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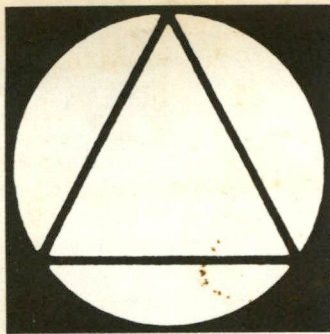
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The COALITION

VOLUME I, NUMBER 1 • Published by the American Coalition of Citizens With Disabilities • FEBRUARY 1977

ACCD—A Coalition. Thirty-six million Americans—one in six—are disabled by physical, mental, and/or emotional impairments. That these people, despite the diversity of their disabilities, encounter similar problems and share common concerns formed the central conviction from which the American Coalition of Citizens with Disabilities, Inc., (ACCD), emerged. Although still a young organization, the Coalition has already begun to demonstrate the wisdom of its 150 founders who were determined, as they assembled in Washington, D.C., early in 1974, that disabled people must unite, share resources, and forge an umbrella organization that would serve all disabled Americans, helping them to help themselves.

The charge to ACCD was twofold. First, the Coalition was to bring together people and organizations that had scarcely even talked to each other in the past, much less cooperated closely. A true coalition had to be formed, one which would advance its members' interests while channeling their contributions, one which involved non-disabled individuals and organizations for disabled people in support of its work, and one that facilitated cooperative planning and action on behalf of disabled citizens. Communication, cooperation, coordination: these continue to be key goals for ACCD.

The second charge delivered at the 1974 Washington meeting was for ACCD to represent disabled people to the government, to the private sector, and to the general public. Concerns common to many disabled individuals—improved education, expanded rehabilitation programming, accessible housing, effective transportation, civil rights, enhanced employment, self-determination and integration into the mainstream of American life—could best be served, the founders believed, by a united effort involving all disabled persons.

ACCD is an organization of organizations. National members include the American Council of the Blind, Epilepsy Foundation of America, National Association for Retarded Citizens, National Association of the Deaf, National Association of the Physically Handicapped, National Paraplegia Foundation, Paralyzed Veterans of America, Teletypewriters for the Deaf, and United Cerebral Palsy Associations. Active members, whether national, state, or local, are primarily consumer-oriented organizations. Associate members are organizations interested in disabled people but which do not meet the qualifications of active membership. Individual members are persons desiring to support the work of the coalition, and may be disabled or nondisabled.

An annual Delegate Assembly brings together representatives of active member organizations and individual members to determine overall policy for the Coalition and to elect officers and Board members. The Board, which meets quarterly, acts through task forces which focus upon specific issues such as housing, transportation, civil rights, education, and health, and through committees which handle essential Coalition business such as membership, fund-raising, public awareness, and by-laws. The ACCD home office, located in Northwest Washington, D.C., executes policy and conducts research and training projects which promise to improve services and enhance the quality of life for disabled people.

The Coalition's strength derives from its organizational and individual members. Through them, ACCD offers a ready resource to programs and activities seeking to serve disabled people and a convenient link with thousands of local, state, and national organizations of and for disabled people. The Coalition's many activities as a nationwide consumer-based organization require active participation of its members. Consumer involvement, itself an important goal of ACCD, is the foundation of its work and the channel through which the Coalition attempts to help disabled people help themselves.

A Model for Communication and Cooperation.

ACCD is exploring alternative organizational models for structuring coordination of activities on behalf of disabled people under a grant from the Rehabilitation Services Administration. The investigation emerged from a conviction that disabled persons, despite differences in impairments, share concerns in education, rehabilitation, employment, civil rights, transportation, housing, and other issues affecting their lives. The question being studied is how best to bring disabled people and their organizations together in joint efforts at enhancing the human rights and improving the quality of life for the estimated 36 million Americans who are disabled.

The model being developed will structure ACCD activities and will serve as guidelines for state coalition development projects throughout the country. The Coalition is researching both theoretical and practical aspects of potential models. The emerging design features "participatory management" and close ties with extra-disability forces. ACCD is attempting to involve its organizational members in all major operational initiatives, seeking their input and benefiting from their participation, both to represent their interests and to channel their activities effectively. Through task forces, committees, and ad hoc working groups, ACCD brings the expertise from its member organizations to bear on issues of common concern in the planning and implementation of programs and projects. Similarly, as an umbrella organization that brings disabled people together, ACCD goes beyond disability to enlist the support of other special interest groups having similar concerns. Close working relationships have been established with several civil rights groups, for example, which markedly enhance the Coalition's efforts in this area.

ACCD seeks to develop and demonstrate a model which permits its member organizations to maintain their full autonomy while offering them substantial benefits from joint activities and planning. Because of its broad constituency, the Coalition often is able to open doors through which to open minds. With the assistance of its member organizations and consultation with other supporting groups, ACCD is able to make the case that needs to be made both cogently and accurately. The model will provide a mechanism for disabled people to obtain and protect services and rights, while facilitating cross-disability cooperation and communication.

Confrontation on 504. The words are bold and starkly simple: "no otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance." Section 504 of the Rehabilitation Act of 1973, as amended in 1974, offers in these brief clauses the most comprehensive civil rights protection ever extended to America's estimated 36 million disabled citizens.

And it is arguably the most controversial piece of legislation ever enacted on behalf of disabled people. Because Federal financial assistance reaches into virtually every aspect of modern American life and because the language of Section 504 is so broad and far-reaching in its impact, these 40 words have enormous potential for enhancing the human and civil rights of disabled people. They also have the potential for creating considerable upheaval and mandating tremendous expenditures in programs and activities serving disabled people.

The words are law and have been since 1973. Without implementation, however, they are mere expressions of policy. Disabled people have already used these words as a basis for legal action demanding equality in service and nondiscrimination in employment but have met with mixed success. Regulations interpreting the language of Section 504 and providing guidelines for compliance and enforcement are urgently needed for the promise to become reality for the hundreds of thousands of disabled people annually seeking assistance in federally funded programs and activities.

And this is why ACCD worked closely with the Office for Civil Rights in DHEW to counteract the intense pressure of more than 600 institutions and organizations for weakened language and delayed implementation of the regulations. Together with its member organizations, ACCD succeeded in maintaining strength and integrity in the regulations, which are now in final form awaiting the signature of the Secretary of DHEW. We met with former Secretary David Mathews during his last days in office urging him, unsuccessfully, to sign the regulations, and have met with the new Secretary, Joseph Califano, and with Assistant Secretary for Human Development, Arabella Martinez, for the same purpose. Signing the regulations and implementing the law with vigorous enforcement efforts would demonstrate, more than any other step, the "new spirit" President Carter has promised. As this went to press, we had every reason to expect that Secretary Califano would sign the regulations.

The next steps are to ensure that the 92 positions appropriated for Section 504 implementation activities in the Office for Civil Rights are filled with disabled and nondisabled individuals experienced in work with disabled people and that a comprehensive enforcement effort is mounted that goes beyond mere investigation of complaints to compile systematic data that will serve as a basis for enforcement. The 92 positions, which are primarily in DHEW regional offices, remain largely unfilled. The need is both to fill them with qualified people and to ensure that these people devote a major share of their work to Section 504. Compliance with the law cannot be on a voluntary basis as previous experience indicates that the administration must clearly show its commitment to enforcing the rights granted to disabled people in the statute. Finally, other Federal agencies must follow DHEW's lead in preparing regulations for enforcement of Section 504 as it applies to their activities. ACCD will be monitoring these programs closely in an effort to protect the rights of disabled citizens to nondiscriminatory service and employment.

Other Regulations. Proposed regulations governing implementation of the Education for All Handicapped Children Act of 1975 (P.L. 94-142) were published in the *Federal Register* December 28, 1976. The law provides for school systems to adopt a "zero-reject" policy recognizing the right of disabled

children and youth to an education in a setting most conducive to their needs. The most comprehensive piece of legislation ever enacted on behalf of America's estimated 8 million disabled children, its full implementation requires the support and vigilant advocacy of disabled people in each State. ACCD urges its members to impress upon State and local education authorities the imperative need for compliance with the law.

The Education Amendments of 1976 (P.L. 94-482) extend the 1974 Amendments and require a 10% set-aside of vocational education funds for programming that benefits disabled students. Full implementation is vital. The nondiscrimination and affirmative action provisions of the Rehabilitation Act of 1973 protect only qualified disabled jobseekers and employees. P.L. 94-482, together with P.L. 94-142, offers the means for preparing disabled students for employment commensurate with their abilities and interests.

The Architectural and Transportation Barriers Compliance Board recently adopted final regulations governing its work in implementing the Rehabilitation Act of 1973, as amended, and the Architectural Barriers Act of 1968. The regulations provide that the nine Federal agencies affiliated with the Board promulgate their own standards for accessibility with the consultation and coordination of the Board. A layman's interpretation of the regulations is available from the Board or from ACCD.

Meet Our Board. ACCD is fortunate to have an illustrious Board of Directors composed of 14 nationally recognized leaders in rehabilitation, law, education, social work, and housing. President Eunice Fiorito, who serves as Director of the Mayor's Office for the Handicapped in New York City, needs no introduction. She has been the guiding force of the Coalition since its inception. ACCD's two vice presidents, Charles Estes and Frederick Fay, have made distinguished contributions to rehabilitation. Secretary Judy Heumann, a former Senate staff member, is Deputy Director of the Center for Independent Living in Berkeley, California, one of the nation's foremost comprehensive service programs for severely disabled individuals. Louis Rigdon, a lawyer who is currently on the White House Conference for Handicapped Individuals planning staff, is treasurer. Other board members are: Cheryl Davis, a housing specialist with the Massachusetts Department of Community Affairs; Gini Laurie, publisher of *Rehabilitation Gazette*; Jack Martin, disabled student coordinator in the University of Washington; Terrence O'Rourke, director of the Communicative Skills Program of the National Association of the Deaf; Roger Petersen, a psychologist who is on the staff of United Cerebral Palsy; Reese Robrahn, director of research and governmental affairs for the American Council of the Blind; Phyllis Rubenfeld, a social worker from New York City; Richard Santos, former director of the Center for Independent Living in Berkeley; and David Williamson, staff assistant in Programs for the Elderly and Handicapped of the Department of Housing and Urban Development. The board members, who serve without compensation, convene quarterly to provide direction for the ACCD home office.

. . . And our staff. ACCD Director Frank Bowe is a research psychologist who joined ACCD in September, 1976, as its first director. Author of the forthcoming Harper & Row publication *Handicapping America*, he holds a doctorate in educational psychology from New York University. Assistant to the Director Jan Jacobi brings to her position experience in learning disability, cerebral palsy, speech pathology and deafness. She received her masters from New York University and her bachelors from Northwestern University.

Transition. Never before had disabled people made their needs and convictions known so effectively or so early in a new administration. Inspired by Jimmy Carter's September 22 press release promising a new era of cooperation and consultation and by his appointment of a National Task Force on Disability, four representatives selected by an ACCD task force worked on the Presidential transition team during December, 1976, and January, 1977, coordinating input from organizations of and for disabled people, preparing position papers, and soliciting resumes of distinguished disabled individuals interested in government service. Larry Allison, Diana Elms, Al Pimentel, and Debbie Yager worked with the issues group and the talent inventory program staff on the transition, bringing the concerns and potentials of disabled people to the attention of top officials. The analyses they prepared and the recommendations they made are already influencing programs for disabled people. Equally important, a powerful precedent has been established for disabled people to be involved from the very beginning in planning programs that affect their lives.

In the Press. Gallery Place is a subway station in Washington, D.C., the only station in the system that remains inaccessible to people in wheelchairs. As such, it is a symbol of inaccessibility and a painful reminder of the years of struggle by disabled people for their right to transportation. After Richard Hedding filed suit against the subway builders, District Court Judge William B. Jones ordered Gallery Place closed until it was made accessible. Then, on December 14, 1976, a hand-delivered late-night waiver from the General Services Administration enabled the system to re-open the station, which it did, with little publicity and almost no advance notice, at 6:00 AM December 15. ACCD responded almost immediately, holding a press conference at the Gallery Place entrance at 1:00 that afternoon to protest the move and to reassert the determination of disabled people to stand firm on their right to accessible transportation. The subway builders have promised that Gallery Place will have elevators by July, 1977. We'll be the first to use them—or to protest if they are not there.

President Jimmy Carter expressed unusual sensitivity to disabled people and their concerns during his campaign. He named a National Task Force on Disability and issued a press release September 22, 1976 promising a new era of cooperation and consultation between government and disabled people. After the election, ACCD began to work with Carter transition officials to implement the promise. We placed four volunteers on the transition team and made available to Carter's aides the resources of the Coalition in planning improved services and programs for disabled people. After months of behind-the-scenes work, however, we became concerned about the extent to which the input our member organizations had provided was receiving the serious consideration it merited by high-level transition officials. While Mr. Carter and his assistants were promising new directions in services and appointments in key policy-making positions for women and members of racial minority groups, no such statements had been made concerning disabled people.

On January 7, 1977, ACCD held a press conference at the Metropolitan Hotel to stress the willingness of disabled people to assist the new administration in its efforts to comprehend and to meet the needs of disabled citizens. Soon thereafter, representatives of disabled people were being consulted on major administration decisions of importance to them. In his September 22 press release, Carter said: "In the next administration, the disabled will be active partners in our attempts to achieve our common goals—full civil rights, full personal dignity, and full human happiness for all Americans who are physically or mentally disabled." The process has begun.

Inauguration. As January 20, 1977 approached, ACCD received an increasing volume of requests for information about accessibility features of the inaugural ceremony and the parade to follow. Soon after we brought the desire of numerous disabled people to attend the inaugural to the attention of the Inaugural Committee, Peggy Smith of the committee staff requested ACCD assistance in making appropriate arrangements. Because of the joint efforts of disabled volunteers and the committee staff, several thousand disabled people were able to participate fully in the inaugural events. Three specially equipped areas were reserved for people in wheelchairs and more than one dozen sign language interpreters were provided for the benefit of deaf people.

Transbus. In 1974, the Urban Mass Transportation Administration of the Department of Transportation began reviewing prototypes for the TRANSBUS project, a \$27 million program designed to develop "the bus of the future." Three competitors submitted entries: General Motors, the dominant force in the industry; Flxible, its chief competitor; and AM General, a division of American Motors, which had just entered the field. Then, in May of 1976, the White House announced that TRANSBUS funds would be terminated. Because Flxible and AM General could not continue development efforts without Federal support, the decision effectively declared General Motors the victor. Then, in July, final regulations for bus design were released which made accessibility optional rather than mandatory. In protest, twelve groups led by Disabled in Action of Pennsylvania filed suit against the UMTA, charging that under P.L. 93-643 projects and programs approved by the Administration must provide for accessibility to disabled persons. ACCD joined the suit as *amicus curiae* and has supported the plaintiffs in their efforts to achieve an important precedent for accessible transportation. DIA President Sieglinde Shapiro put it well when she said: "We're not asking for any special place to sit . . . we just want to be able to get on the bus."

New Initiatives. The rights ACCD seeks to help disabled people obtain and protect are monumental in their simplicity. The right to education, to housing, to employment, to transportation, to health care. We remain convinced that the most urgent need is to secure comprehensive implementation of laws already on the books, legislation unparalleled in our nation's history but laws that are meaningless without enforcement. The affirmative action clauses in Title V of the Rehabilitation Act of 1973, as amended, offer one example. So, too, does the architectural and transportation barrier removal legislation. We will continue to monitor implementation to ascertain that the rights guaranteed in the law for disabled people are protected.

We plan a number of new initiatives. Led by Board members Cheryl Davis, who has done some exciting experimental work in Massachusetts, and Gini Laurie, editor of the recently published Harper & Row text, *Housing and Home Services for the Disabled*, we plan to work for accessible housing for disabled people. We also want to get out some publications alerting disabled people to their rights under recent legislation, because we are convinced a fully informed population is the best safeguard for protection of the human and civil rights of disabled people. State coalition development, together with leadership training seminars, are important next steps in developing the capability of disabled people to plead their own causes and protect their own rights. We also plan to work for the implementation of the recommendations of the White House Conference on Handicapped Individuals to ensure that this historic conference leads to important gains for disabled people.

The involvement and support of disabled and nondisabled individuals concerned about the rights of disabled Americans is vital. You may contribute to the Coalition's work by becoming an individual member and by participating actively on the national, state, and local levels in programs sponsored by ACCD and its affiliates. Individual membership is \$5.00 annually. Organizations are also welcomed. Contributions are tax-deductible. To receive more information or to apply for membership, please fill out the form below.

Delegate Assembly. The third annual ACCD Delegate Assembly will be held May 20-22, 1977, at the Sheraton-Park Hotel

in Washington, D.C. The meeting is scheduled for the weekend preceding the White House Conference on Handicapped Individuals, which will also take place in the Sheraton-Park. The Delegate Assembly is responsible for approving new organizational memberships, officially adopting the budget, electing members of the Board of Directors, selecting officers, and establishing overall Coalition policy. Representatives of active members and individual members may vote on resolutions presented to the Delegate Assembly. Other participants, while not eligible to vote, are welcomed. Registration packets may be obtained from the ACCD home office by completing the form below.

**American Coalition of
Citizens with Disabilities**
1346 Connecticut Avenue, N.W.
Washington, D.C. 20036

- ☐ Please enroll me as an individual member. I enclose \$5.00 dues and \$_____ as a contribution to support the work of ACCD.
- ☐ Please send me a registration packet for the annual Delegate Assembly.
- ☐ Please send me information about (please specify).
- _____

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First Middle Last

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REHAB BRIEF

BRINGING RESEARCH INTO EFFECTIVE FOCUS

Choosing An Independent Lifestyle: Housing Alternatives for Severely Handicapped Persons

Vol. 1, No. 5

May 25, 1978

A paraplegic girl sees herself as "a veritable vegetable trapped in a back room up two flights of stairs."

How did she get there? Through a cycle that has become typical: a person suffers a broken neck. The person may leave a rehabilitation center as a functionally independent individual. But there is nowhere to go except to an institution, which enforces dependency. Thus, the person loses rehabilitation gains.

The problem of housing severely handicapped individuals has reached major proportions. Because elderly persons now live longer than previously and many people survive serious accidents, millions of severely handicapped Americans need housing alternatives to institutionalization.

No universal solution to this housing problem exists. Because society is unprepared to cope with handicapped individuals, they are frequently shut away in institutions, even though with adequate support services they could live independently.

A severely handicapped individual who leaves a nursing home has an increased feeling of worth, independence, and accomplishment. Related to this improved self-image are increased possibilities for employment and education.

When severely handicapped individuals do not achieve independence, the costs become staggering. For example, for spinal-cord-injured individuals alone, they amount to \$2.4 billion nationwide for home and institution care and medical costs. It costs anywhere from \$2,500 to \$7,500 to care for a totally disabled spinal-cord-injured person in an institution.

SEVERAL HOUSING SOLUTIONS ARE POSSIBLE

Various groups and individuals have attempted to provide housing alternatives to living in institutions. The ideal solution would offer the handicapped individual total accessibility to the entire community. We are far from this goal, since less than one percent of U.S. housing has wheelchair accessibility.

A nationwide campaign for the elimination of architectural barriers is necessary for the achievement of community accessibility. Such a campaign is not effectively underway, although some recent developments point to growing recognition of the need for accessible commu-

nity facilities. And the Architectural Barriers Act (Public Law 94-80), which requires accessibility in Federally financed housing built after 1968, is being more strictly enforced. Sections of the Rehabilitation Act of 1973, as amended, hold promise for increased accessibility to community activities (504) and strong compliance procedures (502).

Revised Accessibility Standards

The American National Standards Institute (ANSI), a federation of trade associations, technical societies, and professional and consumer groups, has set standards for making buildings and facilities accessible to physically handicapped persons. ANSI is revising these standards, which, for the first time, will include specifications for construction of residential structures. The new standards are scheduled to be published in 1978. The Department of Housing and Urban Development (HUD) plans to initiate the building of model units that meet the new standards in order to determine if such units will be marketable.

CAMPUS-BASED HOUSING ALTERNATIVES

In this country housing experiments have stressed helping the handicapped individual function at as high a level as possible and providing the least restrictive environment. Not surprisingly, many such efforts have been on college campuses and have involved young adults with high levels of motivation and ability.

The University of Illinois—Urbana-Champaign

Started in 1947 for a handful of handicapped students, a project at the University of Illinois now houses hundreds of students. This program gives students barrier-free access to all aspects of campus life. In the past 30 years, students have lived in a variety of housing facilities, including a nursing home, a transitional halfway house, a mobile home, army barracks, campus dormitories, and community apartments.

The University offers such support services as medical consultation, physical therapy, occupational therapy, counseling, and specially designed buses accessible to wheelchairs. Handicapped students are not assigned

attendants automatically, but only if they really need assistance.

After a week's crash course in independent living, several C5-C6 quadriplegic students have moved into dorms with no attendant care. Those not ready to live independently move into Tanbrier Halfway House, which provides apartments for able-bodied students who help with attendant care.

The University of California—Berkeley

The Physically Disabled Students' Program grew out of a residential program for quadriplegic students that used an on-campus hospital as a dormitory. Created and run by disabled students, the program provides such services as arranging for living in relatively unmodified apartments with backup attendants for emergencies and a 24-hour telephone service using speaker phones. Lists of apartments and of prospective attendants and cooks assist students in arranging to share apartments and services. Program staff also contact apartment managers about making small necessary physical changes in their apartments. Students share their knowledge and experience in cooking, living independently, medicine, equipment, and preventive care. The Berkeley Physically Disabled Students' Program office provides services including resource directories, peer counseling, and advocacy.

The Boston Center for Independent Living (BCIL)

Started in 1974 for nine severely disabled college students, the BCIL served 50 individuals in its first 3½ years. The Center's emphasis is a program rather than a facility, to help disabled persons bridge the gap between total dependence and independent living.

