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Lex Frieden

CONSUMER ADVOCACY: State of the Art

Harold S. Remmes

Project Director

Supported by

Office of Human Development
Rehabilitation Services Administration
Grant Number 16-P-57856/1-01

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CHAPTER I
THE PROJECT

CHAPTER I

EXPLANATION OF PROJECT DESIGN

The consumer Advocacy Project had essentially three goals. These were:

1. The development of a guidebook which consumers might use to form viable organizations as an adjunct to the existing service delivery system.
2. The identification of consumer groups across the country and the determination of the nature and scope of their activities.
3. The examination of the state-of-the-art of consumerism among the handicapped population in the United States.

The project, funded through the Medical Rehabilitation Research and Training Center, Tufts University School of Medicine, Boston, Massachusetts (RT-7), was first conceived by Glen E. Gresham, M.D., then Project Director, and the leadership of the Massachusetts Council of Organizations of the Handicapped, Inc. (an umbrella group of consumer organizations). The concept was refined and supported by Carl V. Granger, M.D., Project Director of RT-7, Dr. A. Bernice Clark, Medical Coordinator for Region One, S.R.S., and Dr. Joseph Fenton, Chief, Special Centers, S.R.S., Washington, D.C.

The complete project was carried out by the Massachusetts Council of Organizations of the Handicapped, Inc. utilizing, for the most part, homebound individuals who possessed the necessary skills but who lacked the mobility for full-time gainful employment.

Such a concept was untried and required some innovative thinking. In the first place, only those who were unable to qualify for employment outside their homes were to be considered. Secondly, those selected must possess the required skills and motivation to accomplish the assigned tasks. Because of the need to utilize the telephone maximally for both instruction and communication, the homebound staff must be able to articulate well and comprehend verbal instructions. Finally, those selected must be self-directive and able to perform with minimal supervision.

From the outset it was understood that the President of the Mass. Council of Organizations of the Handicapped would resign his position and assume the post of Project Director. Since he had been instrumental in initiating the negotiations with the R & T Center and in the formulation of the protocol, an exception was made to the first requirement. The Project Director performed his tasks while holding a full-time job. He did, however, qualify in all other respects including a physical impairment. (It should be noted here that the requirement of using a handicapped staff was in no way discriminatory. The purpose was simply to determine whether or not those who were adjudged unemployable might be used in carrying out the project.)

Memoranda were circulated to each of the member organizations of M.C.O.H. and to all Field Offices of the Massachusetts Rehabilitation Commission outlining the possible job opportunities and requirements. The following are precise resumes of those selected for the staff.

PROJECT DIRECTOR: Former President and founder of the Mass. Council of Organizations of the Handicapped. Residual deformities of all extremities from polio contracted in infancy. A graduate of Boston University and a full-time employee as a Handicapped Services Specialist for the local Housing Authority.

ADMINISTRATIVE ASSISTANT: Graduate student in Rehabilitation Administration. Active with a unit of Boy Scouts at the Industrial School for Crippled Children in Boston. (Non-handicapped)

BOOKKEEPER: Young homebound dystrophic male. Unable to be gainfully employed outside of his home due to severe involvement of all extremities and trunk. Excellent accountant.

TYPIST: Homebound female victim of osteogenesis imperfecta. Wheelchairbound. Height: 30 inches. Had not worked in four years due to non-healing fracture of humerus. Outstanding secretarial skills.

TYPIST: Homebound by radical surgery for removal of malignant tissue. Had lost some speed due to inactivity and was able to work only limited time each day.

The selection of staff was made from referrals of member groups of M.C.O.H. or the Massachusetts Rehabilitation Commission only. It was interesting to note

that, although every effort was made to advertise the positions within the handicapped community, respondents were few and, in one case, great effort had to be expended to convince one person to accept the position.

Equipment was rented and facilities were set up in each of the satellite (home) locations and the Project Director made periodic visits. Even the printing of the documents which emerged from the project was performed by a member organization of M.C.O.H. which used handicapped persons in a limited printing operation. In addition to the core staff which has been enumerated, several other persons were engaged in very limited employment for mailings, etc. when deadlines had to be met.

Since everyone employed by the project was on a part-time basis, the hours were flexible and could be worked into the employees' schedule without conflict with other activities.

The goals of the project were accomplished as originally outlined except that the time frame was longer than anticipated. This was due to the illness of one staff person for over two months and by the fact that additional time had to be given to the print shop which had certain mechanical deficiencies in handling an order of this magnitude. It was deemed best to go along with this in order to provide employment for the handicapped throughout.

Fiscal management for the project was under the control of M.C.O.H. under a drawing account with the R & T Center. The original budget was not exceeded nor was any surplus returned. The limited budget mandated serious constraints in spending and the drastic increase in printing and paper costs caused de-emphasis of certain components (especially evaluation of the effectiveness of the documents produced).

In summary, however, certain things were proven by this project. If

one were to ignore the anticipated results of the project and focus instead on some of the more intangible results, one might conclude that these were as significant as the end products of the research and documents produced.

First, several persons who were considered unemployable were given gainful employment. One of these has gained sufficient confidence and return of lost skills to operate a home typing service.

Secondly, the innovative approach to the methods whereby the homebound employees could be employed opens the door to researching some new techniques for data gathering at minimal cost.

Thirdly, allowing qualified consumer organizations responsibility for fiscal management demonstrates that they can utilize sound business management.

METHODOLOGY

COMPONENT I - Development of Consumer's Guide

The Massachusetts Council of Organizations of the Handicapped had long felt the need for some sort of guidebook to help less sophisticated groups organize to cope with the service delivery system. The interaction of M.C.O.H. with other groups over a six year period had convinced them (M.C.O.H.) that there was a real need for guidance through the development of some sort of comprehensive book which would be valuable to the embryonic "Sunshine Clubs" which were trying desperately to attain social impact as well as to the on-going clubs which needed something to help them form and become more cohesive under some sort of umbrella.

M.C.O.H. had become the bona fide spokesman for Massachusetts' handicapped population and felt that its experience could prove valuable to others. The leadership of M.C.O.H. was especially interested in assisting with the

formation of similar state-wide councils which in turn might be molded into a viable national organization. In this way, the handicapped population might become a force equal in "clout" to other minority groups.

The first step was to discuss needs with those who had been accepted as the national leadership by the majority of the handicapped. Conferences were arranged with Elmer Josephs, National Executive Director of the Congress of the Physically Handicapped; Raymond Cheever, Editor and Publisher of "Accent on Living" Magazine (a publication for the handicapped); Mr. C.J. Lampos, Editor of "Achievement" (a national newspaper for the handicapped); and with several leaders of the National Paraplegia Foundation, Indoor Sports Clubs, etc. In order to stretch the budget, most of these meetings were scheduled to coincide with other national meetings where both parties were present.

Because only a few states were organized into state-wide organizations, it was decided to look at one other Council as a comparison with M.C.O.H. The Florida Council of Handicapped Organizations' invitation was accepted in January 1973 and several meetings took place with the Florida leadership.

The results of all of these interviews were brought back on tape and the "handbook" began to take form. The suspicions of M.C.O.H. were confirmed. The final result of the book should be comprehensive enough to serve as both a primer and as a post-graduate course.

Concurrently with the research, various attempts of others to produce consumer "guidebooks" were reviewed. While many of these gave the technical assistance such as by-laws, committee structure, etc., all but one (produced by a group of Midwestern parents of retarded children) failed to give any insight as to how to be effective and how to deal with the service delivery system. M.C.O.H. had a background of more than six years' experience in this area and felt that its subjective views, together with the subjective views

of the national leadership, would be of far greater value than any objective organizational brochure. Thus was born The Consumer's Guide to Organizing the Handicapped, with all of its bias, cynicism, and "tongue in cheek" philosophy.

Two hundred copies were sent out to all parts of the country and the letters received indicate that it was extremely helpful to a number of groups. Many have requested additional copies, but, because of financial constraints, we have had to restrict each organization to a single copy with the right to reproduce any part that they require for training.

The book was dictated via telephone to a stenographer who had been unemployed for four years and who had been homebound during that period. The stenographer had been employed for more than a dozen years even though she was wheelchair bound due to osteogenesis imperfecta. Much of the stenographic speed she had gained during her employment period had been lost due to her most recent bout with a fracture of the humerus which refused to heal. Through a gradual increase in dictating speed and by extending the length of time for each dictating session, she regained much of the lost skill until she was working as much as twenty hours per week at the conclusion of the manuscript preparation.

The manuscript was proofread and printed at a local Cerebral Palsy Association using the students enrolled in the printing course.

COMPONENT II - Development of a Directory of Organizations

Although several attempts had been made in the past, there was little data available as to the number of organizations of the handicapped scattered about the country or about the activities in which they were engaged. To date, the most complete list had been published by the National Congress of the Physically Handicapped (C.O.P.H.). This list contained about three hundred groups but gave no indication as to the nature of their activities.

Often agencies required knowledge of groups within their geographical jurisdiction in order to attempt better service. In addition, if the goal of M.C.O.H. was to be realized (i.e. the formation of a strong national group), then more knowledge was required before any attempt was made to create a viable, cohesive force.

It was felt by M.C.O.H. that a joint effort by both agency and consumer alike could add to the storehouse of knowledge and expand the listing considerably. This view was shared by the Project Director of RT-7 and by the federal authorities. Utilizing the network of R & T Centers throughout the United States, the state Divisions of Vocational Rehabilitation and the various national known consumer groups, a questionnaire was distributed asking the respondent to identify any "consumer organizations" known to him. When identified, each consumer group was sent a questionnaire asking for information concerning the membership, officers, nature and scope of activities in which his group participated.

While the request for information to the R & T system was initiated by Dr. Carl V. Granger, Project Director of Tufts Rehabilitation Research and Training Center (RT-7) and those to the state D.V.R.'s were requested by Dr. Richard Goldberg, Director of Research for the Massachusetts Rehabilitation Commission, replies were sent to a homebound M.C.O.H. staff person for cataloging and processing. These data were then included in the format of the Directory of Organizations of the Handicapped in the United States.

It should be noted here that the researcher utilized for this process had been homebound and restricted to very limited activity for several years due to radical surgery. Just as in the case of the typist who prepared the Consumer's Guide, she too improved in skills and confidence so that, at the conclusion of the project, she was doing quite well in typing term papers, etc. as a home-based operation.

One thousand three hundred and fifty (1,350) groups were identified by the national consumer groups, R & T Centers, and D.V.R.'s. Each of these received M.C.O.H.'s questionnaire and a letter explaining why the survey was being taken. From these, eighty-four (84) were returned by the postal authorities as undeliverable. The remainder were assumed to be active and included on the list. Those which returned the questionnaire were included in a separate section of the Directory and additional information was included with their listing. The following is a breakdown of the activities of the respondent groups:

356 groups returned the completed questionnaire
910 did not respond but were assumed active
84 returned as "undeliverable"

We were unable to locate groups in eight (8) areas either because they were unknown to the professional and/or consumer groups contacted in that section or, because the source did not itself respond to our initial and follow-up letters. Areas which failed to respond were: Arizona, Arkansas, Kentucky, Louisiana, Nevada, Puerto Rico, Rhode Island, and South Carolina. Of those responding:

234 were involved in social and/or sports activity
225 had activities in national or local legislative effort
218 were involved in educational activities
142 had programs concerning "Attitudinal Barriers"
120 were working on architectural barriers
114 were active in employment efforts
107 were trying to solve transportation problems
101 were actively working on adapted housing

Only forty-six (46) had programs in insurance and one hundred and forty-five (145) mentioned other (unspecified) activities.

COMPONENT III - The Report

The final component of this project was in the preparation of the report which you are now reading. The data gathered in the preparation of the Directory and the Consumer's Guide will be presented here as an attempt to interpret

the data and include the information based on the cumulative knowledge of those interviewed and the experiences of M.C.O.H. in more than a year of intensive research.

CHAPTER II

ANALYSIS OF DATA

CHAPTER II

ANALYSIS

The comparatively low number of organizations which responded to the questionnaire indicates a substantiation of the feelings which were expressed by the National leadership during the personal interviews. Namely, that the handicapped are tired of being studied, written about, and then forgotten until such time as they make a request, and someone decides that they should be studied again.

Countless studies, reports, books, commissions, committees, etc., give constant attention to studying the handicapped, yet no accurate figures have even emerged as to the approximate number of handicapped in this country. Every agency has its own set of figures, all based on different data. If there is a reluctance to continue furnishing information, perhaps it is understandable.

An alternative set of assumptions or conclusions might also be indicated from the low response. For example:

1. That the clubs lack sophistication or internal organization to respond.

While this may be true in some cases, we believe that most clubs do respond to letters they receive. Because of the voluntary status of those charged with responding, there is often a time lag. The Massachusetts Council of Organizations of the Handicapped usually receives a response to our regular correspondence to most clubs.

2. That the clubs were too busy "doing" things to take time out to respond or do paper work.

Our experience has been that the most active clubs are better organized and can cope best with routine queries.

3. That the vast majority are either apathetic or too provincial in nature to feel that yet another questionnaire could be all that important.

We suspect that there is some validity to this viewpoint and we shall delve further into this point later in this report.

4. That most clubs were not anxious to respond, because their programs were minimal.

From those replies which were received, many indicated rather minimal programs or extremely restricted activities. This would assume that a lack of a "track record" was not a major factor in the reasoning of those groups which failed to reply.

An Overview of the Existing Consumer Groups

While the project identified more than 1,000 consumer groups, there are, in fact, only a few organizations which have national affiliations. Perhaps the most powerful of these is the National Paraplegia Foundation which has chapters in most states and has been active in the legislative field both nationally and locally.

