

Originally Processed With FOIA(s):

FOIA Number:
S

FOIA MARKER

**This is not a textual record. This is used as an
administrative marker by the George Bush Presidential
Library Staff.**

Record Group/Collection: Donated Historical Materials
Collection/Office of Origin: Frieden, Lex, Collection
Series: Disability Rights Organizations
Subseries:

OA/ID Number: 52053
Folder ID Number: 52053-002

Folder Title:
ACCD [American Coalition of Citizens with Disabilities] Disability Policy Papers [n.d.]

Stack:	Row:	Section:	Shelf:	Position:
	5	3	1	4

SAMPLERS FROM
ACCD'S SPECIAL PROJECTS OFFICE
A SERIES OF PAPERS DEVELOPED FOR
VARIOUS TRAINING WORKSHOPS HELD
BY ACCD

CONTENT:

- I. A REASON FOR KNOWING (S. ALINSKY)
- II. BACKGROUND REPORT: THE REHABILITATION, COMPREHENSIVE SERVICES,
AND DEVELOPMENTAL DISABILITIES AMENDMENTS OF 1978.
- III. BACKGROUND REPORT: POLICY DEVELOPMENT CONSULTATION IN STATE
VOCATIONAL REHABILITATION
- IV. ACCD FACT SHEET ON REQUIREMENTS FOR STATE PLANS ON INDEPENDENT
LIVING --- TO BE USED AS A WORKSHOP SKILL SESSION
- V. ORGANIZATIONAL OUTREACH FORM --- DESIGNED TO HELP AGENCIES AND
SELF-HELP GROUPS KEEP TRACK OF EACH OTHER
- VI. PROFILES IN ACTION
- VII. BIBLIOGRAPHY

A Reason for Knowing

"One of the great problems in the beginning of an organization is, often, that the people do not know what they want. Discovering this stirs up, in the organizer, that inner doubt shared by so many, whether the masses of people are competent to make decisions for a democratic society. It is the schizophrenia of a free society that we outwardly espouse faith in the people but inwardly have strong doubts whether the people can be trusted. These reservations can destroy the effectiveness of the most creative and talented organizer. Many times, contact with low-income groups does not fire one with enthusiasm for the political gospel of democracy. This disillusionment comes partly because we romanticize the poor in a way we romanticize other sectors of society, and partly because when you talk with any people you find yourselves confronted with clichés, a variety of superficial, stereotyped responses, and a general lack of information. In a black ghetto if you ask, "What's wrong?" you are told, "Well, the schools are segregated." "What do you think should be done to make better schools?" "Well, they should be desegregated," "How?" "Well, you know." And if you don't know, then a lack of knowledge or an inability on the part of the one you are talking to may show itself in a defensive, hostile reaction: "You whites were responsible for the segregation in the first place. We didn't do it. So it's your problem, not ours. You started it, you finish it." If you pursue the point by asking, "Well, what else is wrong with the schools right now?" You get the answer, "The buildings are old; the teachers are bad. We've got to have change." "Well, what kind of change?" "Well, everybody knows things have to be changed." That is usually the end of the line. If you push it any further, you come again to a hostile, defensive reaction or to withdrawal as they suddenly remember they have to be somewhere else.

The issue that is not clear to organizers, missionaries, educators, or any outsider, is simply that if people feel they don't have the power to change a bad situation, then they do not think about it. Why start figuring out how you are going to spend a million dollars if you do not have a million dollars or are ever going to have a million dollars - unless you want to engage in fantasy?

Once people are organized so that they have the power to make changes, then, when confronted with questions of change, they begin to think and to ask questions about how to make the changes. If the teachers in the schools are bad then what do we mean by a bad teacher? What is a good teacher? How do we get good teachers? When we say our children do not understand what the teachers are talking about and our teachers do not understand what the children are talking about, then we ask how communication can be established. Why cannot teachers communicate with the children and the latter with the teachers. What are the hangups? Why don't the teachers understand what the values are in our neighborhoods? How can we make them understand? All these and many other perceptive questions begin to arise. It is when people have a genuine opportunity to act and to change conditions that they begin to think their

problems through - then they show their competence, raise the right questions, seek special professional counsel and look for the answers. Then you begin to realize that believing in people is not just a romantic myth. But here you see that the first requirement for communication and education is for people to have a reason for knowing. It is the creation of the instrument or the circumstances of power that provides the reason and makes knowledge essential."