BCIL coordinates three separate phases of living. A transitional living program trains residents of an apartment complex in social and physical skills. Cluster housing in modified apartments with an attendant pool and night attendants provides greater independence than the transitional program. To live independently, students moved to accessible apartments, usually shared with an attendant.

BCIL residents elect the Board of Directors, and several disabled persons, including former residents, are on the staff.

The Center for Independent Living has obliterated the lock and knocked the cage door off its hinges. It has shown me that there is a functional difference between merely existing and living for something brighter; the challenge of being individually responsible for my own actions. This is what I was prevented from doing before I came to BCIL.—Walter Zarnowski, the first resident of BCIL.

GROUP RESIDENCES

Should severely handicapped persons live in group residences, or should they be integrated into community housing? A matter of much debate, this issue remains

unresolved. Three groups appear to benefit from some sort of group residence, such as hostel, halfway house, motel, dormitory, clustered housing, congregate housing, or commune. High-level quadriplegic individuals (C2-C4) may need skilled nursing care as well as attendant care and housekeeping. A group residence helps them to share costs. Many disabled persons use the group residence as a transitional facility where they can get peer counseling while learning independence. Others simply prefer life in a sheltered facility.

Integrated housing helps the disabled individual feel more a part of the community and promotes independence. One of the few studies of preference suggests that most disabled persons, particularly those who are young and severely disabled, prefer to live among able-bodied people. However, many segregated housing approaches have been successful.

Eastern Paralyzed Veterans Associations (EPVA)

With the philosophy that "any realistic housing program must integrate disabled individuals with the mainstream of society," The EPVA set up Rosogin House. It serves as a transitional facility that attempts to complete the rehabilitation process while integrating disabled individuals into society. It began with three apartments for veterans with spinal cord injuries who wanted to leave a hospital or had unsatisfactory housing. Residents, who stay an average of 6-9 months, share costs. Publicity from this project has made the EPVA a clearinghouse for wheelchair apartments.

There are men living in veterans hospitals who could hold down a job or go back to school and get back to the business of living if they had a place to live.—EPVA President Terrence J. Morkely, a quadriplegic.

Individual-Created Programs

A quadriplegic victim of poliomyelitis created an independent living facility out of an apartment building that was being foreclosed. He hires the staff, and residents pool funds to pay for attendant care. The disabled residents live on the first floor, with attendants and five community families on the second floor. The manager of this project says that it would be practical if the residents owned the complex, and they are seeking funds to purchase it.

A woman disabled by rheumatoid arthritis created the Glass Mountain Inn, Inc. in Anaheim, California. The 10 disabled men and women and their 5 attendants form a close-knit and supportive "family."

Handicapped Independence Proven is a business project created by a San Diego contractor. He converts existing facilities into duplex units that include resident attendants and housekeeping staff for small groups of disabled persons.

COMBINED GROUP RESIDENCES AND COMMUNITY INTEGRATION

Cooperative Living—Houston

Begun in 1972 as a residential project in a dormitory-style setting, this project entered a second phase with housing clusters in apartments in different sections of Houston. The project initially tested ways disabled persons could share services, such as attendants and transportation. It also attempted to assess the changes this different lifestyle would bring in resident behavior and attitudes. The results documented changes in physical independence, medical status, educational and/or vocational activities, leisure activities, social relationships, patterns of interaction, economic status, and attitudes.

By Sept. 1975, all residents had moved from the dormitory building to apartment clusters in the community or into individual living arrangements. As an outgrowth of this program, four housing clusters were developed in community apartments.

A second major outgrowth of the original Cooperative Living project is a 6-week live-in transitional program to teach independent living skills. This project, called New Options, offers training modules in living arrangements, attendant management, financial management, functional skills, sexuality, consumer affairs, mobility, medical needs, leisure time, and vocational/educational opportunities. The program emphasizes field trip experience, and active handicapped persons from the community lead many program activities.

TOTAL COMMUNITY INTEGRATION

Center for Independent Living (CIL)—Berkeley

Generally considered the country's most effective self-help program for physically handicapped persons, this innovative program was created and directed by and for physically disabled and blind persons. It does not offer a residential center. Instead, CIL members live throughout the community in homes and apartments. The program was founded in 1972 as a logical outgrowth of the Physically Disabled Students' Program at the University of California, Berkeley.

The Center provides many services. Attendant referral counselors match prospective attendants with clients and give advice on hiring, firing, and training. Counselors and specialists assist the clients in advocacy, job development, independent skills living, health and maintenance, and using community resources. A housing department helps clients find places to live and facilitates any necessary housing modifications. The Blind Services Department provides special services for blind clients. In addition to a transportation system that makes vans with hydraulic lifts available throughout the area, the Center provides a wheelchair repair shop that services both manual and electric wheelchairs. Mechanics of an automotive and machine shop conduct classes for staff and clients in vehicle maintenance, and they also service all CIL vehicles. The Communications Department publishes *The Independent*, a quarterly magazine with a national circulation.

Many disabled and blind persons have moved to Berkeley because of the CIL, which provides more than 1,400 services a month.

The California Department of Rehabilitation recently used Innovation and Expansion grants to fund several similar programs in other California communities. Michigan and Massachusetts have also used Innovation and Expansion funding to seed the development of community-based independent living programs run by self-help organizations.

PROBLEMS IN FINDING HOUSING ALTERNATIVES

Many obstacles exist to creating housing alternatives for disabled individuals. First housing must be adapted as much as necessary for the handicapped person to live as independently as possible.

In many projects resident employment earnings must meet at least part of the costs. Thus for many, employment or other substantial income becomes a necessary condition for successful independent living. The majority of residents of the various housing alternatives are either in school or employed.

Attendant Care

Recruiting and keeping the attendants who provide the necessary supportive services is a problem that has not been solved completely. Usually the salary offered is not enough to make being an attendant an attractive career choice. Projects located at or near colleges and universities have succeeded in drawing a sufficient pool of attendants from the student population.

Southern Illinois University-Carbondale, which has 600 blind and physically disabled students, offers two credit hours per semester for being a good attendant. Credit is based on evaluation by the disabled person and two counselors. Some success has also come from using mentally retarded persons as attendants for physically handicapped persons.

A program at Woodrow Wilson Rehabilitation Center, Fishersville, VA, is one of several that teach handicapped individuals to carry out procedures themselves or be able to tell anyone how to do them. The program works on the theory that a well-trained quadriplegic individual will never need a highly-skilled attendant. Funding for consumer-directed attendant care or personal care is available in a few states and from such other sources as Social Security, the Department of Vocational Rehabilitation, Medicaid, and Social Services.

Transportation

Transportation, a key to severely handicapped individuals' access to the community mainstream, is still not completely satisfactory. Although most projects offer some transportation assistance, it does not always meet all needs. Few residents of Houston's Cooperative Living Project were entirely satisfied with their transportation arrangements, and this dissatisfaction seems typical. Efforts to make public transportation more responsive to the needs of handicapped persons should have some impact on the current requirement for special transportation as part of independent living programs.

RESULTS OF EXPERIMENTS IN ALTERNATIVE HOUSING

- Sheltered housing is a viable alternative to institutionalization. A HUD project, the Highland Heights Experiment with barrier-free apartments found that type of housing more efficiently utilized medical care facilities and services and reduced unnecessary and costly institutional care. Results of the other housing projects support this finding.
- Social contacts and activities, functional status, and health status improve with independent living. The results of the Houston Cooperative Living project clearly support this conclusion. And the most dramatic results reported by the Berkeley Center for Independent Living were in the area of preventive care. The incidence of pressure sores and urinary infections dropped to almost zero.
- Independent living costs less than institutionalization. In 1975, total monthly living costs for a resident of Houston's Cooperative Living project were \$570. The monthly cost of nursing home care was \$743, and an apartment with private attendant cost \$840. These costs include rent, meals, attendant, transportation, and personal expenses.
- Independent living affords more employment opportunities than institutionalization. Of the 40 residents in Houston's Cooperative Living project, none had jobs before entering the project, but 28 had either full or part time jobs after entering the project.
- Independent living in a group facility gives residents more social closeness, providing emotional support and modeling opportunities. But many persons object to being segregated from the rest of society. Houston's follow-up study found that residents of the Cooperative Living project, dorms, and nursing homes had more social closeness, which fostered group cohesion and some degree of conflict. Frequently, as they gain self-confidence, group residents outgrow the need for closeness and choose to move out into the community.
- There are advantages of both shared and private attendants. In the Cooperative Living project, private attendants gave the resident control over the attendant's time, but with shared attendant services, there was less conflict because no two persons spent a lot of time together, and costs were reduced.
- The location of a group residence in the community is important. Most of the Cooperative Living residents felt that part of the solution to transportation problems lay in locating their residence in a neighborhood that offered contact with the mainstream of society and that was within wheelchair rolling distance of business and community facilities.
- The successes of all the housing alternatives indicate the need for diversity of housing options. There is no one best alternative. Different individuals are comfortable in various settings, and it is important that handicapped persons have a range of choices.

IMPLICATIONS

- Legislation and regulations should be altered to make it easier to establish independent living facilities for handicapped individuals. Legislation to provide front money for staff and services could assist in starting new centers. And providing funds directly to the disabled individual would enable him to select and hire his own personal care provider.
- Large group facilities are undesirable because they become institutional as their residents grow gradually more dependent and isolated.
- A correlation exists between a handicapped person's housing situation and vocational productivity. The results of the Houston project support the trend toward helping persons with severe handicaps move out of institutions and into the community. They also indicated, however, that making the transition into the community can be difficult.
- The degree of physical disability is not a way of predicting success in independent living situations. First to be placed in the Boston Center for Independent Living were quadriplegic persons. One could move only his head, and another needed a respirator.
- Each community should attempt to offer severely handicapped persons an opportunity to get out of nursing homes and into more independent living.
- Rehabilitation programs should teach more effective independent living skills. The Houston project found necessary the ability to manage finances, to locate community resources and manage these contacts skillfully, and to manage social relationships with persons who provide physical assistance.
- Rehabilitation practitioners should work with self-help organizations of disabled persons to develop community-based independent living programs. President Carter's position paper "Jimmy Carter on Americans with Disabilities" states, "We must broaden the traditional concepts of rehabilitation to include independent living as a supported rehabilitation objective."

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Copies of the BRIEF are available from UF-RRI.



Independent Living

By Mike Flynn, Region V CCE Staff

In 1972, Lex Frieden was residing in a dormitory for severely physically disabled persons, a cooperative living project, while attending graduate school. The residential program was the first of several developed with the assistance of The Institute for Rehabilitation and Research (TIIR), Houston, Texas, and the forerunner of a comprehensive effort towards expanding independent living (IL) services for the severely disabled. Seven years later, Frieden has become co-director of The Independent Living Research Utilization Project (ILRUP) at TIIR, along with Dr. Jean Cole, and the program has expanded to the point of national and international prominence.

During a recent interview following a presentation at a conference of the 10 Regional Rehabilitation Continuing Education Programs, Frieden outlined the major goals of ILRUP. The pinnacle of current involvement, he said, has been activities emanating from an independent living research utilization grant from the Rehabilitation Services Administration, the only one of its kind in the country. It has led to the following past and future projects:

- Production of a 62-minute videotape, **Independent Living Six Model Program**, which describes six projects designed to facilitate independent living. Distribution of this program has begun.
- Convening of an international advisory committee on independent living, including representatives from Sweden, the United Kingdom and the Netherlands, in

addition to the United States.

- Sponsorship of the second national conference on independent living, held last September in Houston.
- Production of a handbook on independent living, which includes information on such subjects as funding IL projects and involving consumers. **It includes a series of definitions related to the concept of independent living and a registry of IL programs in the United States.**
- Conducting five educational forums on IL in cooperation with the Council of State Administration of Vocational Rehabilitation. **Chicago is among the sites selected for a 2½ day forum, which will focus on state and local programming for independent living services (more information will be carried on this in a future newsletter).**

In the near future, Frieden said he expects to be involved with obtaining funds to support IL projects authorized by recent federal legislation, and also working with RSA to produce regulations to govern such activities. Regarding the former, he said "\$80 million was originally proposed for independent living projects, but rumors circulate that Congress will only allocate between \$2 and \$10 million. You can't develop programs without financial support, and we will be lobbying to secure sufficient funding."

Frieden, who is currently a Ph.D candidate in social psychology at the University of Houston, said he has seen the independent living movement "spring from the roots of consumer discontent with the (rehabilitation) focus on

"Sometimes we get so concerned with bricks and mortar that we forget about the many other services needed to make independent living a reality. Equally important are transportation, financial counseling, legal services, social skills, political advocacy and recreation, as well as readers, interpreters and attendant care for those so in need."



career goals as opposed to general goals for one's life. This reached maturity with the recent legislation when, for the first time, independent living projects were authorized without specific ties to vocational goals. This symbolizes the peak of consumer involvement — directed and initiated by handicapped people themselves."

The movement towards barrier-free housing and attendant care, according to Frieden, used to evolve around the question "should it (housing) be designed for groups in large houses or for individuals or a few people in small residences?"

"The answer turned out to be 'don't worry about it,'" Frieden continued. "If handicapped people have the skills and information required to be independent, they can assess their own (living) options and find their own solutions."

Noting that "sometimes we get so concerned with bricks and mortar that we forget about the many other services needed to make independent living a reality," Frieden stressed that living arrangements are but one aspect of independent living.

Equally important, he said, are transportation, financial counseling, legal services, social skills, political advocacy and recreation, as well as readers, interpreters and attendant care for those so in need.

How about work or vocational training?

"The research we have available indicates that (handicapped) people who are able to live independently eventually become good candidates for vocational rehabilitation. Contrarily, they may not be good

candidates until their independent living needs are met," he responded.

Another major TIRR activity in which Frieden and Cole are involved is New Options, a transitional living program designed to foster independent living among the severely disabled and enable them to become part of their community. The program consists of a six-week cycle of instructional modules emphasizing the skills required to live and work independently. Since its beginning in 1976, 85 people have completed the program.

Besides TIRR's programs, Frieden is also involved in the Coalition for Barrier-Free Living, a local organization of disabled individuals. The coalition is working with the city of Houston to construct a \$3 million dollar building which will have social and recreational activities for the handicapped. This project, the first of its kind of such magnitude, was spearheaded by both handicapped groups and public and private rehabilitation agencies.

As independent living has come alive and matured in the seventies, it is up to handicapped people themselves to keep it from sputtering, Frieden stressed, adding "we have a long way to go." Individuals and organizations wishing to exchange information with Frieden on independent living can reach him at TIRR, 1333 Moursund, Houston, Texas, 77030, 713-797-1440.

Editor's Note: Independent living is among the major topics to be addressed at the March 26-28 "A Chance To Do Business" conference (see Pages 4 and 5).



CCE Training Schedule

ILLINOIS

Date(s)	Program	Location	Sponsor
March 28-29	JOBS	Carbondale	Illinois Division of Vocational Rehabilitation (DVR)
April 3-4	CLM	La Salle	DVR
April 4-5	BMS	Decatur	DVR
April 11-12	CST	Chicago	DVR
April 11-12	JSS	Carbondale	DVR
April 11-12	SPD	Chicago	DVR
April 18-19	FC	Decatur	DVR
April 23-25	SMI-A	Chicago	Chicago School and Workshop (CSW)
April 25-26	JSS	La Salle	DVR
May 9-10	CST	La Salle	DVR



INDIANA

Date(s)	Program	Location	Sponsor
March 29-30	MC	Indianapolis	Indiana Association of Rehabilitation Facilities (IARF)
April 4-5	WSRR-A	Indianapolis	IARF
April 4-5	SPD	Indianapolis	Indiana Rehabilitation Services (IRS)
April 10-11	CLM	Indianapolis	IRS
April 17-18	JOBS	Indianapolis	IRS
April 26-27	PVRS	Indianapolis	IRS
May 1	WSRR-B	Indianapolis	IARF
May 2-3	WSRR-A	Indianapolis	IARF
May 16-17	PET	Indianapolis	IRS



MICHIGAN

Date(s)	Program	Location	Sponsor
March 20-21	BMS	To Be Determined	Michigan Bureau of Rehabilitation (MBR)
March 21-22	FC	To Be Determined	MBR
April 19-20	PET	Lansing	MBR
April 26-27	BMS	To Be Determined	MBR
May 9-10	DM	Mt. Pleasant	MBR
May 16-17	PVRS	To Be Determined	MBR
May 16-17	DAS	To Be Determined	State Technical Institute & Rehabilitation Center (STIRC)

MINNESOTA

NO PROGRAMS CURRENTLY SCHEDULED



OHIO

Date(s)	Program	Location	Sponsor
March 14-15	WSRR-A	Cleveland	Ohio Rehabilitation Services Commission (ORSC)
April 4-5	SMI-B	Cleveland	ORSC
April 11	WSRR-B	Cleveland	ORSC
April 11-12	WSRR-A	Cleveland	ORSC
April 25-26	PB	To Be Determined	ORSC
April 27	TM	Columbus	Ohio Rehabilitation Counselor's Association (ORCA)
April 27	MC	Columbus	ORCA
April 28	TM	Columbus	ORCA
April 28	MC	Columbus	ORCA
May 1-2	BMS	Cleveland	ORSC



WISCONSIN

Date(s)	Program	Location	Sponsor
March 21-22	VDI	Milwaukee	Wisconsin Division of Vocational Rehabilitation (DVR)
April 18-19	MC	Milwaukee	DVR
April 23-24	WSRR-A	Madison	Rehabilitation Facilities of Wisconsin (RFW)
May 17	WSRR-B	Madison	RFW
May 23-24	SPD	Milwaukee	Wisconsin DVR



PROGRAM KEY

BMS — Behavior Management Skills	PB — Professional Burnout
BSR — Board/Staff Relations	PE — Program Evaluation
CLM — Caseload Management	PVRS — Professional Vocational Rehabilitation Secretary
CST — Communications Skills Training	SPO — Sexuality and Physical Disability
DM — Decision Making	SMI-A — Supervisory Management I - Part A
DAS — Disability Awareness Seminar	SMI-B — Supervisory Management II - Part B
FC — Facilitative Counseling	TMS — Time Management Skills
FPC — Financial Planning and Control	VDI — Vocational Diagnostic Interviewing
JOBS — Job Placement	WPPE — Workshop Pricing, Practice and Economics
JSS — Job Seeking Skills	WSRR — Workshop Supervisor's Role in Rehabilitation
LC — Legal Concerns	WSRR-A — Workshop Supervisor's Role in Rehabilitation: Part A
MC — Management of Conflict	WSRR-B — Workshop Supervisor's Role in Rehabilitation: Part B
MBO — Management by Objectives	
PET — Personal Effectiveness Training	

NOTE: The CCE is not responsible for selecting training program participants. If you wish to attend a program in your area, contact your supervisor.

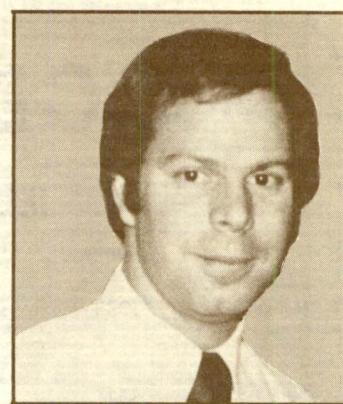


JEAN METZ

An associate professor of Communication Arts and director of forensics at Sinclair Community College, Dayton, Ohio, Ms. Metz is a doctoral candidate at Ohio University. She has done extensive consultative work in group behavior and communication skills for education and rehabilitation organizations. She has served on various national councils on teaching effectiveness and educational policy.

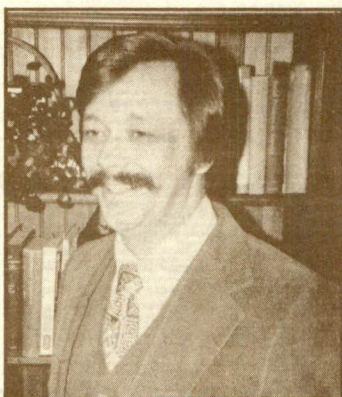
DR. BRIAN T. MCMAHON

Currently in the private practice of forensic rehabilitation, involving vocational evaluation and testimony as a professional witness in personal injury trials, workman's compensation hearings, and social security disability claims, Dr. McMahon is also an assistant professor of psychology at the Illinois Institute of Technology, teaching various rehabilitation courses and supervising practicum and internships.



DAVID STOVER, Conference Chairperson

A charter member of the Region V CCE Continuing Education Advisory Committee, Mr. Stover has served on three consecutive planning committees for this conference. He has been executive director of the Illinois Association of Rehabilitation Facilities since 1975.



I'm pleased and honored to act as chairperson for this year's "A Chance To Do Business" conference, which promises to be another outstanding installment in what has become one of the most worthwhile annual events in Region V rehabilitation.

Since last fall the CCE, with the help of a regional planning committee, has been working to identify and bring together resources that could best help us to look at the most relevant, urgent and possibly controversial current issues for rehabilitation trainers and educators. Among the results: Dr. Lilly Bruck on the consumer movement; Don Warren on the rehabilitation technologies; Dr. Brian McMahon on the privatization of rehabilitation; Jean Metz with a new "body language" approach to education — all noted leaders in their areas — and two panel discussions of important contemporary issues: "Handicapped Student in Graduate Rehabilitation Programs" and the new "Independent Living" projects.

Of course, we'll have a number of other meetings, displays and activities. In addition, the opportunity for informal interaction with top rehabilitation and education professionals should be worth the trip by itself.

—David Stover
Conference Chairperson

CONTINUING EDUCATION UNITS

Continuing Education Units will be awarded for participation in "A Chance To Do Business V." Instructions on obtaining credit will be included in the materials packet you will receive at the conference.