The National Congress of Organizations of the Physically Handicapped has some 14 or 15 chapters scattered around the country. However, it is not a strong organization and the majority of the handicapped feel that it is not a viable force around which to build a strong national group.

Closely aligned with the NCOPH is the National Association of the Physically Handicapped. This is made up of individuals and chapters and allows both visible and non-visible handicapped membership. It includes blind, mobility impaired, neurological impairments, etc. While this group is scattered throughout the country, it too, is not a strong force.

Another force which is perhaps more closely aligned with the National Paraplegia Foundation is the Paralyzed Veterans of America. This consists solely of disabled veterans, the majority of whom have spinal cord injury. This group is relatively strong in that its membership is largely confined

FIG. I.

DISTRIBUTION OF ACTIVITIES BY RESPONDENTS (TOTALS)

TOTAL NUMBER OF RESPONDENTS TO QUESTIONNAIRE 349

ACTIVITY AREA	NO. OF GROUPS WITH PROGRAMS	PERCENT OF TOTAL
SPORTS/SOCIAL	233	66.7%
LEGISLATION	213	61.0%
EMPLOYMENT	114	32.6%
HOUSING	100	28.6%
TRANSPORTATION	106	30.0%
EDUCATION	218	62.0%
INSURANCE	45	12.8%
ARCH. BARRIERS	119	34.0%
ATTITUDE, BAR.	141	40.0%
OTHER	147	42.0%

FIG. II

DISTRIBUTION OF ACTIVITIES OF RESPONDENTS (BY STATE)

S T A T E	Questionnaires Returned (Total)	SPORTS & SOCIAL	LEGISLATION	EMPLOYMENT	HOUSING	TRANSPORTATION	EDUCATION	INSURANCE	Architectural Barriers	Attitudinal Barriers	OTHER
ALABAMA	7	6	6	6	4	1	3	3	4	5	4
ALASKA	2	1	2	1	0	1	1	0	1	1	0
ARIZONA	8	5	5	2	2	2	5	1	3	3	2
ARKANSAS	7	4	4	0	0	1	0	0	0	0	2
CALIFORNIA	7	3	1	1	1	1	0	0	0	0	2
COLORADO	5	2	2	1	1	1	2	0	0	0	2
CONNECTICUT	1	2	1	1	1	1	0	0	0	0	2
DELAWARE	2	5	5	4	1	1	6	0	0	0	2
DIST. OF COLUMBIA	12	3	1	1	1	1	2	1	1	1	6
FLORIDA	3	1	0	1	0	0	2	0	0	0	2
GEORGIA	1	1	0	0	0	0	1	0	0	0	2
HAWAII	1	0	0	0	0	0	0	0	0	0	2
IDAHO	19	10	12	7	5	4	7	1	10	8	7
ILLINOIS	5	5	5	1	2	1	1	0	5	5	0
INDIANA	1	1	1	0	1	1	0	0	1	1	0
IOWA	1	1	1	1	1	1	1	1	1	1	0
KANSAS	22	16	12	6	6	8	15	3	4	3	10
KENTUCKY	1	1	1	1	1	1	1	1	1	1	1
MAINE	64	36	35	15	21	15	50	16	15	24	30
MARYLAND	7	6	5	1	2	0	3	0	3	3	4
MASSACHUSETTS	6	5	5	1	0	4	3	0	4	4	4
MICHIGAN	1	1	1	1	1	0	1	1	1	1	1
MINNESOTA	1	1	1	1	1	1	1	1	1	1	1
MISSISSIPPI	1	1	1	1	1	1	1	1	1	1	1
MISSOURI	1	1	1	1	1	1	1	1	1	1	1
MONTANA	2	2	2	1	1	3	3	1	1	1	3
NEBRASKA	4	2	4	1	2	0	1	1	1	1	1
NEVADA	1	1	1	0	1	0	1	0	1	0	1
NEW HAMPSHIRE	3	2	2	1	1	1	1	1	1	1	1
NEW JERSEY	1	0	1	0	1	0	1	0	1	0	1
NEW MEXICO	1	6	9	5	4	4	7	1	5	1	9
NEW YORK	14	6	3	1	0	4	5	2	4	3	1
NORTH CAROLINA	6	4	4	3	3	2	4	2	3	3	5
NORTH DAKOTA	7	4	4	0	0	0	5	2	5	0	2
OHIO	12	12	11	7	3	3	11	2	10	5	10
OKLAHOMA	1	1	0	1	1	0	1	0	1	0	2
OREGON	4	8	6	1	4	2	3	0	2	3	2
PENNSYLVANIA	11	1	2	1	1	1	3	0	1	1	1
RHODE ISLAND	1	1	1	0	1	0	1	0	1	0	1
SOUTH DAKOTA	1	1	1	1	1	1	1	1	1	1	1
TENNESSEE	1	1	1	1	1	1	1	1	1	1	1
TEXAS	17	16	14	2	1	2	16	1	1	1	10
UTAH	3	3	2	1	1	1	1	0	1	1	1
VERMONT	1	1	1	1	1	0	1	0	1	1	0
VIRGINIA	2	2	1	1	1	0	2	0	1	1	0
WASHINGTON	2	1	1	1	1	0	1	0	1	1	0
WEST VIRGINIA	5	3	4	4	4	0	4	0	3	2	3
WISCONSIN	3	1	1	1	1	0	1	0	1	1	0
WYOMING	12	1	7	5	3	4	4	0	5	5	3

to veteran's institutions, but have access to the outside world, thus enabling them to maintain a "tighter ship" than most organizations and eliminating the difficulty of transporting people to meetings since they are already at the point of assembly.

There is a small number of consumer groups with national affiliation connected with a service agency. For example, the Multiple Sclerosis Service Organization has chapters of consumers which have evolved from local agencies. These are growing in number but are not, as yet, very strong nationally. Other groups, such as The Little People of America, Inc., the Osteogenesis Imperfecta Foundation, Indoor Sports Clubs, National Federation for the Blind, United Ostomy Association, and others are growing in strength, but none has yet reached the point where they could serve as the Hub for any organizational movement.

Perhaps the most recent but fastest growing organization is the relatively new DIA, Disabled in Action. This group was started in New York City and has spread to several states under the able direction of Ms. Judy Heumann, a teacher in New York City, who is confined to a wheelchair. While this group is comprised mostly of young people, and is somewhat more militant than most of the other organizations, it does have an attraction to those who are less inclined to talk and more inclined toward action. It would be impossible to use this group as a focal point around which to organize. However, any organization on a national level would have to include representatives from the DIA in order to get a complete spectrum of the viewpoint of the handicapped, if it is to be representative.

In May of 1974, groups from all over the United States attended meetings which were held concurrently in Washington, D.C., with the meeting of the President's Committee on Employment of the Handicapped. The purpose of this meeting was to form a national coalition, and from this a nucleus has emerged with geographic representation which seems to be the most viable national organiza-

tion to emerge in recent years. The idea behind the coalition is to bring together under one umbrella, as many as possible of the handicapped groups, allowing them to retain their autonomy and yet speak with one voice on issues. It is hoped that the cohesiveness which is thus gained will enable the handicapped to have a stronger voice in the body politic.

Barriers to Organization

In attempting to determine why the handicapped have not organized as well as other groups, we visited many local communities and states. Perhaps the best organized group outside of Massachusetts is the Florida Council of Physically Handicapped Organizations. More than 20 organizations now belong to this umbrella group, and despite the problem of geography and communication, it is an active and viable organization. Contributing to the cohesiveness of the Organization is a Florida-based newspaper for the handicapped which is edited by C.J. Lampos. This publication, Achievement, has a national distribution but is primarily focused at the Florida constituency and serves as a first-rate communication to keep the members informed. It would be unfair to say that Achievement is actually a provincial publication, since it does concern itself with national issues and national happenings. It does, however, devote some space to happenings in Florida, and in this way aims the latest happenings to the membership, many of whom are confined to their homes. This publication is perhaps more significant when one considers the geography of the State of Florida with over nine hundred miles of length, and with the transportation difficulties of the handicapped, it would seem that it would be a very difficult state to organize. Perhaps due to the excellent communication, through this publication Floridians are better organized than in almost any other state.

In other areas too our research has discovered that good communication through various media, such as newsletters, newspapers, and regularly scheduled

bulletins is often an important factor in determining the viability of the organization(s) involved. We found that throughout the Midwest where NAPH and COPH are the strongest, the communications were far better and tended to create a cohesiveness which could not be gained through the usual procedure of a monthly meeting.

This leads us to believe that perhaps the key to organizing the handicapped lies in creating better communications, so that persons may feel involved even if they are unable to attend regularly scheduled meetings. The efforts of those organizations, which have given priority to group communication, is reflected in better progress for their particular area. In those cases where little or no communication exists, organizations are traditionally weak, and often extremely fragile.

We are in no way trying to imply that the small local organization is ineffective. In many cases, these organizations have a tremendous impact on their locality. Many organizations function in a very small geographic area and are able to have ordinances and legislation passed which is helpful to their own particular locus. For the most part, however, such organizations do not have an impact on a state-wide level.

Transportation

A major barrier to organizing has been the inability of the handicapped to attend meetings. For the most part, the disabled must depend upon others to transport them and often are homebound because of weather conditions or lack of transportation. This makes it extremely difficult to conduct an effective program. Most organizations have little or no trouble in finding a place to meet which is accessible and usually donated space. Getting people to the meetings, however, has been a major problem of most organizations which were researched. In A Consumer's Guide to Organizing the Handicapped, we have

suggested alternative methods such as telephone, mimeographed newsletters, etc., for bringing people together without the actual physical transportation required to attend meetings.

Image

The image of the handicapped has been another major factor in preventing organization. Both the self-image which the handicapped have of themselves and the image which others have of the handicapped have played major roles in setting up barriers to organization. The self-image of the handicapped has been for many years that of a "second class citizen." This is especially true of those persons who have had their disability for some time, and less true of those who have been recently disabled. The concept that the handicapped person must depend upon others has been fostered by agencies which have tried to help them, but have given them very little voice in self-determination. In addition, the dependency on the family, friends and agencies for supportive services often causes a person to feel less than adequate to most tasks.

In analyzing the growth of the organization of a handicapped group, we have noted that many were formed several years ago because persons with similar disabilities felt more comfortable in the company of their peers. It was less of a competitive situation and one in which the handicapped person felt comfortable in an environment with which he could cope. Most of these so-called "clubs" were socially oriented and did little or nothing in terms of social action programs. The trend toward changing the system is a recent one, and one which has gained strength in the last seven or eight years. While this is not to say that there were never any groups which attempted social action, our research has indicated that the majority of the small groups were not focused in that direction. Most of the clubs held socials, parties, sports events, and most of these were of a spectator format rather than parti-

cipatory. Many of the functions were held for the handicapped by other persons. Even today, it is impossible to ascertain whether or not the handicapped consider themselves a distinct minority group. It does seem that there is a growing trend among the more active groups to assume this posture.

Finances

The lack of money has been a substantial impediment to organizing the handicapped. Most of the clubs operate on minimal budgets often only from dues of their membership. This precludes having good communications and providing good programs. The lack of funding has been a major concern of all leadership for without it there seems to be little which can be done in the way of expansion and growth.

If a national coalition is to be formed it will require substantial funding in order to insure its success.

Provincialism

It is interesting to note that organizations of the handicapped are not much different from other organizations. There are petty jealousies between organizations and there are interorganizational problems. These problems, both intra- and interorganizational, manifest themselves in the fears expressed by some of the local leadership. An unwillingness to merge with other organizations because the people in power feel that they will lose some of their power base is often quite evident. In many instances, local leadership has been involved at rather high levels of planning, such as Governor's committees, Mayor's commissions, local architectural barrier boards, etc. Also, many agencies have included consumers on their boards. This has caused the leadership to gain a certain status in the community; a status which they are reluctant to relinquish to anyone else. While many are sincere, honest, and

dedicated persons there are others who are on an "ego trip" and are quite willing to sit on boards which accomplish nothing, just because it allows them to mix with important community people. For some, this is as much a social event as it is anything else. It is our opinion that many agencies have capitalized on this fact and have made moves similar to those done in industry of moving a person upstairs in order to keep him quiet, or moving a person who is active in the labor movement into the management position, in order to stifle their activity. The effect is the same. Many persons who started out as good leaders become absorbed into the system where they are ineffectual, because they must depend upon the system for either their income or their status.

While there is no doubt that inclusion of the handicapped into the system can be an effective way of bringing about change, it often has a deleterious effect on the individuals capabilities to be his own man. This situation does not exist when a sincere effort is made to include a person because of his qualifications in a position where he can bring about change. It does exist, however, in most situations where the move is made for political or contrived reasons.

While almost every key leader in the handicapped movement espouses the attempts to achieve solidarity many jealously guard the prerogatives which they have gained over the years and are reluctant to jeopardize them by any merger which does not place them at the top of the heap.

We discern a growing trend toward electing leadership which is responsible to a constituency rather than having leaders who develop their own constituency loyal only to them. If this trend continues it bodes well for the concept of creating a strong national organization. If their leader is responsible to a constituency, the constituency will demand solidarity and the leader will then make his compromises in order to retain his leadership in his own organization. For this reason any national coalition should and must have a provision which

allows the autonomy of the member organizations and allows a member organization to assume a dissenting position on any issue on which it feels it should assume such a posture. It is hoped that in this way, the current leadership or the emerging leadership will not feel threatened and will be more cooperative in a national effort.

CHAPTER III

THE CONFERENCE

REPORT ON THE CONSUMER LEADERSHIP CONFERENCE

RAMADA INN, EAST BOSTON, MASS.