Saul D. Alinsky. Rules for Radicals. New York: Vintage Books, 1972, pp.104-106.

BACKGROUND REPORT:

THE COMPREHENSIVE REHABILITATION SERVICES
AMENDMENTS OF 1978 (P. L. 95 - 602)

(This Act may also be cited as the "Rehabilitation,
Comprehensive Services, and Developmental Disabilities
Amendments of 1978.")

Expanded Consumer Involvement: The requirement for consumer involvement in state VR agency policymaking continues in the 1978 amendments. However, this theme is repeated and underscored in the new legislation.

Comprehensive Independent Living Services: The major breakthrough of the amendments is that they authorize assistance to individuals "whose disabilities are so severe that they do not presently have the potential for employment but may benefit from Vocational Rehabilitation services which will enable them to live and function independently."

State VR agencies will administer programs for comprehensive independent living services. To qualify for the federal matching funds, the states must submit plans describing their strategies for providing these services. The legislation requires that "handicapped individuals shall have a substantial role in developing the State plan" for independent living.

If states establish or provide grants for independent living centers, the centers must "provide assurances that handicapped individuals shall have a substantial role in policy direction and management for such centers, and will be employed by such centers."

Client Appeals Procedures Strengthened: The amendments reaffirm the right of clients to help develop, and agree to, their Individual Written Rehabilitation Program (IWRP). Similarly, the amendments strengthen client appeals procedures. Clients may request reviews of decisions made by VR counselors and coordinators. State agency directors must establish procedures to review such decisions. If a client is not satisfied with state VR ruling he or she may appeal to DHEW.

The client assistance projects (CAP's) are expanded. There will be more CAP's throughout the country, and they will be able to utilize legal advocacy as a strategy for protecting the rights of clients. CAP's are still considered demonstration projects. State VR agencies are not required to establish CAP's. The federal mandate covering client appeals procedures is entirely separate from the program known as "Client Assistance Projects."

Developmental Disabilities Councils: The National Advisory Council on Developmental Disabilities was repealed by the 1978 amendments. A new body, the National Council on the Handicapped, will be created. The House and Senate conference report emphasized that "the developmentally disabled, and the parents and guardians of developmentally disabled individuals who are unable to represent themselves (should) be included in the membership of the National Council on the Handicapped, and that the National Council include within its functions concern with the needs of the developmentally disabled and advice on programs carried out under the Developmental Disabilities Assistance Act and Bill of Rights."

On the state level, at least one half of DD council members must be consumers --- that is, persons with developmental disabilities or the parents or guardians of persons with mentally impairing developmental disabilities.

Other Provisions: As the title of the legislation implies, the amendments are indeed comprehensive and change the VR concept from a program of evaluation, counseling, and training to a philosophy which seeks to access and blend the resources of many government agencies, many strategies, and many points of view. This new scope is obvious when we review some of the other provisions in the amendments:

- o National Institute of Handicapped Research (NIHR): The NIHR will identify research needs, set goals, and ensure that scientific and technological knowledge play a greater role in solving the problems of disabled citizens.

- o Employment Opportunities for Handicapped Individuals: This program, which will be administered by the Department of Labor, establishes community service pilot projects to employ disabled individuals.

- o New Authority for Architectural and Transportation Barriers and Compliance Board (ATBCB): The ATBCB will be able to set standards, bring civil action in U.S. district courts to enforce its orders, act as amicus curiae in compliance-related court actions, and provide technical assistance to agencies seeking to remove barriers.