REGION V OFFICE OF REHABILITATION CENTER FOR CONTINUING EDUCATION

"A Chance To Do Business"



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DON WARREN

The president of Clinical Convenience Products, and director of the Wisconsin Foundation for Applied Technology, both Madison, Mr. Warren holds a master's degree in neurophysiology from Kansas State University. He has served as consultant to several private organizations and, in the last two years, has given 24 presentations to various organizations.

DR. LILLY BRUCK

The author of *Access*, the *Guide to A Better Life for the Disabled*, Dr. Bruck is consumer advocate and broadcaster for In Touch Networks, a radio information service for the visually and physically handicapped in New York City. A highly-sought speaker, Dr. Bruck has a vast background in consumer services for both the disabled and general citizenry.



AGENDA

MONDAY, MARCH 26

- 1 p.m. 1. Registration
2. Special Meetings: National Council on Rehabilitation Education, state agency facility personnel and others as requested
- 3:00 Opening Remarks: Ralph Church, director, Region V Office of Rehabilitation Services, David Stover, conference chairperson
- 4:00 Panel Discussion: The Handicapped Student in Rehabilitation Education. Panelists include Dr. Daniel McAlees, director, Research and Training Center, University of Wisconsin - Stout, moderator; Ron Blosser, coordinator, Specialized Student Services, Southern Illinois University; Cleo Ann Eliason, affirmative action officer, Wisconsin DVR; Dr. Paul Hoffman, director, Stout Vocational Rehabilitation Institute and Dr. Richard Ugland, project director, Rehabilitation Counseling Program, Mankato State University
- 6:00 Social hour

TUESDAY, MARCH 27

- 9 a.m. Innovations in Adaptive Equipment and Job Site Modification - Don Warren
- 10:45 Break
- 11:00 Access to the Marketplace for the "Next Minority" - Dr. Lilly Bruck
- Noon Lunch
- 1:30 Concurrent offerings:
1. Continuing discussion of both morning presentations
2. Body Language: Achieving Education Through Educating the Body - Jean Metz
3. Free Enterprise in Vocational Rehabilitation - Dr. Brian T. McMahon
- 3:00 Break
- 3:15 Repetition of concurrent sessions listed above
- 5:00 Adjournment
- 6:00 Group dinner

WEDNESDAY, MARCH 28

- 9 a.m. Panel Discussion: New Programs for the Promotion of Independent Living. Participants include Raymond Hill, director, Center for Independent Living, Rehabilitation Institute, Inc., Detroit; Euline McCorkle Taratsas, coordinator of human and community relations, Ann Arbor Center for Independent Living; John Allen, principle, Davon Management and Research Co., director, Creative Living Center, Columbus
- Noon Adjournment

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Supplementing the Public VR System

By Brian T. McMahon

Public vocational rehabilitation (VR) services are mired in certain inherent problems. These include the corrosive effects of obtaining government funding, which is marginally unrelated to productivity, efficiency, or consumer satisfaction. A second is management, which is frequently restrained in the proper exercise of authority by civil service regulations, citizen advisory boards, political exigencies, and legislative changes which may suddenly alter the entire direction of the discipline. Third, there exists the nagging realization that disabled consumers do not control their VR dollars and that each client, if provided with reasonable alternatives, might well choose to be served elsewhere. **Finally, the need for VR services in this country still far exceeds the capabilities of the current public service delivery system.**

These basic problems have influenced the development nationally of a network of private providers of VR services. Key ingredients in private rehabilitation are consumerism, quality control and competition. This is not to suggest that public sector rehabilitation is completely lacking these ingredients. Certainly the element of consumerism has been furthered by the IWRP. No one can argue that quality control has been enhanced by the accreditation procedures of CARF and CORE, and the certification procedures of CRCC. But these elements — consumerism, quality control, and competition — are part and parcel of private sector rehabilitation, and for this reason the "privatization" trend is perceived as a formidable movement which merits our attention.

What is the scope of this movement? There are currently hundreds of private providers of rehabilitation services in the country today. Referrals generally come from clients, insurance carriers or self-insured employers, attorneys, physicians, the Rehabilitation Bureau of the Division of Industrial Accidents (this name varies from state to state), and the Social Security Administration Bureau of Hearings and Appeals. The services provided generally mirror those of the public sector, although vocational evaluation, plan development, and job placement are the more frequently requested. In September, 1977, the National Association of Rehabilitation Professionals in the Private Sector (NARPPS) was formed in order to represent the interests of those providing VR services within the free enterprise system. The private vocational rehabilitation movement has tremendous potential for both good and evil. Reasons for optimism include the following:

1. Private sector VR represents an **alternative** service delivery model for persons requiring rehabilitation services. It is intended to supplement, not supplant, the public VR system. Indeed private services appear to compliment the moderate expansion which the profession is currently experiencing. **While the public sector is enlarging the kinds of services provided, i.e. independent**

living, the private sector is reaching out to many disabled persons who are ineligible (or not highly prioritized) for public VR services. In some instances even nondisabled persons are being served.

2. The private sector represents increasing employment opportunities, higher wages, smaller caseloads, greater freedom to innovate, more and faster advancement, and more variety for capable rehabilitation counselors. A corollary to these is the increased potential for counselor responsibility.

3. In the private sector, management is relatively unrestrained in decisions regarding obtaining capital, clients served, services provided and personnel.

4. The current private VR service delivery system is placement oriented. This emphasis on the importance of placement and post-placement services is something the public sector has only recently begun to realize in practice, being still heavily invested in the "training" orientation.

5. The privatization movement has brought to rehabilitation a newfound acceptance and appreciation of the profession by justices, attorneys, physicians, employers, insurance carriers and others heretofore ignorant of the discipline.

What, then, is the potential for evil in the private sector movement? Some of the dangers result directly from the relative lack of controls in a free enterprise system — skimming, profiteering, potential for malpractice suits, ethical conflicts with funding sources, and the "jumping" of competent, well-paid counselors to the competition, along with scores of administrative concerns. None of these is so dangerous, however, as the concern expressed that private operations will deprofessionalize VR services, utilizing nonprofessionals in place of professional rehabilitation counselors.

With respect to this latter issue, some private firms have hired "counselors" from the business world whose knowledge of rehabilitation is to be obtained on the job. Other firms have requested that appropriate changes be made in the local RRCEP's curriculum and have offered internship experience to graduate students interested in the private sector. These latter firms appreciate the value and adaptability of the graduate-trained rehabilitation professional. They actively recruit the best graduates each year. While little is known at this time about the hiring practices and professionalism of private sector practitioners, this is an area of extremely high interest to NARPPS, the National Council on Rehabilitation Education, and other professional and consumer organizations.

Editor's Note: Dr. McMahon will be one of the major speakers at the March 26-28 "A Chance To Do Business" conference (see Pages 4 and 5).



"Private sector VR represents an alternative service delivery model for persons requiring rehabilitation services. It is intended to supplement, not supplant, the public VR system."

IRI Prime Study Committees Finalizing Publication Drafts



Committees for the three prime study topics of the 1978-79 Institute on Rehabilitation Issues (IRI) have all met twice and are preparing final drafts of publications they will present at the organization's annual conference, June 4-6 in San Antonio, Texas. The completed publications will be distributed late this summer.

Following are synopses of the three study topics:

ADJUSTMENT SERVICES FOR THE SEVERELY DISABLED

Following the trend of the independent living movement, this committee is looking beyond vocations and probing comprehensive rehabilitation adjustment. Among areas included in the study are the use of leisure time, transportation, recreation and attendant services.

"The committee is attempting to study allied issues which are normally beyond the scope of traditional adjustment programs but are nevertheless essential to the achievement and maintenance of the total gains made by and for the severely disabled," Robert Brabham, chairperson explained.

Brabham is assistant commissioner, field and case services, South Carolina Vocational Rehabilitation Department, P.O. Box 4945, Columbia, S.C., 29240, 803-758-2278. Region V members of the committee include Ted Witham, program specialist, Office of Rehabilitation Services, Chicago, 312-353-7345, and Jeff Heinzen, Green Valley Enterprises, Beaver Dam, Wis., 414-887-8177. Sponsor is the University of Arkansas R & T Center.

REHABILITATION ENGINEERING — A COUNSELOR'S GUIDE

This committee is charged with the identification and application of engineering techniques to various rehabilitation components, such as evaluation, assessment, plan development, training and employment. According to Basil Antenucci, chairperson, the

rehabilitation counselor has a mandate to apply the aforementioned to the caseloads of the severely disabled, but has been unable to acquire information to assist in so doing.

The eventual document will include "the state of the art," application of rehabilitation engineering, resources available and a training outline. Antenucci is the acting director, Michigan Inter-Agency Bureau of Rehabilitation, Box 30010, Lansing, Mich., 48904, 517-373-3390.

TECHNIQUES FOR WORKING IN THE COMMUNITY

This committee is charged with developing a document which identifies skills needed by VR workers to effectively work in a community and which specifies how advocacy and consumer input can best be handled.

Jean McCorry, chairperson, explained that current program priorities and legislative mandates necessitate that vocational rehabilitation become more involved with community groups and agencies. Among the priority areas for consumer involvement are similar benefits, affirmative action, consumer policy consultation, services to the most severely disabled and implementation of Title V legislation, she said.

Ms. McCorry is the program supervisor, Jefferson Vocational Rehabilitation Office, 8550 W. 14th Ave., Lakewood, Colo., 80215, 303-237-0481. L. Robert McConnell, program development supervisor, Michigan Bureau of Rehabilitation, 517-373-3978, is a member of the committee.



CENTER FOR CONTINUING EDUCATION

The Region V Center for Continuing Education (CCE) is being operated by the Multi Resource Centers, Inc. (mrc), Minneapolis, Minnesota through a grant (44-25546/5) from the Office of Rehabilitation Services (ORS) of the U.S. Department of Health, Education and Welfare. Region V consists of Ohio, Michigan, Indiana, Illinois, Wisconsin and Minnesota. The newsletter is prepared by the CCE staff. Address any inquiries to:

CENTER FOR CONTINUING EDUCATION

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123 E. Grant St.
Minneapolis, Minnesota 55403
(612) 871-5646

CCE STAFF: Nelson R. Otto, Director; Gary Hines, Coordinator; James Boyd, Elizabeth Corp, Brenda Davies, Mike Flynn, Carol Greier, Nancy Halloran, Cyndi Leshner, William Scheurer, Mary Schumacher, Su Thorkelson.
Newsletter Editor: Mike Flynn

Ohio Hosting Deafness Conference

"Pathways to Independent Living with Multiple Handicapped People" is the theme of the Ohio Deafness and Rehabilitation Association annual Spring Conference. It will be held March 8-10 at the Carousel Inn, 4900 Sinclair Rd., Columbus.

Ms. Eunice Fiorto, special assistant to the commissioner, Rehabilitation Services Administration, will be among the guest speakers. Some 20 topics will be addressed at the conference. For more information, contact Carol Minnich, Division of Mental Retardation and Developmental Disabilities, Room 1236, 30 E. Broad St., Columbus, Ohio, 43215, 614-466-6670.



Job Analysis For Effective Placement

Developing job analysis techniques and materials in order to more effectively place disabled persons into community employment will be the major focus of a short-term training grant awarded to the Quadco Rehabilitation Center, Stryker, Ohio, by the Region V Office of Rehabilitation Services.

Traditionally, evaluation emphasis has been upon the disabled person, with little attention given to evaluating the job into which he/she will eventually be placed. Consequently, the demands of the job and the capabilities of the disabled worker may not be sufficiently well matched.

Job analysis is designed to objectively identify work-related skills, plus social, educational, intellectual and physical requirements for successful job performance. Once collected, this detailed information will be compared to the capabilities of the disabled worker to enhance a more complimentary job-worker match. If this matching process identifies areas where job demands exceed the disabled worker's present performance capabilities, specific training programs can be initiated to eliminate or minimize these areas of possible failure.

Most titles give little information about requirements that may be critical to a disabled worker's satisfactory performance of that job. For example, in welding, what specific type of equipment is used? Is lifting required? Once these job requirements are known, plans are made to incorporate these factors into the rehabilitation program, work with the disabled person to master these skills, and/or help the employer modify the job requirements.

At the conclusion of this grant Quadco will host selected rehabilitation professionals from Region V for an intensive three day workshop. The resulting job analysis procedures and materials will then be distributed for use by other HEW Regions. Instructional materials will also be developed so that workshop participants can pass on these procedures and materials to other professionals within state vocational rehabilitation agencies and facilities as well as to employers.

For more information regarding this project contact Keith Frank, Director of Research and Training, Quadco Rehabilitation Center, 527 North Defiance Street, Stryker, Ohio, 43557.



"A Chance To Do Business V"

March 26-28

See Pages 4 and 5



Updated Catalog Distributed; Increased Usage Encouraged

The revised and expanded Region V CCE Training Catalog was recently distributed to nearly 200 agency/facility representatives with staff development and training responsibilities. The catalog provides in-depth information on all major CCE activities. Of central value in the catalog are complete descriptions of all CCE training programs, including such information as program subjects, objectives, intended audiences, length, equipment needs and a topical outline. Forty-four CCE training resources (films, videotapes, etc.) are listed in the catalog, providing such information as the subject and intended audience. In addition, the section provides instructions on ordering training resources.

Newly included in the catalog are a listing of 68 regional rehabilitation education and training programs funded by the Rehabilitation Services Administration, and five national rehabilitation organizations.

Persons maintaining a catalog are urged to make it available and to distribute advance copies of training program descriptions to potential or scheduled trainees.



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REHAB BRIEF

Bringing Research
into
Effective Focus

Vol. II, No. 9

October 26, 1979

Independent Living Rehabilitation: Results of Five Demonstration Projects

Over the past two decades, the concept of independent living rehabilitation (ILR) has expanded. During the 1950's, ILR meant freedom from institutional care or from being a burden on others. In the 1960's, the emphasis was on not only freedom from institutional settings but also freedom in the home, freedom to travel, the opportunity to attend school, and the opportunity to work. Currently, the ILR goal is to provide the severely disabled person with the skills and knowledge necessary to function well enough to live independently. Implicit in achieving this goal is the freedom to participate in most of the usual activities engaged in by nondisabled people.

This goal sounds reasonable enough, but achieving it is difficult and may be costly. Although some funding for states to provide ILR services will soon be available, it has been a long time coming. The Rehabilitation Act of 1973 provided for a study of the most severely disabled population. This study, the Comprehensive Service Needs Study (see REHAB BRIEF Vol. I, No. 1) recommended setting up a series of demonstration projects on ILR. These projects would investigate the extent and characteristics of the severely disabled population, their rehabilitation needs, the cost of needed services, and various organizational patterns for the delivery of services.

Six demonstration projects were funded by the Rehabilitation Services Administration (RSA). One project in Peoria, Ill., was set up to explore the use of cable interactive TV for use in service delivery. It was terminated after the first year, partly because of problems in acquiring needed equipment.

The Urban Institute has been evaluating the five remaining demonstration projects for 3 years and has received annual reports on the progress of the projects. This REHAB BRIEF presents the Urban Institute's preliminary findings. Complete findings will be included in a final report on the projects now being prepared by the Urban Institute.

The Demonstration Projects

The demonstration projects were selected in order to gather as much information as possible about various ILR organizational patterns. The five projects differ by client characteristics, funding sources, service delivery systems, and emphasis.

Medically Oriented Services

Two of the projects demonstrate the role of a comprehensive medical rehabilitation center in providing ILR services. One project, at the University of Washington's Department of Rehabilitation Medicine, works with severely physically disabled clients during and after receipt of services from the rehabilitation facility. The other medically oriented project, at the Institute of Rehabilitation Medicine in New York City, deals mainly with clients who have progressive diseases, such as muscular dystrophy. Both projects operate closely with their state VR agencies.

Services Through VR Agencies

ILR projects in Salt Lake City and San Antonio provide services through state VR agencies. The Utah project, which operates on a parallel with the state's VR program, uses the state agency's basic services and provides specialized services for persons who have been excluded from the VR program because of the severity of their disabilities. In Texas, staff from the Commission for the Blind have teamed up with VR personnel to work with clients who not only are blind, but also have a secondary disability.

Consumer Action Organization

The fifth project, Berkeley's Center for Independent Living (CIL), is a consumer action organization with a strong advocacy program on behalf of severely disabled people. The CIL also provides such direct services as peer counseling and equipment repair. The project is aimed at showing that a consumer-based, self-help organization can deliver services which otherwise may not be provided to severely disabled persons. It works closely with agencies, including VR, to develop and expand programs for persons with severe disabilities.

Urban Institute Study Methodology

The Urban Institute has been monitoring the demonstration projects in order to evaluate them and to analyze service needs and costs incurred to meet these needs. The five demonstration projects served a total of 362 clients during 3 years. The project used two survey instruments — data protocol and cost forms — to collect data from all projects on client status, needs, and progress; and on services provided, cost of those services, and sources of funds utilized.

This information included demographic characteristics, disability diagnoses, medical status, severity (using measures such as PULSES, Barthel, Functional Limitations), social interaction, transportation, architectural barriers, equipment (owned, used, and needed), services received and needed, service programs contacted, and medical expenses. This data was obtained at intake and at yearly intervals.

Demonstration Project Data

Of the 362 clients in the five projects, 60 percent were male, and 40 percent female. The mean age was 38. Their educational status was lower than that of the general population and slightly higher than that of the VR population. All clients were classified as severely disabled; 246 tested as severely handicapped by the Barthel Index, which measures physical limitations. All others were severely disabled according to other indicators, such as PULSES scores, other functional limitations, and work histories.

The mean individual client income at intake was \$3,516 annually. In 1978, the mean client household income was \$8,100, compared with the U.S. average of \$12,787.

A majority of the clients (65 percent) relied on SSI or SSDI as their primary source of income. About half listed this source as their families' primary source of income. Fewer than one-third listed income from employment by family members as the largest source of family income. The clients were heavily dependent on outside income, often from family members or income maintenance programs. Low income frequently is compounded by the inability of income maintenance programs and lower paying jobs to keep pace with inflation. Although 47 percent of the clients had worked in the past, only 18 percent were employed at intake, primarily in part-time jobs or in sheltered workshops. One-third had never worked.

Demonstration Project Clients Compared With VR Population

	Demonstration Projects	VR Population
Mean age	38	32
Proportion		
severely disabled	100%	41%
Primary disability		
in 3 or more limbs	57%	1.5%
High school education	55%	42%
Mean family income	\$7,800	\$3,200*
Proportion living		
alone	8%	24%

*Since 3 times as many VR clients live alone, family income would be lower than for ILR clients living within a supporting family.

Client Needs

Frequent client reevaluation was necessary because client progress caused new needs to emerge frequently. Improvement occurred in all areas. Most clients' physical functioning improved in the first year and stabilized after the second year. Perhaps the best overall indicator of client improvement was social interaction, which increased in all categories of activities, such as visiting, shopping, and attending church and meetings. The largest increase was in visits with friends, which had nearly doubled by the end of the third year.

Equipment Needs

A majority of clients (65 percent) had unmet equipment needs at intake. These included ramps, trapeze/bathtub lifts, wheelchairs, and transfer chairs or boards. As the projects met these basic equipment needs, other higher-level needs arose, such as specially equipped automobiles, typewriters, and tape recorders. As the 3 years passed, 44 percent of clients reported fewer and fewer unmet equipment needs, 40 percent no change, and 16 percent an increase. Most of the clients reporting no change had reported no unmet equipment needs at intake. Those who reported increases in equipment needs experienced increased abilities.

Service Needs

At intake, unmet service needs averaged 4.81 per client; these were reduced to 2.1 per client at the end of 3 years. Most of these remaining needs were supportive or life-enhancing, rather than basic services. The greatest needs at intake were for vocational counseling, training, placement, psychotherapy, and therapeutic recreation. Medically related and physical restoration needs were reduced the most. Least reduced were nonmedical needs, such as therapeutic recreation, home modification, vocational placement, and educational needs.

Household Management Needs

Attendant care and household financial management were the most frequent unmet needs at intake. By the end of the third year, all household management unmet needs were substantially reduced, except household financial management, which increased. In the third year, 13 percent of the clients whose functioning levels had increased for the first time needed assistance conducting personal business activities.

Transportation Needs

Most of the clients (72 percent) had transportation problems at intake, and little progress was made in the first year. Although many specific types of transportation problems were solved, most clients still had some sort of transportation problems at the end of 3 years. Increased use of specific types of transportation indicates improved overall ability of clients to use transportation.

ILR Demonstration Projects

<i>Project Location</i>	<i>Staffing Patterns</i>	<i>Services Offered</i>	<i>Client Characteristics</i>	<i>Unique Characteristics</i>
NEW YORK conducted jointly by the Institute of Rehab Medicine and State Rehab Agency	VR counselor, physician, psychologist, social worker, public health nurse, OT, PT, consultants: architect, home economist	• Comprehensive medical evaluation • Medical services and equipment on outpatient basis • Adjustment to disability and family counseling • Use of ADL aids • Housing and transportation modification • Long-term services	• Severely handicapped neuromuscular diseased persons (whose functional levels decline over time) • Ages 13 and older, who might benefit from extended evaluation or other prevocational services or have potential for improving IL skills	• Due to severity and progressive nature of disability, maintenance of present functioning capabilities equals successful goal
SEATTLE operated by Department of Rehab Medicine University of Washington in close association with Washington State VR	VR counselors, psychologists, psychiatrist, behavioral psychologist, social worker, aide/psychometrist, work evaluator/placement specialist	• Interview to determine needs • Appropriate services (medical, housing, etc.) • Vocational evaluation in job station approach (trying out jobs) • Readministering interviews and evaluations • Long-term services	• Catastrophic disabilities, all ages, many elderly • Inpatients enter after discharge from University Hospital's Dept. of Rehab Medicine • Outpatient clients enter if evaluation indicates they are not ready for VR	• VR counselors stationed with project staff • Each counselor serves 15-20 clients with similar disabilities • Use of "employment salespeople" who specialize in educating employers
BERKELEY Center for Independent Living	Primarily staffed by persons with severe disabilities, many who serve as peer counselors	• Identification of needs such as attendant pools, housing, equipment repair • Services available through cooperation with other agencies	• Diversified severely disabled population	• Attendant care is largest problem • Peer counseling model has operated successfully for 7 years • Strong advocacy role
SALT LAKE CITY State Rehab Agency	2 rehab counselors (full-time), 1 engineer (half-time)	• IWRP (Individualized Written Rehab Plan) • Use of similar benefits • Innovative services • Transitional living center	• Catastrophically disabled clients, 18-64, who had been denied VR services plus community referrals directly to project	• Engineer filled the knowledge gap, for example, a TTY is now used by severely impaired CP clients • Close association with VR program benefits clients who develop employment potential
SAN ANTONIO Texas State Commission for the Blind	Rehab counselor, rehab teacher, placement specialist, orientation/mobility specialist, community service aide, children's caseworker, supervisory technical consultants	• Needs assessment by team • Services to overcome experiential handicaps resulting from sensory deprivations	• Multi-handicapped blind clients • Secondary handicaps: deafness, limb-related or mental	• Specialized language and cultural skills training given to staff • Rehab teacher accompanies client to other service agencies, home, or residential setting to apply transfer of skills learned at rehab facility

Architectural Barriers

The number of barriers were reduced for most clients, but some remained after 3 years. After being in the program for 1 or 2 years, a few clients noted architectural barriers in their homes for the first time. It is possible that these clients' expanded activities caused them to encounter new barriers. It may also be that clients leaving institutions found barriers in the community that did not exist in the institution. Accessibility problems for clients wishing to work or attend school remained higher over the 3-year period.

