community in many ways is much more difficult than in an institution. Greater care is needed that the patient or client does not get lost and forgotten. Considerably more effort is required to insure that all elements needed for comprehensive care are present and coordinated since they may come from a variety of disparate resources under different auspices. The manpower needs are even greater in this type of program than institutional programs. All this is but to say that the need for volunteers becomes ever greater and their role ever more critical.

From our very limited experience in Pennsylvania in the past three years or so, I am becoming rapidly convinced that one of the most important roles anyone can fulfill in insuring the success of our community programs, and this role remains yet to be developed, is that of the client or patient advocate, to insure that the patient does not get lost, to insure

that the patient is integrated into the community, and to insure that the system responds to the needs of the patients. For a variety of reasons I believe this role can only be fulfilled by a non-employee of the system, and can only be fulfilled by one whose primacy of interest is not how good is the mental health center, or clinic, or program that he is identified with, but rather his primacy of interest is how well are those services meeting the needs of the person he is interested in. I suspect if every one of our patients in our institutions had had this type of advocate, our institutions could never have drifted into the kinds of practices which circumstances forced us into.

Although the needs for manpower and the number of ways that volunteers can be used in expanding programs seem overwhelming, this very trend may actually provide the solution to some of our many manpower needs.

As programming for the disabled moves out of institutions into the community and closer to those who need services, we may suddenly have available sources of manpower of a size we never dreamed possible if only we have the brains to use it. Let me give you just one example. Here in Philadelphia just two weeks ago I had the exhilarating experience of visiting what to many would be considered a small insignificant program. Small, it was; insignificant, no!

A few years ago, a handful of mothers of severely multiple-handicapped children just finally refused to accept what was happening to them and their children. The children were excluded from programs for the physically handicapped because they were too retarded; they were excluded from programs for the retarded because they were too physically handicapped. There seemed to be only one recourse—institutionalization. Those of you who are familiar with this type of child know how much individualized care is necessary to help these children progress even a little, and also know, I am sure, the chances of getting such care in our understaffed facilities. To make a long story short, these mothers by dint of their own persistence, and I do mean persistence, have developed a special class for these children. They provide the one to one attention the child needs. They bring the child to school, they provide the teaching, the social experiences, the remedial training under the direction and supervision of an expert teacher on a four to five hour a day basis. It is impressive to hear of the progress these children have made and of how the involvement of the mother in the formal classroom carries over into a well trained person being with the child 24 hours a day, and thus the four hours of training become parlayed into 24 hours.

There are many other examples of a similar nature, I am sure, to which we could all point. Just stop and think for a moment of what possibilities such children would have for a one to one relationship in either our institutions or community programs staffed entirely by employees. Such a program developed State-wide, depending only on paid staff, would be impossible in terms of critically short resources of both money and manpower; however. such a program, utilizing mostly mothers as

the manpower, immediately has the potential for being developed even in our smallest communities of the State.

One of the mothers, in parting, summed up their program and experiences in a way that at least for me is going to require some rethinking about volunteer programs:

"All we asked, all we wanted, was not for some agency, or for the government to take over for us. All we wanted was some help, some guidance, some direction, so that we could continue to care for our own."

To me this is a most profound thought, and may be the only answer to the impossible needs for manpower we have in so many of the human service areas. As more and more of our programs move into the community we have a chance to build on such a concept in a way we never have had in institutional programs, where we separated the patient from his family and community, and found substitutes for them. In fact, as I recall, in most of our volunteer programs we go to great lengths to insure that volunteers do not work with their own. Perhaps in the communities, we need to think of how paid staff can help the "volunteers," including the family, which we never before had so readily available, care for their own. Perhaps, if we could think that way, our manpower needs would not be so overwhelming.

I know we are not thinking that way now. I know we are mostly thinking of how we can expand programs with staff, and very little, if at all, in most community programs of how volunteers could be used. I know we are not thinking of volunteers, families, citizens, as our primary resource and of how staff can be developed and used to help the family and the community care for its own. I do know that the way we are thinking and planning now will never overcome the shortages in manpower and resources we need to overcome if we are to come even close to coming to grips with our problems in the magnitude they exist.