- o New enforcement in nondiscrimination provisions: Title V of the Rehabilitation Act of 1973, which prohibited discrimination against disabled individuals in federal employment (section 501), in federal contracts (503) and in agencies and programs supported through federal funds (504) is significantly expanded to include the use of legal action in order to enforce these provisions.

BACKGROUND REPORT: POLICY DEVELOPMENT
CONSULTATION IN STATE VOCATIONAL
REHABILITATION AGENCIES

(Note: This material is excerpted from Chapter 25 of the Rehabilitation Services Manual. Chapter 25 requires state VR agencies to develop plans showing how they will respond to the views of clients and others concerned with rehabilitation. It does not mandate any specific model or formula, but rather sets the purposes and parimeters for meaningful involvement.)

Legal Basis: Section 101(a) 18 of the Rehabilitation Act of 1973 as amended. Code of Federal Regulations, Chapter IV of Title 45, Part 401, Section 401.19.

Requirements: The Rehabilitation Act requires that the State agency will take into account, in connection with matters of general policy development arising in the administration of the State plan, the views of individuals and groups who are:

- (a) recipients of vocational rehabilitation services, or as appropriate, their parents, guardians, or other representatives;
- (b) providers of vocational rehabilitation services; and
- (c) others active in the field of vocational rehabilitation.

The Regulations further require that the State agency will establish in writing and maintain a description of the methods to be used to obtain and consider such views on policy development and implementation, and will assure that such description will be available to the public.

o o o

Background: Over the past two decades there have been ever increasing efforts to provide and assure that the people and organizations directly concerned with public service programs, particularly the direct beneficiaries of the programs, have a meaningful voice in determining the way in which the programs are structured and administered. These efforts have been variously labelled as "citizen participation," "community participation," "consumer involvement," and "client involvement." While the labels may differ, they all have the same basic purpose--to give the people for whom the programs are designed full opportunity to participate in policy formulation and initial planning to assure that "their" programs are relevant to their needs and responsive to their priorities. This concept fits us well as a society for it is one form of participation of the governed in their government.

o o o

Functional Consultation Areas for Clients, Providers and Others Active in Vocational Rehabilitation: Through the views and advice of clients, providers and others active in vocational rehabilitation, the State Director and his staff can gain added insight into the State agency's effectiveness and efficiency in serving the disabled people in the State. In order to provide this input or external feedback, however, these three groups

of "advisers" must have meaningful participation in various aspects of the State agency's operations. Only with meaningful and genuine roles will these advisers, particularly the consumers, begin to identify the State rehabilitation program as "their" program and provide constructive suggestions for its improvement rather than criticism, censure or dissension. Anything less than substantive participation will be viewed as a sham, offering no assurance that their concerns, their views and their ideas will be taken into account.

o o o

Among the areas of program development and administration in which clients, their representative organizations, providers and other individuals and groups active in vocational rehabilitation should be assigned significant roles and in which they should work closely with the State Director and his representatives in presenting their views and recommendations are:

- (a) Program evaluations to identify strengths in services that would warrant further emphasis, gaps in services, general and specific effectiveness and efficiency of operations including the formulation of methods and techniques for improving the delivery of vocational rehabilitation services.
- (b) Program planning and program development--the planning of future programs and the expansion of current programs to close gaps in service or to improve the effectiveness of the program or programs.
- (c) Assistance in developing legislative proposals and budgets for submittal to the State Legislature, both in their preparation and follow through in hearings before the State legislative committees.
- (d) Assessment of the physical accessibility to the handicapped of all offices and facilities operated, supported or used by the State agency and, as required, formulating plans for making them accessible or more accessible.