Living Status

At intake, about one-fourth of the clients were in institutions. One-half of these clients left the institutions and became a part of the community after 2 or 3 years in the program. This potential was not predictable through type of disability, age, PULSES or Barthel scores, or the availability of a place to go upon discharge. Clients' leaving institutions resulted in new needs related to meal preparation, housekeeping, shopping, and attendant care. All clients, including those who stayed in institutions, reported improved living status, as measured by increased services, decreased unmet equipment needs, and increased social interaction.

Costs

In order to gather information on services provided, their costs, and sources of funds used, cost instruments were completed each quarter for every client. Cost information forms included 10 categories compatible with the regular VR program format so that comparisons could be made. The 10 categories were counseling, diagnosis and evaluation, physical and mental restoration, training, placement, maintenance, service to family members, transportation, aid and attendant services, and other. Records were also kept concerning services which used project funds and services funded through other resources or "similar benefits," such as SSI, SSDI, Title XIX, Title XX, Medicare, AFDC, and Worker's Compensation.

Cost Results

- Costs per ILR client were almost double costs per regular VR client and almost 50 percent greater than rehabilitation costs per client funded through Social Security trust funds.
- The average total expenditure per client was \$9,097 per year. Only \$1,427 of that amount came from project funds, because of extensive use of similar benefits.
- Compared with VR, the ILR projects spent fewer dollars per client and a much smaller percentage of total funds on counseling and placement, and more money and a larger percentage of total funds per client on diagnostic, evaluation, and restoration services.
- Among miscellaneous costs, those for transportation and attendant services were high. The projects met most of these costs through other funding sources.

Cost Consideration

Several things need to be kept in mind in evaluating the costs of the ILR demonstration projects. The high costs may reflect initial startup costs for ILR programs, since the cost figures

were taken from the first 2 years of the project. As more data becomes available, changes in patterns of expenditures are expected. Those who compare costs per client of ILR and VR programs should bear in mind that the ILR population is much more severely disabled than the total VR population.

Preliminary Findings

Information from the ILR demonstration projects will be important in implementing new ILR legislation contained in Title VII of the 1978 Amendments to the Rehabilitation Act of 1973. Preliminary findings indicate that

- Severely disabled clients can benefit from independent living rehabilitation services.
- ILR clients have many basic needs that are diverse and change over time. Counselors will need to develop highly specialized IWRP's and to reevaluate clients and revise IWRP's continually.
- Transportation and architectural barriers will remain a major problem, and most service delivery programs have little direct control over these environmental barriers. More work needs to be done in these areas.
- There is a need for objective reporting of changes in client functioning.
- There is a need for developing ILR eligibility criteria to avoid placing into ILR severely disabled persons who can best benefit from VR services.
- There is a need for closure criteria specifically for ILR — including special criteria for clients who need to be in an ILR program indefinitely.
- ILR costs are high. Although most costs can be covered by similar benefits, the costs remaining to the ILR program will likely remain higher than VR costs. It will be essential to maintain up-to-date information on similar benefits and coordinate programs to use them as much as possible.
- High ILR costs are partly a function of length of time in the program: the average client stays in VR programs only 2 years, whereas many ILR clients were still not closed after 3 years.
- Further exploration of alternative service delivery methods in ILR is needed. There are many possible ways of serving the ILR population, and which methods are best has not been proven.

For More Information

The Urban Institute is preparing a monograph on the independent living demonstration projects. It will be available in late fall from the Division of Social Services, Urban Institute, 2100 M Street, NW, Washington, D.C. 20037. Phone: 202-223-1950.

IL Sourcebook, a technical assistance manual, is available from Lex Frieden, Project Director, Independent Living Research Utilization, The Institute for Rehabilitation and Research, 1333 Moursund, Houston, TX 77030.

Available in print or microfiche from the National Clearing House of Rehabilitation Training Materials, O.S.U., 115 Old U.S.D.A. Building, Stillwater, OK 74074: *The Role of Vocational Rehabilitation in Independent Living*, 1978. Order No. IRI 14.

Copies of the BRIEF are available from UF-RRI. Request braille and tape versions from your regional service library.

The Influence of Environmental Barriers On Independent Living Outcomes

Do certain factors enable some disabled persons to live more independently than others? If so, which are most predictive of a person's ability to live independently? Age? Severity of disability? Accessible transportation?

Such questions are addressed in a three-phase study being conducted by the Medical Rehabilitation Research and Training Center, Tufts-New England Medical Center, Boston. The central issue in the study is an examination of the extent to which environmental factors, as well as personal limitations, contribute to disability outcomes.

This BRIEF reports on Phase I of the study, which has been completed and focuses on spinal cord injured (SCI) persons. Phases II and III of the study will be completed by the end of 1981, and will deal with people who have had strokes and people with different disabilities.

With the advent of the Title VII, authorized in 1978 under P.L. 95-602, came new demands for program accountability. However, it remains unclear what outcome criteria are most valid for the evaluation of independent living (IL) service programs. Therefore, Tufts' researchers sought to investigate theoretical and empirical issues directly related to the development of an IL-based evaluation methodology.

STUDY METHODOLOGY

One reason researchers selected SCI patients for Phase I was that these persons are looked upon (in some regions of the country) as typical consumers of IL services. Therefore, the assumptions of the IL movement regarding the importance of environmental barriers should, at a minimum, hold true for a sample of SCI persons.

The principal data source for the study was a computer file containing information about 307 persons who were discharged rehabilitated from ten medical rehabilitation centers across the nation. The information in the file was taken from a survey of disabled persons compiled by the Urban Institute in 1975. From this list, researchers selected 111 SCI persons.

Participants were interviewed approximately 2 years after their discharge. The interview data was combined with the results of both a mail survey and a review of the individual medical records at admission and discharge.

Research Model

A formal research model was developed to identify the most relevant dependent and independent variables, drawing heavily on the analysis of IL as a social movement. In particular, an examination was conducted of the movement's indebtedness to allied social movements, such as civil rights, consumerism, self-help, demedicalization, and deinstitutionalization.

IL outcomes were hypothesized to be a function of four sets of variables:

- 1) Socio-demographic variables (such as age, sex, marital status);
- 2) Disability-related variables (such as duration of disability, severity of disability);
- 3) Environmental variables (such as attendant care, housing, transportation); and
- 4) Interface variables reflecting the need for assistive devices to bridge the gap between functional limitations and environmental barriers.

SPECIFYING IL OUTCOMES

What does it mean to live independently? How can the concept of IL be operationalized as an outcome measure so that it makes sense to state and Federal policymakers?

To answer these questions, researchers took into consideration the main concerns of this group of people: what a disabled person can do about living in a less restrictive environment; and how a disabled person can become more productive, both in terms of gainful employment and in contributions to community and family life. As a result, three outcome criteria were developed for the IL study: (1) a living arrangement measure; (2) a productivity measure; and (3) an overall IL outcome measure representing a weighted average of the first two outcome measures.

Emphasis was also put on the hypothesis that living arrangements and productivity do not lessen the importance of certain social skills, but that these skills should be viewed as intermediate outcomes that should be attained at the conclusion of an IL program. Ultimately, IL skills should evolve into long-term outcomes.

Living Arrangements and Productivity Outcomes

Twelve productivity outcomes were identified on the basis of a person's level and degree of participation in employment, school/training, formal organizations, homemaking, and leisure time activities.

Seven living arrangement outcomes were identified on the basis of *where* and *with whom* people lived, since these two items indicate the degree of restrictiveness and the level of independence in a person's living arrangement.

Ranking and Weighting of Outcomes

The 42-member Massachusetts Interagency Council on Independent Living (ICIL) served as a panel to rank and weight the outcomes identified in the data set.

Each ICIL member was asked to rank order (from best to worst) each living arrangement outcome and each productivity outcome by assigning a weight to each on a scale of "0" to "10" (with "0" representing the least desirable outcome). Members then were asked to assign a percentage weight to each scale, with the two weights adding up to 100 percent. The purpose of this last step was to get an IL outcome score that represented a weighted average of living arrangements and productivity outcomes.

An analysis of data was made to determine if any significant differences existed in the weightings of outcomes among ICIL members based on respondent's age, sex, and disability status. Results showed that these characteristics presented few statistically significant differences. In fact, the least discriminating characteristic was disability status: respondents with disabilities had weighted outcomes that were similar to persons without disabilities. Therefore, there was an absence of a distinct "consumer perspective" with respect to the weightings of outcomes.

CHARACTERISTICS OF THE STUDY GROUP

To help determine how extensively the study findings can be applied to other disability groups, some of the SCI study group's characteristics are given:

- 70 percent were male;
- 53 percent were under 35 years old;
- 50 percent had been disabled for 3 years or more;
- 75 percent needed or used a wheelchair;
- 88 percent were living in the community;
- 43 percent were married;
- 25 percent were nonwhite;
- 63 percent had at least a high school education;
- 87 percent were *not* employed;
- 71 percent received Social Security benefits; and
- 32 percent had medical problems unrelated to their SCI, such as heart disease, stroke, and diabetes.

The severity of a disability was measured with a modified Barthel Index, a method that measures how much assistance a person needs for personal care activities and mobility. The index ranges from 0-100, from most dependent to most independent. Based on this index, approximately 38 percent

were identified as being very severely disabled (having a score of less than 60).

Because of post-discharge medical complications (such as urinary tract infection and pressure sores), persons with SCI are often rehospitalized. Even though a majority of the study group was discharged as "medically stable" or "improving," 54 percent of the group were rehospitalized in the 12-month period immediately prior to their followup interview. The median length of stay for those rehospitalized was 41 days; the mean was 55 days.

STATISTICAL ANALYSIS

Distribution of IL Outcomes

Close to 57 percent of the study group were living in one of the three least restrictive living arrangements. However, 50 percent were in one of the four least productive outcome categories. For the most part, persons in the SCI study group were living in unrestricted settings, but were contributing little or nothing to community or family life.

Predictors of IL Outcomes

Multiple regression analysis was used to determine which variables were best for predicting a person's ability to live independently. This technique also tells the researcher how much of the variation or "variance" in IL outcome can be explained by personal and environmental variables. The analysis accounted for a high percentage of the variances in IL outcome (58-78).

Transportation plays a key role in fostering an independent and productive lifestyle. Persons who had fewer transportation barriers, especially younger working-age adults, usually were more productive.

The **economic disincentives** embedded in many income and medical assistance programs were significantly related to a person's productivity. In some instances, this variable was the single most important environmental predictor of outcome.

Although importance of accessible housing is usually emphasized in most studies, the number of **architectural barriers** in the home was not a predictor of outcome here.

However, the study did uncover one important home barrier: the ability to get in and out of the house. Thirty percent of the study group indicated that they encountered barriers of this type, which may help to account for the high degree of social isolation observed in the study group. During the course of a week, 22 percent never got out of the home, and 46 percent got out three times or less.

The single most important predictor of living arrangement outcome was **marital status**. Marriage enhanced the chances of living in a less restricted environment, since a spouse usually provided a ready source of attendant care.

The number of **services received** from various human services agencies proved to be a predictor of outcome. For example, if a person's job placement services were unmet, the desired outcome of IL would, in most cases, not be achieved.

The older a person was when becoming disabled, the more likely the person was to be living in an independent setting — the reason being that older persons are more likely than younger persons to be living independently already when an injury occurs. However, while *age* was positively related to living arrangement status, it was negatively related to productivity: younger persons were more productive.

Education was positively associated with productivity. Better educated persons had a competitive edge in the labor market, and were more likely to be involved in community organizations and hold leadership positions.

Persons who received **vocational rehabilitation** services were generally more productive. However, one factor to consider may be that people who receive vocational rehabilitation services are usually considered more employable or productive than those who do not.

The **severity of a person's disability** (as determined by the Barthel Index) was not an important predictor of living arrangement outcome. It was, on the other hand, an important predictor of productivity outcome and overall IL outcome (especially for older persons in the study group). However, the unique contribution of this factor often diminished and, in one instance, vanished after other environmental factors, such as transportation barriers and economic disincentives, were considered.

Personal/Environmental Interactions

An important finding in the regression analysis was the strong interaction between the severity of a person's disability and the limitations of a person's environment: those persons with more severe disabilities were more likely to encounter environmental barriers. Except for the unique variance contributed by each variable, it was sometimes difficult, from a purely statistical point of view, to determine how much of the problem was a personal matter and how much was an environmental issue.

Much of the IL theory has focused on environmental barriers as an important determinant of disability outcomes. In so doing, the IL movement has helped to redress an imbalance that has emphasized personal limitations. The results therefore show the important role environmental support systems play in fostering IL outcomes. However, while the distinction between personal limitations and environmental barriers is both necessary and analytically useful, the regression results nevertheless indicate the interrelationship between the two is far more dynamic and useful than the distinction itself.

IMPLICATIONS FOR DISABILITY POLICY

Disability policy in the United States is at a crossroads, particularly over the issue of environmental accessibility. On the one hand, statutory requirements, such as Sec. 504, make nondiscrimination, accessibility, and the removal of environmental barriers a national policy and a matter of civil rights. On the other hand, new demands call for fiscal constraint, if not a moratorium, on implementation of existing laws.

Transportation Policy

Nowhere is the conflict over environmental accessibility more evident than in the area of transportation. The findings of this study indicate that barrier-free transportation plays a central role in the IL program.

Barrier-free transportation also touches upon other areas, such as vocational rehabilitation and income assistance. Without accessible transportation, vocational rehabilitation will not reach its full potential since the disabled person can not get to the place of employment. As a result, disability income assistance programs will remain the main source of economic support until transportation barriers are removed.

Disincentives

The study's findings support the changes that resulted from the Social Security Disability Amendments of 1980 in which some of the work disincentives were reduced. In fact, the study showed that disincentives accounted for approximately 10 percent of the variation in outcome. Therefore, not only is a careful examination called for, but before adopting or modifying programs affecting disabled persons, a "disincentives impact statement" is needed.

Marital Status/Attendant Care

Because the study showed that marital status was the most important predictor of a person's living arrangement outcome, efforts should be made, within reason, to keep a person's marriage intact, despite the disruptive influence of SCI. However, cautions should be made against overloading the marriage relationship or spouse with too many care-giving responsibilities. Subsidized, supplementary attendant care may be an alternative way of supporting an independent living arrangement.

Medical Rehabilitation

The relationship between Barthel score and IL affirms the importance of medical rehabilitation through the traditional services of physical and occupational therapy. However, there comes a point where the efforts to enhance functional capacity has a marginal payoff. Once that point is reached, intervention strategies must be increasingly directed to removing and coping with environmental barriers.

Overall Implications

Overall, the study's findings confirm the importance of environmental factors. While personal characteristics, such as age, sex, education, and severity of disability, can influence outcomes, they are relatively fixed and not subject to change as are environmental factors, such as transportation barriers, work disincentives, and support services. Therefore, an analysis of the findings indicates that policy interventions directed to environmental factors can significantly affect outcome.

Independent Living as a State of Mind

This study should be viewed as a point of departure for future research on IL issues. One of its central arguments has been that independent living offers a perspective that is unique to the analysis of disability issues and outcomes.

Until now, the field of disability policy and research for physically impaired persons has been largely confined to the disabled person's limitations. The traditional emphasis on one-to-one clinical practice has tended to exclude disciplines from outside the rehabilitation professions. By broadening the problem of disability to include a wide variety of environmental variables, IL can open the field of disability policy and research to other disciplines — law, architecture, economics, and policy research.

It is persons with disabilities who must ultimately set the terms for research and debate on disability policy issues. At the core of all disability research and policy are certain assumptions about disability and its nature than can only be validated by persons with disabilities. Without this check, these basic assumptions may be adjusted, if not twisted, to suit professional self-interest, economic constraints, and pre-existing theoretical biases.

The IL movement is the clearest statement available about how disabled persons want to be viewed in American society — not as passive victims needing constant professional intervention, but as self-directed individuals seeking to remove environmental barriers that prevent their full participation in community life. Thus, independent living should be viewed not merely as a social movement, but also as a state of mind that should become deeply rooted in our basic understanding of disability issues.

IMPLICATIONS FOR RESEARCH AND EVALUATION

The outcome measures used in the study portray how long-term outcomes of significance to policymakers can be developed "from the group up" by incorporating the views of interested parties. Also noted is the importance of developing intermediate outcome measures that are sensitive to the immediate post-program impact of IL services.

Because the study was able to account for a significant portion of the variance in outcome, a research model grounded in IL theory can contribute significantly to the understanding of disability outcomes. Researchers observed a need to extend the model to other disability groups. Moreover, there is a need to integrate psychological variables (not included in the Urban Institute survey) to help account for IL outcomes.

IMPLICATIONS FOR HEALTH POLICY

The impact of disability on health care utilization has been an overlooked issue. For the group studied, rehospitalization cost was estimated at \$13,725 per person for a 12-month period. Since this figure is lower than it would be without an IL program, it represents a general improvement in health status. In other words, less government money is spent on paying medical bills. For this reason, IL programs themselves may be an important cost-savings argument for the establishment of new IL programs.

FOR MORE INFORMATION

Material for this REHAB BRIEF was taken from Gerben DeJong's study *Disability, Environmental Barriers, and Independent Living Outcomes*. For a copy of the book, write: University Centers for International Rehabilitation, D-201 West Fee Hall, Michigan State University, East Lansing, MI 48824. Cost: \$8.00 (prepaid).

For a comprehensive account of IL as a social movement and a review of legislative history, see Gerben DeJong's monograph, "The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research," also published by the University Centers for International Rehabilitation. Cost: \$3.00 (prepaid). See also: Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm." *Archives of Physical Medicine and Rehabilitation*, 60, pp. 435-446, 1979. Or, contact Dr. Gerben DeJong, Box 1039, Tufts-New England Medical Center, Boston, MA 02111. Phone: (617) 956-5992.

For a similar account, see Susan Stoddard's "Independent Living," which appears as Chapter 9 in the *Annual Review of Rehabilitation*, Volume 1, 1980, Springer Publishing Co., Inc., 200 Park Avenue South, New York, NY 10003, pp. 231-278.

For a summary of living arrangements available for severely physically disabled persons and discussion of how to facilitate the IL process, see *New Options*, a book put out by the Institute for Rehabilitation Research, 1333 Moursund Avenue, Houston, TX 77030.

Copies of the BRIEF are available from UF-RR1. Request braille and tape editions from your regional service library.

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COALITION QUARTERLY

*A Publication Offering Specialized Management Information
for Organizations Serving Handicapped People*

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PERSONNEL PRIMER STAFFING THE PARENT CENTER

This issue of **Coalition Quarterly** discusses personnel management in two broad areas — those issues governed by law, and the common personnel practices that have evolved among parent centers.

The first article, "Personnel Law," prepared by Robert Crabtree, Esq., outlines basic legal requirements concerning wages, benefits and working conditions; anti-discrimination laws; and general principles governing the development of sound personnel documents. He stresses the importance of documentation in every aspect of employer-employee relations, and notes precautions to be observed in interviewing procedures.

Even though many issues related to staffing and management are legally spelled out, many other issues are left to the discretion of center directors, to be determined according to the needs of the work to be done and the needs of the workers. The second article highlights personnel practices that parent centers have adopted in response to the nature of the work they do and to the general characteristics of the workers.

It is impossible to examine thoroughly personnel policies and practices within the scope of this issue; however, we welcome your questions and invite you to call us if you need more detailed information or sample documents.

PERSONNEL LAW

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Parent Centers, like other small businesses, are subject to a variety of laws and regulations that affect their relations with employees. In most cases these laws require no more than a Center would do as a matter of common sense, fairness and the maintenance of congenial and productive working relationships. Some impose burdens of paperwork and expense; others present difficult choices for the employer-Center between preserving the employer's rights to make decisions and avoiding the appearance of belittling or denying employees' rights.

The major laws relating to personnel fall into two groups: those designed to prevent discrimination and those concerned with wages, benefits and working conditions. Center employers should, of course, be familiar with these laws (several are summarized below) and take steps to comply with them. They should also develop policies and practices which create an atmosphere of openness and participation and minimize misunderstandings with employees.

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The Importance of Documentation

One of the most important tools to achieve this openness is to have a written personnel policy. Even if a Center has relatively few employees, a written statement of its policies regarding wages, benefits, rules for the workplace, disciplinary procedures and the like is helpful. As the Center grows in size, such a document becomes not merely desirable but essential to good working relations. Personnel policies are required to be in writing by many funding sources, both governmental and private, and are almost always requested by auditors for larger programs.

