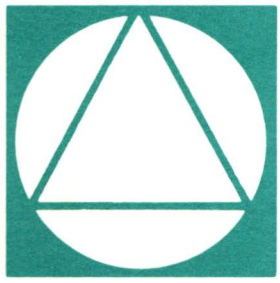
American Coalition of Citizens with Disabilities



CONSUMER AND ADVOCATE INVOLVEMENT IN FEDERAL AND STATE VOCATIONAL REHABILITATION PROGRAM PLANNING

Final Report Grant #12-P-57948/3-04

Prepared by Rita A. Varela

THE AMERICAN COALITION OF CITIZENS WITH DISABILITIES, INC.

November 15, 1980

Note: This document includes:

PROCEEDINGS FROM CHERRY HILL

An Evaluation and Utilization Conference held in Cherry Hill, New Jersey on August 8-10, 1980

SIGNIFICANT FINDINGS FOR REHABILITATION

- Consumer involvement in State rehabilitation agencies is required by Title I of the Rehabilitation Act of 1973, as well as by other sections of the Act and its subsequent amendments. The Title I mandate on policy development consultation was reviewed and described in Chapter 25 of the Rehabilitation Services Manual.

- ACCD's three year project on Consumer and Advocate Involvement in Federal and State Vocational Rehabilitation Program Planning went far beyond the analysis offered by Chapter 25. The project found that the degree of effectiveness of consumer involvement in any particular state will be influenced both by the strengths and capabilities of organizations within the self-advocacy community and by the extent to which agency consumer involvement plans present clearly delineated roles and responsibilities.

- Following extensive research and interviews, as well as close monitoring of self-advocacy efforts in 4 states, ACCD sponsored an evaluation and utilization conference in Cherry Hill, New Jersey to examine the factors that shape the capabilities -- and viability -- of self-advocacy groups. The Proceedings from Cherry Hill analyze such factors as leadership styles, management capabilities, and cross-disability communication.

- ACCD also developed a Model State Plan for Consumer Involvement in Rehabilitation (MSP/CIR). The Plan was developed with the active participation of rehabilitation officials and advocates throughout the country. The MSP/CIR process, and final draft, has been published by ACCD under the title, Participating Citizens.

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Grant #12-P-57948/3-04 November 15, 1980

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AUTHOR'S ABSTRACT

During the 1970s, while other civil rights struggles were ebbing, the spirit of militancy and self-determination among disabled people surged. This three year study examined the self-advocacy movements, and their impact on State rehabilitation agency programs, in 4 states -- Massachusetts, Michigan, New Jersey, and Virginia. Our findings and procedures were based on on-site visits, interviews, and surveys from those states, as well as from an extensive, ongoing review of the literature.

The effectiveness of consumer involvement in a state will be influenced by: a) the strengths and capabilities of self-advocacy organizations; and, b) the extent to which agency consumer involvement plans have clearly delineated roles and responsibilities.

This report focuses primarily on factors affecting the organizational strengths and weaknesses within the self-advocacy community. It features the proceedings from a conference held in Cherry Hill, New Jersey, in which 60 disabled activists examined such issues as leadership, management capabilities, and cross-disability cooperation.

In a separate publication resulting from this project, ACCD offers guidelines for a Model State Plan for Consumer Involvement in Rehabilitation (MSP/CIR). The process to design an MSP/CIR utilized a modified delphi survey approach which featured the following phases: 1. Pre-conference meetings with CSAVR members, RSA officials, and advocates to generate topics; 2. A preliminary, open-ended questionnaire which was sent to 40 rehabilitation officials and advocates; 3. An MSP/CIR topic outline, drawn from responses to the questionnaire, which was used by MSP/CIR conference participants to develop a first draft; 4. Nationwide dissemination of the draft, followed by analysis of the comments received; 5. Development and dissemination of a second draft; and, 6. Final publication of an MSP/CIR in the form of a book entitled, Participating Citizens (available from ACCD).

CONSUMER AND ADVOCATE INVOLVEMENT IN FEDERAL AND STATE VOCATIONAL REHABILITATION PROGRAM PLANNING

Final Report

Grant #12-P-57948/3-04

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November 15, 1980

This study was supported in part by Research and Demonstration Grant #12-P-57948/3-04 from the National Institute of Handicapped Research, Department of Education, Washington, D.C. 20201. It covers research performed from October 1977 to November 1980.

PREFACE

It is quite difficult to encapsulate three years of a project's life into a final report, particularly when the aim of the project was to study how to make the rehabilitation system more responsive to the demands of disabled citizens. Too often, final reports rely so heavily on charts and summaries that they leave little room for the people who tested its premises or who may be affected by its consequences. Clearly, a final report must examine the assumptions, methods, and activities that shaped the project, and we will do so in Chapters 1 and 2. However, in discussing the findings of the project (Chapter 3) we will turn to the proceedings from an evaluation and utilization conference held in Cherry Hill, New Jersey on August 8-10, 1980.

The Proceedings from Cherry Hill report on the deliberations of over 60 disabled advocates from 4 states who gathered to discuss organizing, coalition building, politics, and the future of the disability rights movement. Their task was to examine the advocacy and organizing efforts in their states over the last three years and offer guidelines for advocates in other states. The 4 states -- Massachusetts, Michigan, New Jersey, and Virginia -- had been focal points of study on the role of advocate involvement in rehabilitation programs. This 4-State project, conducted by the American Coalition of Citizens with Disabilities, Inc. (ACCD), was supported by a grant from the National Institute of Handicapped Research.

To those who believe that ACCD has drafted all the rules on disability-related coalition building, parts of the proceedings may be disturbing, for they reveal diversities, controversies, unsettled questions, and the vitality of a dawning tide. To those who believe that the purpose of ACCD is to be as relevant as possible to the needs and views of 36 million disabled people -- a constituency marked by a spectrum of impairments, economic backgrounds, races,

creeds, and ideologies as wide as the country itself -- the Proceedings from Cherry Hill come as part of our pledge to listen to the people on the front lines of the disability rights struggle.

As the project drew to a close and our thoughts turned to the need for assessments, they also turned to the need for acknowledgments. The greatest guarantor of quality is commitment. No one could have set higher standards, issued stiffer challenges, or offered stronger support and encouragement than the Principal Investigator of the project, Dr. Frank G. Bowe. The extent of his leadership and contribution to every phase of this project will probably never be fully recognized.

The thoroughness of this project, and particularly of the work leading to our Model State Plan for Consumer Involvement in Rehabilitation, is due very largely to the diligence and caring of ACCD's Research Utilization Specialist, Harriet W. Loeb.

Of course, the richness and dynamism of this project is due almost exclusively to the advocates and agency officials in the 4 states. Many of them were participants of the Cherry Hill conference, and we have included their names in Appendix A. ACCD is particularly proud to have had the support of Joseph H. Owens, Jr., Executive Director of the Council of State Administrators of Vocational Rehabilitation; Dr. L. Deno Reed, Senior Research Scientist, National Institute of Handicapped Research, Department of Education; and the directors of the 4-State rehabilitation agencies, Elmer C. Bartels (Massachusetts), Donald Galvin and Peter Griswold (Michigan), George Chizmadia (New Jersey), and Altamont Dickerson, Jr. (Virginia).

The dedication of the ACCD staff was demonstrated throughout this three year project. ACCD worked as a team and special acknowledgments must be made to those people who helped us maintain our target of excellence: Marcia Miller, Assistant to the Director; Rose Ann Jackson, ACCD Office Manager; Janice LaLonde,

Information and Referral Specialist; Barbara Fink, Secretary/ Interpreter of ACCD's Section 504 Citizen Training and Technical Assistance Project; Bernard Glazer, ACCD's Comptroller; and, Peter Myette, Technical Assistance Director of ACCD's Section 504 Citizen Training and Technical Assistance Project.

Special thanks go to Michael Hartman for his review and comments on the text of this report.

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Massachusetts -- A Need for Renewal

Massachusetts, in many ways a pioneer, was the first to establish a statewide coalition of organizations that were directed by disabled people. Some of the leaders of that effort, the Massachusetts Council of Organizations of the Handicapped (MCOH) also helped to establish ACCD in the early 1970s. By 1978, however, several disabled activists were charging that MCOH was losing its membership and political clout.

These charges coincided with an awakening interest in consumer involvement research within the rehabilitation field. Chapter 25 of the Rehabilitation Services Manual discussed the Federal provision (in Title I of the Rehabilitation Act of 1973) requiring State agencies to issue written plans showing how they would solicit and respond to the views of clients, advocates, and providers. As the tenor of the disability rights struggle grew more strident, professionals began wondering what Chapter 25 would do to the service delivery system. Among those looking at this question was Dr. Frederick Fay, director of the Tufts-New England Rehabilitation Research and Training Center #7 (RT-7). Fay and his staff had received a grant from the Massachusetts Rehabilitation Commission to study consumer involvement. (Since ACCD was working on a similar study, there was frequent communication between the ACCD and RT-7 staffs.)

One of the activities sponsored through the RT-7 grant was a retreat (held in Worcester, Massachusetts in November, 1978) to discuss the future of the disability rights movement in the state. The retreat drew representatives from disability groups throughout the state, a number of whom were then elected to a steering committee to form a new organization, the Massachusetts Coalition of Citizens with Disabilities (MCCD). Four issues shaped the future of this new venture. First, the problem of determining the relationship between MCOH and MCCD; there was obviously a degree of rivalry between the two. How fierce would that rivalry be allowed to become? Second, which organization would become the "official" state coalition? Third, what would be the relationship between each of these groups and ACCD? The fourth issue may be characterized as a "style" issue in politics. MCCD people tended to see themselves as younger and more radical, while many in the MCOH leadership tended to see themselves as the keepers of a tradition which "worked" the political game from the inside.

During the November 1978 retreat, the issue of membership criteria provoked a great deal of debate. Did the conferees want an organization of organizations, with each member group electing representatives to the new coalition? If so, how should voting powers be allocated between local groups and local chapters of statewide organizations? Lastly, what about individual disabled activists who were not affiliated with any organization -- should they have a vote? If individual voting membership was allowed, what was to stop 20 or 30 people from a single organization from demanding the right to vote as individuals?

While this and other structural controversies raged, MCCD people were very active on numerous efforts. They mounted campaigns to urge President Carter to sign the 1978 Rehabilitation Amendments, they struggled against Congressional plans to limit funding for accessible mass transit, and, with a mini-grant from ACCD, conducted a series of statewide advocacy training workshops.

MCCD finally came to terms with the membership issue. Their by-laws now show that MCCD is a coalition of individuals, and its leaders recognize MCOH as an organization of organizations. The rivalary is seen as a state matter, one which outsiders should avoid, and as such is being kept within reasonable bounds. Yet most of the unresolved questions in Massachusetts underscore an issue that has plagued and baffled other states as well; namely, what is the difference between a group and a coalition?