APRIL 19-20, 1975

SPONSORED BY TUFTS REHABILITATION RESEARCH & TRAINING CENTER AND MASSACHUSETTS COUNCIL OF ORGANIZATIONS OF THE HANDICAPPED, INC.

I. REASONS FOR THE CONFERENCE

In the preparation of A Consumer's Guide to Organizing the Handicapped and A Directory of Organizations of the Handicapped in the United States, the research indicated that there was a proliferation of organizations of the handicapped but that there was little real interaction; only pockets of organization in a few scattered areas of the country.

This research also indicated that the range of sophistication among the handicapped groups ranged from the almost totally unsophisticated to a very small number of well organized and knowledgeable organizations. It was also found that the leadership of the better organized groups was expanding its interests beyond the provincial setting and that many of the key persons were impacting at the state and national levels.

It is interesting to note that while MCOH was conducting the research (and perhaps partially because MCOH was conducting the research) a greater momentum for creating umbrella groups and the recognition of the need for a strong national voice seemed to develop.

Concurrent with the research, councils of organizations were initiated in Florida, Minnesota, and similarly in several other locations. Also, in May 1974, handicapped leaders throughout the country who were attending the President's Committee on Employment of the Handicapped Annual Meeting met (more than 200 strong) to form the American Coalition of Citizens with Disabilities.

It was recognized by MCOH and the R&T Center that, despite this progress, the handicapped were still relatively poorly organized. While several groups had had excellent successes in attracting funding for specific programs, and while in at least one case the "Consumer Organization" itself was serving more efficiently certain needs than were the local agencies, this information was not being shared so that it could be expanded to other areas of the country.

More than 800 copies of A Consumer's Guide to Organizing the Handicapped had been distributed throughout the U.S. and indications from the recipients stated that it was of immeasurable value. There was still a need for disseminating this type of information to those areas which were not well organized.

In meeting with Dr. Joseph Fenton, Chief of Special Centers, (R&T Centers) it was suggested that greater impetus might be achieved if closer cooperation by the organized consumer groups and the professional agency could be achieved. Thus it was determined that the most efficient way to achieve these goals would be to bring certain key leadership to a central meeting to develop

a plan of action. The R&T Center together with MCOH drafted the proposal which was approved.

II. PRECONFERENCE PLANNING

Because of funding constraints, a great deal of research was indicated in order to select those participants who could contribute maximally to such an undertaking. Letters were written to known handicapped leaders in all parts of the country requesting that they submit suggestions for participants and requesting information regarding the backgrounds of those nominated. The research for this aspect of the project was carried out utilizing homebound individuals as a continuum of the Consumer Advocacy Project. The ultimate goal of the Conference was not only to bring together the best possible leadership, but to also evaluate the Consumer's Guide and, in fact, increase its impact on the handicapped population.

More than 80 names were submitted and the background of the nominee was carefully screened and verified from more than one source. While this took a great deal of time it served multiple purposes:

1. It provided homebound employment for those doing the screening.
2. It enabled MCOH to determine whether or not the person selected would be in a position to travel.
3. It brought into focus what was being done in other parts of the country.

It was determined from the outset that a person with a severe disability would not be denied access to the Conference because of physical problems. Many of the best leaders were severely disabled and, in a few cases, the degree of disability was almost catastrophic. While it was realized that this would significantly increase transportation costs, it was felt that the contribution made by the individual could be far greater than the cost of getting him/her to the Conference site.

A list of the participants will be included in the Conference material which will be an appendix to this report. It should be noted, however, that these materials do not indicate the extent of disability of the participants. Many required attendants to travel with them. One required a portable respirator, another had to bring someone, not only as an attendant, but also to interpret his unintelligible speech as a result of cerebral palsy. Despite these physical problems, each participant had a rather large constituency, a good background in organizing, and a demonstrable record in the area of consumer advocacy.

Six months before the Conference, the various hotels in and around Boston were surveyed by the Project Staff. Some locations offered more in terms of accessibility than the site which was selected. They did not, however, exhibit the attitude and spirit of cooperation as did the staff at the site which was finally chosen.

The effort here was to achieve accessibility to all parts of the hotel, but more importantly to have the participants treated in the same way as a non-handicapped guest. The Ramada Inn agreed to

ramp any location where stairs might be a problem, to remove bathroom doors, thus making bathrooms accessible, to provide certain amenities, and to work closely with us to insure the success of the physical arrangements.

Attention was even given to the menu selection so that all food served would not require cutting, and special help was available if needed (it was not).

Arrangements for transportation to Logan Airport (Boston) were made by the participants themselves. MCOH Staff checked with all the airlines to verify ticket prices and provided each participant with a check for the appropriate amount. Transportation from the airport to the site was provided by Norton Systems, Inc., (a transportation system for the disabled) and by an adapted van donated for the Conference by the Easter Seal Society for Crippled Children and Adults of Massachusetts, Inc.

These prior arrangements, while time consuming, paid off handsomely since no problems developed and the Conference was held without incident.

III. THE CONFERENCE

Participants arrived on Friday evening, April 18, were provided with rooms, Conference materials and a few refreshments. This was done on a very informal basis owing to the span of time required for the arrival of the Conferees.

The actual content of the discussion will be found in the Appendix. It should be noted that the materials concerning the activities

which took place on Saturday were typed, duplicated, and into the hands of the participants prior to their departure on Sunday. Two staff members worked all night preparing the papers and the local Cerebral Palsy Workshop stayed open Sunday morning in order to accomplish this. The materials for Sunday's sessions were transcribed and disseminated after the participants had returned home.

Physically, the Conference took place in two adjacent rooms divided by a folding wall. This allowed meals to be set up in one room during the workshops, and at meal time the wall was removed so that those attending had only to cross the room in order to eat. This was done to eliminate the physical expenditure of energy since the workshops were long and had very few "breaks." There were no complaints from those involved regarding the demands made on them.

As noted earlier, most of the participants had established distinguished records in the field of consumer advocacy over the years. Many were personally known to the Project Director, in addition to being recommended by others from various geographic locations. Some participants were not personally known to the MCOH staff, but were selected on the recommendation of leaders in the field. This points out a deficiency within the consumer movement. Those persons who were not known to MCOH should have been known because of the significant achievements of their efforts at the local level. Until these accomplishments were uncovered while researching the project, most of the country was

unaware of these significant contributions.

It was recognized prior to the Conference that, while some of the participants were known to each other either from occasional meetings or by reputation, for the most part the group was not homogeneous from the outset. The purpose of Saturday's program was to create a homogeneous atmosphere and try to build an atmosphere of cohesion so that the assignments accepted by the participants would develop as a team effort.

Saturday's sessions were stringently controlled so that each participant had an opportunity to contribute ideas, but so that nobody could monopolize the meetings. Purposely, no plans were allowed to be developed on Saturday in order to create a sense of urgency to the Sunday morning session. This was frustrating to the participants, but afforded them an opportunity to get together during meals and free time periods, to plan how to "move the meeting along."

On Sunday morning, copies of Saturday's dialogue were distributed and a plan was proposed for organizing the country through the use of Area Coordinators. They would unofficially contact the leaders in a given geographic area and try to develop local state-wide councils which would then align themselves with the American Coalition of Citizens with Disabilities. In this way, it is hoped that a structure can be developed which will be strong locally (state-wide) and which can contribute to a national organization.

The actual content of the discussion group can be found in the Conference material which appears as an Appendix to this report.

There are, however, certain indications that the Conference itself should really be only a starting point for further efforts in this area. It was the feeling of the MCOH staff that the participants, while they had outstanding records really lacked training so that their natural talents were not being utilized maximally.

IV. RECOMMENDATIONS

Since the inception of the Consumers Advocacy Project, funds have been expended for the creation of organizing tools [i.e. A Consumer's Guide to Organizing the Handicapped, and A Directory of Organizations of the Handicapped in the United States] funds have also been expended for producing this Conference. It is our opinion that these funds have contributed greatly to the improvement of the status of consumers so that they are now in a better position to work with the Rehabilitation Delivery System. The research indicates, however, that there is much room to improve this situation so that, in fact, the adversary posture between consumer group and agency is eliminated and so that each might serve as an adjunct to the other. To do this would require a continuum of the efforts thus far expended. We have come a long way, and yet all progress could be jeopardized were we to stop in mid stream. For this reason, the following recommendations are made:

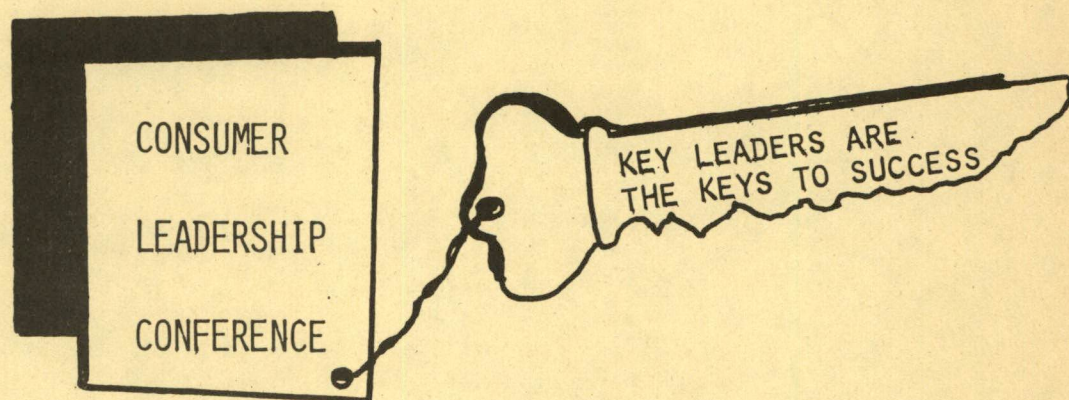
1. That a "core-team" of articulate consumers be established, knowledgeable in training techniques and in the field of advocacy.

2. That these persons visit various parts of the country and work with R&T Centers [and others] to develop local training Conferences. These training Conferences would educate both consumer and professional alike.
3. That the Department of HEW be encouraged to establish this kind of activity utilizing the R&T Centers [since it was done initially through Special Center funding.]
4. That MCOH and Tufts R&T Center be designated to continue this program.

V. ACKNOWLEDGEMENTS

One would be remiss if one did not give credit to those who were involved, who gave unstintingly of their time in order to conform to the extremely tight time schedule. While we are giving plaudits, mention should be made of Mr. Richard A. LaPierre, Executive Director of the Mass. Easter Seal Society, who not only donated the agency's van, but who, together with his wife, utilized his own station wagon to provide the participants with a tour of Boston at the close of the Conference. It should also be noted that Carl V. Granger, M.D., Project Director for R&T7, and Peter Chapman, Associate Project Director, were present throughout the Conference, and gave many helpful suggestions. They also opened the R&T Center on a day when it was closed so that those who were interested might visit it and learn about the facility.

MASSACHUSETTS COUNCIL OF ORGANIZATIONS OF THE HANDICAPPED, INC.
IN COLLABORATION WITH
TUFTS REHABILITATION RESEARCH & TRAINING CENTER



APRIL 19-20, 1975

RAMADA INN, E. BOSTON

BOSTON, MASSACHUSETTS

(THIS BOOKLET PRINTED BY THE STUDENTS OF THE CEREBRAL PALSY
CENTER OF METROPOLITAN BOSTON, NEWTON, MA)

RAMADA INN

BOSTON, MASS.

APRIL 19-20, 1975

Sponsored by

MASSACHUSETTS COUNCIL OF ORGANIZATIONS OF THE HANDICAPPED, INC.

In Collaboration With

TUFTS REHABILITATION RESEARCH & TRAINING CENTER

P R O G R A M

FRIDAY: [Evening]

Arrival and Registration Get Acquainted
NEW ENGLAND ROOM [A & B] [1st. floor]

SATURDAY:

8:00 A.M. Breakfast [in the BOSTON HARBOUR ROOM, 2nd floor].

9:00 A.M. Opening Session [In the OLD HARBOUR ROOM].

Welcome: Maureen Winn, President, M.C.O.H.

Keynote Address: Carl V. Granger, M.D.
Project Director R&T-7.

Orientation: Harold S. Remmes, Project Director, M.C.O.H.

9:30 A.M. Workshop -
Communications

11:00 A.M. Workshop -
Consumer Agency Relationships

11:45 A.M. Break

12:00 NOON Luncheon [in the OLD HARBOUR ROOM]
Speaker: Russell E. O'Connell,
Commissioner, Mass. Rehabilitation Commission

1:30 P.M. Resume Workshop

2:30 P.M. Break

2:45 P.M. Workshop -
On Organization

5:00 P.M. Break

6:00 P.M. Happy Hour

7:00 P.M. Dinner

8:30 P.M. Informal Activities & Post Dinner "RAP"

SUNDAY

8:30 A.M. Breakfast

9:15 A.M. Workshop -
Review Progress and Design Action Plan

11:30 A.M. Break

12:30 P.M. Closing Luncheon

M E N U

SATURDAY: BREAKFAST

AMERICAN HERITAGE BREAKFAST

Choice of Chilled Juice
Citrus Fruit Sections or Melon in Season
Fluffy Scrambled Eggs
Bacon, Ham or Sausage Patties
Home Fried Potatoes or Grits
Homemade Biscuits or Toast
Butter and Preserves
Coffee, Tea or Milk

SATURDAY: LUNCH

Salad
Salisbury Steak
Whipped Potatoes
Carrots
Rolls and Butter
Fruit Cup with Sherbet
Coffee, Tea or Milk

SATURDAY: DINNER

Salad
Beef Stroganoff on Noodles
Baked Potatoes
Green Beans
Rolls and Butter
Ice Cream Sundae
Coffee, Tea or Milk

SUNDAY: BREAKFAST

CONTINENTAL BREAKFAST

Choice of Chilled Juice
Assorted Danish Pastry
Coffee, Tea or Milk

SUNDAY: LUNCH

Salad
Chicken a la King in a Patty Shell
Peas
Rice Pilaf
Rolls and Butter
Apple Pie
Coffee, Tea or Milk

* * *

CONFERENCE STAFF

HAROLD S. REMMES,	PROJECT DIRECTOR
ANTHONY J. KINAHAN,	ASSISTANT PROJECT DIRECTOR
THOMAS C. O'BRIEN,	SENIOR COORDINATOR
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ELMER C. BARTELS
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WE ACKNOWLEDGE WITH SINCERE THANKS THE DONATION OF THE USE OF A VAN EQUIPPED TO TRANSPORT WHEELCHAIRS DURING THE CONFERENCE BY THE EASTER SEAL SOCIETY FOR CRIPPLED CHILDREN & ADULTS OF MASS.