A Center should also develop a written job description for each position defining concisely an employee's duties and responsibilities, the supervisory structure, qualifications for the position, salary, and what the employee must do for advancement at the Center.

Along with personnel policy statements and job descriptions, a Center should maintain an orderly system of records covering its relations with individual employees. This documentation is especially important to protect against charges of discrimination in hiring or firing. Concerning an employee's disciplinary termination, for example, a Center is well protected against discrimination claims where its employee file shows a systematic attempt to work out problems with the employee using progressively more severe disciplinary measures, culminating finally with termination. Copies of filed reports should be given to the employee. Of course, some types of misconduct call for immediate termination. If this occurs, a letter should be sent to the ex-employee and filed as soon as possible specifically stating the reason for the firing.

Major Anti-Discrimination Laws

1. **The Civil Rights Act of 1969, Title VII** (as amended by the Equal Employment Opportunity Act of 1972) applies to employers of 15 or more employees. It prohibits discrimination against job applicants and employees because of race, color, religion, sex, or national origin in any term, condition or privilege of employment. Employers must post a notice telling how to file charges with the enforcing agency, the Equal Employment Opportunity Commission (EEOC), and must eliminate "artificial, arbitrary and unnecessary barriers to employment."

The EEOC will try to conciliate a charge made against an employer, but if that fails, may file a civil action in Federal court to enforce the law. Job applicants and employees may file a complaint in the EEOC and may also sue employers directly in court.

Employers in violation may be ordered to make retroactive salary payments and pay the claimant's attorney's fees and expenses as well as to submit a plan for changing their employment practices.

2. **The Federal Age Discrimination In Employment Act of 1967** (as amended in 1978) provides the same protections as the Civil Rights Act to persons age 40-70 where the employer has 25 or more employees.
3. Federal contractors and subcontractors with contracts of \$10,000 or more must engage in affirmative action programs (generally identifying and changing practices with discriminatory effects and positively recruiting and providing an accepting work environment for women and minorities). The affirmative action program must be in writing and will be monitored by a Federal compliance agency if the contractor has 50 or more employees and the contract is \$50,000 or more. "Contracts" does not include "grants." Executive Order 11246 (amended by Executive Order 11375).
4. Federal contractors and subcontractors of \$2,500 or more and grant recipients are prohibited by the **Rehabilitation Act of 1973 — Sections 503 and 504** from discriminating on the basis of handicaps and must develop affirmative action programs.
5. Under the **Vietnam Era Veteran's Readjustment Assistance Act of 1974 — Section 402**, Federal contractors and subcontractors are prohibited from discriminating against qualified Vietnam Era Veterans during the first four years after discharge and against Vietnam Veterans disabled 30% or more throughout their work-life. Affirmative action programs are also required.

In general, the best protection against charges of discrimination by unsuccessful job applicants is to limit questions in the hiring process to those seeking information which is really necessary to evaluate the applicant's qualifications and avoid those that are unnecessary. Inquiries about race, handicap, etc. should be used only as part of an affirmative action program. As for terminated employees, a systematic program of employee discipline and record-keeping as described above is the best protection. Anti-discrimination laws do not prohibit firing employees for just cause where rational disciplinary procedures have been followed.

Laws Concerning Wages, Benefits and Working Conditions

1. **Fair Labor Standards Act of 1938**, as amended by the Education Amendments of 1972, and the laws of most states establish certain requirements relating to minimum wages, overtime pay, and other basic provisions of the work environment. Executive, administrative and professional employees are exempt from the FLSA's provisions.

Particular provisions of the FLSA include these: (a) a minimum wage of \$3.35/hour (as of this writing); (b) overtime pay at 1½ times the regular rate after 40 hours; (c) provisions restricting children age 14 and 15 to work limited hours outside of school hours; (d) provisions prohibiting discrimination on the basis of sex where employees are doing substantially equal work with equal skill, effort and responsibility.

The importance under the FLSA of keeping simple, clear records of employees' time and wages paid cannot be overstated. The enforcing agency, the Wage and Hour Division of the U.S. Department of Labor, sometimes treats poor record-keeping itself as a sign that the law is being violated. Penalties include payment of back wages, injunctive relief, and sometimes payment of additional money damages. In particularly egregious cases, criminal fines may be imposed.

2. Federal and state laws combine to provide unemployment insurance benefits under the **Federal Unemployment Insurance Tax Act of 1939** and the **Social Security Act of 1935**, as amended. Not-for-profit organizations must participate in most state programs if they employ a sufficient, usually small, number of people.

In most states, an employer may either self-insure or contribute to an unemployment insurance fund. A center should weigh carefully the possible cost of having to pay benefits to an ex-employee against the certain costs of contributing to an insurance fund to decide between the two alternatives.

Usually a terminated employee will be eligible for benefits unless she/he left voluntarily without good cause, or was fired for misconduct that was against the interests of the employer. The ex-employee must be able and available to work at employment comparable to the job she/he has left, but need not accept (1) a job open because of a labor dispute or (2) work where the wages or working conditions are lower than standards in the area or (3) work offered on the condition that she/he join a company union or that she/he not join a union.

The options available to Centers which are tax-exempt under Sec. 501(c)(3) regarding social security taxes will be discussed in the next issue of *Coalition Quarterly*.

3. **Worker's Compensation** laws apply to employers in every state, although typically a state will exempt organizations with only a small number of full-time employees. These laws are to protect against the consequences of injuries sustained on the job, usually including those occurring while traveling to or from the job. The employer's responsibility to provide benefits attaches regardless of who caused the injury.

Injured employees, and in case of a death, their dependents, are typically entitled to one-half to two-thirds of their weekly wage plus hospital and medical benefits. In return, employees give up their rights to sue their employers, but they may sue any person who negligently caused the injury. If such a suit is successful, any payments they recover must first be used to reimburse the employer or his insurance company, and the remainder belongs to the employee.

Centers often use consultants who may not be considered employees covered by the worker's compensation provisions because they are "independent contractors." Generally speaking, independent contractors are persons who agree to produce a product, but remain independent of the employer and do not submit to his or her particular instructions concerning how to produce the product.

Most states require employers to carry worker's compensation insurance and do not give them the option of being self-insured. The potential costs to an employer of having to pay a claim itself are so great in any event that it is ill-advised not to carry insurance.

4. Parent Centers, which are typically small, are unlikely to face union organizing campaigns, but should not consider themselves immune, especially if they grow in size. Law defining the rights of employees of employers "in interstate commerce" is found in the **National Labor Relations Act**. Other employers are often covered by state laws similar to the NLRA. Should a Center be confronted by requests that a labor organization be recognized as representing the Center's employees, the Center should consult with an attorney or other expert in the area of labor relations.

With or without a union, a Center is well-advised to have fair and sensible procedures for handling discipline, disputes over wages and working conditions, and individual employee grievances. As dedicated and professional as employees of Parent Centers are, they have the same needs and rights as any other employees. If those needs and rights are not honored, Parent Centers, like other employers, run a serious risk of low morale and burnout which in turn undermine a Center's ability to serve families in need.

PERSONNEL PRACTICES

Introduction

In addition to the legal items Mr. Crabtree discusses, other aspects of personnel management need clarification from the beginning to assure smooth Center functioning. Written personnel policies and job descriptions help define these areas.

Beyond statements of compliance with the laws governing the Center's relationship with its employees, written personnel policies include details on operating procedures designed to reflect each Center's philosophy and priorities in personnel management. These policies should be based upon the needs of the Center itself, rather than upon the staff profile at a given time. It is easy to assume that certain problems are not likely to plague one's own Center if the staff is dedicated and skilled. There is no guarantee, however, that such a situation will remain stable forever.

Job descriptions further specify employer-employee roles in day-to-day operations. This article discusses both personnel policies and job descriptions as they apply to parent centers.

Personnel Policies

Personnel policies are a statement of mutual expectations. They provide guidelines for judgements and should reflect the Center's commitments and philosophy. Since personnel policies are often similar for most non-profit organizations, request copies from other parent centers and similar organizations, preferably larger and older than your own, before embarking on the task of writing them. Excellent resources for additional information are available from the Grantsmanship Center, 1081 South Grant Ave., Los Angeles, CA 90015. We especially recommend the publications **Personnel Policies for Your Agency: Get Them In Writing Now**, and **How To Design Your Agency's Employee Benefits Program**. The following discussion highlights those components of personnel policies that may be less standardized or that have particular relevance to parent centers.

Hiring — Whenever possible, Centers have been careful to maintain their original volunteer staff in paid positions when, and if, funding becomes available. Experience has shown that it is especially important from the beginning that there be a single strong leader who is in that position by consensus, and this person should be the first one to assume a paid position. Usually such a leader has been instrumental in founding the center, obtaining initial funding, and in assuring its continuance. In most proposals for funding, key personnel are identified and money is awarded on the condition that those personnel be involved as specified in the proposal.

Occasionally friction develops when some staff can go on a payroll and others must continue as volunteers. Care should be taken to build in rewards for volunteers, and, whenever feasible, to give them priority when adding to the payroll. In addition to monetary rewards, volunteer and paid staff are often motivated by such things as recognition, achievement, and opportunities for personal development and challenge.

Often Centers downplay the importance of academic credentials and emphasize volunteer experience. However, some areas, not related primarily to the content of the work, may require more formal training: for example, financial management, office management, supervision, writing, and research skills. Overall staffing patterns should allow for a range of talents and abilities.

Affirmative Action — An affirmative action statement in writing may be legally required for your organization. (See previous article for guidelines). Affirmative action requires a more active seeking out of ways to employ women, minorities, veterans, and handicapped persons than a simple statement of non-discrimination. Usually, additional financial and time commitments are required.

Even if not required, many Parent Centers practice affirmative action for parents of children with handicaps (in keeping with their overall intention to maintain a parent perspective) and for disabled adults (as a means of expanding employment opportunities).

Setting Pay Levels — This task is a delicate one. Salaries are often predetermined by specific requirements of contracts or grants. One Parent Center stressed that, "At the outset, care should be taken to think in terms of sexist policies. People are likely to undervalue themselves because they are women, especially if they work part-time and continue to do much the same work they did previously on a volunteer basis."

Scales should reflect current levels in state and federal government, as well as salary levels and cost of living in one's own community. Contacting another Parent Center and your local United Way organizations will offer some guidelines before establishing salary levels.

A method for granting salary increases should be spelled out. These are usually made according to an automatic schedule, presuming satisfactory work performance, or by merit review. Specifications for times when salaries will advance or be reviewed, as well as criteria for determining pay, should also be included. Each job should have a salary range to set limits on salary progression. This projection will help predict payroll costs, and give employees the security that pay will be equitably adjusted on a regular basis.

Some mention should be made of cost of living increments. Funding sources seldom expand enough to totally protect Center employees from the effects of inflation, but sound financial planning should permit a small allowance for this purpose, even if in combination with merit increases.

Benefits — In addition to programs in which, by law, the employer must participate, there are other benefit options which an employer may offer as ways to augment the salary, such as the obvious benefits of holidays and vacation time. Remember, benefits usually cost money, so calculate carefully the potential cost before offering them.

In developing benefit packages, consider the needs of the workers; for example, if they are predominantly young, they may appreciate maternity and educational benefits, as well as consideration given to days off which correspond to school holidays. Older staff may appreciate life insurance and retirement plans. Health and dental plans have universal appeal.

Credit union advantages are not difficult to set up, do not cost the company anything, and employees appreciate the service. Often Centers receive vouchers for college courses in exchange for supervising work-study students. These can be offered to employees without cost to the Center. Don't overlook opportunities for training which are offered through the Center itself and do explore other avenues of educational assistance.

Promotion — Opportunities for advancement and change within an organization are good for staff morale and every effort should be made to promote from within the existing ranks of staff and volunteers. Maximize talents of the staff by using the Center itself as a means of "learning by doing" through apprenticeship programs. For example, Centers often start workers in a receptionist position as a means of familiarizing them with basic procedures, or give a learner opportunities to participate in panel discussions after observing more experienced staff at speaking engagements. Such training and observation may enable the worker to gain the skills needed for promotion when the opportunity arises.

Delegation of Authority — Centers agree that to bring out the leadership potential of workers, they must be given meaningful responsibilities from the beginning. The continuity and stability of the Center depend upon leadership development.

Probationary Period — A three to six month probationary period offers opportunity for mutual evaluation for workers and is also valuable in cases of promotion. Remember the Peter Principle!

Work Schedules — Although most Centers keep regular daily hours, there are usually more part-time than full-time workers. Staff members who are most involved in direct advocacy or training need a degree of flexibility in the hours they will be in the office. It is vital, however, that events outside the office and in-office meetings be scheduled so that there is adequate coverage in the office at all times. Ideally, there should be at least one full-time person in the office the greatest percentage of his/her time in order to assure continuity. Whenever possible, it is preferable to have part-time workers in the office daily, rather than two or three full days per week. Even under the best of conditions, care must be taken to build in opportunities for all staff to be present at the same time to facilitate communication and continuity.

Job Descriptions

Typically, workers in parent centers are action-minded and service-oriented and the development of written operating documents has been of secondary priority. This was especially true immediately following the passage of P.L. 94-142 when the enthusiasm and commitment of parents provided the necessary energy and direction to create and maintain effective programs. Often staffs were small, and little differentiation of job descriptions was needed. Indeed, a spirit of equality and democracy prevailed, with all staff basically having the same job descriptions, although seldom written down. As Centers grow, and differentiation becomes necessary, viable job descriptions increase the chances of maintaining this spirit of cooperation and enthusiasm by providing paid and volunteer workers with definitions of their responsibilities. Such clear lines of responsibility form a structure which allows workers to continue in a genuinely caring and effective manner.

It is not uncommon for workers in parent centers to have more than one job title — one a generic, internal title, and a second, functional title assigned to a particular grant or contract which is subject to change when a temporary assignment is completed. Internally, a worker may be referred to as a "resource parent" or "information specialist," while at the same time acting as a project director for a particular grant.

For this reason, the job description must be flexible enough to allow for changes and should be updated as needed. Annual review of job descriptions as well as pay levels and schedules has proven helpful in established centers.

Job descriptions should contain the following information:

- title of position, supervisor, overall duties to be performed, and amount of time involved;
- necessary skills (technical, communication and interpersonal, or managerial);
- concise and clear statements of the tasks involved in performing the job;
- a specified time when evaluation will be performed;
- salary range.

Volunteers

A valuable part of the work of many Parent Centers is done by volunteers. They work out of a sense of identification with the Center's philosophy and goals, a desire for personal fulfillment and an urge to serve.

The relationship between the volunteer and the center should be regarded as contractual — everyone from the first must understand that a volunteer's commitment is as serious as that of a paid worker.

Some Centers have written agreements, signed by the volunteer worker and the Center, that spell out their mutual obligations and provide a basis for understanding. Space does not allow us to include samples, but we will be happy to send them on request.

The federal government recognizes the work of volunteers and grants them some of the same consideration given to paid workers. The IRS code allows volunteers to deduct certain travel, gas, food, and lodging expenses incurred on the job from their taxes. The Civil Service Code allows applicants for government jobs to include relevant volunteer work in their employment history.

Involvement and motivation are as vital to good volunteer management as to paid staff. Since they are not motivated by a paycheck, volunteers are unlikely to continue in jobs they think are unimportant. Efforts to keep them involved and to develop their skills and talents will help keep interest and enthusiasm strong.

In addition to Voluntary Action Centers, which are run by the United Way, centers have been successful in recruiting volunteers from the following sources: local colleges and universities; parents who have been trained or helped by the center are often willing volunteers; elderly or retired persons; disabled adults.

FOLLOW UP ASSISTANCE

Dear Reader,

Your input is important to us! In order to supply you with the information you need, we need to hear from you. Let us know if you have found the *Coalition Quarterly* helpful and how you have used it. If there are any topics you would particularly appreciate being covered, please let us know that, too. The more responses we receive, the better we can suit the information to your needs.

Also, if information contained in any of the issues stimulated further questions or a need for more in-depth information, please call or write to us at the Federation. We will do our best to provide you with the assistance you need. Contact:

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FUTURE ISSUES

Publication and distribution of *Coalition Quarterly* may be delayed for a few months after March, 1982. Please be patient — distribution will resume in the near future.

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REHAB BRIEF

Bringing Research
into
Effective Focus

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REHABILITATION INDICATORS

A Method for Enhancing Accountability and Services

The mission of the Rehabilitation Indicators (RI) Project is to develop a method, a common language, for describing client functioning.¹ Why is such a language needed? What are "rehabilitation indicators?" What can they do for rehabilitation counselors, administrators, researchers, and others? The purpose of this BRIEF is to summarize the most basic answers to these questions. The possession of a common-language method for describing client functioning in itself constitutes a giant leap in rehabilitation's state-of-the-art. If widely disseminated, understood, and correctly used, it can designate functional status far better than existing diagnostic labels. In this way, it can greatly facilitate the work of rehabilitation.

THE PROJECT'S PURPOSES

The original purpose was to develop a tool for measuring the benefits produced by vocational, psychosocial, and medical rehabilitation programs. This was a response to increasing demands for program accountability from funding sources and consumers, and emerging threats of reduced resources if service benefits did not appear to justify costs. It also acknowledged that existing methods were insufficient. Benefits were defined too narrowly (e.g., "closed, employed") to take into account the full range of outcomes actually achieved in rehabilitation. With experience, the project's purposes expanded because the staff saw that RI's could meet many other needs as well. Four of these are:

- to state client goals and objectives in precise, measurable ways that can be understood by all

¹ The RI Project began in 1974, through a grant from the Rehabilitation Services Administration (RSA), and is now funded by the National Institute for Handicapped Research (NIHR). It is located at the New York University Medical Center, and is directed jointly by Leonard Diller, Wilbert Fordyce, and Durand Jacobs. Margaret Brown serves as Project Coordinator. In November of 1982, NIHR's funding aid is expected to end. However, the RI Project hopes to continue working toward completing its mission through a combination of private and public sector funding.

concerned in all rehabilitation settings

- to measure changes in client functioning, strengths, problems, and needs, so that client progress and programs can be evaluated accurately
- to use such assessments in case management
- to define disability as to type and severity of functional limitations in consistent, equitable ways, so that rehabilitators can know just what assets and liabilities a given client has.

Accomplishing these interrelated purposes required massive efforts by cooperating professionals and consumers in rehabilitation settings all over the country. Initial materials development called for advisement from many points of view, and numerous test sites were needed to test the reliability, validity, and utility of the materials developed.

REHABILITATION INDICATORS: WHAT ARE THEY?

According to RI Project staff,

RI's constitute a *language of descriptors* which can be used to obtain and organize large amounts of information about the functioning of clients . . . (They) focus solely on client *functioning*, and then only on *observable* elements and variables. RI's are not descriptors of disrupted or disabled functioning *per se*, but instead describe skills, activities, etc. that contribute to *any* person's functioning . . . Therefore, RI's can be used with any group of disabled . . . or able-bodied persons.

To develop the RI language, Project staff analyzed client functioning from three points of view:

- behavior of the client in day-to-day living, what the client *does do* in home, work, and community contexts

- the client's repertoire of behavioral tools, not what the client actually does, but what he or she *can do*
- environmental factors that support or hinder the client's activities.

From these analyses, three sets of Rehabilitation Indicators emerged. These cover statuses, activities, and skills. A fourth set covering environmental factors is awaiting development. Extensive field testing and refinement of materials resulted in sets of tools designed to assess individual functioning and procedures for using them in varying situations and for varying information needs. The term "rehabilitation indicators" refers to these tools, procedures, and the functional assessment data obtained from using them.

Status Indicators describe categorical statuses or roles such as "employment" or "living arrangement." In some ways, Status Indicators appear to be similar to "demographics." However, an important distinction should be noted. Demographics include factors which cannot be changed, such as race and place or date of birth. Status Indicators include only statuses that are crucial to clients' functioning and are influenced by disability. They must also be amenable to change through the rehabilitation process. Six areas of functioning are covered:

- Work
- Self care
- Income
- Transportation
- Education
- Family

The data are gathered in five to ten minutes by interviewing the client or significant others, or through self administered questionnaires.

t03 Activity Pattern Indicators describe day-to-day activities such as "visiting friends" and "cooking meals." They reflect the client's pattern of living in terms of mobility (locations of activities), variety of activities, frequency and duration of activities, levels of social interaction, and the physical assistance needed. The data are recorded on an inventory or a diary format, both of which can be self administered by the client or obtained by interview. Data collection time varies, according to format and level of detail sought, from ten to sixty minutes of interviewer and/or client time.

Skill Indicators describe behavioral tools people need in order to attain their activity goals in such areas as vocational, educational, recreational, family role, and self care. More than 700 skills are organized into 70+ skill packets. Users pre-select only those packets relevant to their clientele, and only the relevant skills within each packet. All Skill Indicators assess tasks that are functionally meaningful to the client, such as "turns knob to open door." They do not assess partial tasks or movements, such as rotating the forearm. The

time needed can vary from a few minutes to several hours, depending on the number of skills assessed and the data gathering approach used.

Environmental Indicators are still being developed. They will describe elements of the client's physical and social environments—within home, work, and community contexts—that may help or hinder goal attainment. "Curb cuts" and "employers willing to hire disabled workers" serve as illustrations.

Thus, the RI language reflects the four *functional* areas just outlined. It also is structured by *content* areas that cut across the four types of indicators, notably: communication, social/leisure, legal/political, vocational/educational, self care/family role, economic, rehabilitation, and transportation. To illustrate, vocational content has been developed into indicators that reflect the different aspects of vocational functioning: vocational statuses, activities, skills, and environments. Finally, the RI language reflects varying *levels of detail*. For example, the Activity Pattern Indicator data can be analyzed to describe general patterns of activity (e.g., percent of time spent away from home or in recreation) or to describe specific activities (e.g., hours spent on the job or in watching TV).