Michigan -- A Need to Keep Listening

Michigan is not new to the idea of coalitions -- its "handicappers" (i.e., disabled citizens) form them all the time. Between 1970 and 1978, most major legislative objectives were achieved successfully, largely because handicappers, organizations, and in some instances public agencies realized they had a vested interest in working cooperatively on specific issues such as civil rights statutes, special education programs, and building codes to promote barrier free designs. These were ad hoc coalitions, though, which disbanded after each battle.

The word "handicapper" was adopted by people in Michigan in an effort to break out of the binds of perjorative labels. Activists were uncomfortable with the word "disabled," which they said implied helplessness and impotence, as well as with the term "handicap," which they said meant operating at a disadvantage. "Handicapper" appeared to be the best term for the image they wanted to convey; i.e., one who determines the degree to and the manner in which one's own definable physical or mental characteristic might direct one's life.

On a wintry afternoon in March 1978, an ACCD staffer from the 4-State project attended a meeting of handicappers and rehabilitation agency representatives to discuss the topic of coalition building. The facet of that concept which most seized the imagination of handicappers concerned networking -- i.e., establishing a statewide communication and input mechanism which would help group leaders

share their problems and priorities in the interims between the legislative battles. Toward the end of the meeting participants designated a steering committee to begin structuring an organization to meet that need. The steering committee faced many of the same questions that MCCD struggled with, such as membership criteria and defining their relationship to ACCD. Many of these issues were brought to a larger forum of handicappers in the spring of 1979 when ACCD sponsored a workshop for representatives of advocacy and self-advocacy groups in Michigan. Moreover, the contacts that were made in order to design the new structure were also tapped to coordinate statewide advocacy efforts, such as preserving the integrity of barrier free design building codes. The Michigan people formed Michigan P.E.O.P.L.E., Inc. (People Educating Other People for Lifestyle Equality), in the autumn of 1979, and used a mini-grant from ACCD primarily for a newsletter to keep advocates throughout the state aware of issues facing different sectors of the handicapper movement.

Throughout the literature describing why P.E.O.P.L.E. was established, it is clear that networking is nearly as central to their philosophy as is mobilization. As one document indicates, P.E.O.P.L.E. seeks to accomplish its goals partly by "acting as a forum for coalition members to develop majority and perhaps, minority, positions on issues of interest. These positions will represent the collective posture of the community of Michigan citizens who are called 'disabled,' 'handicapped,' or 'handicappers.' The coalition does not require organizational members to give up their identities or to agree to a single coalition position. Majority and minority positions (when they exist) will be prepared and transmitted and the organizations supporting each side will be identified as will the percentage of individual members on each side of the issue."

New Jersey -- Growth or Decline

At the outset of the 4-State project, virtually the first group ACCD staffers contacted was New Jersey's Disabled in Action (DIA). In the Northeast, DIA -- with chapters in New York, New Jersey,

Pennsylvania, and other states -- was synonomous with disability rights, militancy, and people who were willing to man the barricades. As the staff began to interview its leaders and serve as participant observers at its meetings, however, a new, more intimate portrait of grassroots activism emerged. That portrait was the basis for the "hypothetical" group meeting described in Chapter 2 of Self-Help Groups in Rehabilitation, published by ACCD in 1979.

DIA leaders knew their strengths and were proud of them. The organization was a microcosm of the disabled community, whose members included lawyers, teachers, psychologists, office workers, and too many friends who were unemployed. DIA people cared about each other, and had very strong, supportive bonds. They also knew their weaknesses and discussed them openly with the project staff. Since most had been together a long time and knew each others' limits, the organization was characterized by a 'play it safe' management style in which a handful of people did most of the work. Group maintenance took precedence over group growth. Far more time and energy was devoted to the priorities of current members than, for example, to recruiting within other organizations. ACCD's interviews with DIA members led, in large part, to the decision to hold a consumer involvement conference in each of the 4 states during the second year of the project.

ACCD's pre-conference activities during Year 2 focused on statewide mailings, follow-up phone calls, and on-site visits. All were part of our effort to demonstrate the importance of cross-disability communication, one of the goals of the project. We worked closely with our New Jersey contacts and built new ties with rehabilitation agencies, including those serving blind, hearing impaired, and developmentally disabled citizens.

New Jersey's consumer involvement conference attracted a number of people who had been only peripherally involved in cross-disability efforts. Some parent activists, for example, expressed new interest in joining forces with the disability rights movement, a struggle which they had felt was too far removed from the concerns affecting the rights of handicapped children.

Conferees established a committee to organize a statewide coalition. Some of the people on the committee were DIA members, others represented uni-disability groups, and still others were new to the movement. Following the conference the committee concentrated on outreach. As their supporters increased they set up committees on by-laws, membership, and other matters. The coalescing impetus for the New Jersey Coalition of Citizens with Disabilities (NJCCD) surrounded plans for Solidarity Day.

In the spring of 1979, a group of disabled activists from across the country met in Washington, D.C. to discuss ways of combating what they saw as public retrenchment from Federal regulations guaranteeing their rights. They decided to designate October 20, 1979 as Solidarity Day, and encourage nationwide celebrations. The NJCCD used the event to draw attention to its statewide organizing initiatives. NJCCD spent all summer planning for Solidarity Day, and on October 20th presented a three hour program -- in front of the state house in Trenton -- which attracted a prominent roster of public officials, an audience of well over 300 people, and statewide television coverage.

In the spectrum between a tightly knit organization and a loose network of individuals, NJCCD's structure lies somewhere near the center. NJCCD maintains an active recruitment and public awareness campaign, has applied for several grants, including subgrants from ACCD, conducts statewide conferences, and holds frequent board meetings. However, a number of NJCCD's leaders also head local organizations; some of which are, increasingly, beginning to expand into the field of independent living and peer support services.

Virginia -- The Need to Nurture Local Power Centers

Disabled leaders have worked hard since 1978 to build Handicaps Unlimited of Virginia, Inc. (HUVA) into a statewide umbrella organization of disability-related groups. Yet they placed equal emphasis on strengthening local member groups.

The statewide organization began with the alliance of three self-advocacy groups: Mobility on Wheels, Inc.; the Association of Handicapped Persons in the Tri-City Area; and Handicaps Unlimited of the Peninsula. Forging the alliance was not simple, and often included turf controversies over where to hold meetings and what name to use for the new, statewide organization. Strategic disputes also emerged. One camp believed that the best way to serve disabled people was to turn all energies toward pressure at the top; that is, toward swaying public officials. Though the other camp agreed that disabled leaders must serve on councils, committees, and task forces, they were equally concerned about the viability of grassroots groups.

This second camp became the vanguard of HUVA's organizing initiative. It's leaders travelled across the state recruiting local chapter groups. However, irrespective of the results of any given recruitment foray, they tried to keep in touch with each of the groups, to help with fund raising events, and to keep them abreast of emerging issues. HUVA's leadership helped officers of local groups get on statewide committees and participate in national conferences. As a result, local leaders not only came to trust HUVA people, but to see themselves as HUVA people.

Today, HUVA has over 13 state and local organizational members which together represent 3,000 citizens. Their emphasis on strengthening each link in the chain continues. When HUVA talks about itself, it often talks about money -- about getting grants (large and small) and about helping local organizations to raise funds. HUVA has received mini-grants from ACCD to support its newsletter and to sponsor leadership training sessions at its fall work conference; has received a contract from the Virginia Commission for the Arts to conduct training on the implications of section 504; and, most significantly, has received independent living funds from the State's Department of Rehabilitative Services to operate a peer counseling program.

HUVA's yearly main event is a fall work conference, which draws over 200 people to its lectures, training sessions, and public forums. In keeping with its philosophy, the fall work conferences are held in a different part of the state each year, with most of the planning and logistics handled by the local host organization.

Summing Up

The differences that emerge within each state are as fascinating as are the similarities. In all likelihood, some of the issues were influenced by the fact that the American Coalition of Citizens with Disabilities, Inc. conducted the 4-State project, as opposed to, say, the University of Chicago or the American Enterprise Institute, yet most reflected what people were talking about and struggling with at the time of the study.

1. The 4-State project was an extension of a fall 1976-1977 study to develop a national model of cross-disability communication and cooperation. The results of that original study, reported in ACCD's first publication, entitled Coalition Building, examined the role that "organizing issues" can play in bringing people together and sparking dialogue. For ACCD nationally, the key issues had been 504 and, later, accessible mass transit. By the time the 4-State project began, coalition building itself -- that is, the spirit, the power, and the possibilities of coordinated action -- was becoming a key topic.

2. The last three years of the disability rights movement in Massachusetts has drawn attention to an issue which recurs repeatedly but which few people have shown an interest in discussing openly: namely, what is the difference between a coalition and an organization?

3. The disability rights movement in Michigan, as in the other states and the country as well, did not begin with the start of the 4-State project or even with the formation of ACCD. Michigan's people have raised an issue which is similar and as complex, or more so, than the one which emerges from the Massachusetts experience; namely, what are the distinctions between an organization and clusters of individuals working toward similar goals?

4. In New Jersey, we found the issue of "renewal" -- which also emerged in Massachusetts -- appearing not just as one of the old guard vs. the new, but as one of outreach. The recurrent theme for NJCCD was: given the fact that some old soldiers burn out and some do not know how to fade away, how do you develop a new leadership class?

5. Virginians have a strong military tradition. That fact may have influenced the motif that became so central to HUVA's procedures: namely, the care and nurturing of troops during the lulls between battles. In that sense, HUVA's objectives were similar to those of NJCCD: leadership training and burnout control.

These issues emerged repeatedly, at times dramatically, when over 60 leaders from the 4 states were billeted in Cherry Hill, New Jersey for a two-and-a-half day workshop on cross-disability constituency building.

Section 2: The Formal Title

Throughout this report we use the phrase "4-State project," and we began, in fact, by reviewing the trials and triumphs of activists in each state. The project, however, had a far more formal title: "Consumer and Advocate Involvement in Federal and State Vocational Rehabilitation Program Planning." The proposal abstract submitted to the Rehabilitation Services Administration in the early spring of 1977 set bold objectives:

1. To demonstrate that ACCD's model of cross-disability communication and cooperation could improve consumer and advocate involvement in rehabilitation planning.

2. To enhance consumer and advocate representation in rehabilitation planning.

3. To encourage greater program responsiveness through such representation.

4. To document the benefits achieved by improved representation.

5. To provide guidelines for other states.

6. To provide technical assistance to rehabilitation officials and advocacy organizations in order to facilitate communication and cooperation.