- (e) Assistance in studies and surveys being conducted by the State agency or its district and local offices, i.e., data gathering, client sampling, and follow-up.
- (f) The interpretation of State agency policies and program services to their constituencies and to the public at large.
- (g) Assistance in the State agency's in-service training and staff development programs to aid staff in achieving greater understanding of client problems and attitudes, providers' problems and in maintaining better working relationships with organizations representing clients, providers and other people engaged in vocational rehabilitation.
- (h) Assistance to the State agency in whatever role it may have in State and local activities leading up to the White House Conference on Handicapped Individuals, and assistance to the State agency in the implementation of recommendations, having State relevance, resulting from such activities and conferences.
- (i) Assistance to the State agency in tapping and securing full utilization of the resources of other public agencies and of private agencies in meeting the needs of the handicapped, particularly the severely disabled whose economic, adjustment, medical, housing and other needs may be the responsibility of these other agencies.
- (j) Assistance to the State agency in implementing the 1974 Amendments to the Rehabilitation Act, requiring that the State agency and facilities in receipt of assistance under Title I of the Rehabilitation Act "shall take affirmative action to employ and advance in employment qualified handicapped individuals covered under, and on the same terms and conditions as set forth in Section 503."
- (k) Assistance in the establishment of specialized facilities and programs to be operated by consumer and other groups through funding by the State agency, to meet the special needs of the severely disabled applicant or client such as peer counseling, centers for independent living, halfway houses and other transitional living arrangements, transportation and post-employment services.
- (l) Proposing research to deal with unresolved problems in vocational rehabilitation, and to help assess research proposals in terms of their applicability to the needs and priorities of a particular group of handicapped people or to handicapped people in general.

ACCD FACT SHEET ON
REQUIREMENTS FOR STATE PLANS ON INDEPENDENT LIVING
PLANNING SESSIONS

The Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 significantly broadens the role disabled persons and advocacy organizations will play in both policy planning and service provisions. The independent living sections of the new law, for example, requires that handicapped individuals have a substantial role in developing the state plan for independent living. The law also requires that handicapped individuals have substantial involvement in planning, managing, and staffing independent living centers.

The following exercise focuses on consumer involvement in developing state plans for independent living. One of the key problems in implementing meaningful consumer involvement in VR decision making is distinguishing between policy issues and advocate issues. When advocates focus on issues, they focus on needs. When policy makers focus on issues, they focus on how to allocate manpower and funding resources within a system.

Your worksheet is divided into three columns. The first column, titled "REQUIREMENTS," is quoted directly from the new rehabilitation act. In the next two planning sessions, we will be asking you to discuss the policy issues and involvement strategies which may arise in implementing the requirements.

EXAMPLE

Requirement #7 reads, "provide assurances that handicapped individuals shall have a substantial role in developing the State plan." Some of the policy issues which may be involved in this issue are: a) What is substantial involvement? b) How much will substantial involvement cost --- that is, who will work with the advocates? How many groups or individuals do you have to contact in order to be in compliance? How many meetings does substantial involvement mean, how much follow-up, and how much secretarial assistance? Strategies for consumer involvement can cover a wide range of activities: Newsletters, workshops, advisory committees, efforts to put disabled individuals on the governing boards of state VR agencies, and contracts to consumer groups to conduct telephone surveys and outreach campaigns.

Every state VR agency will be asked to develop a state plan on independent living. We hope this exercise will help start you thinking about the implications, and opportunities, that task offers.

INSTRUCTIONS

Planning Session I (Tuesday)

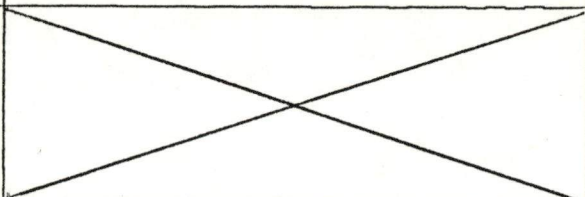
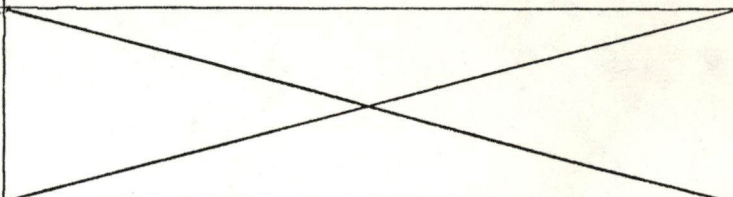
1. Choose a reporter for the group to take notes.
2. For the first 15 minutes of this session, read over the REQUIREMENTS (column 1) of your Work Sheet on State Plans on Independent Living. After reading them, each person should fill in the POLICY ISSUES (column 2) which he or she feels would be most likely to arise from each requirement.
3. Then, discuss the issues each participant has identified and prepare a report for the group.