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[The following participants were confirmed too late for inclusion in the original list. While they are listed separately, they are to be considered bona-fide participants.]

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- (b)(9) Release would disclose geological or geophysical information

ELMER C. BARTELS

VICE PRESIDENT N.P.F.

Born in [REDACTED] (C), [REDACTED] (C), Mr. Bartels currently resides in Bedford, Mass., with his wife, Mary, and two children.

Educated at Hebron Academy, Hebron, Maine, and Colby College, Waterville, Maine, he received his B.S. in 1962, and his M.S. from Tufts University in 1964.

An expert in the field of computer programing, he is employed as a Department Manager by Hunnewell Information Systems.

Mr. Bartels has published many papers in the areas of programing related to rehabilitation of the spinal cord injured person.

He is a Past President of the Mass. Association of Paraplegics, a Vice President and Board Member of the N.P.F., a Past Vice President of the Massachusetts Council of Organizations of the Handicapped, and is a Board member of the Boston Center for Independent Living, the Mass. Easter Seal Society, the Mass. Association of Paraplegics, and serves as President to the New England Spinal Cord Injury Foundation.

In 1966, he was voted as one of ten outstanding young men by the Boston Jaycees and has received citations from the President's Committee, the Mass. Association of Paraplegics, and the Mass. Chapter of the National Rehabilitation Association.

CHARLES W. BEDOW
LITTLE PEOPLE OF AMERICA, INC.

Mr. Bedow proudly proclaims that he comes from Owatanna, Minnesota. He was the President of the Little People of America [1968-70]. Prior to that he had served his organization as Vice President [1966-68] and Treasurer [1964-68]. Currently, he is Chairman of the Vocational-Training Loan Committee.

Mr. Bedow is a Board Member of the Little People of America Foundation, and holds membership in the Southern Minnesota Steering Committee for Vocational Rehabilitation, Minnesota Governor's Commission for Employment of the Handicapped; President's Committee for Employment of the Handicapped; and the Minnesota Committee for Removal of Architectural Barriers.

Mr. Bedow was a participant in a symposium dealing with handicapped automobile drivers in Denver, Colorado, in 1968, representing the consumer with special problems. He is married, the father of a young son, and has long been an advocate for the rights of the handicapped.

MICHAEL J. BJERKESETT
EXECUTIVE DIRECTOR, UNITED HANDICAPPED FEDERATION

Mr. Bjerkesett serves as Executive Director, United Handicapped Federation. This is a coalition of 36 organizations of the handicapped in the Twin Cities Metropolitan area. This group has been instrumental in advancing the rights of the disabled in many fronts. Mr. Bjerkesett also serves as Director of Marketing for a nonprofit housing corporation which provides a 90 unit apartment complex for the disabled in South Minneapolis. He is also a consultant to a local architectural firm which specializes in barrier-free design.

Mr. Bjerkesett received his B.A. in Business Administration from Southwest Minnesota State College, and completed a year of special training in Community Organization at the Center For Urban Encounter, Minneapolis, Minnesota. He is a member of the Board of Directors of N.P.F.; President of the Board-2100 Bloomington Nonprofit Housing Corporation; President of the Board of National Handicapped Housing Institute. He is a past President of the North County Chapter N.P.F. and is affiliated with the National Ataxia Foundation; United Handicapped Federation; Mayor's Advisory Committee on the Handicapped; Metropolitan Transit Committee for the Disabled, and the American Mass. Transit Association.

PETER A. CHAPMAN
ASSOCIATE PROJECT DIRECTOR
TUFTS RT-7

Mr. Chapman was born on [REDACTED] (C), and hails from [REDACTED] (C). Married, and the father of two children, he held a 2nd Lieutenant's rank in the United States Army Reserve, and holds a Master of Education degree from Northeastern University [where he also did his undergraduate work].

He has held several concomitant responsibilities at Tufts New England Medical Center, serving as Administrator-Rehabilitation Service, Rehabilitation Institute; Administrator-Emergency Room and Associate Project Director-Research and Training Center 7.

Mr. Chapman has worked intimately on the several projects funded by Tufts to Massachusetts Council of Organizations of the Handicapped, Inc. He is a strong advocate for adding the consumers prospective to the field of hospital and rehabilitation programs and policies.

Professional membership include:

Nominee-American College of Hospital Administrators
American Hospital Association
Maine Hospital Association
Massachusetts Hospital Association

RAYMOND C. CHEEVER
PUBLISHER AND EDITOR
ACCENT on Living Magazine

Ray Cheever received his B.S. Degree in Sales Management from Northwestern University in 1950. In 1952, he contracted polio which confined him to an iron lung for six weeks and left residual involvement of all extremities. In 1956, Ray published his first issue of the quarterly magazine, ACCENT on Living. This publication has now grown to a paid national circulation of over 13,000. Each issue is avidly anticipated by readers with physical disabilities, their families, and professionals interested in rehabilitation.

The first of a planned series of special books has now been published, and is available from ACCENT PUBLISHERS. It is entitled "Sexual Adjustment: A Guide for the Spinal Cord Injured."

Another area which has evolved from questions asked by ACCENT readers is ACCENT ON INFORMATION-a computerized retrieval system to help persons with disabilities to help themselves, and live more effectively. AOI files are continually being updated from information received daily from many sources.

Ray Cheever is a member of the President's Committee on Employment of the Handicapped. He served on a steering committee which established the new consumer division within N.R.A. He is on the newly formed Board of another new division within N.R.A., a Division of Rehabilitation of the Homebound and Institutionalized.

He was a member of an advisory group to the American Institute of Architects, National Barrier Free Environment Conference, which drafted the present national policy statement and which is being adopted by many leading organizations and groups.

Mr. Cheever is listed in "Who's Who in the Midwest," and "Who's Who in Commerce and Industry." He has received several awards including two Citations for Meritorious Service for the President's Committee.

ELLEN DICKEY DALY
PRESIDENT, MILWAUKEE AREA CHAPTER N.P.F

Ellen Daly is married, and the mother of five children. She was educated at Marquette University, School of Business Administration.

Mrs. Daly is a Vice President of the National Paraplegia Foundation, in addition to being President of the Greater Milwaukee Chapter. This Chapter is extremely active, and under her leadership can boast of many remarkable accomplishments in the removal of architectural barriers, and in the legislative area.

She is Secretary-Treasurer of Able Industry, Inc., in Milwaukee—an organization which utilizes the skills of the physically handicapped to perform a wide variety of industrial and commercial employment tasks.

Active with the Sacred Heart Rehabilitation Hospital; Milwaukee Voluntary Action Center; and the National Rehabilitation Association, Mrs. Daly has received many tributes and awards including the Greater Milwaukee Area Chapter N.P.F. Award, and Award of Merit from N.P.F. for "Outstanding Service in the Field of Allied Health Education"; a Citation from the President's Committee, and was a 1972 Wisconsin's Handicapped Person of the Year. She also has been cited by the Milwaukee Jaycettes for "Outstanding Leadership in Public Service to the Community."

As a member of the N.P.F. Convention Planning Committee in 1970,71,72, she is perhaps best remembered as coordinator for the outstanding 1972 N.P. F. Convention. Mrs. Daly's leadership has been effective on both the local and national levels.

ANNA A. FAY
CHAIRPERSON, CONGRESS OF PEOPLE WITH DISABILITIES
PRESIDENT, N.Y. METROPOLITAN CHAPTER N.P.F.

Mrs. Fay received her Associate in Applied Science Degree in 1957 from New York City Community College for Applied Arts and Sciences. She serves as Administration Secretary to the Clinical Director at the Institute of Rehabilitation Medicine, New York University Medical Center, a post which she has held since 1962.

Skilled in the art of organizing, she has been recognized on many occasions to serve on panels and to speak before groups of professionals, paraprofessionals, and consumer groups both locally and nationally. She served as Secretary, Psychology-Vocational Dept. Institute of Rehabilitation Medicine N.Y.U. Medical Center [1957-1962].

Mrs. Fay serves on Governor Hugh Carey's Task Force on Equal Opportunity; is Executive Board Member of the New York Metropolitan Chapter of the N.R.A.; member of the Advocacy Committee on Architectural Design, Mayor's Office, New York City, and serves as a member and in a leadership capacity to several other local organizations.

FREDERICK A. FAY, Ph.D.

Dr. Fay was born on [REDACTED] (C) in [REDACTED] (C). He is married and the father of one child. He received his B.S. in Psychology and M.S. in Counselling Psychology from the University of Illinois, and presented his Doctoral recitation there on "Effects of a Persuasive Educational Film, Task Groups, and Emotional Role Playing on Architecture Students Behavior and Attitudes Toward Barrier Free Design."

Dr. Fay co-founded Opening Doors, a Washington, D.C. service organization, and has been active in the N.P.F. in the District of Columbia, and several other cities where he has resided.

Presently, he is employed by the Urban Institute in Washington, D.C. He has served [or currently serves] as Assistant Professor, Dept. of Physical Medicine and Rehabilitation, School of Medicine, Boston University; Special Consultant to N.Y. State Rehabilitation and Research Center; Rehabilitation Consultant and Spinal Cord Injury to HEW-SRS-RSA; Consultant Mass. Rehabilitation Commission, Facilities Board; Rhode Island Department of Vocational Rehabilitation. Dr. Fay is a member of the Board of Directors of N.P.F.; a member of the Planning Committee, New England Regional Spinal Cord Injury System; member Steering Committee, Easter Seal Society Center for Applied Studies, and many other Board positions with various agencies, nursing homes, and consumer groups.

Fred Fay has received the N.P.F. Silver Plate Award, the Mass. Association of Paraplegics Certificate of Appreciation, and the Mass. Easter Seal Society Gallantry Award.

LEX FRIEDEN

Lex Frieden was born in [REDACTED] (C), [REDACTED] (C). During his high school and college career, Mr. Frieden received many awards for his accomplishments both academically and in the area of community action. In 1967, he was in an automobile accident and became quadriplegic. By the summer of 1967, he had resumed his education and is currently enrolled at the University of Houston, working on his dissertation and thesis, "A Longitudinal Study of Personal Independence in the Daily Living Activities of Quadriplegics." He has been awarded an SRS Doctoral Fellowship.

He has published in Rehabilitation Literature, [A Tale of Two Lives, January, 1973], and has numerous speaking engagements. His interests are music, Scouting, and swimming.

CARL V. GRANGER, M.D.
PROJECT DIRECTOR - R&T-7 T-NEMC

Dr. Granger is Project Director of Tufts Rehabilitation Research & Training Center (R&T-7), sponsoring agency for this Consumer Leadership Conference. Dr. Granger is Professor and Chairman of the Department of Physical and Rehabilitation Medicine at Tufts University School of Medicine and is Physiatrist-in-Chief of the Rehabilitation Institute.

It is largely through his efforts that several collaborative studies with local consumer groups and agencies have been achieved in the Boston area. Dr. Granger has collaborated on several projects with MCOH and has been a leading proponent of consumer involvement. The consumers have excellent representation on several of the advisory boards connected with the Tufts Rehabilitation Research & Training Center.

A resident of Cohasset, Massachusetts, Dr. Granger is the father of two children, Glenn, born in 1953 and Marilyn, born in 1957. He is a graduate of Dartmouth College where he received his AB in 1948 and of New York University Bellevue Medical Center, where he received his M.D. in 1952. Dr. Granger's internship was at Meadowbrook Hospital, Hempstead, New York, for twelve months followed by a six month pathology residency in 1953.

Prior to coming to Boston, Dr. Granger had a general practice in Huntington, New York. He was on active duty with the United States Army from October 1954 to June 1961, and in the U.S. Army Reserve until 1969, as a Major. His residency was in physical medicine and rehabilitation, Walter Reed General Hospital, Washington, D.C. He is licensed to practice in New York, California, Connecticut and Massachusetts. With many professional activities and publications, and more than two dozen publications to his credit, he has lectured at many colleges and universities and held various important posts at several medical schools and hospitals.

Currently, Dr. Granger is Professor and Chairman of the Department of Physical and Rehabilitation Medicine, Tufts University School of Medicine, Physiatrist-in-Chief, Rehabilitation Institute, New England Medical Center; Lecturer at the College of Special Studies, Tufts;

a member of the Hospital Council at New England Medical Center Hospital Medical Board, Medical Records Committee, Computer Advisor Committee. He is also medical consultant to the Boston-Bouve College of Physical Therapy, Northeastern University, and a consultant at five hospitals.