7. To help establish in the states ongoing capacities that would continue after the project ended.

These commitments reflected ACCD's earlier research. It is important to realize that the 4-State project was an extension study, whose aim was not to develop a model but to determine to what extent

an existing national model would work in the states. That model, designed by ACCD and tested at the national level, was described in Coalition Building, the organization's first publication. The philosophical cornerstones of that work played a major role in shaping the procedures of the 4-State project. Particularly critical was the book's discussion of the conditions that lead people to join coalitions:

> /Potential members/ must be convinced that the process for joint action will return to them the benefits for which they joined.
>
> They must believe that the mechanisms for conflict resolution and consensus building will assure them the autonomy they require to move freely on issue positions that they choose to hold outside the purview of the coalition.
>
> They must believe that they will have a fair voice in setting the directions of the coalition.
>
> The implicit and explicit distribution of influence within the coalition must not appear to favor one group -- at another's expense.[1]

Table 1 offers some examples of how we sought to implement these objectives. The following sections examine our methods and procedures more closely.

TABLE 1

OBJECTIVES AND IMPLEMENTATION

OBJECTIVES	IMPLEMENTATION
1. To demonstrate that ACCD's model of cross-disability communication and cooperation could improve consumer and advocate involvement in rehabilitation planning.	1. Premises and procedures (i.e., "the model") of cross-disability communication were used in discussing topics for the (Year 2) consumer involvement workshops, generating interest, assembling mailing lists, and getting speakers.
2. To enhance consumer and advocate representation.	2. Major ACCD effort to describe and promote dialogues on Chapter 25 of the Rehabilitation Services Manual.
3. To lead to greater program responsiveness through such representation.	3. ACCD's ongoing, aggressive dissemination of information about such issues as debates over the proposed 1978 rehabilitation amendments, the Cleveland Amendment, and SSI helped increase the number of people who spoke out on these issues.
4. To document the benefits achieved by improved representation.	4. Self-Help Groups in Rehabilitation, in part, discussed how peer support services were meeting some of the unmet needs of disabled people.
5. To provide guidelines for other states.	5. Participating Citizens: A Model State Plan for Consumer Involvement in Rehabilitation provided specific evaluation standards with which to examine consumer involvement plans.
6. To provide technical assistance to rehabilitation officials and advocacy organizations in order to facilitate communication and cooperation.	6. Project staffers maintained ongoing contacts with agency officials and consumers. Invited officials and advocates to various national training workshops. Spoke at in-state meetings and provided ACCD publications. Responded to field-initiated requests.
7. To help establish ongoing capacities in the states that would continue after the project ended.	7. Follow-along consultation. Training for Trainers conference (Fall 1978). Cherry Hill conference (Fall 1980). Subgrants of $3,000 to an organization in each of the 4 States during Year 2 and Year 3. Publication and distribution of Planning Effective Advocacy Programs.

METHODS AND PROCEDURES

Section 1: Project Overview

The implementation examples in TABLE 1 reflect three distinct types of activities:

1) Assessment activities, in which we sought to form a general picture of what was happening in the rehabilitation field and the advocacy community,

2) Implementation activities, in which we sought to provide training or technical assistance, and

3) Evaluation activities, in which we sought specific information about the impact of policies, programs, and pressures affecting the people we were working with.

The year-by-year charts in appendix B group the activities by category. Year 1 focused primarily on assessment. Year 2 included many implementation activities, such as conducting a consumer involvement conference in each state and awarding a $3,000 subgrant to a group in each state in order to increase the planning and programming capacities of resource-starved organizations. During Year 3 we awarded a second round of subgrants. However, much of our work in Year 3 focused on evaluation; on going back to our 4-State people in an effort to discuss, draft, and finalize guidelines for a Model State Plan for Consumer Involvement in Rehabilitation (MSP/CIR); and on trying to draw some conclusions about the role of the disabled

self-advocacy movement in policy development. It may be useful to briefly review the methods and procedures that brought us from the objectives in the abstract to the activities we designed in order to achieve them.

We spent most of Year 1 assessing the terrain and reviewing literature on citizen participation. Our first step was to identify the actors who would be involved in the study. Our project was not conducted in a laboratory but in a policy environment colored, and sometimes torn, by issues which had a profound impact on people's jobs, people's families, and people's lives. Thus we had to get to know both those who made policies and those who sought to change them. Since our grant said we would provide technical assistance -- which is clearly a form of intervention -- we had to make sure that our relationship to the actors was responsible and supportive. More important, because we wanted to go beyond the catalyst model and to develop patterns and resources that would stay in place long after the project ended, we wanted to make sure that we did not take over the change mechanisms we helped fashion. If the people in the states did not claim ownership, those mechanisms would die. Similarly, although every project mailing encouraged advocates and rehabilitation officials to contact us if they had questions, suggestions, or wanted help, we did not foist our technical assistance on anyone. The funding level for the project placed harsh limits on the resources and assistance we could offer. Interestingly, though, demands from the field, particularly among self-advocacy leaders, varied considerably. Some only responded when we asked them for help. They helped us update our mailing lists, arrange meetings, line up speakers, and become participant observers in their civil rights struggles. Our project clearly benefited from the hard work of self-advocates and agency officials in all 4 states. Other leaders, however, put our offer to the test. They utilized our limited resources effectively and aggressively, and we feel that the self-advocacy efforts in their states benefited from those initiatives.

Along with identifying the actors in each state, we had to be able to describe their relationship to each other. We conducted on-site visits, held meetings in Washington, and kept in touch with the 4-State people by phone. Our interviews revealed a multiplicity of images of self and others, each presenting a different aspect of what agency officials thought about self-advocacy leaders, what those leaders thought about agency officials, and what self-advocacy leaders thought about each other. We found we were not dealing with two camps but with a rehabilitation/disability rights community of distinct interest groups which at times formed ad hoc alliances (in most cases on legislative matters) but which often resisted the kind of cohesion necessary for ongoing planning and coordination. In addition, we began to see that the degree and effectiveness of advocate involvement in rehabilitation planning depended on:

a) Whether agencies were sufficiently committed to consumer involvement to develop strong policy consultation plans, and

b) The strength of the self-advocacy community in the state.

TABLE 2 offers a far more formal presentation of this discussion. Phrased in yet another way, the two questions which emerged during Year 1 and continued as dominant themes were:

a_1) What guidelines can you use to evaluate the effectiveness of a policy consultation plan?

b_1) What variables influence the effectiveness of disabled self-advocacy groups?

In essence, these were the themes we examined during our 4-State Project on Consumer and Advocate Involvement in Federal and State Vocational Rehabilitation Program Planning. The first was addressed

as part of our effort to design a Model State Plan for Consumer Involvement in Rehabilitation (MSP/CIR). The MSP/CIR was designed through a six month survey process based on a modified delphi approach to collecting, analyzing, and refining data. For the first phase of our delphi survey we held meetings with members of the Council of State Administrators of Vocational Rehabilitation (CSAVR), RSA officials, and disability rights leaders. During these meetings we drew up a list of concerns which were then used for the second phase of the survey process -- i.e., developing a preliminary, open-ended questionnaire that was sent to approximately 40 rehabilitation officials and advocates. In phase 3, we used feedback from the preliminary questionnaire to develop an MSP/CIR topic outline. That outline was used by rehabilitation officials and advocates during ACCD's Conference to Design a Model State Plan for Consumer Involvement in Rehabilitation. The draft written by the conference participants constituted the fourth phase of the survey process. That draft was edited by ACCD's staff and sent to all participants. After analyzing the comments, we substantially revised the document and sent it out to approximately 200 officials and advocates. For the concluding phase of the survey, we reviewed all comments, made revisions, and issued the final draft. The final product, a description of the process, and a list of all those who contributed to it is contained in ACCD's publication, Participating Citizens.

We now turn to the second dominant theme of the project, the factors influencing the effectiveness of the self-advocacy community, in our review of the Proceedings from Cherry Hill.

TABLE 2

YEAR 1 ASSESSMENTS AND PREMISES

Target Group	AGENCIES	THE DISABLED SELF-ADVOCACY COMMUNITY
	(Discussion) Chapter 25 of the Rehabilitation Services Manual discussed the Federal mandate requiring State rehabilitation agencies to develop written plans showing how they will solicit and respond to the views of clients, advocates, and others involved in rehabilitation.	(Discussion) Studies from the Tufts-New England Rehabilitation Research and Training Center suggest that there are over 2,000 disability-related groups across the country.
Target Issue	CITIZEN PARTICIPATION	ORGANIZATIONAL INTEGRATION
	1. Agencies can display strong support for advocate involvement in policy development OR 2. Agencies can display ambivalent or negative (i.e., lack of) support toward advocate involvement in policy development.	1. Disability rights groups can demonstrate patterns of cross-disability communications that are relatively strong, that can be mobilized in legislative battles, and/or that reveal organizations with large memberships and ambitious projects (such as sponsoring peer support programs, searching for grants, etc.) OR 2. Groups may demonstrate difficulties in cross-disability communication in recruiting or maintaining members and in carrying out group business (such as having meetings several times a year, publishing newsletters at regular intervals, etc.).

Section 2: Conference Overview

The issues and problems discussed in our brief review of the 4 state histories are not unique; they emerge in other states as well. Dr. Frederick Fay, in fact, warned the conferees at the organizing retreat held in Worcester, Massachusetts that if their intent was to start a new organization they would probably wind up arguing about its name, its membership criteria, its meeting places, and its way of reaching out to others. Those, he said, were the topics the founders of ACCD struggled with and the founders of any group are likely to stumble over as they attempt to come together.

What makes the 4 states unique is that because they participated in a three year project on consumer involvement, they shared much of their organizing history with us and we were able to get back to them to ask questions and see how they felt about what they were doing. We undoubtedly have more complete records of what the 4 state people went through than most disabled activists have kept on their own activities. One of the characteristics of the disability rights movement has been that its leaders have been so busy fighting for change that they haven't had time to write -- or preserve -- their histories. As the 4-State project drew to the end of its final year, it became evident that we wanted more than just a record of what the participants thought they had done; we wanted a

framework within which to discuss, and perhaps even predict, factors influencing the effectiveness of the disabled self-advocacy community in the 4 states and other states as well. This goal became one of the themes of ACCD's 4-State Conference on Cross-Disability Constituency Development.

In planning the conference we convened an advisory group of people from the 4 states who had been working with disability rights groups for at least three years. All were active in efforts to promote cross-disability communication and cooperation; activities which ACCD refers to as "state coalition building." During the meeting, they talked about mobilizing disabled people, educating legislators and strengthening small, community-based groups. In essence, they were talking about politics; in much the same way that Max Weber talked about it as he addressed his students at the University of Munich 62 years ago:

> politics...means striving to share power or striving to influence the distribution of power, either among [nation] states or among groups within a [nation] state. ...When a question is said to be a "political" question, when a cabinet minister or an official is said to be "politically" determined, maintenance, or transfer of power are decisive for answering the questions and determining the decision or the official's sphere of activity.[2]

Although people from the 4 states seem to have accepted Weber's perspective -- that is, politics as influence -- their main concern was not defining "power" but, rather, examining the conditions, the skills, and the resources which affect how successfully different groups exert influence. When they looked at the topics of grassroots organizing, for example, they spoke not only about the importance of combating apathy but also about the importance of maintaining up-to-date mailing lists. It was this dual preoccupation with theory and technique -- with the need

for a framework of how power works, and the need for a review of what kinds of skills will help people plan and carry out objectives -- which dominated the planning meeting.