Planning Session II (Wednesday)

Repeat the process for STRATEGIES FOR CONSUMER INVOLVEMENT (column 3)

WORK SHEET

REQUIREMENTS FOR STATE PLANS ON INDEPENDENT LIVING

REQUIREMENTS	POLICY ISSUES	STRATEGY FOR CONSUMER INVOLVEMENT
1) designate the designated State unit of such State as the agency to administer the programs funded under this part;		
2) demonstrate that the State has studied and considered a wide variety of methods for providing comprehensive services to severely handicapped individuals (such as regional and community centers; halfway houses, and patient-release programs) and that the State will provide, to the maximum extent feasible, meaningful alternatives to institutionalization;		
3A) describe the quality, scope, and extent of the comprehensive services for independent living to be provided to handicapped individuals under this part, and specify the State's goals and plans with respect to the distribution of funds received under part B of this title; and B) provide satisfactory assurances that facilities used in connection with the delivery of services assisted under this part and part B of this will comply with the Act of August 12, 1968, commonly known as the Architectural Barriers Act of 1968;		

WORK SHEET

REQUIREMENTS FOR STATE PLANS ON INDEPENDENT LIVING

REQUIREMENTS	POLICY ISSUES	STRATEGY FOR CONSUMER INVOLVEMENT
4) provide assurances that (A) an individualized written rehabilitation program meeting the requirements of section 102 will be developed for each handicapped individual eligible for independent living services under this part; (B) such services will be provided in accordance with such program; and (C) that such program be coordinated with the individualized written rehabilitation program, habilitation plan, or education program for such individual required under section 102 of this Act, section 112 of the Developmental Disabilities Services and Facilities Construction Act, and sections 612(4) and 614 (a) (5) of the Education for All Handicapped Children Act of 1975, respectively;		
5) provide assurances that the State will conduct periodic reviews of the progress of individuals assisted under this title to determine whether services provided to such individuals should be continued, modified, or discontinued;		

WORK SHEET

REQUIREMENTS FOR STATE PLANS ON INDEPENDENT LIVING

REQUIREMENTS	POLICY ISSUES	STRATEGY FOR CONSUMER INVOLVEMENT
6) provide assurances that special efforts will be undertaken to provide technical assistance to urban and rural poverty areas with respect to the provision of comprehensive services for severely handicapped individuals and describe such efforts;		
7) provide assurances that handicapped individuals shall have a substantial role in developing the State plan;		
8) provide assurances that not less than 20 percent of the funds received by a State under this part shall be used to make grants to local public agencies and private nonprofit organizations for the conduct of independent living services except that the Commissioner may waive the requirement of this clause if the Commissioner determines, on the basis of evidence submitted by the State, that such State cannot feasibly use the funds required to be expended under this section for the purposes of this clause; and		
9) contain such other information, and be submitted in such form and in accordance with such procedures as the Commissioner may require.		

Date of Entry for Contact Data: ____/____/____

ORGANIZATIONAL OUTREACH FORM

I. NAME OF ORGANIZATION _____
MAILING ADDRESS _____

ZIP _____
TELEPHONE NUMBER(S) (____)_____ (____)_____
CONTACT PERSON(S) _____

II. OFFICERS

<u>TITLE</u>	<u>NAME</u>	<u>TERM EXPIRES</u>	<u>TELEPHONE NUMBER</u>
_____	_____	_____	(____)_____
_____	_____	_____	(____)_____
_____	_____	_____	(____)_____
_____	_____	_____	(____)_____

III. PRINCIPAL ACTIVITIES, PROJECTS, PUBLICATIONS

IV. LOG OF CONTACTS

1. DATE: ____/____/____

PURPOSE AND OUTCOMES: _____

MEANS: _____ LETTER
_____ PHONE
_____ MEETING
_____ ON-SITE VISIT
_____ OTHER

(Enter subsequent contact data on following sheets or forms)

PROFILES IN ACTION

A series of papers illustrating the ways some people who have disabilities are facilitating the habilitative process.