In addition to this active schedule, Dr. Granger has numerous local affiliations with sheltered workshops, agencies, medical advisory committees, and the Easter Seal Society for Crippled Children and Adults of Massachusetts, Inc., Committee for Applied Studies. He holds numerous national and international posts and has directed four seminars at Tufts between 1970 and 1973.

Dr. Granger has been awarded the Gold Pick Axe Award from Dartmouth, class of 1949, in October of 1973.

JUDITH E. HEUMANN
PAST PRESIDENT, DISABLED IN ACTION

Born in [REDACTED] (C), on [REDACTED] (C), Judy Heumann has had an active and colorful career in the area of human rights for the handicapped. She received her B.A. from Long Island University, Brooklyn, New York, and did graduate work at Columbia University School of Social Work and at the School of Public Health at the University of California, Berkeley.

In the spring of 1970, her application for a teaching position was denied on the grounds that she was physically disabled. Ms. Heumann initiated a suit in the New York City Federal Court. In June 1970, the Board of Education settled out of court and awarded the teaching position. This was the first suit of its kind in the Federal Court in the United States. Following this litigation, the New York State Legislature passed a law requiring that all qualified individuals with disabilities had to be hired for teaching positions.

Presently, she is employed as a Research Assistant for the Labor and Public Welfare Committee for Senator Harrison A. Williams, Chairman of the Committee.

Ms. Heumann's activities are extremely numerous and diversified, but all have the communality both vocationally and advocationally of work related to the betterment of mankind, and especially the handicapped. She is sought after as a speaker on a national basis, is a member of the N.R.A. Consumer Task Force Organizer for National Civil Rights Work for the Disabled, member of the President's Committee on Employment of the Handicapped and Consultant to TV and Radio shows for the Public Broadcasting Company.

More recently, Ms. Heumann gained national attention when she and her wheelchair were forcibly ejected from an airplane because the pilot refused to fly a wheelchair passenger. The Airline is currently being sued for damages and it is the hope of the handicapped population that this litigation will be as successful as her first law suit.

C.J. [CONNIE] LAMPOS

EDITOR, ACHIEVEMENT

Born in [REDACTED] (C), on [REDACTED] (C), Connie Lampos moved to Chicago where he lived from 1926 to 1967. He studied creative writing at the University of Chicago, and by 1941 was proficient in three languages. This was followed by several years of additional study and free lance writing. Lampos became a Byzantologist and literary editor for Athene Magazine and subsequently with Ologos [religious publications]. He held each of these positions for ten years. He had an editorial printing business and was involved in Real Estate. He moved to Florida in 1967.

Lampos has been an activist for the handicapped, and is regarded as a pioneer militant whose activities are similar to, but predated the late Dr. King. He has been a fighter of injustice, and has had long and often successful wars with agencies during his noteworthy career.

In 1964, Connie and a friend founded DARE [a housing group in Chicago]. He founded ACHIEVEMENT in September, 1969, with one hundred copies. It is now the fastest growing and only national monthly newspaper by, of, and for the handicapped.

Married, with no children, Lampos says of himself that he holds "just a 31 day a month volunteer job."

GINI LAURIE

Mrs. Joseph S. Laurie was educated at Randolph-Macon Woman's College. Her early volunteer work was with the St. Louis Chapter and the Chagrin Valley Chapter of the American Red Cross. In 1949, she became involved with the Regional Respiratory Polio Center [Toomey Pavilion] in Cleveland, Ohio. From this involvement, she became the driving force of the "Toomey j Gazette," an international journal and information service for the disabled. This has since grown to an annual publication renamed Rehabilitation Gazette. This informative publication has a large circulation internationally, and features news items, general information, travel features, and many other notable columns. It is respected by consumer and professional alike for its pertinent and current information.

Gini has received honors from the Mayor and City of Cleveland; the National Rehabilitation Association's President's Award, and the St. Louis Chapter NPF.

A sought after panelist, Mrs. Laurie has participated in numerous conferences across the country.

THOMAS C. O'BRIEN
SENIOR CONFERENCE COORDINATOR

Thomas O'Brien was born in [REDACTED] (C), [REDACTED] (C). He attended Peabody Schools and Saint Mary's High School. At age 16 he was injured and became paraplegic, but continued his education at the Mass. Hospital School of Canton, and did post graduate work in drafting and design.

He has been active in the consumer movement for many years. He is a Past President of the Mass. Association of Paraplegics and Mass. Council of Organizations of the Handicapped, and under his leadership these organizations adopted a positive program in the areas of legislation and published reports. Some of his more national accomplishments were in lobbying for the Workmens Compensation Second Injury Fund and the sales tax exemption on automobiles for paraplegic drivers.

Also, during his presidency, the Mass. Association of Paraplegics published the well known Housing Needs of the Handicapped survey. While president of the Mass. Council of Organizations of the Handicapped, A Consumer's Guide to Organizing the Handicapped, and A Directory of Organizations of the Handicapped in the United States were published.

Tom O'Brien has been the driving force behind the Mass. Wheelchair Games [which he founded in 1968]

He is currently a member of the Corporation of the National United States Cerebral Palsy Association; a board member of the National Paraplegic Foundation; is President of United Cerebral Palsy of Metropolitan Boston; an alternate delegate to the National Easter Seals Society; a member of the House of Delegates to the Mass. Easter Seal Society; serves on the Governor's Committee on Vocational and Technical Education [where he designed a state plan]. O'Brien serves on many commissions and Task Forces; served as Information Officer for the Governor's Committee on Employment of the Handicapped, and has been guest speaker at many conferences and meetings all across the country.

He is employed as a Special Needs Program Coordinator for the Mass Bay Transportation Authority. Prior to this, he was with a federally funded program concerned with special transportation needs and with the Massachusetts Rehabilitation Commission.

Mr. O'Brien is married, and the father of a seven year old boy.

RUSSELL E. O'CONNELL
COMMISSIONER, MASSACHUSETTS REHABILITATION COMMISSION

Commissioner Russell O'Connell has been Commissioner of the Massachusetts Rehabilitation Commission since 1972, charged with the responsibility of administering Vocational Rehabilitation and Social Security Disability Determination Services in Massachusetts.

For six and one-half years prior to being appointed Commissioner of Rehabilitation, Mr. O'Connell served as Executive Director of the Quincy Community Action Organizations, Inc., administering Office of Economic Opportunity and labor funded programs for a non-profit corporation. In this capacity, great emphasis was placed on heavy consumer participation and involvement.

From 1964 to 1966, Commissioner O'Connell was Director of the Work Training and Experience Program, responsible for administering a program for the purpose of developing and implementing work opportunities and support services for publicly dependent individuals. Prior to this, he was a social worker in the Family Services Program of the Public Welfare Department.

Commissioner O'Connell is a 1961 graduate of the University of New Hampshire, where he was a psychology major and attended the Boston University Graduate School in Administration.

Commissioner O'Connell serves on many advisory boards and is an advocate of consumer involvement in the rehabilitation process.

HAROLD S. REMMES
PROJECT DIRECTOR

MASSACHUSETTS COUNCIL OF ORGANIZATIONS OF THE HANDICAPPED, INC.

Mr. Remmes is the Past President and Founder of the Massachusetts Council of Organizations of the Handicapped, Inc., where he currently serves as Project Director. A graduate of the Industrial School for Crippled Children (now Cotting School for the Handicapped) and Boston University, Mr. Remmes is employed as a Handicapped Services Specialist for The Boston Housing Authority. In that capacity, he supervises the selection, placement, problem solving, of handicapped tenants, the training, and inter-agency relationships of the BHA. Mr. Remmes is well known and has travelled extensively to various agencies and consumer groups throughout the country, speaking on consumer advocacy, and the role of the consumer in the rehabilitation process. He is a member of the Mass. Council of Organizations of the Handicapped; Mass. Association of Paraplegics; Cotting School for Handicapped Children, Alumni Association; Vice President and member of Trustees of the Cotting School for Handicapped Children; member of the Advisory Board of Tufts Rehabilitation & Training Center; member of the Commission on the Handicapped for the City of Boston; Founder on the Task Force on Employment of the Handicapped; a member of Boston University Alumni Association; Chairman of Mass. Easter Seal Society House of Delegates; member of the Board of Directors, Easter Seal Society for Crippled Children and Adults of Massachusetts, Inc.; and holds memberships in various other organizations.

Mr. Remmes is the author of The Consumer's Guide to Organizing the Handicapped, and has had articles in Rehabilitation Record, Rehabilitation Literature, Accent on Living Magazine, ACHIEVEMENT, and served as Project Director in the compilation of a Directory of Organizations of the Handicapped in the United States. He is the author of the Boston Housing Authorities Handbook for Housing the Handicapped, and the co-author of Adaptions for the Housing Adjustments for Disabled Persons, published by the Massachusetts Department of Community Affairs.

Mr. Remmes is active in the Boy Scouts of America, where he was awarded the Silver Beaver Award for Distinguished Service to Boyhood; the Saint George Award from the National Catholic Lay Committee, the Scouters Key, and the Scouters Award. He also holds the MAP Award, an award from the Mass. Chapter of the National Rehabilitation Association, and has been awarded certificates from several local organizations. He was the first recipient of the Distinguished Service Award of the Industrial School for Crippled Children.

VIVIENNE THOMSON
TREASURER

MASSACHUSETTS COUNCIL OF ORGANIZATIONS OF THE HANDICAPPED, INC.

Mrs. Thomson is the mother of two children, a son 17, and a daughter 11. She is a graduate of Girls Latin School, Boston University, Boston Clerical Business School and the Margery Webster Jr. College, in Washington, D.C. Mrs. Thomson was born in Oklahoma, of American Indian parentage (Choctaw tribe).

This native American has a career of public service dating back to 1949, in her community where she has been extremely active in community agencies, and in the local anti-poverty program. Her flashing wheels may be seen traveling from meeting to meeting in activities ranging from the Boston Indian Council, to Employment of the Physical Handicapped.

In 1972, Mrs. Thomson received a scholarship from Massachusetts Department of Community Affairs and the Boston Housing Authority for an eight week training program on Housing Management given by the National Association of Housing and Redevelopment Officials in Washington, D.C. She is currently employed by the Boston Housing Authority as a Handicapped Services Aide, and in that capacity processes applications, finds appropriate housing, and assists in problem solving of handicapped tenants. She is also active in training professionals in the housing field.

Mrs. Thomson has memberships in the Mass. Association of Paraplegics, where she is a member of the Board of Directors and Legislative Chairman; serves as Secretary of the Massachusetts Council of Organizations of the Handicapped; serves on the Boston Task Force for the Handicapped as a member of the Board of Directors; is a member of the National Association of the Housing and Redevelopment Officials, Mass. Easter Seal Society, where she is a member of the House of Delegates; a member of the Mass. League of Women Voters; the Mass. Mental Health Area Board; New England Schaghticoke Indian Association, a Federated Eastern Indian League; the Metropolitan Boston Consumer Health Council where she is a member of the Executive Committee; the

National Consumer Health Council; the Boston-Brookline Collaborative Center; Jamaica Plain Community Council, where she is an Executive Board member; Mass. Association for Community Schools; Citywide Educational Commission; Boston Bicentennial Committee, Boston Home and School Association.

Mrs. Thomson holds awards from the Metropolitan Boston Consumer Health Council; the First Baptist Church of Jamaica Plain; Mass. Association of Paraplegics; and from many other local groups.

She has been involved with various seminars and meetings across the country in the area of education, consumer health, the handicapped, and has attended the National Easter Seal Society Convention in Washington, D.C. In 1974, Mrs. Thomson was a delegate to the National Consumer Health Conference in San Jaun, Puerto Rico.

MAUREEN ANN WINN
PRESIDENT,
MASSACHUSETTS COUNCIL OF ORGANIZATIONS OF THE HANDICAPPED, INC.

Mrs. Robert T. Winn is the President of The Massachusetts Council of Organizations of the Handicapped, a post to which she was elected in 1974 in recognition of her leadership and accomplishments in the field of consumer involvement.

Mrs. Winn is a graduate of Arlington High School and Harvard University Extension Courses. She is currently a student at the University of Massachusetts, in Boston, in a program of Public and Community Service. Active on many boards and commissions, on both State and local level, and is extremely interested in the area of legislation.

As a result of Multiple Sclerosis, she functions from a wheelchair—but maintains a pace which would leave many able bodied persons far behind. She works as a professional at Boston University as the Coordinator of Handicapped Students, attends classes at the University of Massachusetts, manages to serve on various committees and flies back and forth between Boston and Washington on a regular basis for the National Multiple Sclerosis Society. Most of Mrs. Winn's free time is spent in lobbying at the State Capitol. As the results of her efforts, she has assisted in the formulation of the Social Security Bill HR5151. While in Washington, she was invited to speak on her Social Security Bill before the President's Commission on Multiple Sclerosis and attended three of their meetings. She was instrumental in the inclusion of the socio-economic impact of MS in the final report. She was also invited to participate in the President's Committee on the Employment of the Handicapped in Washington, in 1973-74. Mrs. Winn writes a monthly column on legislation on pertinent information for the disabled in the ATOMS NEWS.

Among Mrs. Winn's legislative accomplishments has been the drafting and successful enactment of Senate 1579-Chap. 689 Handicapped Housing Bill, which established a Bureau of Handicapped Housing within the State Department of Community Affairs, and Senate 1699-Chap. 528, an

Architectural Barriers Bill which strengthened the existing laws on architectural barriers for the Commonwealth and gave greater powers to the Department of Public Safety Architectural Barriers Board for the enforcement of regulations. Mrs. Winn serves as a member of this Board.