The workshop: The advisory group discussed the need to record the trials and achievements within the project states during the last three years, to help activists solve some of the difficulties they were now having, to give them diagnostic tools with which to identify organizational trouble spots, and to make a statement about both the science and the art of state coalition building. Weighing these topics, the group identified the following conference functions:

a) To provide a forum in which delegations from the 4 states could discuss histories of coalition building in their states (these histories would be written by the liaisons before the conference).

b) To use the conference as a training opportunity, particularly for transmitting recruitment and organizational skills.

c) To offer diagnostic (or, "troubleshooting") guidelines that help activists identify organizational problems.

d) To use the weekend conference as an opportunity to accumulate, synthesize and report the coalition building knowledge of the 4-State people.

The agenda reflected the planning discussions. We began with a history of coalition building in the 4 states. We also offered two training sessions (one on recruitment and one on management), a panel on the relationship between service agencies and self-advocates, and a session on the Cleveland Amendment, an important Congressional battle faced by the disabled community.

Before the conference, we developed a worksheet to be used as a disussion guide for the state caucuses that met during the first evening at Cherry Hill. The worksheet focused on the three phases of coalition building -- initiation, establishment, and maintenance -- and asked the caucuses to discuss the problems their state encountered during each phase. This document combined the findings from Coalition Building and feedback we had received throughout the three year project. (Note: the Agenda and Worksheet appear on the following pages)

We indicated earlier the dual preoccupation with theory and technique. At times during the conference it seemed as though the issues participants grappled with were closer to the "pitfall" list described by Dr. Fay than the cool, technician's agenda we developed. The following sections will try to recreate the intellectual struggles that transpired during our weekend in Cherry Hill. We began with membership. Why does this issue stymie so many coalition builders?

ACCD 4-STATE CONFERENCE ON CROSS-DISABILITY CONSTITUENCY DEVELOPMENT

	Friday	Saturday	Sunday
8:00		BREAKFAST	BREAKFAST
9:00		Training Session Management Principles for the New Leadership Class (Mike Zullo)	Reports from Writing Teams
10:00			
10:30		Issue Session The Helping Professions and the Self-Advocacy Movement (Panel)	COFFEE BREAK Work Session II
11:00			
12:00		LUNCH	LUNCH
1:00	Registration		
1:30		Diagnostic Session The Cleveland Amendment-Pressure Group Politics (Peter Myette)	
2:00	Conference Overview		Final Reports from the Writing Teams
2:30	Field Reports History of Coalition Building in 4 States		
3:00		COFFEE BREAK	
3:15		Work Session I Small Group Writing Teams-Guidelines/Issues on State Coalition Building	
4:00	Training Session Community Organizing-Concepts and Skills (Ira Resnick)		
6:00	DINNER	DINNER	
8:00	Issue Session Each state will caucus and identify key issues or problems	FREE	

WORKSHEET - VIEW FROM THE STATES

TASKS AND OBJECTIVES

The questions and issues on these pages are meant to serve as a guideline for the State Caucus. As you read through them, please feel free to add other items. This WORKSHEET focuses on three phases of coalition building:

I. Initiation, referring to that period of time when you or your colleagues first started talking about the need for better cross-disability communication and cooperation in your state;
II. Establishment, referring to that period when you began building a structure that would increase cross-disability communication and cooperation;
III. Maintenance, referring to current needs and objectives.

I. Initiation - Talking about statewide cross-disability communication and cooperation
   A. Arguments
      1. Which arguments on behalf of statewide cross-disability communication and cooperation seemed most effective?
      2. Which proved least effective?
   B. Definitions
      1. How did people define the term coalition?
      2. How did people perceive a distinction between a coalition and an organization?
      3. What other definitional problems arose in your state?
   C. ACCD
      1. During the initiation/discussion phase, was ACCD an issue in the debate?
      2. If so, please describe how ACCD was perceived?
   D. Barriers
      1. What were the main barriers to statewide cross-disability communication and cooperation?
   E. Other Issues
      1. Please describe

II. Establishment - Setting up a structure to improve statewide cross-disability communication and cooperation.
   A. Membership
      1. Did controversies emerge over whether to have organizational members or individual members?
      2. Did controversies emerge over whether organizations and or agencies controlled and staffed by non-disabled persons should be members?
   B. Outreach
      1. How did the core group inform people about their attempts to set up a structure to improve cross-disability communication and cooperation?
      2. Was most of the work for establishing a structure done by a core of individuals who were closely affiliated with one group or a core of individuals loosely affiliated with several groups?
      3. How was the core expanded?
   C. Recruitment
      1. How were additional members brought into the work of the new structure?
      2. How were new people informed about the activities, positions, and priorities of the new structure?
      3. Please discuss the strengths and weaknesses of your recruitment strategies.

continued.....

III. Maintenance - Current concerns.
   A. Decision Making
      1. Does your constitution or charter describe such matters as the role of officers; the role of board members, the number of board meetings per year, etc.
      2. Since the structure was first established, have perceptions about the role of officers, board members, and constituents changed?
   B. Planning and Implementation
      1. What types of problems emerge in identifying issues for action?
      2. What types of problems emerge in implementing policies?
      3. What types of problems emerge in informing members about policies that require action?
      4. What types of problems emerge in distributing tasks equitably in order to implement policies effectively?
      5. What methods are used to monitor implementation?
   C. Factionalism
      1. What topics or issues are most likely to cause factionalism?
      2. What methods are used to respond to factional disputes?
   D. Other

RESULTS:

PROCEEDINGS FROM CHERRY HILL

Section 1: Activism and Divisiveness -- The Early Skirmishes

Why do membership issues provoke such conflict? As Bill Scott, one of the conferees from New Jersey, told the group, "Membership is the first 'distribution of power' issue a fledgling group tackles. Membership criteria dictate who votes and how many votes they get."

The controversy emerges early, when the founders are trying to recruit allies while trying to preserve their original vision of the organization's purpose and structure. The first group of individuals invited to join the inner circle have their own visions. They are likely to lead busy lives and to have their own allies. If they are group leaders, they also have their own set of responsibilities. Getting involved in a new organization takes a physical and emotional toll. Thus, outsiders will want to know how much they can get and what kind of people they are dealing with. Initially, everyone is testing each other's mettle.

The Cherry Hill conferees were quite familiar with these early skirmishes and discussed them freely; more so, perhaps, than when they lived them out in their own states. A number of social scientists have pointed to the fact suggested above:

namely, that there are two facets of group life -- personal and programmatic. Since there have been many studies in this field, there have been many sets of labels to describe these two facets, including "affective vs. instrumental," "personal vs. programmatic," or "process vs. content." Researchers say that people in groups have two types of needs. Personal needs include the desire for companionship, recognition, respect, and support. Programmatic needs refer to the tasks and goals of the group. The researchers also tell us that group conflict can arise either when the personal needs are being frustrated or when the programmatic needs are. What's more, the so-called "personality clashes" between two or more people (fighting for recognition, respect or influence) can be as serious as ideological conflicts over what goals should be followed. Often it is difficult to tell which type of conflict is occurring.

Because many of us feel groups are supposed to "do things," to have a purpose, we sometimes downplay process factors. Students of organizational behavior suggest this attitude is a risky one which leads to too many surprises. They insist that in order to understand interpersonal relationships you must examine both facets. Their literature, in fact, often downplays content factors. The Self-Advocacy Workbook, by Nancy E. Gardner, offers a highly specific glimpse of the varieties of group needs. The Workbook was written for a segment of the disabled community that has generally been overlooked and often abused: persons with developmental disabilities. This population, many of whose members have been confined to custodial institutions most of their lives, is new to self-advocacy and to the protocols of self-governing groups. Chapter 8 of the Workbook talks about committees. But it mostly talks about people, and begins as follows.

> I think having committees in our self-advocacy group has been the biggest reason we have gotten so many things done. Sure, we've all spent time on group goals that don't have anything to do with the committees. But I don't think we could have kept everyone happy if we did not let people choose what they want to do.
>
> Our group has a lot of members who come mostly to see their friends, meet new people, and have a good time. We also have people in the group who want to change things about the way we live and get our rights by law.[3]

We have drawn attention to the process and content issue because it is very important to some of our pre-conference assumptions about offering guidelines to self-advocacy groups. As we indicated in Section 2, one of the objectives of the Cherry Hill conference was to develop "how-to" guidelines for coalition builders in other states; perhaps even to develop a "model." We found, however, that talking about why things happen is <u>at least</u> as important as trying to tell them how to do things. The issue of membership criteria is a critical one. However, it involves two dimensions. We can discuss content by examining the by-laws adopted by organizations in each of the states, by examining ACCD's by-laws, and by looking at other groups as well. But to rest with that approach, to write a report which is solely prescriptive, is to miss most of the story of this project.

As the conferees discussed the conflicts they had had with this issue, they did offer one recommendation. Leonard Sawisch (Michigan) said that their group had finally decided to appoint a committee and let them argue it out. Although some of his listeners laughed, they did so in the recognition that setting up a committee was, in fact, a very traditional way of handling conflict.

Analysts of organizational development often use the term "task avoidance" to describe discussions and controversies which never seem to be resolved. Quarantining a controversy in a committee can be a form of task avoidance -- or, it can be the best cure. Some indicators of whether or not the committee approach is working are:

1) Are committee members serious enough to meet and, if necessary, to keep scheduling meetings until they develop a report?

2) If they do not meet or do not develop options, what is the reaction of the leadership? Must every controversy be faced and settled? Membership criteria are so central to the purpose and uniqueness of an organization that the group's viability often hinges upon it. Other controversies, however, may not be.

3) Does the organization follow the recommendations of the committee? Does the organization choose one of the options presented or is the discussion that emerges so heated that the group tables the issue? This situation could indicate either that the issue was sent to committee prematurely -- cutting off debate before it should have been -- or that the group was not serious about resolving the issue in the first place.

Such early skirmishes can stall the work for which the organization was established. As Ira Resnick, a professional community organizer who led one of the conference sessions, told the group, "When you focus on internal stuff, you tear each other up. You've got to have an enemy."

Section 2: Incendiary Issues -- Must You Wait?

This section will review the topic of "precipitating factors" as it is described in the literature; as it was discussed by Ira Resnick, a community organizer; and as it was questioned by disabled activists who face the day-to-day responsibilities of keeping their groups ready for action.

First View: The Premise

What makes people march and struggle? The question has fascinated scholars, historians, generals and prophets throughout the ages, and has generated a large body of literature. Sociologist Neil J. Smelser[4] has identified six concepts central to the study of collective behavior:

1. Social conduciveness: This concept refers to the opportunity for people to interact. Professional groups such as a teachers' union or a patrolmen's benevolence association provide an opportunity for people with similar interests to exchange views. Black churches in the south traditionally served as centers of spiritual, social, and political life for people barred from other forums. Similarly, a number of today's disability rights leaders once belonged to peer groups organized primarily for social and recreational purposes.