PURPOSES, USES, AND USERS

RI's provide a tool for use by rehabilitation administrators, practitioners, and researchers who must carry out tasks which rely on consistent, valid information about client functioning. Major examples are listed below.

For Administrators:

- Program planning and management
 - Stating program eligibility criteria
 - Defining "disability" functionally
 - Defining the needs of a client group

For Practitioners:

- Case management
 - Defining presenting problems
 - Defining client goals and objectives
 - Developing individualized written plans (IWRP's, WILP's)
 - Tracking client progress

For Researchers/Evaluators:

- Program evaluation and other research
 - Setting suitable benefit or outcome criteria
 - Measuring multi-dimensional outcomes
 - Operationalizing closure definitions

For all:

- Facilitating communication
 - Between providers in different rehabilitation settings

- Between providers and consumers
- Between providers and funding sources or legislators
- Among providers from different disciplines or at different organizational levels within the same settings

FIELD TESTS AND DEMONSTRATIONS

More than 40 field tests and demonstrations of RI's have been conducted in ten states. These studies have sought to test and refine the reliability, validity, sensitivity, comprehensiveness, and acceptability (to clients and providers) of the tools, procedures, and assessment data yielded. The investigators report that:

After much and varied field experience . . . reliability and validity of assessment with RI's are as much a function of the usage situation and the usage model as they are of the RI tool . . . Thus, our objective at this point is to *explore* these issues, to discover how to set up situations to maximize reliability and validity—through appropriately designed usage models, adequate training, etc.

Despite the limitations, they report that the weight of positive evidence is increasing on such matters as test-retest reliability and sensitivity of the RI's to expected changes in the rehabilitation process. With respect to further validating the measures and increasing their utility to users, they point out that the volume of evidence needed must be amassed over time through dissemination and use of the tools, and systematic analysis of the data obtained. This is suggestive of the decades of cooperative research conducted by the U.S. Employment Service and the various state employment services to develop and augment the reliability and validity of the General Aptitude Test Battery (GATB). In other words, the Rehabilitation Indicators Project may have only begun what will prove to be an ongoing program of research and development.

Brief summaries of two demonstrations are presented below to illustrate varied RI uses and a sampling of field test findings.

Program Evaluation. The United Cerebral Palsy Association of New York State used RI's to evaluate the Post-Institutional Placement Program (PIPP) for deinstitutionalizing residents of the Willowbrook Developmental Center. PIPP places residents in apartments throughout New York City, and arranges for day programs and support services. PIPP staff wanted to evaluate how life had changed for ex-residents when they entered community living. To assess this, they administered Status and Activity Pattern Indicators to

29 people at the Center, and again eight months after their deinstitutionalization. RI Project staff report:

The RI data indicate large and consistent changes in statuses and patterns of activity, for example:

- Ex-residents' lives were *more active* after leaving the institution. The number of occurrences of activities increased by 39%; recreation, family role (e.g., cleaning house) and vocational activities became more frequent, while the frequency of other activities—personal care (e.g., eating), medical and quiet (e.g., sleeping)—remained constant.

- The lives of ex-residents were *more mobile*; the frequency of activities implemented outside the residence increased nearly 100% (from 16 to 31 away-from-home activity occurrences per week).

- Ex-residents' lives were *more diverse*. The variety of activities in which the ex-residents engaged increased more than 100%. Again, diversity increased in recreation, vocation and family role, but not in personal care, medical or quiet activities.

Case Management. Several counselors in the Dayton Area Office of the Ohio Bureau of Vocational Rehabilitation decide which RI tools are relevant for which clients. For example, Status Indicators are often used to document information that is elicited but not recorded in official files, to gain insights into income disincentives, transportation problems, or other barriers to employment. Activity Pattern Indicators are administered during the assessment and plan stages to clarify problems of functioning that may block goal attainment. Two self-administered API's—Delegatable Activities and Special Events—give planning information on independence in activities of daily living and integration into the community. Skill Indicators are proving most useful in establishing job goals and defining skill deficiencies that need correcting. According to RI Project staff:

With selected service vendors, counselors have found the Skill Indicators useful as a tool which allows them to prescribe in specific functional terms what is being requested. This fosters a common language with which the counselors and referral services can communicate *vis-a-vis* the problems, remedies, and progress of their mutual clients. Repeated administration of the RI tools offers counselors specific information on the effectiveness of services and their impact on the client's goal attainment, while offering a blueprint for eventual program evaluation should the agency elect to adopt the RI approach statewide.

ADVANTAGES OF USING RI's

A goal of many rehabilitation agencies is to reduce paperwork, and virtually all resist allowing it to increase. How, then, could yet another data gathering device appeal to these agencies? RI Project staff are keenly attuned to the paperwork burdens of human service delivery systems in this era of accountability. Accordingly, they have tried to develop tools and systems that can replace rather than be added to existing documentation practices. Also, the tools and systems can do multiple duty; the same data can meet case management, program evaluation, and other information needs as well. Thus, the RI Project appears to have developed an approach which can meet agencies' paperwork criteria. However, whether it will be in the hands of its users. If users are willing to put initial investments of time and effort into establishing new records systems using the clearer RI language, no added paperwork should be required in the long run. In fact, elimination of duplicative records—those describing the same events in different terms for different purposes—could result in an overall reduction in paperwork.

RI's can be used flexibly. They are designed for selective use to meet the particular information needs of any rehabilitation discipline in any setting serving any client group. Also, the data can be gathered in myriad ways—observation, self-report, interview, self-administered questionnaire; by a range of professionals or paraprofessionals; and at any time during the rehabilitation process. This flexibility allows program evaluation to focus on as wide or narrow a range of functioning as needed to accurately reflect an agency's areas of accountability—from “vocational only” to “independent living” or even more broadly defined areas. Data can be obtained at relatively gross levels or they can be very specific, as appropriate to the needs.

Important to most of us, RI's avoid jargon, and use lay language understandable by all.

RI's can give rehabilitation agencies an accurate picture at the outset of service of just what functional capacities or incapacities exist in a given instance. This allows rehabilitation workers to better understand the scope of work ahead.

RI's can give more useful, accurate functional descriptions than can existing diagnostic labels. Bert Griffis, of NIHR, points out that, “Their utility should lie in counteracting or improving on the inaccurate stereotypes (in terms of functional capacity) often associated with the usual diagnostic labels.”

Finally, an advantage exists apart from the characteristics of RI's, or the outcomes they can help us accomplish in terms of program planning, case manage-

ment, and program evaluation. The *process* of using RI's can help us individually and as a professional field to clarify and “tighten” our thinking about clients' needs and how we can best respond to them. A precise and comprehensive generic language in which to *think* as well as communicate about client functioning can help make future services more precise and comprehensive than they are today.

UTILIZATION PROBLEMS FORESEEN

The advantages of using these new tools are many, but the other side of the coin must be inspected, too. Utilization problems are foreseen at two levels. First, *fears* of extra recording, despite reassurances, are likely to discourage some from making use of RI's. Also, *change* from an existing system—even to a better one—does absorb time, effort, and money. This investment may be reluctantly faced or refused.

Second, as RI Project staff have cautioned, the reliability and validity of RI's vary with the suitability of the usage models employed. Thus, if technical assistance on devising workable usage models is not available, users could become disillusioned and discard the RI's. This should become less of a problem as user manuals and training materials become available.

HOW TO GET THE RI TOOLS

The RI Project is nearing the end of its third phase, which has been devoted largely to exploring the utilization of the materials developed. Broad-scale dissemination is to begin in the fall. If you are interested in using, or exploring the possibility of using, Rehabilitation Indicators for any or many of the purposes cited, a copy of “Decision-making Guidelines for Potential Users of RI's” and a list of other Project publications can be obtained from:

Margaret Brown, Ph.D., Project Coordinator
Rehabilitation Indicators Project
400 E. 34th Street
New York, NY 10016

SOURCES

Rehabilitation Indicators: A Method for Enhancing Accountability and the Provision of Rehabilitation Services.

- Progress reports to the National Institute for Handicapped Research, August 1, 1980 and August 1, 1981.
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Rehabilitation Indicators UPDATE, Numbers 1-6, January 1979 through April 1982.

REHAB BRIEF

Bringing Research
into
Effective Focus

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CONTINUING RESEARCH FINDINGS: ATTITUDES TOWARD PEOPLE WITH DISABILITIES

Itzhak Perlman, a violinist whose legs were paralyzed by polio when he was five, speaking at the International Year of Disabled Persons ceremony held last year in New York City:

Most disabled persons adjust well to their disabilities. Ask many of us what we would like most in life and we will say, "To be a better father" or "To be promoted in my job." You would be surprised how few of us would say, "Not to be disabled." It is others who have a problem dealing with our physical impediments.

From the READERS DIGEST

These words of Perlman's seem to convey an important truth. Although their validity has not been established, casual observation suggests they may well be true.

Most of the knowledge directing the efforts of rehabilitation workers is clinical wisdom rather than research-based information. For example, we act daily on the presumption of attitudinal barriers existing virtually everywhere—in the classroom and job market, within the family, in stores and restaurants, even within people who have disabilities themselves.

Jerome Siller and his colleagues and students in the Department of Educational Psychology at New York University have for many years attempted to provide research-based information in this area. Their earlier work in identifying and measuring the dimensions of attitudes toward people with disabilities was reported in two *Research and Demonstration Briefs* (Vol. I, No. 4, November 1, 1967; and Vol. IV, No. 6, December 5, 1970). They found seven stable factors describing attitudes of nondisabled people toward amputation, blindness, cosmetic conditions, deafness, obesity, and disability in general. These include:

- **Interaction Strain**—uneasiness in the presence of people with disabilities and uncertainty as to how to deal with them.
- **Rejection of Intimacy**—a rejection of close, especially intimate, relationships.

- **Generalized Rejection**—unpleasant personal reactions with derogation and advocacy of segregation.
- **Authoritarian Virtuousness**—ostensibly "pro-disabled," this orientation is rooted in an authoritarian context and advocates special treatment. Despite its benevolent appearance, the evidence suggests that it is fundamentally negative.
- **Inferred Emotional Consequences**—an assumption that disability impairs the character and emotions of its "victims."
- **Distressed Identification**—personalized reactions to disability arising from anxiety about one's own vulnerability.
- **Imputed Functional Limitations**—restricted evaluations of the ability of people with disabilities to function in the environment.

It is worthy of note that six of the dimensions are clearly negative and the one which appears to be positive has been interpreted as actually reflecting negativity by the Siller group. None of the positive attitudes which are occasionally described, such as beliefs that people with disabilities develop compensatory strengths, was found. It would seem that the clinical wisdom which assumes the existence of pervasive attitudinal barriers has received substantial confirmation.

Psychometric scales to measure the dimensions were developed and are considered satisfactory in terms of reliability, validity, and sensitivity to experimental effects. They are referred to collectively as the Disability Factor Scales (DFS). Using these, Siller et al. have studied relationships between personality variables and attitudes toward people with disabilities. *Ego strength* and *ability to form relationships*, measured by a variety of objective and subjective instruments, were found to correlate significantly with their indices of disability-related attitudes. These findings influenced the direction of their current work.

The programs of study just described were funded by the Social and Rehabilitation Service of the former Department of Health, Education and Welfare. Con-

tinuing efforts consist primarily of nonfunded doctoral research conducted under Siller's direction. Several examples are summarized directly below.

EXPERIMENTAL STUDIES

Factors Influencing Evaluation and Interaction Between Disabled and Nondisabled People

The common purpose of these studies has been to clarify how people with disabilities promote or inhibit positive interactions with others. The variables studied include responsibility for causing disablement, the adaptation style used (coping vs. succumbing), and whether disability is explicitly acknowledged by the person who is disabled.

Donald H. Vann questioned whether male subjects, previously identified as high or low in authoritarianism, would respond differently to obese men who were or were not believed to be responsible for their obesity. One hundred subjects participated in what was understood to be a learning situation. They were instructed to administer shocks to obese men (assistants of the experimenter) who "spontaneously" admitted they were/were not responsible for their obesity by claiming gluttony or hormonal causes. Three measures were taken: shock duration (punishment), pressure exerted on the shock key (antagonism), and a verbal evaluation scale.

The results showed that when an obese man was seen as being responsible, the subjects were significantly more antagonistic and more derogating than when he was seen as not responsible. Also, highly authoritarian subjects were more antagonistic than those low on that dimension.

Rose Bazakas studied whether the ways in which people with disabilities present themselves to others would influence nondisabled people's reactions to them. She defined self presentation in terms of whether their adaptation styles reflected coping, dependency, or denial, and whether they explicitly acknowledged their disabilities.

The experimental situation was a tape-recorded interaction between a nondisabled student (108 white, undergraduate students) and an experimental assistant who simulated disability by using a wheelchair (4 drama students trained to play the various roles). Both responded alternately to two topics: briefly describe yourself to your partner, and discuss the importance of a good personality. Measures included a partner rating scale and assessments of the affect expressed in a written communication, length of communication, self-reported discomfort, and feelings of distance from the other person.

The results showed an interesting interaction between the two dimensions studied. Explicit acknowledgement of the disability resulted in more favorable reactions, but only when the "disabled" experimental assistants presented themselves as coping individuals.

These findings require serious consideration. It could be that the instructions to "describe yourself to your partner" created a situation wherein failure to mention an obvious disability seemed more peculiar than it would ordinarily. However, to the extent that the findings can be generalized to real-life first encounters, they suggest that for a disabled person to get "credit" for coping, explicit mention of the disability may be advisable. (Please see Implications below.)

Shurka, Siller, and Dvorch used a different approach to assess the impact of coping/succumbing adaptation styles and responsibility/nonresponsibility for causing the disablement on nondisabled people's attitudes toward people with disabilities. Four groups of 24 business students viewed five-minute videotapes showing structured interviews with a wheelchair user who was trained to portray the 4 experimental conditions and discussing future work. The subjects then completed a subject rating scale, an interview rating scale, and a measure of affect (expressed in a written communication).

The results suggested that portraying oneself as coping and not responsible leads to the most favorable evaluations, and coping is a more powerful determinant than responsibility. The order of favorability was coping-not responsible, coping-responsible, succumbing-not responsible, and succumbing-responsible.

Generalization of results from laboratory simulations, using subjects who are not representative of the general population to study complex real-life encounters, must be done with caution. However, the findings agree with the clinical wisdom that the ways in which people with disabilities present themselves to others influences the climate of their social interactions. In other words, nondisabled people may not necessarily carry stereotyped notions into their interactions with disabled people regardless of the latter's individual styles. This has important implications for rehabilitation practice. We should teach people with disabilities that their own behavior does make a difference and offer specific ways to improve their interactions with other people. (Please see Implications below.)

Perceptions of Disabled People About Themselves and Others

Ephraim Friend studied the attitudes and social interactions of amputees and nonamputees—the accuracy of perceptions in each group, and the influence of perceptual distortions on social interactions. Also, he questioned whether contact between amputees and nonamputees, involving discussion of amputation-related attitudes, would reduce perceptual distortions and improve attitudes.

The subjects were 30 patients in a U.S. Naval hospital with unilateral lower limb amputations incurred 4-8 months prior to the experiment. They were matched with 30 medical corpsmen (age, sex, race, education, marital and socioeconomic status, and at-

titudes on a subject not related to disability) and paired by randomized procedures.

Each subject took the Disability Factor Scales - Amputation (DFS-A) and then recorded the opinions he supposed would be given by the opposite experimental group. A day later, each pair of subjects interacted by discussing the items on the scale and coming to a single combined opinion. The next day, the DFS-A was readministered to each subject for self and projected scores. The tape-recorded interactions were assessed by rating scales scored at both speech-by-speech and global levels.

The results showed that amputees expressed more favorable attitudes toward amputation than did (nonamputee) corpsmen on the DFS-A. In their interactions, however, the corpsmen were more positive. One possible interpretation of this is that the medical corpsmen were trying to reassure the recently injured patient-subjects. The amputees expected the corpsmen to have more unfavorable attitudes toward them than was found on the initial DFS-A measure. This agrees with clinical observations that newly disabled people expect and fear the worst with respect to their social acceptability. However, the post-interaction DFS-A scores reflected better agreement between the amputee-projected and actual attitudes expressed by the corpsmen. This suggests that their discussions of amputation-related attitudes, even though brief, had rehabilitative value. (Please see Implications below.)

William B. Zuckerman, generalizing from theories of prejudice, predicted that the personality variables *ego strength*, feelings of *alienation* from others, and *authoritarianism* would be related to attitudes toward disabled people.

Samples were drawn from populations of people who are deaf, blind, and nondisabled (N=90, 95, and 89 respectively). Materials and procedures were modified to be appropriate for deaf and blind subjects, and validity checks were made. Measures of authoritarianism, alienation, and ego strength, a demographic questionnaire, and the Disability Factor Scales for Deafness and Blindness were used. Blind subjects responded to the DFS-Deafness form; deaf subjects to the DFS-Blindness form; and nondisabled subjects took both forms.

The results of correlational analyses between the various personality and attitude measures showed that:

- The more authoritarian and alienated subjects who were blind or deaf expressed more negative attitudes toward people with the other disability.
- Those with greater ego strength expressed more positive attitudes.
- Feelings of alienation from others was a more powerful predictor than ego strength or authoritarianism.
- The attitudes of deaf subjects toward blind people were found to be more negative than those of blind

subjects toward deaf people, and more negative than those of nondisabled subjects toward people who are blind.

This last finding is somewhat startling. To the Siller group, it suggested that intrapsychic or unconscious influences on attitude formation should be studied. However, it may be equally important to consider it in the light of socio-political information which bears face-value relevance. That is, leaders in the deaf community express severe frustration and political concern over the tendencies of people-in-general to under-appraise the handicapping effects of deafness. At the same time, they agree with leaders in the blind community that the handicapping effects of blindness tend to be over-appraised. The comparative effects are often highlighted with the following suggested experiment:

When you are watching television, close your eyes and see if you can follow what is happening. Then open your eyes, turn off the sound, and try again.

With rare exceptions, loss of the auditory receiving channel will impair understanding far more than will loss of the visual channel—even though television is known as a visual medium.

Advocates for the deaf community say that society's failure to appreciate the severely handicapping effects of deafness has resulted in disproportionately low levels of service attention and funding support. People who are blind and wheelchair users are seen as receiving far more. It seems reasonable to hypothesize that the negative attitudes Zuckerman discovered could stem from conscious, experiential factors related to feelings of losing the competition for social support.

Unconscious Influences on Disability-related Attitudes

Jeffrey A. Fine studied the age at which nondisabled preschool children begin to be aware of physical disability, and how they evaluate it. Also, he questioned whether castration anxiety and self concept would influence how early disability is noticed and how it is evaluated.

The results showed that when the age of 5 years and 6-8 months was reached, 50% or more of the children identified a picture of a child missing the left arm as different from two control pictures (identical except for the presence of the left arm). He found a high rate of negatively toned adjectives for the different picture for the entire sample (ranging in age from 3 years-6 months to 6 years-5 months). Children who perceived the disability earlier tended to have higher castration anxiety scores and more negative self images. Children who evaluated disability negatively tended to have higher castration anxiety scores, but no relationship was found between attitudes and self concept.

Ann Follansbee found evidence that higher castration anxiety levels are associated with less favorable

attitudes toward disabled people in a sample of male college students. Also, more favorable attitudes were associated with higher levels of *object representation*. This psychoanalytic concept refers to unconscious conceptions of self and others. At low levels, the self concept is unclear and others are seen only as need gratifiers. At higher levels, one's own identity is grasped and empathy can be felt for others.

Lillian K. Gladstone found that rigidly defended subjects, as defined by their scores on the Defense Mechanism Inventory, expressed more rejection of physically disabled people in their responses to the Disability Factor Scales - General.

A PICTURE EMERGES

Actually, two pictures emerge. One is a mural depicting both the potential value and problems associated with on-going research programs of this type. The other is a snapshot of where we are in our understanding of disability-related attitudes and what we should try to do about them. With respect to the former, Siller states:

The studies described here in themselves are not definitive. What is required is the continuation of a network of inter-related efforts that bring the various aspects of the psycho-social situation of those with disabilities into sharper focus.

The concept of a network of interrelated efforts is an important one which merits expansion. Other research settings, guided by different theoretical orientations and knowledge bases, should join and broaden the network.

With respect to disability-related attitudes, the New York University work suggests that negative attitudes toward people with disabilities are so widespread as to be the norm. At the same time, their evidence suggests that the more negative your attitudes are, the more likely you are to possess undesirable personality traits: poor ego strength, poor ability to form relationships, authoritarianism, feelings of alienation from others, castration anxiety, low levels of self identity and capacity for empathy, and rigid ego defenses. Conversely, the less negative your attitudes, the more likely you are to possess traits that are considered desirable, reflecting higher levels of psychosocial development. Thus, having disabled people in our midst to react to seems almost to comprise a test of our abilities to transcend the common, negative response tendencies.

IMPLICATIONS

Teaching What We've Learned. The evidence suggests that people with disabilities have considerable control over how others respond to them. Their own behavior makes a difference; whether they present themselves as coping versus succumbing, what they say or don't say about themselves, influences others'

attitudes. Teaching people with disabilities specific ways to improve their interactions with other people can and should become a key element in the rehabilitation process.

Using Open Discussion of Attitudes. The evidence further suggests a mechanism for doing this. Open discussions between rehabilitation workers and clients could be used to identify and reduce inaccurate perceptions of the other's attitudes. This generally leads to increased trust. In this context, the two (or larger groups) can mutually develop strategies for "reading" others' reactions and reducing the discomforts and tensions that underlie most of the negative attitudes described.

Managing Guilt. Many rehabilitation workers feel guilty when they catch themselves holding negative attitudes about people with disabilities. Strongly negative reactions may be clues to personal problems that need immediate attention. However, if negative attitudes are mild, it may be most sensible to make note of them, forgive yourself for being human, and proceed with the business of rehabilitation.