In addition to the activities enumerated above, Mrs. Winn also serves as the Legislative Chairman for MCOH; is a member of the Board of Directors of ATOMS; a member of the Board of Trustees of the Mass. Chapter of the National Multiple Sclerosis Society; a member of that chapter's Patients Services Committee; and Chairman of the Legislative Committee of the Massachusetts Chapter of the Multiple Sclerosis Society. She is also a member of the Governor's Special Commission of the Handicapped; the Easter Seal's Task Force and Architectural Barriers; a member of the Human Services Advisory Council, where she is Legislative Chairman.

Mrs. Winn has received several awards, among them the ATOMS Achievement Award, Wheelchair Decor Certificate of Merit, Mass. Council of Organizations of the Handicapped Distinguished Service Award, the Easter Seal Award, and the Mass. Association of Paraplegics Certificate of Appreciation.

ERVIN H. [BUDDY] WRIGHT, JR.
EASTER SEAL SOCIETY FOR CRIPPLED CHILDREN AND ADULTS
REGIONAL DIRECTOR WEST TENNESSEE REGION

Born in [REDACTED] (C), on the [REDACTED] (C), Mr. Wright attended Haywood High School, Brownsville, Tennessee, and received his degree from Memphis State University in 1958. He has done post graduate work at the University of Minnesota in Minneapolis. During his undergraduate work, he was involved with many organizations and was twice President of Sigma Alpha Epsilon Fraternity, and was a charter member of Alpha Phi Omega [Scouting Fraternity].

Since graduation, his involvement has been with the Jr. Chamber of Commerce, local health agencies, Easter Seal Society, [where he holds membership and is Chairman of some committees on both the local and national level]. He is also involved with the Governor's Committee on Employment of the Handicapped; Memphis Goodwill Industries; Handicapped, Inc.; Boy Scouts of America Committee for Handicapped Scouting; Lions Club; and several other community groups.

Mr. Wright holds Eagle Scout rank, is a member of the Order of the Arrow [B.S.A. Honor Camping Society]. In 1966, he received the Governor's trophy as the Handicapped Citizen of the Year, the Gallantry Award from the Easter Seal Society, and the Distinguished Service Award from the Memphis Jaycees.

CHAPTER IV

WORKSHOPS

COMMUNICATIONS WORKSHOP

ELMER BARTELS DISCUSSION LEADER

One of the major problems which has contributed to the lack of cohesion among the handicapped population is the small number of communication vehicles on a national level. While excellent progress has been made over the past decade, there is still a long way to go so that the maximum number of disabled persons can receive news' items relative to their situation.

Persons with disabilities need to know what is happening elsewhere. They need the encouragement of learning of the progress of other individuals or groups. They need to know of the current most pressing issues, of what to write to their congressmen, of new or pending legislation, of new self-help devices, and of how they can help themselves.

In addition, they desperately need to form a new self-image. They need some successes to reinforce the value of their efforts. In short, they need a vehicle through which they can channel new items which might help others.

WHAT DO WE HAVE NOW?

Currently there are several major and significant publications for the handicapped. Fortunately, each has a different format and, while each is trying to reach the same population, the format focus and "personality" is individual.

They range in scope from the militant to conservative. They range in content from straight news' items to columns on special interest. Some are all newsprint, while others are on glossy stock. Some focus a complete issue on one major area [housing issue, transportation issue, etc.] while others are of a much more general nature.

In addition to the national publications there are literally hundreds of newsletters which are distributed by local groups and organizations to a much more provincial population. These range from mimeographed sheets to good quality offset printing. In all probability this latter group reaches a population which the former group is unable to reach. The reason for this is that these newsletters usually are distributed free of charge while the national publications are paid subscriptions.

Often we fail to realize that there is yet another group of newspapers which most consumers fail to utilize. These are the professional publications of health agencies [both national and local] and the professional journals. There is a distinct possibility that a way could be found to get significant articles and items in this latter group.

There is a unique dichotomy in our own national media in that the editors desperately want to get the contents into the hands of as many handicapped people as possible, and yet must charge a nominal amount in order to publish. This precludes a large segment of the handicapped population who are subsisting marginally.

Questions which will be asked at this Conference on Communications will be:

1. Can the national publications retain their competitiveness and still share items of interest?
2. How could this be done?
3. Is there a way to utilize local publications in order to disseminate new vital information?
4. Can we utilize health agencies and agency "house organs" to better advantage?
5. Can we develop a plan which is viable to circulate information to a significantly larger population than we are currently reaching?
6. How could this operation be financed?

WORKSHOP CONSUMER AGENCY RELATIONSHIPS

FREDERICK E. FAY, PH.D.

For many years the relationships between the recipients of services [consumers] and the deliverers of services had an adversary relationship in which each felt the other to be almost "the enemy." While on the one hand the agencies were stating that they were trying to provide services, they often looked with disdain on the clients they purported to serve. The consumers were constantly complaining that the agencies did not, in fact, serve their needs.

More recently, consumers have had more opportunities to become better educated. Nonetheless, there has still not been an improvement in relationship between consumer and agency.

The reasons for this are not as simple as they may first appear. In fact, they are quite complex and vary from locale to locale, from agency to agency, and from consumer group to consumer group.

This workshop will try to address itself to the questions of:

1. Why has there been an advisory posture between consumer and agency?
2. Is it to our advantage to improve these relationships?
3. Is it to the agencies advantage?
4. How can we best resolve the problem?

One of the major benefits to the resolution of this problem which would accrue to an agency would be assistance in establishing realistic priorities in terms of what the consumers see as their real needs rather than what the agency assumes its clients need. Another would be that the agency could educate the organized consumer as to what it [the agency] sees as its mandate under its charter or by the legislative constraints imposed upon it.

Benefits to the consumer would include learning which agency is most appropriate for which purpose [i.e. most DVR's can cope only with vocational rehabilitation but many have given this a broad interpretation while others strictly interpret this as employment]. The consumer would also become aware of sources of potential funding for prospects which they might be interested in producing.

Most important to both agency and consumer alike, a professional atmosphere would evolve.

WORKSHOP ON ORGANIZATION

DISCUSSION LEADER
HAROLD S. REMMES

As noted in The Consumer's Guide to Organizing the Handicapped, and as documented in the Directory of Organizations of the Handicapped in the U.S., there is a proliferation of more than a thousand consumer groups nationwide. Attempts to organize on the national level have been minimal and even those who have enjoyed the greatest success have been charged by some as being impotent and twenty years behind the times. The newly emerging American Coalition of Citizens with Disabilities probably offers the most viable contemporary medium for establishing a cohesive constituency with national "clout."

The excellent beginnings will be lost, however, unless two prerequisites can be fulfilled. These are:

1. State organizations capable of marshalling a significant number of persons who truly represent the broad spectrum of disability
2. Sufficient funding to operate.

We have the tools for organizing. The Consumer's Guide offers one approach and there are, we are sure, other equally effective methods available. We have the pattern for success in several states [Mass., Wisc., Ill., Fla., etc.] of umbrella groups which allow their membership to retain their autonomy and yet which provide a functional umbrella.

What is needed is to organize each state and to have some people assume responsibility for this task. Such persons [who might be known as regional coordinators] would be those who:

1. Know the region
2. Know the leadership
3. Can organize this leadership

To do so, will require some money. Experience has shown that:

1. We cannot depend on consumer groups to provide their own "seed money."
2. Agencies will support this kind of undertaking provided that they do not feel that they will be supporting a "Frankenstein" which will one day destroy them.

Thus, it is essential to build relationships with mutual respect between agency and consumer organizations. This must be done before there is any hope of receiving subsidy.

We, as consumers, have a tool which we have not attempted to utilize previously. That is, we could enter the competitive market in fund raising and actually compete with the agency for John Q. Public's dollars. MCOH does not advocate this course of action, but

proposes it as an alternative should the agencies fail to see the value of supporting our cause.

If contributions could be secured without losing our integrity, the campaign for organization might easily be financed.

This workshop will focus on:

1. Methods of organizing [regions and states]
2. Alignment with the American Coalition
3. Exploration of funding sources
4. Assignment of responsibility
5. Developing a viable organizational and funding plan.

Keynote Address by Carl V. Granger, M.D., Physiatrist in Chief,
Tufts Rehabilitation Institute and Project Director, Tufts
Rehabilitation Research and Training Center (R & T - 7)

Dr. Granger's opening remarks were brief. He cited the fact that the collaborative effort between MCOH and RT7 did not start easily, but that as they worked together a mutual respect developed and several meaningful achievements had emanate from the "marriage."

Dr. Granger noted that the consumers had to learn the discipline for research projects required by the R & T Center and that once done, documents emerged which had had significant impact.

Dr. Granger expressed his hope on behalf of RT7 that there could be a continuation in the area of consumer advocacy so that the role played by both the local consumer groups and the Rehabilitation Center might serve in a positive fashion to improve the life-style of the handicapped.

In short, Dr. Granger said that the rehabilitation system "must serve and be served."

The following is a summary of the Workshop Sessions.

No attempt has been made to quote verbatim any of the participants' comments.

WORKSHOP ON COMMUNICATIONS
HAROLD S. REMMES

C. J. (Connie) Lampos, Editor, ACHIEVEMENT

Various publications could cooperate and share items. Most small publications usually have "a small gem." ACHIEVEMENT receives queries from all over the country requesting information on wheel-chairs and other aids and information pertaining to their disabilities.

Raymond C. Cheever, Editor & Publisher, ACCENT ON LIVING

Levels of information - local, state, national. The format or the quality of printing is not as important, but there is a need for communications media in the area of local publications. Need for publications which would be disseminated on a state level. ACCENT ON LIVING has a fund to provide subscriptions to persons unable to afford the publication. Twenty-five million handicapped in the U.S. (approximately 10% of the total population). Larger publications have a very small piece of this market. Mailing to "highly qualified list of handicapped people - 20% return, where do the 80% go? It is important to try to get more people to subscribe and to make them more aware. Lists of these publications which have been mailed to professionals, i.e. doctors, rehab centers, etc. have resulted in virtually no interest in subscribing.

Eunice Fiorito, Director, Mayor's Office for the Handicapped, N.Y.C.
National publications need to spend more space on consumer development. Social rehabilitation must also begin from the moment of injury. Publications for the disabled should be used in group counselling and should be available in rehabilitation hospitals.

Carl V. Granger, M.D., Project Director, Tufts Rehabilitation Research & Training Center

Recommend packaging of consumer-oriented communications for presentation to rehabilitation units in order to make professionals aware of what is available.

Dianne Lattin, Editor, PERFORMANCE, PCEH

PERFORMANCE is a free, monthly publication of the PCEH. Presently reaches more able-bodied persons than disabled, now trying to increase disabled subscribers. Moving toward issues rather than individual success stories.

Richard LaPierre, Easter Seal Society for Crippled Children and Adults of Massachusetts

Consumer publications very helpful to the advocacy groups. What about electronic media? It would be wise to use radio and TV

programming in a direct, "orchestrated", not haphazard, manner.

Frederick A. Fay, Urban Institute, The American Coalition of Citizens with Disabilities

New Massachusetts Resource Guide available, published by the Massachusetts Association of Paraplegics.

Phyllis Zlotnick, UCP, New Haven, and Legislative Chairman, Coordinating Comm. on the Handicapped

Would like more news on group activities, more support, rather than about individuals and their accomplishments. Need for bibliography.

Gini Laurie, Editor and Publisher, REHABILITATION GAZETTE
The Easter Seal Society publishes various bibliographies for various interest areas.

C. Lampos

People who do subscribe seem to take more than one publication. The problem is attracting people who don't get anything.

Roger Petersen, The American Coalition of Citizens with Disabilities
There seems to be a rift between publications for the blind and publications for the rest of the disabled. INDEPENDENT is the only publication open to the general disabled population which is in a form that the blind can use. Other publications should be made available in either recorded form or Braille form.

E. Fiorito

Need for a central source of publications related to the disabled. Need to share our message with the non-disabled or we just end up talking to each other. What are the resistances, what are the techniques?

Charles W. Bedow, Past President, Little People of America
Suggest that more disabled join organizations. Stressed that one of the problems of the handicapped is difficulty in finding clothing to fit. Publications could include more information on specific handicaps, such as dwarfism. Feels persons with dwarfism are not accepted as equals by persons with other disabilities. In the same way, they are discriminated against by non-handicapped persons.

Harold Russell, President's Committee on Employment of the Handicapped
What is a handicapped person? Define needs and wants of the various handicaps and go on from there. Important to identify with various groups and then to set communication.

At this point, Harold Remmes summarized:

1. Three major categories of publications, state, local, national.
2. The problem is getting them to the constituency:
 - a. handicapped
 - b. service people
3. Central source for a list of publications. (Should consumers or a national agency do this?)
4. Places that should have publications.

Peter Johnson, Cleveland, Ohio

Target areas for available information: 1. Newly disabled, their families and friends, 2. Veteran disabled, that is, persons who have been disabled for a long period of time, and 3. General public. When a member of family was injured, he received no information from social workers in regard to problems of the disabled. Agencies and rehabilitation units could provide information regarding aids to the handicapped. We should try to get local newspapers to group issues together, such as articles on housing, transportation, etc. Many abled bodied persons would also benefit from this information. The handicapped should try to get cable television channel.

R. Cheever

Necessary to get more handicapped persons to accept the opinions, interests of other groups. Orientation regarding the handicapped for airline stewardesses and other service personnel should be made available.

Michael J. Bjerkesette, Executive Director, United Handicapped Federation

Organization cannot be effective unless there is a broad-based involvement on a local level. Organization cannot be effective without strong consumer involvement- Important to stimulate more interests. Although national publications for the disabled are very helpful, we must use local media such as local newspapers, TV, etc.