2. Social Strain. Differences among identifiable groups (be they white and non-white, disabled and non-disabled, or party members and non-party members) with respect to such factors as yearly income, school enrollment, access to and quality of medical care, and other social indicators can serve as the source of unrest, and can, in some cases, lead to violence. Other factors, however, must also be present.

3. Growth and spread of generalized belief. Social strain and glaring inequities exist throughout the world yet do not automatically lead to rebellion. According to Smelser, one of the other six concepts that must be analyzed is whether there appears to be a growingly pervasive agreement among people about the causes of their plight. Have people developed a common interpretation of the social strain and its remedies?

4. Precipitating factors. Events, sometimes totally unexpected, sometimes the consequences of other, ongoing situations, can trigger mass action. The assassination of Martin Luther King, Jr. sparked riots throughout the country. Another example of the impact of precipitating factors was ACCD's efforts to persuade former HEW Secretary Joseph Califano to sign regulations implementing section 504 of the Rehabilitation Act of 1973. As noted in Coalition Building, the nationwide demonstrations and takeover of public buildings by disabled people was not precipitated by a single event but by a series of negotiation efforts, frustrations, and evasions.

5. Mobilizing for action. The possibility for mass action is also influenced by the degree to which there is a coordinated effort to organize immediately after people start reacting to precipitating factors. Some of this mobilization may be done by established leaders, while some may be carried on by new activists whose fervor -- or energy -- propels them into center stage.

6. Operation of social control. The way public officials respond to a riot, to a court decision, or, for that matter, to a natural disaster such as a hurricane can have a substantial impact on how crowds behave, on whether effective community leadership emerges, and on how people feel about each other long after the precipitating factors have ebbed.

Some caveats must be included with these six concepts. First, they are general propositions, not scientific laws. They may help us to describe reality, but not to measure it. For example, while

they tell us to look for indicators of social strain they do not offer scales to determine how much is too much. Similarly, they do not tell us how much ideological conformity there must be among people in order for their beliefs to be called "generalized." As we saw previously, sometimes it is difficult to distinguish between ideological conflicts and personality conflicts.

Second View: Creating Issues

One of the concepts which draws particular attention is that of "precipitating factors," for it implies that there are incendiary issues which can ignite even the most passive and oppressed communities. As Ira Resnick put it, "nothing helps you as much as the enemy."

During our pre-conference planning the advisory group asked us to include a training session on recruitment which would be led by a professional community organizer who had worked with minority groups and the poor. The advisory group felt that many disabled activists were so absorbed in the problems of their peers that they had not had the opportunity to be exposed to other segments of America's civil rights movement. The ACCD project staff first contacted the Washington, D.C. office of the Center for Community Organizations, Inc. This office gave us the name of several field organizers. After speaking with a number of them, we chose Ira Resnick to present the training session on recruitment. Ira works for one of the Archdioceses in New Jersey, primarily in an inner-city, multi-racial district.

Ira had discussed the idea of catalyst issues (i.e., precipitating factors), during his training session. It was during one of the open forums, however, that the

most dynamic exchange on this topic occurred. The conferees had been engaged in a long debate on membership and organizational structure when Ira stood up and started asking what 504 was and who was the person in the government designated to implement it. Many people spoke up, offering a lot of insider's information. One individual, for example, started talking about the Justice Department, saying that throughout 1979 there had not been more than 3 or 4 fulltime people assigned to 504 cases and cases involving the rights of handicapped children to public education. "That's what I need. That's an outrage. Now tell me how much of a case backlog there is at Justice." "Well, probably none. All the backlog of cases are at the Office of Civil Rights in the Education Department. They get the cases and then they don't want to give them up, so they never refer them to Justice. Only Justice can prosecute." Here, said Ira, was the information he had been missing, and he charged the group with being too intellectual. He said that throughout the weekend all people seemed to be talking about was legislation and court cases, whereas the folks he worked with in the blue collar neighborhoods of Jersey knew little about such matters.

Part of the reason why this group seemed to focus on facts, of course, had to do with the nature of their most recent battle. Section 504 of the Rehabilitation Act of 1973 said that no otherwise qualified individual could, solely on the basis of a handicap, be denied the services or benefits of any programs or agencies that received federal funds. Disabled people throughout the country had spent nearly a decade in courts, legislatures, and city councils trying to get this principle implemented. A number of those court cases sought to make transit systems usable by disabled people. In 1980, however, several Congressmen in the House and Senate began introducing legislation that would severely

jeopardize the prospects for accessible mass transit. The early version of one of these bills, the Cleveland Amendment, would have given local authorities such wide-ranging options that 504 would have become meaningless. (Note: the bill has gone through various changes.) This battle pitted the disability rights movement, which is largely an ill-financed, volunteer army, against the lobbyists of General Motors and the transportation industry, who were armed with volumes of industry-financed cost studies.

Still, the charge of being too intellectual came as a surprise to some conferees. Many disabled people feel that because they were a late entry to the forefront of the civil rights struggle other minority groups tend to be more politically sophisticated. The discussion on incendiary issues focused not on what people know but on why people march. Ira insisted that you had to have a target, and that issues had to be personalized. He said that you can rile them up with a story telling them how "one bureaucrat in Washington is keeping disabled people from getting a fair deal."

Ethan Ellis (New Jersey) remarked on the liveliness of the discussion. He told Ira, "last night I disagreed with you about the importance of personalizing issues, but you've proved your point today. When we started talking about the Justice Department, we stopped arguing among ourselves about organizational structure."

Clearly, Ira Resnick believed that one of the main jobs of a community organizer is to translate statistics, problems, and injustices into the kinds of precipitating factors that make people light a fire under city hall. During an informal gathering between sessions, Barbara Oswald (Massachusetts) gave another example of

personalizing an issue. She discussed an incident that took place in Seattle, where she had once worked as a community organizer. The city had ordered that a certain building be torn down. Under pressure from local activists, officials promised that the resulting debris would either be hauled away quickly or be broken into pieces no larger than 2 feet by 3 feet so as to limit the barriers that would be faced by disabled people. Soon it became evident that the construction crew was ignoring the agreement and the city was ignoring the complaints. Activists hired a truck and had a half ton slab from the construction site hoisted on to it. They painted the inscription "2 feet by 3 feet" on the slab and rode to city hall to deliver it to the mayor. The mayor apologized to the group, and took appropriate steps to fulfill his pledge.

Third View: Troop Preparedness

Theorists stress that precipitating factors are only one facet of collective behavior. During the conference some people suggested that at times it was over emphasized. John Chappell (Virginia), for example, asked, "What do you do in between the big issues? Sure, everybody likes to get involved in the glamouous stuff, but after a bill is signed or a court case is won you have to have people around to watch what's going on and to let others know if their rights are being trampled on."

These are the matters we will examine next. Specifically, what strategies promote troop preparedness?

Section 3: Bonding, Networking, and Associations -- Some Implications

At the pre-conference planning meeting our advisors stressed the need to provide management training to disabled self-advocates. As they discussed the movement, they presented a portrait of grassroots leaders which is far move complex than the term "volunteer" generally implies.

Most self-advocacy groups have neither paid staffs nor office space. The people who make these groups work serve as fundraisers, bookkeepers, secretaries, editors, grant writers, legislative analysts, arm twisters, and gurus to a large number of people whom society has left behind. The distinction between policy making and policy implementation which is considered so important in the corporate world is not as easily preserved among smaller, grassroots organizations, a fact which our advisors often stressed when they talked about the problems of implementing group decisions. Even as leaders are trying to develop plans and delegate tasks, the objectives themselves are at times being re-examined; leaving leaders wondering what went wrong: Was the original decision a mistake or was the plan to implement it so sketchy that the group became frustrated and wound up changing the rules.

During the conference Leonard Sawisch (Michigan) analyzed the distinction between structural issues and planning issues. He likened it to that between a set of by-laws and a plan stating

the organization's annual objectives. Whereas the by-laws are supposed to stand the test of time and to require few revisions, annual objectives are supposed to point to the changes that will take place. Both documents are successful to the degree that they further the purposes of the organization, yet they further them in different ways.

This distinction, together with our previous discussion on policy and personality conflicts, offers a framework to identify the management topics that concern the disabled self-advocacy movement as it enters the 1980s.

1) People. Management involves the way in which resources are utilized. Many groups start with only one resource: people.

2) Networking: The ability of a group to make the most of what they have, to find new resources, and to meet its objectives will depend largely on its ability to get information, give information, and stay abreast of the information glut.

3) Association America. Management styles in small groups, the rules of the game affecting associations, and the viability of any one particular group will be significantly influenced by a trend we are only now beginning to examine: the proliferation of small groups in America.

Bonding

Michael Zullo, an IBM executive-on-loan who served as director of ACCD's New York Office for one year, conducted the session on management training. He reviewed some of the key

principles taught in management seminars, giving conferees an opportunity to weigh the similarities and differences between the corporate sector and the grassroots.

Although we often picture the corporate world in terms of such phrases as "pyramids" and "chain of command," management textbooks place a surprising emphasis on one-to-one relationships, sometimes referred to as "bonding." As Mike told the conferees, "if you want somebody to do something for you, you can't just issue an order. You have to make sure you have that person's cooperation. The best way to determine whether you do or not is to talk to them directly."

Effective management, therefore, has a lot to do with getting accurate feedback. Most of the conferees saw the importance of bonding, for in their own work they had seen how solidarity among peers can stretch the seeming limits of endurance. However, were the differences between the corporate sector and grassroots organizations too great for other management precepts to apply? Weren't such concepts as "managerial authority" distinctly inappropriate to the grassroots scene? According to some management analysts, the characteristics of authority and responsibility will hold true for either setting.

When you delegate responsibility you are transferring authority. Therefore, insist the analysts, both you and the person working with you must have the same understanding of how much authority is being transferred. The notion of "delegating authority" is useless without the notion of "levels and limits of the authority conferred." The analysts list three levels of delegated authority:

1) Complete authority. A manager can give someone authority to make and carry out all decisions affecting an assignment.

2) Act and report. A manager can give someone authority to make decisions and then report back.

3) Act on approval. A manager can give someone authority to carry out specific tasks.

If a subordinate has a series of assignments, each may reflect a different authority level. Effective managers, therefore do not just delegate authority. Often what they do is negotiate the delegation of authority by finding out how much responsibility they and their subordinates are comfortable with. This process implies that the outcome will be determined by more than one person. It also implies that the manager's decision about which type of authority to confer will not be determined just by his/her relationship with a particular subordinate, but by observations culled from other work situations. Those observations, clearly, do not refer only to results, but to the assessments the manager should be making before an assignment begins, as it is being carried out, and after its conclusion.