When the time for self examination is available, go with those feelings, study them as non-defensively as possible, and try to understand their roots and possible impact on your professional effectiveness. For example, faulty assumptions and negative feelings about people with disabilities might lead you to be overly harsh and demanding or too protective, expecting little. You may want to ask a colleague to help you. It is more than likely that s/he will feel a similar need, and will welcome a mutual helping session.

Broadening One's Understanding. It may help to put negative attitudes toward people with disabilities into a larger context. We all have negative feelings about catastrophic loss: losing a loved one to death, losing our worldly goods in a fire, or losing our freedom. Most of us believe—before the fact—that we just couldn't handle it, yet we know others have. After the fact, two things tend to occur that match the experience of disabled people. Others often seem uncomfortable in one's presence and may avoid contact for awhile. Also, the person to whom it does happen usually learns that s/he can handle it after all, as Itzhak Perlman observed. We expect most victims to recover from their rage, mourning, or both. Perhaps because disability leaves a permanent, visible reminder, we are less sure that recovery is possible. Clearly, however, it is; Perlman is only one of thousands who attest that disability is just another form of loss that seems unbearable to the uninitiated but turns out, with experience, not to be.

Source

Readers interested in reviewing the research reports briefed may contact:

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EVALUATING INDEPENDENT LIVING PROGRAMS

Medical rehabilitation efforts have been documented since Hippocrates' time. Vocational rehabilitation (VR) became a legal entity in the 1920s. Independent living (IL) programs are the newcomers to rehabilitating people whose lives have been complicated or disrupted by disability. The people who plan and deliver IL services are already asking, "How are we doing?" A hard question for any field to answer, it is, very difficult for independent living—for reasons given below.

The field of rehabilitation has an unusually strong tradition of evaluating its own costs and benefits. Of great importance to winning continuing support, it has developed success criteria which both elected officials and the lay public can understand. As a simple illustration, VR's objective behavioral measure "return to gainful employment" is widely acceptable as a criterion of success. By contrast, subjective measures (e.g., claims of "improved insight") usually lack meaning to outside observers.

Still, VR's criteria and measures have not enjoyed much popularity within the field. They are criticized often as being simplistic, arbitrary, incomplete, or short-sighted. Nonetheless, we have cause to be grateful to them because they have aided rehabilitation's survival in times of economic crisis. Facts and figures which make sense to the uninitiated can influence hard decisions better than data interpretable only by experts. By contrast, social moralizing and pleas for faith in outcomes claimed but poorly defined become nearly worthless during hard times.

If IL programs are to survive, their value must be proved. Unfortunately, this must be done on the basis of a very brief track record compared with other human services. This is a primary reason why IL evaluation is so difficult, but there are other factors.

The desired outcomes of IL services are multidimensional. There is no convenient unitary goal comparable to VR's "return to gainful employment." Also, the many possible IL goals are inherently less observable than whether an individual goes to work. Qualitative issues are less easily avoided. For example, to assess whether clients can perform certain functions *satisfactorily* calls for subjective judgements, not the mere presence or absence of a behavioral indicator.

Recognizing the difficulties, many state VR agencies are exploring the best ways for them to support IL

program evaluation efforts. In addition, the Council of State Administrators of Vocational Rehabilitation and the Independent Living Research and Training Center at the University of Kansas are developing IL methods and instruments. This BRIEF will summarize reports made available by the states of Washington, Wisconsin, and California. These documents illustrate differing aspects of IL evaluation by their varying approaches. Washington describes a generic IL evaluation system; Wisconsin provides a traditional program evaluation overview; and California looks at management issues which influence IL center operations.

Previous Rehab BRIEFs have summarized the basic IL concepts and programs in describing *Independent Living Rehabilitation: Results of Five Demonstration Projects* and *The Influence of Environmental Barriers on Independent Living*. Interested readers may refer to Rehab BRIEFs, Volume II, Number 9 and Volume IV, Number 5 for this background information.

HISTORICAL PERSPECTIVES

The Independent Living Movement

"The focus of the IL movement is to offer an alternative to the traditional medical and rehabilitation framework . . . and to provide services to move (severely disabled) individuals into the mainstream of society, in control of their own decision making . . . Since the long-term disabled person will never "recover," . . . (the sick role) . . . dooms him/her to a frustrating dependency on a system which is unlikely to change his/her condition and removes the individual's freedom and obligation to take charge of his/her own affairs. . . .

From *Programs for People: The California Independent Living Programs*, California State Department of Rehabilitation.

Evaluating Independent Living Centers

"Based largely on the results of (prior) demonstration projects, as well as a strong consumer movement, a comprehensive independent living services program was included as Title VII of the 1978 amendments to the Rehabilitation Act of 1973. . . ."

"Although logically perceived to be of benefit to severely disabled individuals, the assessment of the

independent living centers must be conducted in the absence of any preconceived biases which might prevent an objective review of the benefits and value of the centers. Since the centers are relatively new, no uniform evaluation method has been developed. The parameters of an evaluation, however, have been somewhat defined. For example, the reasons for evaluating independent living programs include. . .

- to determine what methods of providing IL services work best under what conditions;
- to justify the existence of the IL program;
- to provide accountability for the use of federal/state/local tax dollars;
- to insure that the target population is being served."

From Document Digest of *Centers for Independent Living*, Wisconsin Department of Health and Social Services.

WASHINGTON'S IL EVALUATION SYSTEM

The Washington State Division of Vocational Rehabilitation (DVR) receives federal funds to operate an IL program. It has subcontracted center operations to eight pre-existing organizations through a competitive process. DVR funds the Independent Living Evaluation Project (ILEP) at the University of Washington to document the new approach. ILEP began work in 1979. Its 1982 report, *Independent Living Center Evaluation: Washington State Data System and Data from the First Year of Title VII*, focuses on a system for evaluating an IL program. A small portion of the report describes the limited findings available at the time of writing. The system is potentially exportable; it could be adopted or modified by other agencies, saving them developmental time and effort. Consequently, this BRIEF will highlight Washington's approach rather than their preliminary findings.

Most evaluation approaches are input/outcome comparisons; for example, the funds needed to run a VR agency compared with some yardstick such as the accomplished number of "26 closures" (clients rehabilitated, employed). ILEP's search for comparable yardsticks to use in IL yielded little. The report sums up the situation bluntly; "Unlike older service delivery systems, IL does not even have a bad measure; it has none." ILEP limited its goal to defining which variations of input and outcome should be included in an evaluation plan. Who are the people served? What services are rendered? What changes do the people served experience in their lives? Answers to these questions now, they say, will lay the groundwork for defining yardsticks and setting standards later.

Criteria for the System

The first order of business was deciding what the system should be able to do. The criteria, or purposes, they decided on may help others planning to evaluate IL programs. ILEP believes a system should:

- Provide adequate information to funding authorities to describe the scope of an IL program, evaluate its funding needs in each service area, and assess the impact (outcomes) of the services provided;

- Impose minimal disruption to centers and clients in collecting data;
- Accommodate wide variations in levels of services provided;
- Offer easy ways to record, retain, and maintain data; and
- Reflect the basic philosophy and mission of the IL program.

These further imply needs to collect information from individual participants on items pertinent to a center's services, on precoded forms amenable to computerization.

Elements of the System

IL services are multi-level in two ways. There are group- or community-oriented services as well as individually-oriented services; and individually-oriented services occur at varying levels. These are designated:

- *Non-Intake* - requests, usually for information and referral, which can be handled in less than an hour, often by phone;
- *Intermediate* - needs which can be met in a relatively short time without requiring assessment, long-term planning, or case coordination;
- *WILP* - complex needs do require planning, goal setting, and coordination, and a written IL plan (WILP) is developed and followed.

Accordingly, the system elements include the following types of participant and center data:

Participant Data

- Intake questionnaire - information on participant and program needs
- Status Indicators - (from *Rehabilitation Indicators*, please see below)
- Services provided - a numerical recording system

Center Data

- Non-intake individual services - tallies of numbers served
- Community-oriented services - levels of center investment of effort
- Service gaps - community needs existing but not being met.

The Role of the Rehabilitation Indicators

For a description of the Rehabilitation Indicators (RIs), the reader is referred to Rehab BRIEF Volume V, Number 6, *Rehabilitation Indicators: A Method for Enhancing Accountability and Services*. The RIs are designed to measure client characteristics, activities, and skills for service delivery and research purposes. ILEP needed a measure of participants' functional limitations; their service needs; and the outcomes/of services and the RIs were chosen for use. They include three sets of measures. The *Status Indicators* are used to collect of descriptive data from all (eight) center sites. Elements from the *Activity Pattern Indicators (API)* and *Skill Indicators* were used by a few centers.

The report asserts that *Status Indicators* data are "proving to be invaluable." The centers and DVR are finding multiple uses for them: in reporting to boards and committees, conducting internal reviews, and supporting funding applications. The consistency of documentation across centers is considered "a direct

aid to the determination of needs and services." The community-oriented nature of the information gathered (contrasted with medically-oriented functional assessment tools) is deemed singularly appropriate for IL centers.

API data are not yet sufficient for drawing conclusions, but expectations are positive. The *API* exhibits a conceptual 'fit' with IL philosophy." The *Skill Indicators*, are considered the least well suited to broad-scope or newly established centers. Their use is recommended for centers doing specific skill training, after the programs are well underway.

The remainder of the Washington report describes the format and content of the data base. Readers expecting to be involved in IL program evaluation could profit from reviewing the full document (please see Sources, below).

DATA FROM WISCONSIN

Centers for Independent Living, a Document Digest issued by the Wisconsin Department of Health and Social Services, summarizes a 1982 evaluation report of that State's IL program. Wisconsin has five IL centers; three were funded under Title VII of the Rehabilitation Act and State funding was secured for two. The purposes of their centers are to provide or arrange for services to help disabled people function more independently in the community, and, if appropriate, to secure and maintain employment. The Digest provides demographic information on the population served and a breakdown of service- and outcome-related findings.

From October of 1980 through March of 1982, 799 individuals applied to the centers for IL services. They were almost equally divided between males and females, and over 50% were unmarried. Also, over 50% were over 40 years of age; and over 75% had high school diplomas or less. Only 5% were competitively employed, and 52% were not working at the time of applying for services. A wide range of disabilities was represented, with spinal cord injury, cerebral palsy, hearing impairment, heart and vascular disease, arthritis, and multiple sclerosis being mentioned.

The services most frequently needed included: personal care assistance, information and referral, independent living skills assessment and training, peer counseling, housing assistance, and transportation. These findings were consistent across the five centers.

For the 301 clients whose cases had been closed, 67% were rated by IL program counselors as "improved" with respect to overall independent living status. In addition, changes in residential and attendant care status were "identified as being likely to demonstrate a change in a person's capacity for independent living." For example, at the time of referral, approximately 52% of clients lived in their own homes or apartments. At closure, this figure was approximately 68%. This suggests movement to less restrictive settings. At the same time, attendant care usage increased. The report speculates that as individuals who reside in institutions or parental homes at referral are enabled to move to

less restrictive settings, they need and report more use of outside attendants.

The Wisconsin centers were found not to be vocationally oriented. Only slightly over 10% of the clients were referred to the VR agency with identified prevocational or vocational needs. The report observed that the VR agency should declare its position with respect to the role of the IL centers, and determine its responsibilities to them. In the short term, it recommended that the agency include the centers as a continuing cost item in its next budget request. In the long term, it recommended that the agency review the merits of continued direct administration of the centers, and explore funding options to supplant seed funding (e.g., fees for services and for-profit subsidiaries).

CALIFORNIA REVIEWS CENTER ADMINISTRATION

California's IL centers were established to provide independent living and prevocational services to disabled people. Most of the centers are freestanding facilities, not attached to pre-existing rehabilitation organizations. In 1979, the California State Department of Rehabilitation (DR) received funding from NIHR to conduct an Independent Living Research Study (ILRS). This involved evaluating 12 of their 22 IL programs. Those selected for study represent the ranges of center size, length of operation, urban/rural location, funding bases, and disability groups served. The goals of California's ILRS coincided in part with those pursued by Washington and Wisconsin; that is, to describe the people served, delineate the services provided, and examine the outcomes or changes which might ensue. In addition, however, they placed a heavy emphasis on examining the *organizational characteristics* of the centers—administrative features and management practices which influence the success of center operations.

Programs for People: The California Independent Living Centers, a 1982 report, describes the study design and procedures briefly, then gives detailed attention to the data analysis results and recommended follow-through actions. Action, of course, is what program evaluation is all about—using the information gleaned to make program improvements. Accordingly, this BRIEF will highlight the California's findings and recommendations relating to center management and administration.

The ILRS comprised two parts. A *Client Gains Study* assessed the centers' effectiveness in helping clients progress toward independence over a ten-month study interval. Whereas Washington used the *Rehabilitation Indicators* as a client assessment tool, California developed its own self-administering *Client Gains Scale*. It covers financial skills, time usage/quality of life, activities of daily living, health care independence, and psychosocial well being. A *Process Study* measured the centers against various administrative criteria, using staff interviews and client record reviews. The study variables included: staff knowledge of center organization, use of client records and data

collection systems, communications, staff hiring/training, use of program policies, fiscal management, community outreach/support, program awareness, and use of administrative records.

Overview of Findings from Client Gains Study

The services offered varied considerably across centers, but tended to include: attendant referral, peer counseling, advocacy, housing assistance, and referral. Other services identified were: benefits counseling and advocacy, TTY and message relay, vocational counseling and referral to training, alcohol/drug abuse counseling, equipment repair, attendant training, and civil rights advocacy. Clients showed significant changes on their financial management abilities and activities of daily living during the ten-month study period. The client changes are assumed to result from services provided. However, due to the short duration of the study, the results are considered exploratory.

Center Administration-Findings and Recommendations

The program evaluation team offered a number of recommendations to their departmental colleagues based on the findings from the Process Study. These included the following examples.

- **Finding**-California IL centers had few written policies.

Recommendation-DR should help them develop definitions and guidelines reflecting federal, state, and local views regarding IL center operation. Centers should then use these standards to create written policies.

- **Finding**-No uniform data collection system exists by which the centers can obtain data for reports, evaluations, and needs assessments.

Recommendation-DR should develop a uniform data system which, after trial implementation and refinement, would be used by all centers. (Note: This is the primary issue addressed by the report from Washington State.)

- **Finding**-Standard hiring and orientation procedures were lacking in many centers.

Recommendation-To avert problems in selecting, developing, and maintaining qualified staff, centers should be helped to develop and use standard procedures.

- **Finding**-Most centers had no written staff training policies. Eighty-four percent of staff reported training needs, and 32% specified needs in the administrative area.

Recommendation-Centers should be helped to establish staff training needs assessment mechanisms; encouraged to inform staff about available training, and give time and tuition or on-site training as resources permit. Centers should coordinate expertise sharing and jointly explore funding resources for staff training.

- **Finding**-Most centers had inadequate record

keeping procedures. Some did not use standard intake or client contact records, or have clearly defined services or service units.

Recommendation-DR should provide definitions for services and service units, standard intake formats, guidelines for client record keeping, and clear expectations as to what client records should include.

- **Finding**-Several centers reported *strained relationships between staffs and boards of directors*. One identified cause was board members' lack of administrative expertise.

Recommendation-DR and center staffs should jointly define the roles and responsibilities of boards of directors and establish member selection criteria which would assure boards' abilities to meet their responsibilities.

CONCLUDING COMMENTS

These early efforts suggest that IL evaluation is off to a good start. Although no direct comparisons can be made, it is interesting that with respect to types of services provided, Wisconsin found uniformity across centers while California found diversity. This may be simply a function of California's greater number of centers. However, it is noted too that whereas Washington established its centers in pre-existing rehabilitation organizations California typically did not. Free-standing, "grass roots" centers tend to develop unique styles, tailored to local need. This factor may bear upon California's administrative findings as well since consumer-run centers, by definition, have less managerial experience than the typical service organization. Because this pattern is followed in many localities across the nation, California's "early warning" about administrative weaknesses may be a particularly valuable aspect of their report to others.

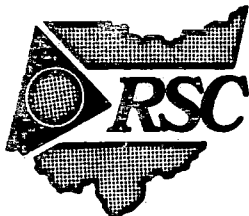
A final comment relates to Washington's use of the Rehabilitation Indicators as a client assessment tool. The NIHR has devoted substantial funding to developing these instruments. Its intents are to facilitate evaluation research consistency and comparability among programs throughout the country. Thus, to the extent that other states can follow Washington's lead, these valuable goals can be brought more quickly to fruition.

SOURCES

- Independent Living Evaluation Project, 1982, *Independent Living Center Evaluation: Washington State Data System and Data from the First Year of Title VII*. Department of Rehabilitation Medicine, University of Washington: Seattle. This report can be ordered through Debra Wilkerson, Department of Rehabilitation Medicine, RJ-30, Seattle, WA 98195 for \$10.00.
- Wisconsin Department of Health and Social Services, 1982, *Centers for Independent Living*. Document Digest, report is available through D. Zimbars, DVR, P.O. Box 7852, Madison, WI 53707.
- Independent Living Research Study, 1982, *Programs for People: The California Independent Living Centers*. California State Department of Rehabilitation: Sacramento. This publication is available from Gene Hiekle, Statistics, Program Evaluation, and Research Section, California State Department of Rehabilitation, 830 K St. Mall, Sacramento, CA 95814.

We welcome any comments you may have on this and prior Briefs put out during the past year, on other topics needing to be covered and any suggestions you may have for improving this publication. Address your comments to:

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advocator

DIVISION OF CONSUMER AND LEGISLATIVE AFFAIRS

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July 1, 1983

WASHINGTON UPDATE:

FY'84 BUDGET: On June 23, Congress gave final approval on an \$859 billion 1984 budget (House Concurrent Resolution 91). President Reagan, who called for a defeat of the compromise budget reached by a House-Senate budget conference, opposes the plan on the basis it increases taxes too much, does not spend enough on the military and provides too much money for non-defense programs. The president does not sign a budget resolution, because it basically is a guideline for Congress, but he can veto the spending and tax bills later that are based on the numbers in the resolution.

In arriving at these overall targets for the various congressional appropriations committees to follow in deliberating upon the various appropriation bills, the Congress (through the advice of the various authorizing committees and as determined and recommended to the full Houses by the respective budget committees) "assumes" certain possible levels of funding for various programs which comprise each function.

Function 500, which covers "education, training, employment, and social services," is the function containing the rehabilitation services program--all programs authorized by the rehabilitation act and falling within the jurisdiction of the House committee on Education and Labor and the Senate committee on Labor and Human Resources.

Unlike in previous years, the FY'84 first budget resolution does not contain assumptions for rehabilitation and other programs in the education department, leaving the actual breakdown of the appropriations for education programs up to the appropriations committee.

It should be remembered that the Senate version of the resolution contained "assumptions" for rehabilitation at the level of federal funding appropriated in FY'83, and that the House version "assumed" a funding increase of approximately 9.5 percent. The lack of any "assumptions" within the education category, as well as any pertinent reconciliation instructions, thus provide almost total discretion to the appropriations committees as to actual appropriations for rehabilitation in FY'84.

In short, there is room for funding increases in rehabilitation programs within the education target in the budget resolution. It will depend, however, on where rehabilitation programs fall within the priorities of the appropriations committees and on the actual authorization figures provided in the rehabilitation extension legislation.

EXTENSION AND AMENDMENT OF THE REHABILITATION ACT (HR 2461): The measure is in the House Rules Committee for scheduling for a floor vote. It is hoped that the full House might consider its passage prior to any final markup sessions of the House Appropriations subcommittee for the Department of Labor, Health and Human Services and Education (Function 500). No recent report has been received on S.1340 (the Senate version) following passage by the Senate Labor and Human Resources committee.

OHIO LEGISLATIVE UPDATE

Bills acted on in the 115th General Assembly which began January 1 are as follows:

- Sub.HB 58 (Bowers) Establishes mandatory vision testing when renewing drivers' licenses. Passed the House; in Senate Transportation and Public Improvements committee.
- Am.Sub.HB 83 Amends the Ohio Revised Code (ORC) to require municipal and county boards of building appeals, under certain circumstances, to decide appeals from adjudicating orders of local enforcement officials. The bill provides that a local organization representing handicapped persons be informed of any hearings or a state organization if a local group does not exist. Pending governor's signature.
- Sub.HB 157 (Thompson, J.) Amends the Revised Code to require home health agencies to register with the Department of Health, to establish a home health agency advisory council, and to establish a penalty for failure to register. Passed the House; in Senate State Government, Health & Human Resources committee.
- Am.HB 174 (Guthrie) Amends the Revised Code to expand the types of physical conditions that qualify a person as handicapped for the purposes of the law governing special handicapped license plates and parking cards, and parking in locations reserved for disabled persons. Pending governor's signature.
- Sub.HB 205 Provides for the licensing or registration of counselors and social workers. Civil Service employees, although exempt, would have the option to apply. The bill would create the Counselor and Social Worker Board. The definition of "professional counselor" and "counseling procedures" would suggest that many practitioners in the private sector, e.g., staff of rehabilitation facilities, would be covered by licensing or registration requirements. (The original companion bill in the senate is SB 111.) Passed the House; in Senate State Government, Health and Human Resources committee.
- HB 220 (Hartley) Provides for regulation and licensing of adult day-care centers. In House Human Resources committee.
- Am.HB 333 Prohibits discrimination on the basis of epilepsy in admitting college students to coursework leading to teacher certification. Passed the House; Senate committee assignment pending.
- HB 396 (Secrest) Increases personal allowances of mentally ill and mentally retarded patients and residents at certain institutions. In House Human Resources committee.
- HB 401 (Beatty) Changes name of Welfare Department to Human Services Department. In House State Government committee.
- HB 408 (P. Jones) Allows driver of vehicle displaying license plate or parking card for disabled person to pay self-serve prices at gas stations also providing full-service gas dispensing. Assigned to House Highways and Highway Safety committee.
- SB 5 (Butts) Requires clerks of juvenile courts to maintain certain records in delinquency cases if the alleged victim of the alleged delinquent act was sixty-five years of age or older or permanently and totally disabled at the time of the commission of the alleged delinquent act. Passed the Senate; in House Judiciary and Criminal Justice committee.
- SB 130 Prohibits discrimination on the basis of height and weight. Passed the Senate; in House Human Resources committee.
- Am.SB 152 Amends the ORC to require the fine for parking in spaces reserved for the handicapped to be at least \$25, and to require fines collected for such illegal parking to be paid to the county and the political subdivision whose officer charged the offender. Passed the Senate; in House Highways and Highway Safety committee.
- Am.SB 178 Amends sections of the ORC to provide for the issuance of a temporary parking card to any handicapped person whose handicap is expected to continue for less than twelve consecutive months. The amendment to include pregnancy was deleted. Passed the Senate; in House Highways and Highway Safety committee.
- SB 206 (Schwarzwalder) Provides rights for physically disabled persons with support dogs. In Senate Judiciary committee.