C. Lampos

We must utilize "rebuttal" time which is available on television. He has had much contact from Congressmen regarding problems of the disabled.

The participants were asked to prepare three suggestions for each of the following points, for discussion during the Sunday morning session:

1. Handicapped Publications on local, state, national level
2. Conventional Media--radio, TV, newspapers, etc.
3. Professional Groups
4. Service Agencies
5. Consumer Organizations

WORKSHOP ON CONSUMER AGENCY RELATIONSHIPS
FREDERICK E. FAY

R. Petersen

It is a mistake to say that lack of communication is the only barrier to understanding by the general public. Some of the worst attitudes are among people in agencies.

C. Bedow

Agencies are more interested in quantity than quality: the quota system.

Kathy Crawford, Blind Leadership Club

Agencies are resistant to hiring blind counselors. Able-bodied counselors look down on blind counselors.

D. Lattin

Agencies have funds available which can be used by consumers. We should try to work with them rather than around them.

J. Heumann

How do consumer groups avoid being coopted by agencies providing funding?

E. Roberts

We are not using regional agencies as well as we could, for example, comprehensive health planning councils.

There was a discussion of training programs for rehabilitation professionals and what makes the professionals the way they are. Eunice Fiorito stated that most people go in with the greatest feeling of dedication which is not sufficiently reinforced in training and is replaced by a need to become professionally recognized. We must look at the systems, the procedures. The people are not bad people, they become that way. (Recorder's note: professionalizing is the opposite of sensitizing. D.S.)

J. Heumann

It is crucial that programs like the C.I.L. change attitudes. We have to change training, textbooks.

E. Fiorito

First we have to do some work with our own people. The disabled leaders have to help our own people on the grass roots level, get them involved.

Ed Roberts, Director, Center for Independent Living, Berkeley
We have to learn how to organize. Start with one issue to build up interest and expand. Organizing is a simple step-by-step process. There is a cadre of 200-300 people in California who can be mobilized quickly for a range of issues

C. Bedow

What about a small city? People are so busy making a living, they don't want to go up against the big guns.

R. LaPierre

The reason for cooperative effort between agencies and consumer groups has been mutual respect and understanding, working on issues that neither could solve alone.

Speaker: Russell E. O'Connell

Commissioner, Massachusetts Rehabilitation Commission
Statistics say that 3.25% of the population 16-64 is eligible for DVR assistance. That means, in Massachusetts, 185,000 people would be eligible, but actually only 14,000 or 5-6% of those eligible are in the system. There is an assumption that balanced DVR programming will occur for all disability groups.

In Massachusetts between 1966 and 1971, the mentally ill lobbied. As a result, 52% of the expenditures were to people whose primary illness was mental illness. There were no counselors who could communicate with the deaf, and architectural barriers were present.

A consumer of vocational rehabilitation services is defined as someone presently receiving, or who has just received, or who needs VR services.

Eliot Richardson teaches that three barriers to effective communication are excessive cynicism, unrealistic expectations, and complexities.

Recommendations:

- (1) A body of consumers in a policy-making board to RSA, one from each region, five at large, reporting to and elected by consumers . . . staffed and paid by RSA . . . meeting in Washington four or five times a year. This does not need legislation, will hold people accountable for what's enacted now.
- (2) Ten regional offices with elected representatives. If consumer involvement is important, we have to pay for it.
- (3) There are three levels what advocacy can be important. RSA has responsibility for making rules and regulations. At the state leadership level, even with laws and guidelines, there is much flexibility. At the counselor-client level there is flexibility in how the relationship is supported and maintained.
- (4) Vocational rehabilitation directors should not be involved in the process. There should be a pool of 200-300 people available to manage state programs in voc rehab. They would serve on a three-year term, renewable only once. Help to neutralize state directors who come up through the system and who would have difficulty being objective.

R. O'Connell (continued)

Three-fold thrust: A balanced program that talks of accessibility and advocacy.

J. Heumann

Have you begun to implement a consumer council pilot project in Massachusetts?

R. O'Connell

The way the system works, it has to begin at the top.

R. Cheever

Would like to see model at state level because it will not be done at the federal level. We have to start someplace.

R. LaPierre

Word just received that a national health insurance plan for the unemployed will be enacted this year. What provisions are included for disabled persons? (Nobody knew.)

R. O'Connell

In answer to a question, pointed out that the voc. rehab lay is to obtain or retain employment.

Discussed Innovation and Expansion money which is available (\$2.5 million in Massachusetts). For specifics, consult Rehabilitation Services Manual 4005-01

E. Fiorito

Raised question of how consumer groups can develop a good relationship with Boards.

R. LaPierre

In Massachusetts, MCOH was formed at the ~~same~~ time that Easter Seal was doing a self-study. We were able to work together around issues of mutual interest. 50% of what Easter Seals in Massachusetts is doing is due to consumer input in the last five years.

E. Roberts

Similarly in Berkeley, a strong group of consumers was able to provide staff support in helping Boards survey needs. Importance or persuasion rather than coercion.

Leaders are getting picked off by established agencies. This hurts because people are co-opted, although it helps by getting people inside. Need to train new leaders and reeducate old leaders.

Question: how do you suggest to a Board that it be accountable?

E. Roberts

United Way depends on volunteer labor for program review, budget, etc. They brought in disabled people. Attitudes are changing. Agencies like United Way are subject to pressure from small groups of consumers.

J. Heumann

Find out when Boards meet and say you would like to give testimony as a consumer.

D. Lattin

Consumers should not be shut out of consumer groups because they work for agencies.

L. Frieden

What is the responsibility of the agency to speak for the consumer, for example in the area of medical equipment.

F. Fay

They should do much more. We as consumers should help them see that as an issue.

The conversation digressed at this point to a discussion of legislation and the importance of implementation.

Roger Petersen invited everyone to come to Washington with job applications (in relation to Federal sections 503 and 504 of the voc rehab act relating to affirmative action programs).

F. Fay

The participants were asked to consider the following questions overnight:

1. How can consumers effectively infiltrate or work with agencies to make them more responsive to the people they serve?
2. What concrete steps can we take to organize ourselves to have a more effective impact from top to bottom?

H. Remmes

There are a lot of persons who have been on Mayor's Committees and such, and prefer rubbing elbows with the elite. Most of the people here were chosen because they are not of that group. MCOH has allowed these persons to retain their positions but asked them to join us around issues.

What has prevented cohesion?

- A. Lack of Power Structure
- B. Lack of Communication
- C. Ignorance

Solved by dialog between agencies and consumer groups.

- D. Fear of developing into an agency

MCOH contracts to do a job and does it. We are not beholden.

- E. Lack of funding

A major obstacle. Everything must be done by volunteers who have other responsibilities. Agencies don't have that problem. If we want national cohesion, we need money. Some consumer groups may want to raise money in competition with agencies; or ask them to plan, say 1% of next year's budget for consumer organizations.

E. Florito

This sounds like a good idea, but fund-raising has diminished substantially. If we propose this to local agencies, they will ask how this will benefit them. There are always restrictions on how to use the money. How do you find out what the strings are.

H. Remmes

Ask for funds for specific projects, including some extra for administrative costs. Ask agency to contribute and in turn determine what strings you will put up with.

J. Heumann

How objective can one remain being funded by agencies? We do not need more organizations. We need to consolidate.

E. Florito

How do other specific agencies deal with fund-raising?

M. Bjerkesette

Fund-raising is a continual problem, something you can never lose sight of. Emphasized principles of Saul Alinsky on how to organize.

M. Bjerkesette (continued)

A responsible community organizer cannot start working until there is seed money in the bank. His group started with a two page proposal and sent it to 250 foundations, every large church in the metropolitan area, especially those with social action funds. Met with Boards with a minimum of three handicapped people. In $1\frac{1}{2}$ years raised \$32,000. Nine months later, they held a constituting convention with 250 delegates. The agenda book with thirty pages of advertising raised another \$4,000. There is a community pot of money which we are able to tap with the approach that we are competing with everybody else and that we are the most important thing to come down the pike. Now into programming. Presently a proposal on discrimination toward the handicapped. The conventional fund-raising thing can be done. You have to sell.

E. Roberts

In the last year, we raised \$400,000. We have \$1 million more coming. You need somebody who can write, preferably disabled. At first, University proposal writers helped, but they used too much jargon, not enough real feelings. Funding sources... foundations, preferably local (for example, the San Francisco Foundation).....Revenue sharing. Community Development Grants are wide open.....Individuals - a tough route and sometimes you have to play crimp games.....Payment for services, for example, if rehab wants an attendant, evaluations of other people. Now we have 45 paid staff, a lot of severely disabled employees. In California now \$450/month for attendant care comes direct to individual and you hire and train your own attendants. We have started a 24-hour wheelchair repair service - last month grossed \$8,000. Suggest starting other businesses; it is difficult to get hard money. Need for alternative fund-raising. What about a "Good Housekeeping Seal" for crimp equipment, getting manufacturers to pay us.

H. Remmes

That presents a possible area of cooperation between professionals (Tufts Biomedical Engineering) and handicapped consumers.

E. Roberts

We hope to get into manufacturing, for example, durable power chairs.

E. Fiorito

How does this effect change in quality of service in long-term agencies, and how do you continue to work with these agencies.

E. Roberts

Advocacy.

An Occupational Therapist (whose name the lazy recorders missed) spoke about being tired of professional attitudes of maintaining a distance. She went to the C.I.L. to become a community-oriented O.T.

E. Roberts

We established a clinic as medical care was so poor. More funding agencies....Business community has to give away part of what they make every year. Linked with IBM for computer training; they also provided money grant and equipment. Business is worried about affirmative action for disabled. C.I.L. work with about fifteen businesses, including Bank of America, Del Monte, Safeway.

J. Heumann

There were a lot of people on welfare at Berkeley who were free to work on program development. The pride element on the East Coast is hindrance. This is a matter of philosophy.

E. Roberts

Now they are the nation's experts on S.S.I. You have to be able to use it.

L. Frieden

What Berkeley is doing is creating a competing agency.

J. Heumann

But competition improves the agency.

H. Remmes

No one answer will hold true for everyone. No one seemed to go for asking agencies for percentage of their budget (free money) It seems we are going in the direction of fee for services.

C. Granger

National push toward program evaluation and accountability--a good area to train ourselves.

H. Remmes

Individuals were designated to identify the consumer leadership in their geographical areas. They were asked to select one person in each state who would be willing to work with organizations within their state, to encourage them to join the American Coalition and, hopefully, develop a united effort locally. This effort will strengthen the American Coalition. The long-range goal is to establish a viable, cohesive representative for the handicapped.

J. Heumann

The American Coalition could be a disseminating force--sending out and receiving information. They hope eventually to have paid staff. Roger Petersen has been working in the office. Eventually the Coalition will be able to provide services--showing organizations how to grow, how to organize, providing services as needed. The Coalition is a clearinghouse. Policies are established by member organizations.

WORKSHOP TO REVIEW PROGRESS AND DESIGN ACTION PLAN
HAROLD S. REMMES/THOMAS C. O'BRIEN

H. Remmes

In this session, we shall attempt to produce a viable action plan, not merely recommendations or resolutions.

C. Lampos

I was delighted to find the people I met here, who were formerly just a name on a mailing list or letter, are charming people, who speak with strong voices. We learned here that the stronger you speak, the more friends you make. You make enemies, but those people don't count, because you couldn't work with them in the first place.

Florida Council was one of the first organizations to join the American Coalition, together with the Massachusetts Council. I feel very cordial toward the Coalition. It is something I have been wanting for years and years.

We found in Florida that it was very easy to get media coverage (newspapers, radio, TV), whenever you have hard news, a little different from the ordinary sob stories. The media calls us for news.

ACTION

Would like to see a "United Handicapped Press Agency" to send us news, because there are people doing things in other cities that we don't hear about.

One thing we have to work out in Florida--cordial relationship with agencies.

H. Remmes

ACTION

To facilitate dissemination of information, it might be helpful to local publications if national publications could somehow identify, in each issue, certain articles which should have broad coverage (such as hearings, national legislation, etc.) and may be reprinted in local newsletters without prior approval, but with appropriate credit to the source.

R. Cheever

Not ethically correct to reprint articles paid for or copyrighted material. Define type of material.

H. Remmes

National news items on public hearings etc.--not articles or stories.

D. Lattin

Under Freedom of Information Act, anything printed in PERFORMANCE may be reprinted by anyone.

P. Johnson

ACTION

In urban areas where three or four existing handicapped consumer groups each publish a newsletter, it might be helpful for them to join together to establish a publication center. Information would be fed to one location. Consolidate efforts for typing, printing and mailing each publication. Use bulk rate mail. Need for local publications to develop expertise in layout.

H. Remmes

Last evening, the editors of the various national publications met together informally. What were some of the suggestions made?

G. Laurie

ACTION

The Resource Guide for the Disabled of Massachusetts is gorgeous. It's a beautiful thing to start with and we need to get each state to duplicate it for their own area.

Press releases from Coalition headquarters. Local people also have to learn how to prepare releases with who, what, when and why in the first paragraph.

Newspaper format of ACHIEVEMENT is great!

ACTION

Every state must work toward having a newsletter of its own, so its own local legislation program can be publicized. Start with regional publications.

D. Lattin

Remember when submitting press releases and other material for publication, PERFORMANCE works two months ahead of publication date.

G. Laurie

ACTION

I think we all (national publications) should have a section for the Coalition to summarize what is going on.

C. Lampos

I think that the information should come from the Coalition.

G. Laurie

Even if the same information appeared in five or six publications, it still would not hurt.