Bonding, delegation of authority, and observation -- each a key to good management -- connotes orderliness and closeness. Yet the disability rights movement is not a corporate structure. It is a series of over 2,500 groups of people whose fates are, albeit loosely, tied and whose ability to reach given objectives often depends on the actions and inaction of others. How do these groups keep tabs on each other?

Networking

During our lab session on the Cleveland Amendment, we sought to bring together some of the many themes we explored in previous sessions. We also sought to bring the topic of cross-disability communication under a stronger lens.

As indicated, the early version of the amendment introduced by Congressman James C. Cleveland would have given communities so much leeway on how they would respond to the call for accessible transit as to almost encourage non-compliance. (Note: A full analysis of the Cleveland Amendment is beyond the scope of this report. However, ACCD has just issued two important publications on transportation: Access to Transportation, by Dr. Frank Bowe, and Full Mobility, by Dennis Cannon.) The Cleveland Amendment was one of several similar challenges to 504 introduced in Congress in 1980. During the lab session, Peter Myette discussed the Cleveland struggle from the vantage point of an ACCD staff person assigned to 504 issues, while Steve Janick (New Jersey) discussed it from the perspective of an activist on the state level.

The struggle tells much about how the movement operates, how Congress operates, and how industry lobbyists operate. The transportation industry has mounted an aggressive, well-financed campaign against 504; in the courts, Congress, and the press. Seizing on the public's anti-spending and anti-big government mood, they have tried to portray the issue as a confrontation between distant federal bureaucrats and oppressed local officials, and have steadfastly denied that they were taking a stand against policies designed to meet the transportation needs of disabled and elderly people.

The Cleveland Amendment was introduced without much fanfare. In fact, it was sneaked into the hopper. As disability organizations such as ACCD, Paralyzed Veterans of America, and Berkeley's Center for Independent Living began hearing about the Amendment, their first strategy was to delay consideration of the bill, and to alert other movement groups as quickly as possible. Newsletters and press releases

were prepared and distributed throughout the country, but printed material provides only the opening lines for a dialogue. It does not constitute the process of a dialogue. As Peter Myette, an ACCD staffer, indicated, most of that dialogue was carried on by phone. Local activists are busy trying to keep promises to the people they serve. They can't be ordered to set aside priorities -- they have to be persuaded.

Steve Janick's (New Jersey) first reaction to the Cleveland Amendment was an interesting one. He started hearing rumors, he couldn't get information quickly enough, he realized that whatever was going on was tremendously important, and he got scared. Steve did not consider himself a state leader at that time, though others do now, yet he seemed to be at the center of the year's most critical disability rights issue. What placed Steve at the center of the action? Time and a telephone.

Steve Janick had been working closely with the group that was organizing the New Jersey Coalition of Citizens with Disabilities (NJCCD). When he started hearing rumors on the Cleveland Amendment he did not want to be the only one with that kind of information and he called other leaders in New Jersey. Their reaction, in essence, was, "Keep on it, call me back." The more information he received the more he had to process and pass on, and the more time he took away from the issues he had been dealing with previously. Steve was the man who reported at small meetings, Steve was the man with the most information, and Steve, therefore, was the man in New Jersey most closely identified with transportation.

The role ACCD's national office staff played with respect to the Cleveland Amendment is similar to the one it played in 1976-77

with respect to the 504 regulations, and similar to the role played by Steve in New Jersey. In its first publication, ACCD described that process as a central, operational component of coalition building. Today, a number of people might refer to that process as networking. The shift in terms reflects some of the changes in America over the last four years.

Association America

The 4-State histories in Section 1 raised a number of issues which remained unresolved during the conference and which this report has left untackled. They include such questions as: what is the difference between a coalition and a group; what is an organization; and what is the difference between coalition building and networking? Some of these topics were examined in Coalition Building, and discussed in ACCD's by-laws. It may be useful to take a look at how the founders of ACCD saw their mission.

Most of the founders had strong ties to single-disability groups. They were not forsaking those groups, but merely trying to represent them in a new, wider arena. Some of those groups had paid staffs, and a few even had offices in Washington. ACCD was set up to be a loosely-knit coalition in which member organizations retained total autonomy. The criteria for active membership (i.e., a member organization which had voting privileges) made few demands. According to ACCD's by-laws, active members shall be consumer organizations which:

1) consist of and have a governing body composed of a majority of persons with physical and/or mental disability(ies) and their adherents;

2) are not state or local chapters of a National Active Member;

3) are non-profit organizations; and,

4) have purposes similar to those of the Coalition.

ACCD's founders were steeped in the politics of the '60s, in which succeeding waves of disenfranchized people shouted hastily written manifestos into borrowed loudspeakers and marched toward their place in the sun. By the end of the '70s, however, activism in America had changed. Janice E. Perlman, assistant professor of city and regional planning at the University of California in Berkeley, observes that the young radicals of the '60s were enveloped by fantasies of mass movements and mass uprisings. When those fantasies did not materialize, they were replaced by more pragmatic commitments to working for social change at the most basic and immediate level -- the community.[5] Today's activists are far more likely to be screaming about garbage collection than about war and peace and the redistribution of income.

In a sense, the disability rights movement is quite in keeping with the times. There are many more disability rights groups today than there were a decade ago. Self-advocacy and leadership roles are no longer associated exclusively with militants. Section 504 has opened a few professional jobs, including jobs in the service delivery system, to disabled people. These factors, in turn, have meant that disabled professionals are more likely to identify with the movement. We also find an increasing number of disabled people serving on advisory councils of public and private agencies. Friction between disabled providers and disabled

advisors, though neither serious nor new, is more apt to occur today than it was a decade ago. These provider and advisor roles do not guarantee anyone room at the top, yet do offer more access to the system, to information about grants, to news about jobs, and to rumors about scandals. Within the states, we see more professionals willing to open doors for a chosen few who happen to be activists, and more disability rights leaders 'anointing' a chosen few professionals by inviting them to serve as guest speakers and, at times, board members for self-advocacy groups. What we may be seeing is less than the politics of the "me" generation than of the "me and a few friends" generation.

Because we are talking about new trends, we really do not understand all of their implications. In terms of ACCD, the proliferation of grassroots groups raises fascinating questions with few answers. Uni-disability ties remain important. There is still a tendency toward legislative solutions which address only one need at a time. Yet the new groups are less likely to be the outgrowths of single disability milieus (i.e., the social group that first met in the special hospital, special center, or special school). Therefore, there is a possibility that tomorrow's divisive issues within the movement may be less along disability lines and more along regional lines.

The proliferation of grassroots may, at the outset, create management strains at the ACCD staff level. The 504 battle described in Coalition Building centered on the need to keep disability groups across the country abreast of a fast changing situation. Conceivably, as the number of groups increase the ability of ACCD to satisfy their communication needs -- as they perceive them -- may decrease. Yet the fact that the staffers assigned to the Cleveland Amendment issue were able to develop

relationships with activists such as Steve Janick suggests that perhaps networking will carry the banner for coalition building in the '80s.

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4. Ronald A. Hardert, et. al., Sociology and Social Issues, San Francisco: Rinehart Press, 1974, pp. 239-241.

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APPENDIX A

List of Conference Participants

ACCD'S 4-STATE CONFERENCE ON CROSS-DISABILITY CONSTITUENCY DEVELOPMENT

PARTICIPANTS

Massachusetts

Robert Alexander
Robert Berwaldt
Moro Fleming
Sylvia Glickman
Steve Goodwin
Allen Johnson
Sandra Loew
Dianna Melin
Barbara Oswald
Maggie Shreve
Enid Talambiras

Michigan

Pat DuFort
Bob Hill
John King
Ken Laux
Kathy Miller
Lee Nelsey
Len Sawisch
Wanda Stevens
Dale Winnie

New Jersey

Betty Broecker
Susan McCusker
John T. Cronin
Ethan Ellis
Larry Jaggars
Stephen Janick
Thomas Jennings
Beth Karp
Mike Lawrence
Diane Mutchler
Doris Popadick
Howard Roszel
Bill Scott
Bob Stout
Mary Sysesky
Ina White

Virginia

Frank Addison
Ina Bledsoe
Charles Bledsoe
Kathy Chappell
John Chappell
John Collins
Linda Field
Jerry Flowers
Martin Hancock
Barbara Harris
Sara Inscoe
Justine Maloney
J. J. Mooney
Norman Nelson
Pat White

Facilitators and Observers

Martin Benton
Maggie Malsch
Mark Mueller
Ira Resnick
Michael Zullo

APPENDIX B

Project Abstract

and

Year-by-Year Summaries

Room 817, 1346 Connecticut Avenue, N.W. • (202) 785-4265
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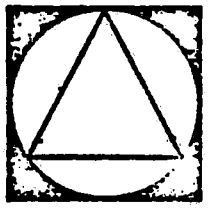

American Coalition of Citizens with Disabilities Inc.

CONSUMER AND ADVOCATE INVOLVEMENT IN FEDERAL AND STATE VOCATIONAL REHABILITATION PROGRAM PLANNING

Abstract

The American Coalition of Citizens with Disabilities, Inc., (ACCD) has established the feasibility of a national model of cross-disability communication and cooperation between organizations of and for disabled people (RSA Project 12-P-57948/3-01). ACCD now proposes to demonstrate the effectiveness of this model in producing improved consumer and advocate representation in the rehabilitation program planning process. The proposed project, which has full Council of State Administrators of Vocational Rehabilitation (CSAVR) endorsement, will focus upon needs identification and service delivery aspects of the planning processs on the national level and in five states. The project is expected to enhance consumer and advocate representation, lead to greater program responsiveness through such representation, document the benefits achieved by improved representation, and provide guidelines for other State VR programs to follow in effecting similar results. Annual surveys designed and conducted with CSAVR assistance will identify specific problem areas and provide objective bases for project evaluation. Improved consumer and advocate representation will be effected through the national ACCD office and State organization affiliates and will involve, inter alia, identification of program areas requiring greater consumer and advocate involvemen selection and referral of representative individuals who are capable of providing responsible representation, provision of technical assistance to rehabilitation officials and consumer and advocate organizations for the purpose of facilitating mutual communication and cooperation, and assistance in establishment of ongoing capacities on the State level for continuation of reponsible representation. ACCD will monitor project progress and collect systematic evaluation data with which to guide subsequent project work and to assess performance. Project findings will be reported in papers prepared for rehabilitation-oriented conferences and journals, in articles submitted to publications sponsored by consumer and advocate organizations, and in regular reports to the sponsoring agency.