THE NEED:

Lack of adequate housing has caused many elderly and disabled people to compromise their futures and restrict their vocational choice, and in too many instances has forced them prematurely into institutional residences.

National Center for a
Barrier-Free Environment

THE GROUP:

Handicap Housing Service, Inc.
230 Metro Square Building
7th and Robert Street
St. Paul, Minnesota 55101

Contact: Mary O'Hara
Staff Director
612/222-1813

THE GOAL:

Coming Home

o o o o

Even if one does have independent living skills, finding accessible housing can be a major ordeal. Plans for renovating houses abound -- in libraries, yes; but not always where one can get to them and talk about them with a contractor or landlord.

Handicap Housing Services, Inc. (HHS), a Minnesota group, was established as a result of frustration among consumers and of their need for usable, liveable housing. The group receives funds from the Department of Housing and Urban Development, as well as other public sources. Their approach, though simple and straightforward, is quite unique: After initial consultation with potential buyers, HHS acquires suitable property, prepares designs in accordance with the needs of the family, supervises the rehabilitation of the property to ensure that it will meet or exceed all applicable codes, and sells it to the buyers.

HHS staffers receive a variety of calls each day from disabled people and their families who need housing, who want to know about what

grants are available for renovations, and who have complaints about architectural barriers. The organization has received a contract from the Minnesota State Council for the Handicapped to produce a Housing Resource Book which will help persons throughout the state cope more effectively with these issues. In addition, HHS has worked with various state agencies, and with legislatures as well, to eliminate some of the obstacles which keep disabled citizens from participating fully in society.

THE NEED:

Perhaps the warning to "assume nothing" about a person with a disability until evidence and not inference holds sway can become a motto, a sobering reminder of the importance of holding those forces at bay that press toward "knowing" a person where, in fact, knowledge is lacking.

Beatrice A. Wright
Psychology Department
University of Kansas

THE GROUP:

Center of Handicapper Affairs
1026 E. Michigan Avenue
Lansing, Michigan 48912

Contact: Leonard P. Sawisch
Executive Director
517/485-5887
Voice or TTY

THE GOAL:

Friendship -- Action -- Change

o o o o

They call themselves handicappers, people who define their own degree of abilities. And, according to Leonard Sawisch, executive director of the Center, "handicappers are about the business of helping handicappers."

The Center of Handicapper Affairs, a peer support agency in Lansing, is funded partly through an HEW grant administered by the Michigan Bureau of Rehabilitation. Its chief activity is information referral. The staff compiles "who-what-where-how" data on housing, transportation, accessibility, civil rights, and various other concerns, and will publish a resource directory and an Access Lansing guide.

The Center is actively involved in outreach. Through its rap sessions, seminars, and one-to-one peer contacts, it provides opportunities for handicappers to interact, share, plan, and grow. Their newsletter keeps hundreds of citizens informed of major activities in the Lansing area and throughout the state. In addition, they have produced a television series entitled "We All Live Here."

That title vividly reflects the handicapper philosophy. In a letter distributed to the delegates of the White House Conference of Handicapped Individuals, the founders of the Center wrote: "We have all said or thought, 'Thank God I'm not mentally retarded or deaf or crippled or blind or deformed' each from our own sheltered perspective. When we tear down these internal walls, we will become the most powerful political and social movement in decades."

THE NEED:

"Architectural and transportation barriers are a major obstacle to the mobility of the handicapped, affecting all phases of life. Lack of accessibility to the work place and to public transportation is the problem many qualified individuals face in their attempts to achieve their employment goals."