R. Cheever

Up to the Coalition to send out their own news.

H. Remmes

One point we should touch on--the possibility that a publication can be a source for generating enthusiasm. I would be very hopeful that all of you would try to generate some enthusiasm for what has been going on here this past two days, through whatever media you have access to. We can even turn some people on to the fact that a lot of busy people have come to one city to see if they could come up with something concrete.

R. Peterson

Re developing state coalitions, could a model by-laws or guidelines to organizing be developed?

H. Remmes

MCOH publication 'A Consumer's Guide to Organizing the Handicapped' gives model by-laws, has sample press releases and tells you all the "nitty-gritty" you need to know to organize.

F. Fay

Can the Coalition get 50 copies?

H. Remmes

ACTION Question to Carl Granger: We are out of copies and fast running out of money, can these be reproduced at your facility?

C. Granger
Agreed.

L. Frieden

Not only can the national publications serve as a communicator of information about the Coalition, but they can also provide a forum for debate of certain issues.

This may reflect something about the part of the country I am from, but we have to be very careful when using electronic media to protect our image. For example, in Houston, Texas, if we go out and picket and demonstrate and this is picked up by the media, we are looked on as bad guys. We have to come across just as many times as good guys, doing something in a positive manner.

C. Bedow

Would like to see on a national level, either in a publication or in some type of a clearinghouse where we can find out what is going on in Washington and on a state level regarding bills that are passed. The local publication is also important--who married whom and who had whose baby gives the human touch. Have to, above all, give a good, positive image in our publications.

C. Granger

ACTION Idea of an information package for medical and rehab centers is very viable and should be done soon. Will help introduce usefulness of consumer input into medical/rehab hospitals. There is an association called CARF, Commission on Accreditation of Rehabilitation Facilities. One of their standards relates to communicating to patients about services etc. Perhaps CARF could be approached with this idea.

E. Fiorito

ACTION The original MCOH "Directory of Organizations of the Handicapped" must be redone and, more important, the national coalition should be responsible for updating the Directory. When anyone hears of a new organization developing, they should send the information to the ACCD office.

We are constantly talking to ourselves, but we need more public education. New people can be recruited through articles in local newspapers. Organizations must know how to use tools such as press releases.

R. Cheever

We are talking about communications, but there has to be a reason for communication first. I think we should direct the attention of this group of experts here on "how to" suggestions to start getting things done locally. I firmly believe in a national coalition and have done everything I can to try to promote it, but the great strength of any organization, including the national coalition, has got to be built on local groups. Logical for local groups to organize on state level. Within each state there are fantastic opportunities for people to work together. We need a plan of action. I worked for a company that gave salesmen a very specific series of instructions to accomplish their goals. We need specific plan to tell people what to do in each state, with specific goals that can be addressed.

ACTION

ACTION

D. Lattin

Approach local service organizations who run fund-raising projects, requesting them to support organizations of the handicapped, rather than agencies such as Easter Seal Society, etc.

E. Wright

Newspaper columns by disabled persons are helpful in public education.

H. Remmes

Summarizing: Need for state-wide organizations with dissemination of information at state level first, supplemented by the national publications. As Lex pointed out, geographically we are different, we have different problems in different states and we cannot impose the standards of a Western state on an Eastern state or vice versa.

We have developed some of the tools, such as the Consumer's Guide to Organizing, which has been distributed to 600-800 persons. Unless people utilize it, it is worthless. The Rights Handbook available from the Massachusetts Easter Seal Society Child Advocacy Project and the Resource Guide developed by the Mass. Association of Paraplegics are tools which can be replicated in any state and can be very useful.

C. Lampos

Did you get a response (to the Consumer's Guide to Organizing)?

H. Remmes

Received many letters, but one from Pennsylvania really made me feel good. The letter implied that they really did not know where to begin and this had given them a step-by-step guide and they were now really becoming organized.

F. Fay

Would you have any objection to Connie or Ray reprinting the Consumer's Guide, one chapter per issue?

H. Remmes

Can be reproduced provided credit is given where it comes from. We would be more than happy to have it disseminated as broadly as possible.

(At this point, there was a discussion of the geographic areas assigned to each regional coordinator, led by T. O'Brien. Some of the states originally assigned on an arbitrary basis were traded. The coordinators selected the states where they felt they had the most contacts and each chose the number of states which he or she felt they could handle. The end result of this process is indicated on the attached sheet of Regional Development Coordinators and their "territories.")

E. Fiorito

There is a need to bring in other disability groups besides the ones represented here.

T. O'Brien

The coordinators must go back and identify all consumer organizations.

R. Cheever

That is some of the "how to" information I was talking about. Make a list of the disability groups and health organizations that should be invited into an organizational meeting.

ACTION

H. Remmes

All of you were selected because we assumed, and rightly so, that you all shared the viewpoint that Eunice just expressed, that is that you were not just interested in your own disability groups. Original criteria for persons selected: track record, broad interests, knowledgeable. You are not expected to go out and organize. You are expected to select people who will organize, coordinate their efforts and tie them into the American Coalition.

We have to make the meaning of a coalition clear to everybody. In Massachusetts we have a Coalition with the Elderly. It's not a marriage that is binding. We coalesce around issues. It does not say you lose your autonomy. Each organization is perfectly good and viable.

Now that the country is divided, we want to go into how to do it. Some possible resources:

Agencies--In some cases, you have not explored possibilities of getting help from agencies. In other cases, this is not possible because some groups are having wars already with agencies. For example, if you have a mailing or need secretarial service, an agency might be willing to give you in-kind service, if they are not willing to give you money.

Telephone--Explore use of conference calls. Telephone network.

Someone said we could not get this group together because they were such busy people. Don't be afraid to ask busy people to help you out. Don't overlook people who do not have the same disability as you--look to all groups that have common interests.

E. Roberts

Described telephone network in California. The list of people attending this Conference will be a good beginning for a national telephone network.

For communications:

Diane Lattin - (202) 961-2474

Roger Peterson (Coalition phone) - (202) 785-4265

Frank McNulty, Mass. Gov. Comm. on Employment of the Handicapped
Described WATS line for Commonwealth of Massachusetts, which was paid for through grant from the state Executive Office of Manpower Affairs. Coalitions or groups in other states may want to get one of these WATS lines in their own state.

R. Peterson

There are lots of free tie-lines and WATS lines around in government offices, the use of which may be borrowed to facilitate long-distance communications.

T. O'Brien

Also remember that your Senators and Congressmen have free phone and franking privileges. For example, a Senator has let me use the phone for several hours at a time. Regarding the franking privilege, you ask your Senator or Congressman to issue a news release about your program, saying that Senator _____ endorsed it or whatever; as long as his name is mentioned, very often he will send a mailing out for you. The Division of Employment Security or State Employment Service often has franking privileges. Very often, the state programs for the handicapped or the Gov. Comm. on Employment of the Handicapped is tied in and could send out mailings for you.

H. Remmes

If you want to reach the top person in any company or agency, the best trick is to wait until 5:05 p.m., when the secretary has just left, and chances are the top man or lady will answer the phone personally.

E. Fiorito

Would have liked to have seen some other agency people. Hope we can meet again next year to take on some of these issues in greater depth and bring in outside people in the field of organization, so we can learn some basic skills from what others have done.

F. Fay

Re Coalition Delegate Council Meeting to be held in Washington, D.C., May 2 and 3, 1975. Anyone with any resolutions or issues which should be discussed or anyone who is interested in running for office, notify the appropriate chairperson. Most important, join and elect your delegates and get them to the meeting, so you will have a voice in the direction of the Coalition.

D. Poling

I realize the Coalition must organize geographically, but wonder if we realize how much resistance we are going to encounter from different types of disability groups. You all are aware of the great prejudice many disabled people have against other types of disabilities. Therefore, if you are going to adopt geographical organization, then you must develop beforehand a realistic plan for overcoming this irrational prejudice.

H. Remmes

If you do reproduce the Consumer's Guide, we suggest you delete the last page. Since there was no national coalition in existence at the time, we were looking at COPH and NAPH as possibly the most viable organizations to go with.

The purpose of this conference was to get the leadership to know each other, try to get certain issues addressed. We may not have done this in the best possible way, but it was a beginning. It was important to us not to have it lopsided with agencies. It was our intention to have few agency people here so that this was the "consumers' show".

D. Poling

We have to concentrate on developing our own identity. We have to decide what we want and how to go about getting it.

R. Cheever

Two psychological things which we have to address ourselves to at some time. One is what Dan said, to get various disability groups to accept each other and work together. Second is how do you get more handicapped people involved. How do you get a person who has a disability to not be afraid to identify with disabled groups. We have to work on the image thing, so that being disabled is not something to be ashamed of.

Also, handicapped groups must get their houses in order and consolidate activity on issues.

E. Wright

This meeting has been very productive for me. The larger this organization will get, you will have a great vulnerability to many problems discussed here. Communications is a tremendous problem. Be aware of the pitfalls that lie ahead. I'm certainly all for the Coalition.

ACTION

F. Fay

The one specific thing that I would like to see come out of this is funding to do consumer training around the country. I think we can get a grant from either the R and T centers or from RSA to the Coalition, to work together with the regional expertise such as MCOH, CIL, UHF, etc. to do consumer organizing and training.

J. Heumann

We need to support each other and hope everyone will utilize the Coalition office. If there are any problems, we have to know about them to solve them.

M. Bjerkesett

It's fantastic that it was possible to get so many capable people together. I felt for the first time that the American Coalition can be a reality. We don't know it all. Our expertise is in the area of the needs of the handicapped. Our expertise is not necessarily in the area of organizing. I strongly recommend that we bring in that expertise from the outside--there are professionals trained in forming coalitions.

E. Daly

My only concern is that when we go into the states, that we have enough to really turn those people on.

ACTION

R. Peterson

I see a need, if we could find some way to fund them, to have a conference like this in each one of the regions. Our meetings in Washington are going to be bogged down with the mechanics of business meetings. I think that we need these regional weekend organizational and issue-oriented seminars or workshops where perhaps the person who has agreed to handle the region could get the thing together, and a few others of us who have been involved in this conference could participate also.

(At this point, minutes of the previous day's workshops were distributed to all those present.)

Bill Power, Easter Seal Society, Boston, Mass.

If you deal with the issues, the major issues transcend disability groups. Re infiltration of agencies, provider agencies of services or any type of organization. One way that organizations can be accountable and have credibility today is by providing consumer input.

Here in Massachusetts, one thing that has been done is the formation of a Coalition on Special Education. Tom spoke of paper tigers. If you ever want to see a paper tiger who can move mountains, this is an example. What they consisted of was a loose coalition of a lot of people interested in education of kids with all handicaps. The Coalition consisted in reality of a letterhead listing a lot of organizations down the side. The amount of response they got and the things they were able to initiate ought to be a great model. You could produce a letterhead that lists a lot of organizations and can be used regionally by the regional coordinators.

ACTION

H. Remmes

I really appreciate the fact that everybody came here with a cooperative spirit, even though we do come from different areas and from different directions sometimes, and yet no belligerency, no animosity. There was a real concern and a really good dialogue. The thing that made this conference successful, if it was a success, was YOU. We have dropped a concept, an idea, and a lot of responsibility in the laps of a comparatively small group of people, but things have started with a lot fewer people. Christianity started with 12. I won't say what shape it is in, but look how many people belong to it!

This Conference would not have been possible without the support and encouragement of the R & T Center. The Easter Seal Society, while they were not formally involved in the Conference, were more than happy to donate the use of their van and staff time to come down and help us evaluate it. I think we could also have received the same kind of involvement from other agencies, had we asked.

D. Sarkisian

I hope it will be possible for us to meet again next year.

R. Cheever

Would it be appropriate to suggest that the powers that be, Hal, Dr. Granger, etc., to consider the feasibility of a follow-up study a year from now to see what has happened and where we are going.

C. Granger

You have all said what I was planning to say, but I did want to mention how pleased I have been to have been associated with this Conference and I want to compliment Hal and the staff for doing such a good job.

I have been sensitized over the years by consumers, but perhaps other providers have not had this opportunity. As you mentioned, if this can be done without upsetting the applecart--what I mean is, if it can be done in the spirit of cooperation, as has been the case with our Center and MCOH, it can be a very positive step, with immeasurable ramifications throughout the entire service delivery field.

As the consumers here learned, there is a discipline which one must impose upon oneself when dealing with providers (speaking from the consumer's viewpoint). The problem of documentation, the problem of learning the nature and scope and constraints with which the agency is forced to comply. Thus, any good plan which is to be a collaborative effort must be envisioned as a mutual give-and-take proposition.

If our experiences here can help to show the way for others, if what we have started can be expanded to a continuum, then our job has been done well.

Perhaps after assessing this Conference, we can justify seeking funds for a continuation of this effort.

Hopefully we can meet again next year.

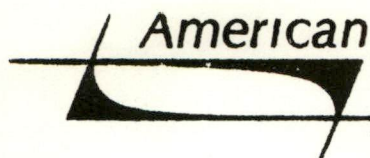
M. Winn

I would like to reiterate my thanks to everyone for their participation, to Dr. Granger for his support, which made the Conference possible, to the recorders and Conference staff, and especially to Hal Remmes for putting the Conference together and for all he has done over the years as founder of MCOH and leader of the consumer movement in Massachusetts.

M. Winn

I think, coming out of this Conference, of what I am accused of a lot, and that is being an idealistic kind of person. Regarding the need for sensitivity to each other's disability, remember that the most important thing we have going for us is that we all care about each other and we want the same things.

A journey of a thousand miles begins with a single step and even though we can't walk, we sure can wheel and we had better start rolling!



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