YEAR 1 SUMMARY OF PROJECT COMPONENTS, ACTIVITIES, AND PRODUCTS

CONTRACTUAL COMPONENTS	ACTIVITIES AND PRODUCTS
ASSESSMENT	a) At least one on-site visit to each of the 4 States. b) Interviews with leaders of self-advocacy groups. c) Establishing liaison with one official in each state agency to maintain on-going consultation. d) Working closely with CSAVR Washington office staff to "test" 4-State feedback against national perspective. e) Convened one-day meeting with representatives of each of the rehabilitation agencies.
Implementation (activities to enhance involvement)	a) Clarification of Chapter 25 of the Rehabilitation Services Manual which required advocate involvement in policy development. b) Working with individual groups to determine how they could improve their patterns of involvement (as part of our efforts to ensure that as many individuals and groups as possible heard about our project and received project updates). c) At key junctures during the first year, we served as "listener-liaison catalysts" between the consumer groups and the agency to encourage greater consultation (i.e., to move toward greater patterns of power sharing).
Evaluation	a) Analyzed/synthesized results from an extensive literature review. b) Consultation with staff from the Research and Training Center of the Tufts-New England Medical Center to study results of their consumer involvement survey. c) Conducted a consumer involvement survey of 42 State rehabilitation agencies. (Survey supported in part by a short-term grant from the RSA Manpower and Training Division, grant #45-P-81285/3-01.) Project Products: a) Meeting of representatives of 4 State rehabilitation agencies. b) Survey of 42 State agencies (See Bowe, Frank G., "Approaches to Consumer Involvement." American Rehabilitation, Volume 4, Number 4, March-April 1979, pages 26-28. Reprinted in Varela, Rita. Self-Help Groups in Rehabilitation, American Coalition of Citizens with Disabilities, 1979).

YEAR 2 SUMMARY OF PROJECT COMPONENTS, ACTIVITIES, AND PRODUCTS

CONTRACTUAL COMPONENTS	ACTIVITIES AND PRODUCTS
Assessment	a) Continuous consultation with State agency liaisons. b) Pre-workshop meetings with State advocates and agency representatives.
IMPLEMENTATION (activities to enhance involvement)	a) Extensive pre-workshop cooperation with in-state advocates. Advocates in the 4-states help us assemble mailing lists so we could send out project updates, locate speakers and panelists, and design agendas. b) Consumer involvement conferences, one in each state. c) Specially designed material, in the form of a packet dubbed the CONSUMER INVOLVEMENT NOTEBOOK, containing fact sheets on Chapter 25 of the Rehabilitation Services Manual, the new Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978 (P.L. 95-602), and other material. d) Publication and distribution of Self-Help Groups in Rehabilitation and Planning Effective Advocacy Programs. e) Distribution of Coalition Building. f) Meeting with 4-state agency and advocate liaisons to discuss ACCD's subgrants component. g) Issues a Request for Proposals for a $3,000 subgrant. RFP was sent to all groups known to us in each state. h) Awarding and monitoring of one $3,000 subgrant to an organization in each of the 4 states. i) Began process (August, 1979) of designing a Model State Plan for Consumer Involvement in Rehabilitation (supported in part by a grant from the RSA Manpower and Training Division, grant #45-P-81345-3/09. Though the MSP/CIR process was begun during the second year, we have described it as a third year activity -- see below).
Evaluation	a) Conducted a consumer involvement survey during the 4 conferences. b) Designed a modified delphi evaluation strategy for the MSP/CIR process and conducted initial phases of the survey, meetings with State officials, RSA officials, and advocates (see, "EVALUATION," year 3).
	Project Products: a) Various pre-conference meetings. b) 4 consumer involvement conferences. c) Two publications, developed in part through support from the RSA Manpower and Training division. d) 4 subgrants.

YEAR 3 SUMMARY OF PROJECT COMPONENTS, ACTIVITIES, AND PRODUCTS

CONTRACTUAL COMPONENTS	ACTIVITIES AND PRODUCTS
Assessment	a) On-going consultation with State agency liaisons. b) On-going consultation with state advocates. c) Pre-conference meeting to discuss MSP/CIR and to plan the Cherry Hill agenda.
Implementation (activities to enhance involvement)	a) Conference to design a Model State Plan for Consumer Involvement in Rehabilitation (MSP/CIR). b) Awarding and monitoring second year of subgrants. c) Presentation of project findings at national and international forums. d) Consultation and technical assistance to state advocates on an "on call" basis. (All project updates encouraged people in the states to contact us if they had questions or needed assistance. Certain advocates utilized ACCD's albeit limited resources far more effectively and aggressively than others). e) Training provided in connection with ACCD's 4-State Conference on Cross-Disability Constituency Development.
EVALUATION	a) The process to design an MSP/CIR utilized a modified delphi survey approach which included the following phases: 1. Pre-conference meetings with CSAVR members, RSA officials, and advocates to generate topics; 2. Preliminary, open-ended questionnaire, shared with approximately 40 rehabilitation officials and advocates; 3. An MSP/CIR topic outline, used by the MSP/CIR conference participants to develop a preliminary MSP/CIR draft; 4. Dissemination of the preliminary draft and analysis of comments; 5. Development and dissemination of second draft, followed by analysis of comments. 6. Publication of final draft. b) The 4-State Conference provided an unusually rich source of data about the project, as is clear from the Conference report on the Proceedings from Cherry Hill. c) Analysis and comparison of the subgrants given during Year 2 and Year 3.
	Project Products: a) Conference to Design a Model State Plan for Consumer Involvement in Rehabilitation. b) Publication of Participating Citizens: A Model State Plan for Consumer Involvement in Rehabilitation. c) A 4-State Conference on Cross-Disability Constituency Development. d) Distribution of 4-State Conference report, Proceedings from Cherry Hill.

APPENDIX C

Issues in Consumer Involvement --

An Annotated Bibliography

ISSUES IN CONSUMER INVOLVEMENT
AN ANNOTATED BIBLIOGRAPHY

(Revised: November 1980)

Prepared by Rita A. Varela
ACCD Special Projects Director

The preparation of this document was supported in part by Grant #45-P-81295/3-01 from the Rehabilitation Services Administration, Office of Human Development, Department of Health, Education and Welfare, Washington, D.C. and Grant #12-P-57948/3-04 from the National Institute of Handicapped Research, Department of Education, Washington, D.C. It covers research originally performed from September 1977 to September, 1980. Its revision is part of the Special Projects Office's continuing commitment to knowledge transfer in the field of consumer involvement.

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Adams, Andrew. "Rehabilitation Consumerism: Confrontation or Communication and Cooperation?" Journal of Rehabilitation. Washington, D.C.: National Rehabilitation Association, January-February 1976.

Discusses the practical and philosophical underpinnings of the participation of disabled citizens in rehabilitation policy making. Adams examines how citizen involvement can improve the service delivery system.

America Rehabilitation. Washington, D.C.: DHEW Rehabilitation Services Administration, July-August 1978.

Special issue on independent living. Reviews the history of independent living as a program goal and as a consumer movement. Articles examine independent living models in Massachusetts, Texas, California, and other states. It also features a legislative overview.

Arnstein, Sherry. "The Ladder of Citizen Participation," AIP Journal. July 1969.

Arnstein warns against tokenism and argues that the quality of citizen participation improves when the power of citizens to influence government programs increases. She draws examples from federal programs in urban renewal, anti-poverty, and Model Cities.

Bartels, Elmer. "Consumer Involvement in the Rehabilitation Process." Mimeo. Bedford, Massachusetts: National Paraplegia Foundation, (undated).

Bartels discusses the benefits of consumer involvement to the disabled community and to rehabilitation professionals. He proposes a definition of consumer involvement, and offers guidelines for effective participation models.

Bell, Daniel V.J. Power, Influencé and Authority. Toronto: Oxford, University Press, 1975.

Bell examines these three concepts of political behavior from a communications perspective. His analysis is especially useful in describing the relationships between bureaucracies and consumer groups.

Birnbaum, Norman. Toward a Critical Sociology. London: Oxford University Press, 1973.

Birnbaum's reflections on man and bureaucracy challenge many of our democratic assumptions and serve as an interesting counterpoint to the work of Daniel Bell.

Blalock, Hubert H. An Introduction to Social Research. Englewood Cliffs: Prentice-Hall, 1970.

This basic text reviews many of the methodological problems involved in studying groups and public opinion. It provides a useful discussion of the role of participant observers studies in social research.

Bowe, Frank G. Handicapping America. New York: Harper and Row, 1978.

An intimate portrait of what disabled people face and feel. The book traces the struggle of disabled citizens and their families to eliminate barriers. It reviews the major judicial and political breakthroughs of the disability rights movement.

Bowe, Frank G. "On Severely Disabled Consumers and Rehabilitation." Remarks before the District of Columbia National Rehabilitation Association Conference, December 10, 1976. Mimeo.

Bowe summarizes the concerns of severely disabled individuals with respect to policy and client involvement, and points out the difference between legislatively mandated services and the services that are actually available. He offers suggestions for enhancing consumer involvement in rehabilitation.

Bowe, Frank G., Jacobi, Jan E., and Wiseman, Laurence D. Coalition Building. Washington, D.C.: American Coalition of Citizens with Disabilities, 1978.

A history and analysis of ACCD's efforts to design and implement a national model of communications and cooperation between self-advocacy, parent, and professional groups. The authors show that advocates of different disability groups can be brought together on key issues.

Bowe, Frank and Williams, John. Planning Effective Advocacy Programs. Washington, D.C.: American Coalition of Citizens with Disabilities, 1979.

This tool kit for self-advocates tells disabled people how to influence legislation, encourage coalition formation, apply for grants, conduct workshops and build year-round media programs. It is an invaluable source of ideas that can significantly enhance the self-advocacy movement.

Bradford, Leland P. Making Meetings Work. L. Jolia: University Associates, 1976.

This book, intended as "a guide for leaders and group members": examines the problems that emerge in all groups. Its chapters focus on leadership, interpersonal conflicts, and methods of promoting consensus. Bradford's work is based on the group dynamics theories developed by German psychologist Kurt Lewen.

Citizen Participation. Washington, D.C.: Community Services Administration, 1978.

Outlines theories and methods for increasing community involvement in publicly administered programs. The book also lists the citizen participation requirements within federal agencies.

Consumer Involvement: Rehabilitation Issues. Little Rock: Arkansas Rehabilitation Research and Training Center, University of Arkansas, June 1975.

This report begins by examining the federal regulations on policy consultation in VR programs. It then looks at the benefits and implications of consumer involvement in rehabilitation.

Cook, Terrence E. and Morgan, Patrick M. (eds.). Participatory Democracy. San Francisco: Canfield Press, 1971.

The introducation and readings give a comprehensive view of the history and philososphical controversies surrounding participatory democracy. Some of the authors argue that citizen participation is essential to keeping our society free and creative. Others insist that most community involvement plans offer only tokenism, never real power.

DeJong, Gerbon. "The Movement for Independent Living: Origins, Ideology, and Implications for Research." Boston: Medical Rehabilitation Institute, Tufts--New England Medical Center, 1978.

Reviews the history of the independent living concept as a social movement. DeJong contrasted the views which this movement generates about disabled people with the views which is generated by what he calls the "medical model."