Patricia J. Thoben,
U.S. Civil Service Commission

THE GROUP:

Mobility On Wheels, Inc.
1712 Glendon Avenue
Norfolk, Virginia 23518

Contact: Wm. Pat White
President

THE GOAL:

Access -- for ALL Citizens

o o o o

Like most consumer groups, MOW has many interests. There's one project, however, which they're especially proud of: their accessibility campaign in the Tidewater area of Virginia.

MOW set out to survey all public gathering places in the 4-city Tidewater area of Southeast Virginia (Portsmouth, Norfolk, Chesapeake, and Virginia Beach). Though this effort began as an all volunteer project, they now have eleven CETA-paid inspectors who go into the community. CETA also pays the salary of the project director and of a clerk. As part of the survey process, the inspector asks the individuals visited whether they intend to improve accessibility and if so, whether they would like technical assistance in order to make establishments accessible. According to Mr. William (Pat) White, over fifty individuals have accepted MOW's offer so far. "We expect 8-10,000 entries in the Guide we plan to issue," said Mr. White,

MOW has a membership list of over 500 people. Their newsletter keeps constituents and others informed on State and national legislation, programs, and coming events. Their accessibility survey, publications, and legislative advocacy shows their commitment to being active, concerned citizens, and that is how business and community leaders have come to see them.

THE NEED:

If the time that has been devoted to discussing avoidance of the /Rehabilitation Act of 1973/ or debating its financial implications could be applied instead to innovative thinking regarding compliance with the Act, then perhaps by next year at this time the phrase "employ the handicapped" might be more than just a motto clouded by uncertainty and controversy.

Carol S. Carter
Affirmative Action Specialist,
Pennsylvania State University

THE GROUP:

Disability Rights Center
1346 Connecticut Avenue, NW
Washington, D. C. 20036

Contact: Debby Kaplan
202/223-3304

THE GOAL:

Keeping Tabs on the System

o o o o

How effective are our regulations mandating affirmative action in Federal hiring practices? This is what the Disability Rights Center is trying to find out as it studies the implementation of section 501 of the Rehabilitation Act of 1973.

Currently, the Center is focusing on twelve Federal agencies. Project staffers survey the agencies through a series of statistical inquiries, interviews, barrier removal surveys, and affirmative action plan analyses. Debby Kaplan, executive director of the Center, finds that many of the individuals assigned to coordinating their agency's affirmative action program are not quite sure how to maximize their time and resources, and welcome a chance to talk with DRC interviewers. Thus, though the Center is engaged in a research project, it is involved in awareness training and advocacy as well.

The Disability Rights Center will be publishing its findings and recommendations soon, and hopes the report will serve as a catalyst to more effective affirmative action programs in Federal agencies. The most exciting aspect of the project, however, may be that it will show citizens on the state level how to monitor and facilitate compliance with affirmative action mandates.

The Center also has plans to publish two guides on how to use the newly issued complaint procedure for disabled applicants and employees of Federal agencies who are victims of disability discrimination. One guide will be written for attorneys, union representatives and other advocates. The other will be written for disabled people. The guides should be available from the Center in the fall.

THE NEED:

" ... only when we work together, the handicapped who are leaders, the handicapped who will always be dependent, the potentially handicapped child who wants to have that disability prevented and the non-handicapped adult leader ... can we continue to make even greater progress."

President Jimmy Carter

THE GROUP:

Florida Council of Organizations
of the Handicapped, Inc.
5201 Lazy Lake Lane
St. Petersburg, Florida 33708

Contact: Joseph Veisz

THE GOAL:

Environmental Accessibility and Legislative Advocacy

o o o o

Florida has one of the strongest coalitions of disabled consumer groups in the United States. The Florida Council of Organizations of the Handicapped has affiliate groups throughout Florida, and a voice in Tallahassee -- the State capital.