To think and plan this way is not easy, though it may seem to be so on the surface. It requires the professionals to think first not of what they can do and then what the volunteers can do to help them, but rather what the non-staff can do and what the staff can do to help them. It requires the volunteer coordinator not to analyze institutional programs, the roles of staff, and the kinds of jobs volunteers can do, but rather to analyze the needs of patients, the kinds of needs volunteers can meet, and how staff can help them meet those needs. It requires the volunteer coordinator to think of an entirely different type of volunteer, no longer just the citizen who has time and wishes to give of himself to help others, but rather of the individual who is already involved with some one needing care, who is willing and able, with help, to extend himself to provide large elements of the care, not just as a member of the family in the family situation, but as an active equal member of the treatment team.

Perhaps the most sophisticated example of this that I can think of at the

moment is one that exists in what I am sure we would refer to as a very primitive community in Africa with a dearth of mental health resources.

A rather comprehensive psychiatric treatment program has developed there that in many ways takes the place of our institutional programs. Patients come from the surrounding villages from many miles away. Although many need to be under treatment a long time, there is no hospital as such. Members of the family accompany the patient and set up housekeeping in the community where the treatment is being provided. The family provides the residential aspects of care; they in turn are welcomed and integrated into the total community by the other residents. This indeed seems like a dream program, adequate manpower to provide dedicated 24 hour a day care on a highly individualized basis by those who really know the patient, have always been involved with him, and will continue to be closely involved after he leaves the program.

This, of course, is a model that is not readily translatable to our own culture, but nevertheless there are aspects that could probably be well developed if we set ourselves to it. There are programs for older people, where the disabled one has not been separated from his or her mate, but rather where they have been admitted as a couple so the one who is not disabled can help care for the disabled. How much more humanitarian to help couples who have been devoted a lifetime to the care of each other, to continue to provide that care, rather than by separating them from each other and making each one's life a little more empty, a little more meaningless just when they need each other the most. We have experimented, all but on a very limited basis, with moving an entire family into one of our institutions for a period of time to care for their very disturbed child. I can attest not only did it help the child, but it provided us with a source of manpower needed to help a very disturbed child 24 hours a day that we would not produce from staff or the other more traditional use of volunteers.

I bring these up not for the sake of illustrations of programs for volunteers, but rather as a means of urging all of us to start thinking differently about volunteers—who they might be and how they might fit into a program, or even of how a program might be built around them. I have dwelt considerably on community programs, but the need for new and different approaches in our institutions is just as apparent. Our institutions are becoming less and less hospitals and more and more like communities in which a variety of people with specialized needs are living. Increased participation in all aspects of that community by citizens, who are not similarly disabled and who are not employed, to take care of the disabled is critical if that community is to avoid the dehumanizing aspects in our institutions of the past as well as to ensure the concept of normalization, that we hear so much about currently, underlies all of our programming. I do not see our institutions disappearing. Rather, I see them changing and changing rapidly.

In our own instance we are coming to view our hospitals as a collection

of resources, human in terms of staff, physical plants, budgets and programs which can be used to meet the changing needs of the communities they serve. We see their horizons broadening rather than constricting, even though their role may be quite different. We suspect programs will become more intensive and rehabilitative rather than less so. We suspect our need for citizen participation in those programs will increase and not decrease.

As I conclude, I feel I must apologize for rambling more than I intended and for being more abstract than I wanted to be. You asked me to talk about "Volunteer Services in the Decade of the Seventies." What they will be like, I'm sure I don't know. But of this I am sure, we are entering a decade in which volunteer services as a matter of the more fortunate, giving of their time and efforts to help the less fortunate will rapidly change. We will see less of doing for and more of being involved with; we will see less of a limited involvement of only a narrow strata of society to involvement of all the socio-economic levels; we will see less of volunteers serving as auxiliary to staff, and more of citizens participating in their own right and in their own unique roles as equals with staff in policy making, program development and direct service. In fact, this latter level of participation is critical to the success or failure of this whole new mental health revolution, as some are wont to refer to the changes we are now going through. And, as part of this revolution, I suspect we will hear less and less of mental health services, but more and more of human services in which mental health/mental retardation services will become thoroughly integrated health and welfare services, and we will hear less and less of mental hospitals and mental health centers and more and more of human service institutions and centers.

Of this we can be sure—the decade ahead can be the most frustrating and disillusioning one of many of our professional careers, or it can be the most exciting of all, if we allow ourselves to have new visions and to find new ways. Those of you who are directly involved with responsibility for volunteers' services and citizen participation should be most excited. This is the decade you must come into your own, or we all fail and slip back again.