Engstrom, George A. "Research and Research Utilization -- A Many-Faceted Approach," Rehabilitation Counseling Bulletin. December, 1975.

> Research is now a major industry in America. Unfortunately, application of research innovations, particularly in the rehabilitation field, is sporadic. Engstrom discusses some of the ways researchers can ensure that the results of their studies will gain greater attention among practitioners.

Fay, Frederick A. "Housing Alternatives for Individuals with Spinal Cord Injury." Reprinted from Selected Research Topics in Spinal Cord Injury in Rehabilitation. Washington, D.C.: DHEW Rehabilitation Services Administration, Research and Training Centers Task Force Project, July, 1975.

> Fay describes the problems that persons with spinal cord injuries face when they try to find accessible housing. Two alternatives are discussed: total accessibility of all housing units, and accessible group residencies. The author encourages expanded partnerships between rehabilitation professionals and self-help groups.

Fay, Frederick A. "Consumers Respond to Results in Rehabilitation." Reprinted from Rehabilitation and the Measurement of its Results. Washington, D.C.: Commission on Accreditation of Rehabilitation Facilities, 1973.

> Demonstrates how disabled self-advocates can play major roles in the planning, delivery and evaluation of rehabilitation services. The author stresses that providers should work with, rather than for, disabled persons.

Fiorito, Eunice K. "Advocacy and Constituent Relations." Washington, D. C.: DHEW Rehabilitation Services Administration, (undated).

> Fiorito's paper presents an overview of the traditional relationship between disabled citizens and rehabilitation providers. Often this relationship has fostered dependence among disabled citizens and paternalism among providers. Fiorito notes the new activism within the disabled community, and outlines the steps government must take to utilize the resources of the community and to improve service delivery systems.

Groenning, Sven, Kelly, E. W., and Leiserson, Michael. The Study of Coalition Behavior: Theoretical Perspectives and Case Studies from Four Continents. New York: Holt, Rinehart and Winston, 1970.

Especially valuable for its case studies, this collection of essays examines how coalitions are formed and maintained.

Hubbard, J. C., et. al. "Mass Media Influences on Public Conceptions of Social Problems," Social Problems. October 1975.

Explores the various stages in the evolution of social problems, from their emergence through their legitimization and finally to their institutionalization. Hubbard describes how bureaucracies and interest groups form around an issue and help to shape it.

Katz, Elihu and Danet, Brenda (eds.). Bureaucracy and the Public. New York: Basic Books, 1973.

The book represents one of the first efforts to collect articles on the factors that influence relationships between bureaucrats and clients.

Kelly, E. W. "Techniques of Studying Coalition Formation," Midwest Journal of Political Science. Vol. 12, 1968.

Kelly describes four characteristics of an on-going, effective coalition.

Kleyman, Paul. Senior Power: Growing Old Rebelliously. San Francisco: Glide Publications, 1974.

Kleyman traces the history of advocacy in the senior power movement. Although it focuses on one activist group in San Francisco, the author stresses that the broader the viewpoint of issues and constituencies, the more effective and practical the politics.

Krause, Elliot. "Functions of a Bureaucratic Ideology: 'Citizen Participation'," Participatory Democracy. Cook, Terrence E. and Morgan, Patrick M. (eds.). San Francisco: Canfield Press, 1971.

Argues that the chief beneficiaries of citizen participation plans are the bureaucrats themselves. Krause says that community involvement models do not give any real power to the citizenry but do serve to give the decisions of administrators a cloak of legitimacy.

Lehnen, Robert G. American Institutions, Political Opinion and Public Policy. Hinsdale: Dryden Press, 1970.

Gives an excellent discussion of the concept of "attentive publics." Lehnen notes that citizen involvement in public affairs is limited and selective. Some individuals do not take an interest in any public issues, while others are highly active and seek a role in various matters. There are, however, individuals who follow and focus on one particular set of issues and help determine how they will be discussed.

Mitrany, David. The Functional Theory of Politics. London: St. Martin's Press, 1976.

Mitrany is the founder of the "functionalist school" of political science. His assertion that groups come together through "the experience of rewarding common activity" served as one of the conceptual foundations for plans to create a European Community.

National Health Council, Inc. "Consumer Input -- Why?" Mimeo. (undated).

The article presents six practical and philosophical reasons for consumer input into health services planning and action. It emphasizes cooperative decision-making by health service providers and consumers. The article is representative of the impact of consumerism on the health services field.

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Discusses the impact of the Client Assistance Projects (CAP's) around the country. The report notes that although some VR counselors indicated initial anxiety over the idea of having an ombudsman serve as a facilitator between clients and agencies, the CAP's have improved services, led to greater client satisfaction, and won the endorsement of VR personnel.

Neufeld, G. R. "Advocacy: An Examination of its Interaction with the Human Services Delivery System," Advocacy Systems for the Developmentally Disabled. Bensberg, Gerald J., et al. (eds.). Lubbock: Texas Tech University Press, 1976.

Neufeld describes the maze of agencies that disabled persons and their families face when they try to get services. He argues there is a need to have advocates who can help cut through that maze.

"Policy Development Consultation," Rehabilitation Services Manual, Chapter 25. Program Regulation Guide RSA-PRG-76-7. Washington, D.C.: DHEW Rehabilitation Services Administration, September 1975.

Chapter 25 requires all state VR agencies to develop and submit a plan showing how they will solicit and respond to the views of clients and others interested in rehabilitation. Though Chapter 25 does not specify any model for consumer involvement, it does say that the plan must offer the chance for meaningful participation in policy making and service delivery.

Polling Magazine. New York: funded by the DHEW Office of Developmental Disabilities, Fall, 1976.

This issue of Polling Magazine emphasizes that persons with developmental disabilities should be involved in shaping the decisions that will affect their lives. The Magazine echoed the growingly assertive voice of disabled citizens struggling for self-determination -- struggling to define themselves.

Rehfuss, John. Public Administration and Political Process. New York: Charles Scribners and Sons, 1973.

Rehfuss explores the essentially political nature of bureaucratic decisions. He suggests that the relationship between bureaucratic and consumer/client is shaped by a range of factors, including the political power of the client or his representatives.

Remmes, Harold S. Consumer Advocacy: State of the Art. Funded by DHEW Rehabilitation Services Administration. Grant No. 16-P-57856/1-01.

This work reports on a consumer leadership conference held in April 1975. The conference, an advocacy project sponsored by the Massachusetts Council of Organizations of the Handicapped and by Tufts Rehabilitation Research and Training Center, brought together disabled self-advocacy leaders from across the country.

Remmes, Harold S. A Consumer's Guide to Organizing the Handicapped. Hyde Park: Massachusetts Council of Organizations of the Handicapped, (undated). Funded by DHEW, Grant No. 16-P-65800/1-08.

This excellent and readable work brings together the experience of more than twenty member groups of the Massachusetts Council of Organizations of the Handicapped and provides a tool for consumers who want to develop cohesive organizations. The book recommends alignment with the American Coalition of Citizens with Disabilities.

Riker, William. The Theory of Political Coalitions. New Haven: Yale University Press, 1962.

A basic introduction to the theoretical aspects of coalition building, this book examines the ways interest groups come together and develop a framework for joint action. Riker also explores the instability of political coalitions.

Shulman, Robert. "The Normalization Principle and its Implications for Residential Services for the Mentally Retarded." Mimeo. Department of Educational Psychology, New York University, Fall, 1974.

This paper traces the attitudes of society toward "deviants" and discusses the emerging principle of normalization of human services for mentally retarded persons in the United States. It stresses the need to have citizen advocates who can safeguard the rights of mentally impaired persons.

Silvert, Kalman H. Man's Power. New York: Viking Press, 1970.

Silvert analyzes the factors that shape people's political behavior. He looks at values, money, ethnic ties, and a host of other variables. This work is girded on the belief that individuals are not puppets, but rather creative, self-conscious beings who can and do design their environment.

Stearns, James C. "Crutch Power." Reprinted in Hearings on H.R. 8395, Senate Committee on Labor and Public Welfare, Subcommittee on the Handicapped. 92 Congress, second session, part 1, 1972.

The paper discussed the need for disabled people to unite and become their own advocates. Stearns also sheds much light on the political history of the rehabilitation legislation that Congress was debating in 1972.

Stewart, Larry, (ed.). Perspective in Education of the Deaf: Proceedings of the National Forum V, Council of Organizations Serving the Deaf. DHEW Rehabilitation Services Administration, 1972.

Discusses how effective leadership and involvement of deaf professionals and self-advocates can strengthen educational services.

Thoben, Patricia J. "Civil Rights and Employment of the Severely Handicapped," Rehabilitation Counseling Bulletin. Journal of the American Rehabilitation Counseling Association, June 1975.

Argues that architectural barriers, inadequate transportation, and employer bias severely limit the job options of disabled people. Thoben discusses how the civil rights movement among disabled citizens has helped to highlight these barriers. She also discusses the antidiscrimination provisions in the Rehabilitation Act of 1973 (P. L. 93-112).

Thursz, Daniel. "Consumer Involvement in Rehabilitation," Rehabilitation Record. Washington, D.C.: DHEW Rehabilitation Services Administration, September-October 1969.

Dr. Thursz' remarks appeared in a special issue of Rehabilitation Record that reported on the National Citizens Conference on Rehabilitation of the Disabled and Disadvantaged, held in June 1969. He warned that unless disabled people were given a meaningful voice in decision-making and new career opportunities in the service delivery system, they would continue seeing that system as an uncaring, ineffective bureaucracy.

Varela, Rita A. "Self-Advocacy and Changing Attidtudes," Public Awareness Viewpoints. Richman, Gary and Trohanis, Pascal (eds.). Chapel Hill: Developmental Disabilities Technical Assistance System, University of North Carolina, Spring 1978.

Reviews how telethons and public service announcements have depicted disabled people, and argues that self-advocates must be consulted and involved whenever agencies embark on community awareness campaigns.

Varela, Rita A. Self-Help Groups in Rehabilitation. Washington, D.C.: American Coalition of Citizens with Disabilities, 1979.

The book offers a panorama of what disabled self-advocacy throughout the country have done in such fields as peer-services, rehabiltiation policy development, and politics. It also discusses the implications of the self-help movement for the service delivery system.

Vocational Rehabilitation Manual, Chapter V. Washington, D.C.: March 25, 1949.

This Chapter, which has been replaced by Chapter 25, envisioned advisory committees as public relations vehicles for VR agencies. The difference between this Chapter and the mandate of Chapter 25 is striking.

White House Conference on Handicapped Individuals Final Report, Vol. 2, Part A. Washington, D.C.: DHEW Rehabilitation Services Administration, 1977.

This historic document reflects the views of hundreds of disabled persons, parents, and rehabilitation providers. Delegates to the White House Conference were chosen in meetings and caucuses held throughout the country. The volume also contains a minority report which reveals many of the attitudes of the militant sector of the disabled self-advocacy movement.

N O T E S

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