FCOH keeps someone in Tallahassee every day that the legislature is in session. But the legislature also hears from the FCOH people back home, who send in 300 to 400 letters, cards, and mail-o-grams during each session. FCOH tries to ensure that legislators serving on important committees hear from their disabled constituents. According to Joe Veisz, one of FCOH's best known advocates, "Public apathy is so widespread that seven or eight letters to the right senator can swing a vote."

FCOH has been very successful in fighting for increased VR funding, certain important categorical programs, civil rights bill, and the Early Intervention Program to provide better pre- and post-natal care. The Early Intervention Program was a high priority

issue for professionals and consumers alike. "You can't do it all from the State Capitol," says Joe. "You have to have people -- people who are organized, who get together with friends in local groups and talk about these issues. The guy in the legislature will want to know if there are folks back home who approve of the way he's spending their money."

THE NEED:

"Why wait until the applicant is severely impaired by the multiple handicapping effects of long-term, unattended disability?"

George N. Wright
American Rehabilitation
Counseling Association

THE GROUP:

National Paraplegia Foundation
Greater Milwaukee Area Chapter
3575 North Oakland Avenue
Milwaukee, Wisconsin 53211

Contact: Ellen Daly
Executive Director
414/332-3930

THE GOAL:

Preventing Irreparable Damage

o o o o

The newly disabled individual often feels alone, frightened, and very uncooperative. The folks at GMAC understand the plight of the person who must suddenly adjust to a spinal cord injury. They've been through that mill, and have uncovered two vital facts: First, that you can adjust. Second, that the sooner you get out of the hospital bed and begin therapy, the easier it is to prevent additional physical problems.

The first few days in the hospital can be crucial to the physical and emotional welfare of someone newly disabled with a spinal cord injury. GMAC is often asked, by family members of disabled individuals, to send a volunteer to the hospital and visit with the newly injured person and family. The GMAC staff has been running this peer support program for over ten years, and generally try to match the the volunteer and referral according to such characteristics as age, sex, marital status, and profession.

These volunteers can supply much more than a sympathetic ear. They know their business, and can often express critically important

opinions as to whether the newly injured person is getting proper medical attention. Insurance companies, who have a vested interest in preventing severity and getting people back to work, have learned to trust the GMAC volunteers. And so have the people they visit, who, years later, often say, "I couldn't have made it without you."

THE NEED:

"... it is probably technically possible to teach anyone who is reasonably alert and has some movement to work. The problem is the jobs."

Report of the Comprehensive Service Needs Study

THE GROUP:

Resources for Independent Living
3540 42nd Avenue
Sacramento, California 95824

Contact: David Pout
(916) 422-1733

THE GOAL:

An Affirmative Action

o o o o

According to David Pout, Peer Counselor of the Resources for Independent Living, there are a lot of myths about the disabled job seeker, and you can't always correct them by sending out "Hire the Handicapped" booklets.

RIL's job advocacy project is highly personal, innovative, and effective. RIL trains disabled persons to serve as job advocates. They visit prospective employers, collect data on hiring practices, and find out the organizations' labor needs. What jobs have to be done, what skills and abilities are required? In addition, advocates talk to the employers, telling them about studies showing the disabled workers have good performance records and low turnover rates.

RIL has worked with some of the largest enterprises in California. The key to RIL's effectiveness is that its policy of establishing one-to-one relationships with employers. After learning the company's needs, RIL searches through its lists to find suitable

candidates. RIL contacts them, and often helps them through the application and orientation process. This sort of outreach and follow through reinforces the idea that disabled citizens can be good advocates, good workers, and good friends.

BIBLIOGRAPHY

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 citizens' 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, Influence 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.

Bradford, Leland P. Making Meetings Work. La 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 introduction and readings give a comprehensive view of the history and philosophical 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.

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.

National Summary of Client Assistance Projects Annual Reports. Washington, D.C.: DHEW Rehabilitation Services Administration, March 1978.

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 anti-discrimination 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 Attitudes," 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.

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.