STATE BUDGET UPDATE

House bill 291 is expected to be finally adopted and signed into law by the governor by July 1, the beginning of the new two-year budget period. In addition to numerous dollar changes, the Ohio Senate in its version also adopted more than 120 law changes in a wide range of areas.

The Senate version adds monies for the Community Centers for the Deaf. The Senate version deletes House language for a Commission for the Deaf and Hearing Impaired and requires a needs study to be completed by the Legislative Services Commission by January 1, 1984. The Senate also reduces funds for the MR Respite Care program from \$6 million for the two years to \$2,250,000.

Amounts for RSC programs are as follows:

	House	1984 Senate	RSC Request	House	1985 Senate	RSC Request
VR Programs	\$9,800,000	Same	\$11,800,000	\$10,000,000	Same	\$12,800,000
Attendant Care	\$ 600,000	Same	\$ 1,350,000	\$ 609,280	Same	\$ 1,850,000
Community Centers for the Deaf	\$ 264,000	\$347,500	\$ 347,000	\$ 271,992	\$347,500	\$ 445,000

WILLIAMS NAMED DIRECTOR OF NEW ADVOCACY OFFICE

David T. Williams, 34, Cleveland, has been appointed by Governor Richard F. Celeste as director of the newly-established Governor's Office of Advocacy for Disabled Persons.

Williams, who has certification in nuclear medicine technology, has been active in the disabled advocacy movement since 1978 when he was disabled by multiple sclerosis. He served as his community's liaison in 1981 during the International Year of Disabled Persons [IYDP], and subsequently was appointed to the IYDP board, now the board of the National Office on Disability [NOD]. He is a member of the Garfield Heights Council on Disabled Persons, the Northeastern Ohio Spinal Cord Injury Foundation, the Greater Cleveland Disabled Rights Task Force and the American Coalition of Citizens with Disabilities.

Williams served as staff consultant to Nuclear Medicine Associates, Inc., Cleveland from 1978 until accepting the new position. He and his wife, Gail, have two children, Eric and Nathan.

The office address is: State Office Tower, Room 1375, Columbus, Ohio 43215. Columbus phone: (614) 466-9956; Cleveland State Office phone (Fridays only): (216) 622-3240.

UPCOMING ADVOCACY CONFERENCE

Thomas S. Szasz, M.D., Professor of Psychiatry, State University of New York, will be the featured guest at the Ohio Legal Rights Service Advocacy Conference to be held on July 19, 1983 at the Quality Inn in Columbus. The registration fee of \$10 includes a buffet luncheon. To register contact Gail Sines, OLRs, 8 East Long Street, Suite 600, Columbus, Ohio 43215. To call toll-free: 1-800-282-9181. In Columbus call 466-7264.

DISABLED PEOPLE NEED A NATIONAL LEADER

by: Collins-Williams News Service

In every major movement, there is a leader who can persuade people to follow either him or her. Examples of such leadership in the United States in the past 20 years are John and Robert Kennedy, Martin Luther King, Lyndon Johnson, Ronald Reagan, Cesar Chavez, and Eleanor Smeal. They had ideas that appealed to a broad spectrum of people of all ages, races, sexes, nationalities, classes. They knew how to motivate. They could associate with the powerful and the influential because they were powerful and influential. Their words were listened to by educators, politicians, church leaders, economists, and countless more, because they had national support behind them.

For more than a decade we have heard disabled people talk about our movement. We have heard them say how our movement parallels the civil rights movement of the 1960s. We have even heard them say how the 1980s will be the decade of disabled people, just as the decade of the '60s was for Black Americans and as the '70s was for women. We believe, however, that this dream will not become a reality until disabled people have a leader who can unite the major forces of national consciousness and support, the national media, and the federal government behind our efforts to become full citizens.

Unfortunately at this time, there is not a disabled leader in Washington, D.C., of sufficient influence to make our movement a national one. For disabled people to have a significant national movement with impact, they must find a person who is disabled to be our leader. Qualifications that this leader must possess are vision, strength, and statesmanship; knowledge of disability issues and of Capitol Hill; the ability to form and sustain coalitions; the ability to work on a national level with politicians, the media, and other people of influence; and the ability to communicate persuasively the inhuman social, economic, employment, and educational conditions of millions of disabled people today.

We believe there are disabled people who fit these qualifications and feel that organizations representing disabled people must come to maturity and find this leader. Having found this leader, the following steps must be taken and recognized by disabled people: [1] Supporters must rid themselves of pettiness and develop a national agenda. [2] Supporters must recognize that a national leader may often have to make political decisions with which they do not agree, but which are necessary. [3] Supporters must understand that a national leader will be in the lime-light and receive more publicity than the supporters. [4] Supporters must be willing to raise money locally to achieve national objectives. Traditionally, the cry has been that organizations of disabled people do not have the money to support national programs, and too many groups have refused to raise money for national objectives. This approach hurts them and a national program. [5] Lastly, we believe that a major weakness in the disabled movement is that there are too many national offices of disabled people representing individual disability interests. They siphon off valuable resources and money that should be used by a national office. It will require strength, intelligence, and the desire to surrender personal fiefdoms to eliminate many of these offices. But they must be eliminated and one strong national leader and organization must emerge.

We recognize these are not easy tasks. They are necessary, however, if disabled people want to move forward; if they want to speak with one voice; if we want others to hear us and to work with us; if we want to rid ourselves of the image of second-class citizenship and as people who are always being funded by others. A national leader would help make these changes. A national leader is needed now!

(from The Braille Forum April, 1983)

GRANTS ALERT:DISCRETIONARY REHABILITATION GRANT PROGRAMS

The Department of Education announced application deadlines for its fiscal 1983 discretionary rehabilitation programs. Most of these awards will be for one year only. This program was announced in the June 8 Federal Register. Nonprofit and for-profit private and public institutions and organizations may apply for these grants. The application deadline for recreation programs for handicapped individuals and projects with industry is July 25. The application deadline for special projects and demonstrations for providing vocational rehabilitation services to the severely handicapped, and handicapped seasonal farmworkers is July 29. For further information about these programs, contact Fred C. Windbeck, Associate Commissioner for Developmental Programs, Rehabilitation Services Administration, U.S. Department of Education, 400 Maryland Ave., SW, Room 3038, Mary E. Switzer Bldg., Washington, D.C. 20202, (202) 245-0537.

Awards will be made in the following program areas:

SPECIAL RECREATION PROGRAMS FOR HANDICAPPED INDIVIDUALS: The purpose of this program is to support projects which initiate programs of recreational services to handicapped individuals. **FUNDING:** Approximately \$1 million is available for an estimated 13 new projects in FY'83.

PROJECTS WITH INDUSTRY: Cooperative agreements will be made under this program to provide handicapped individuals with training, employment, and supportive services and assistance within the business community and in realistic work settings. **FUNDING:** The total amount available for this program is \$13 million, including \$5 million set aside under the Jobs Bill to support an estimated 20 new projects.

VOCATIONAL REHABILITATION SERVICES TO SEVERELY HANDICAPPED PERSONS: The purpose of this program is to support projects that are designed to expand and improve vocational rehabilitation services for severely handicapped persons. **FUNDING:** Approximately \$3.2 million is available for this program, including \$1.8 million for an estimated 15 new projects.

HANDICAPPED SEASONAL FARMWORKER VOCATIONAL REHABILITATION SERVICES: The purpose of this program is to support projects for providing vocational rehabilitation services to seasonal farmworkers. **FUNDING:** Approximately \$951,000 is available for this program in FY'83, including \$741,000 for an estimated seven new projects.

ECUMENICAL WEEKEND

The Disabilities Task Force of the Ohio Council of Churches will sponsor the third annual Ecumenical Summer Weekend on July 22-23-24, 1983 at the Pilgrim Hills Conference Center in Brinkhaven, Ohio. The three speakers will be Dale Locker, Ohio Director of Agriculture; Dean Walters, Clergy, United Methodist Church; and Ron Getsay, Clergy, United Church of Christ. To register (\$35 per person for the weekend includes lodging and meals) mail check payable to Ohio Council of Churches, 89 East Wilson Bridge Road, Columbus, Ohio 43085. Phone: (614) 885-9590.

JOB TRAINING PARTNERSHIP ACT OF 1982: A SUMMARY

The Job Training Partnership Act of 1982 [JTPA], Public Law 97-300, is legislation permanently authorizing job training programs for economically disadvantaged individuals and others who face serious barriers to employment. JTPA replaces the Comprehensive Employment and Training Act [CETA]. It gives a larger role to states, which will now have administrative responsibility for training programs, and to the private sector, which will have equal authority with local governments in planning and implementing programs. The five titles in the act are outlined below:

Title I--Job Training Partnership

- Title I outlines the service delivery system. Each state governor will designate service delivery areas [SDA] within the state, based on proposals made by the state job training coordinating council. Local government units and voluntary consortia with populations of 200,000 and over will be designated service delivery areas upon request. In each SDA, local government units and the private industry councils [PIC] will be equal partners in deciding on procedures for development of two-year job training plans and in choosing grant recipients and administrators for the plans. The PIC will provide policy guidance for and exercise oversight of the job training plan. Members of the private industry council will be appointed by local government officials from nominations offered by business and other specific interest organizations. A majority of members must represent business; the others will represent education, labor, rehabilitation agencies, community-based organizations, economic development agencies, and the employment service.

Performance standards mandated by the act will be based on increases in employment and earnings and on reduction of welfare dependency. Seventy percent [70%] of the funds available for each SDA must be spent on training. The act puts a cap of 15 percent on administrative costs, and a ceiling of 30 percent on administration, supportive services, allowances, and wages combined. However, under certain specified conditions, a waiver of the supportive services ceiling may be granted by the governor. No funds may be used for public service programs. The act prohibits discrimination based on race, color, religion, sex, national origin, age, handicap, or political affiliation or belief; laws prohibiting discrimination in federally assisted programs are specifically applicable to the act.

Title II--Training Services for the Disadvantaged

- Funds appropriated by Congress will be passed through the Secretary of Labor to state governors according to a formula based on unemployment and the number of economically disadvantaged persons. The formula allocates one-third of the funds on the basis of substantial employment [at least 6.5 percent], one-third on excess unemployment [excess of 4.5 percent], and one-third on the number of economically disadvantaged persons in the state. Funds will then go to service delivery areas within the state by the same formula.

Under Title II, a broad range of training activities are authorized, including on-the-job and classroom training, work experience, remedial education, counseling, job development and supportive services. Forty percent [40%] of the funds must be spent on youth 16 through 21 years of age [percentage to be adjusted if necessary].

Ninety percent [90%] must be spent on the economically disadvantaged. Up to 10 percent may be spent on those not disadvantaged if they have other employment barriers, such as those with limited English language proficiency, displaced homemakers, school dropouts, teen parents, and older workers. Seventy-eight percent

(more)

(continued)

[78%] of the funds allocated to each state must be distributed to the service delivery areas. Eight percent [8%] of the state funds are allocated to joint education projects, three percent to programs for older workers, and six percent to incentive grants for programs exceeding performance standards or serving hard-to-serve individuals. Summer youth programs are authorized separately under Title II.

Title III--Employment and Training Assistance for Dislocated Workers

- . This is a new state-administered program to provide training and other employment services to dislocated workers [those laid off due to plant closings, the longterm unemployed, and those who are unable to return to the same industry or occupation]. States must match the federal funds, but the matching requirement is reduced if the state has higher than average employment.

Title IV--Federally Administered Programs

- . This title extends and strengthens the Job Corps program, reauthorizes the programs for native Americans and migrant and seasonal farmworkers, and establishes a new program for veterans. Also authorized on the national level are multi-state programs, pilot projects, research and demonstration, evaluation, and labor market information programs. [Under multi-state programs, the act includes programs for women, single parents, displaced homemakers, and older workers.] The National Commission for Employment Policy is reconstituted as a nongovernmental commission.

Title V--Miscellaneous Provisions

- . This title amends the Wagner-Peyser Act to require the employment service to coordinate its activities with local job training programs. It also amends part C of Title IV of the Social Security Act [the WIN program] to remove discriminatory language and to provide for coordination with JTPA service delivery area programs. It requires that participants in JTPA programs not be violators of the Military Selective Service Act.

(Prepared by the Women's Bureau, U.S. Department of Labor, November, 1982)

NEW PUBLICATIONS

Meyer Children's Rehabilitation Institute & University of Nebraska Medical Center have published two publications for people working with the developmentally disabled.

Giving Families a Break: Strategies for Respite Care is a how-to manual on establishing and operating a respite program in your community. Cost is \$12.00. The Respite Care Fact Packet is an information packet in which to record special procedures for the care of a developmentally disabled individual. The cost is \$1.25.

For additional information contact The Media Resource Center, Meyer Children's Rehabilitation Institute, 444 South 44th Street, Omaha, Nebraska 68131.

The RSC office of the Governor's Council on Disabled Persons has three recently revised publications available: Rights of Ohio's Handicapped Citizens According to the Ohio Revised Code; Publications Brochure; Special Report: Handicapped License Plates, Parking and Identification Cards. Copies may be obtained from RSC-GCDP, 4656 Heaton Rd., Columbus, OH 43229, or call toll-free: 1-800-282-4536 ext. 1392; In Columbus call 438-1392

THE BRIDGE MODEL: A NEW APPROACH TO HELP BUILD PARENT-EDUCATOR TEAMS FOR HANDICAPPED CHILDREN

The Bridge Model, a new approach for building parent-educator teams for handicapped children developed by the Parents' Campaign for Handicapped Children and Youth and the Council for Exceptional Children, is now available in published form. A manual providing a complete guide for carrying out the training model has just been released.

The goal of the bridge model--to strengthen communication skills and positive working relationships among parents and educators--is woven into a sequence of planning activities culminating in a unique, highly motivating one-day workshop. The model has been tested successfully in urban and rural locations throughout the country. Although all the pilots have involved parents of handicapped children and teachers, the model is highly applicable to all situations in which it is important to foster collaboration based on mutual respect between parents of handicapped children and concerned professionals.

The manual contains step-by-step instructions covering all phases needed to produce the workshop with a section on effective planning, a detailed curriculum with how-to tips for all activities, and a guide to assist facilitators in conducting the training. In addition to disseminating the manual, the project staff will provide technical assistance to groups wishing to use the bridge model.

The project on which the manual is based was funded by a national training grant from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, Special Education Programs, to the Parents' Campaign and the Council for Exceptional Children. The Parents' Campaign is best known for its work in operating Closer Look, the national information center which serves parents of handicapped children.

Single copies of The Bridge Model are available free with a minimal charge for postage and handling. One hundred copies are available in Spanish. For a copy of the manual, send \$2.00 to: The Parents' Campaign for Handicapped Children and Youth, 1201 16th Street N.W., Washington, D.C. 20036.

GOVERNOR'S COUNCIL LAUNCHES PARKING CAMPAIGN

The Governor's Council on Disabled Persons in conjunction with the Police Chiefs Association recently undertook a parking campaign. Letters were sent to all police chiefs and sheriffs in Ohio asking for their help in enforcing the handicapped parking law. "Parking Ticket Reminders" and a brochure describing who is eligible for handicapped license plate and parking card accompanied the letter. Response by the police departments was encouraging. To date, over 70 departments have contacted the office to obtain additional brochures and reminders. The Council will solicit the help of other state advocacy organizations to collaborate on a parking campaign to make the public more aware.

The Handicapped Drivers Courtesy bill was introduced by Rep. Thomas J. Downey (D-N.Y.). It encourages reciprocal parking agreements among states. The council will write a letter to the sponsor endorsing the bill.

Also, in the coming months the staff will be working with the Ohio Extension Services to implement a memorandum of agreement between the President's Committee on Employment of the Handicapped and the U.S. Department of Agriculture. The agreement focuses on services to disabled persons in rural areas.



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World Rehabilitation Fund INTERCHANGE

INTERNATIONAL EXCHANGE OF EXPERTS AND INFORMATION IN REHABILITATION

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Shift In Social Policy: Denmark's Help To Self-Help Philosophy Toward The Elderly

The Shift to Deinstitutionalization and Independent Living

It seems rather ironic that Denmark, which has been a world leader in creating institutions to meet the social and health needs of its citizenry, may now provide an example of how to meet these needs through self-help and deinstitutionalization. Having been in the vanguard in the creation of these institutions, they have come to recognize many of their shortcomings, including the fact that few people flourish where everything is provided in an impersonal environment of over-protection and institutionalization.

Denmark, like the U.S. and other developed countries, is experiencing a sharp increase in demand for services for the frail and handicapped elderly. The number of Danes above the age of 80 is expected to increase by 25 percent by the year 2000, with a corresponding need for 15,000 new nursing home beds. This is a conservative estimate, in that future advances in health care may increase longevity and possibly the need for facilities. Estimates are based on current surveys of Danish elderly, i.e., 75% need no special services, 8% enter nursing homes, and 17% are termed "at risk" in terms of possible institutionalization.

Recognizing both the expense and the quality of life issues involved in responding to the needs of the elderly with increased institutionalization, the Danish Commission on Aging recommended, in 1982, that services should be available to individuals where they live rather than moving people to institutions where such services are available. This single statement put the Commission on record in support of independent living and deinstitutionalization. Another recommendation, was that governmental subsidies no longer favor the building of nursing



homes at the expense of alternative housing for the elderly, such as congregate housing and protected housing (some personal and health care). They also recommended that funding be increased for services that support the individual in living independently in his or her own home. This basic shift in public policy, combined with a general lack of funding, has resulted in a drastic reduction in the number of nursing homes being built in Denmark. Current plans call for the gradual phasing out of nursing homes over the next 15 years. It seems that budgetary limitations have provided an additional incentive toward the help-to-self-help movement as expressed in the following principles:

- Society should support the capacity of people to care for themselves.
- Older people should be offered the opportunity to maintain their independence as long as possible.
- Older persons' integrity and individual resources should be recognized and utilized.

Attitudes

It is anticipated that the adoption of these principles will have a significant impact not only on the elderly, but on all age groups. Encouraging and recognizing the potential of older people should aid younger people in taking an active role in planning for their own futures. The negative cycles created by treating people as if they were helpless can be broken by expecting people to aid in their own care. This attitude contrasts sharply with current expectations that someone who enters a nursing home should be passive, dependent and conform to institutional policy.

Retirement may bring about a number of positive changes in an individual's life, including better housing for less money (a pensioner's rent cannot exceed a certain percentage of income), access to a wider variety of social programs, adult education, travel, etc. However, the creation of institutions and programs to aid the elderly may foster attitudes that encourage

(continued on page 4)

MONOGRAPH TOPICS AND AUTHORS FOR 1983-84

- Societal Provision for the Long-Term Needs of the Mentally and Physically Disabled in Britain and in Sweden Relative to Decision-Making in Newborn Intensive Care Units (Dr. Ernie W.D. Young — WRF Fellow)
- Three Models of Independent Living in The Netherlands (Dr. Gerben DeJong — WRF Fellow)
- Community-Based Rehabilitation Services: The Experience of Bacolod, Philippines and the Asia/Pacific (by Dr. Antonio O. Peruiquet — Philippines)
- Linguistical Based Program for the Rehabilitation of Adult Aphasics (by Dr. Gunther Peuser — West Germany)
- The Principle of Equality: European Perceptions of Employment Policy and Disabled Persons (Dr. Harlan Hahn — WRF fellow) and The Future of Work and Disabled Persons (Paul Cornes — United Kingdom)

We cannot now be certain when each of these monographs will be available for distribution. However, as in the past, target groups/categories in our mailing list will be mailed monographs appropriate to the work setting and interest areas represented. Any readers wishing to alert us to their particular desire to be sent (at no

cost) a specific title, should do so by writing to WRF. Include your WRF mailing label or facsimile. (Anticipated publication for all monographs — March '84)

1983-84 FELLOWSHIP AWARDS

A total of ten fellowships will be awarded during the 1983-84 project year which is the third and final year of the International Exchange of Experts and Information in Rehabilitation. December 15, 1983 is the deadline for all applications. All the four-to-six-week fellowships must be completed by June 15, 1983, and applications must be submitted at least four months in advance of the anticipated study-visit.

Some Program Criteria:

- Fellowship study-visit is to benefit U.S. rehabilitation policies, programs, research and/or practice; to fill knowledge gaps in the U.S.
- Plan should be relevant to NIHR priorities
- Well-planned host-country arrangements
- Dissemination and utilization plan for U.S. should be well-defined

As of November 1, 1983 four fellowships had been awarded:

- *Gary Athelstan, Ph.D.*
Professor, Department of Physical Medicine and Rehabilitation
University of Minnesota
(Iceland, November — December 1983): "A Cross-Cultural Study of Functional Assessment, Comparing Counselor and Self-Perceived Severity of Disability as Related to Vocational Rehabilitation Potential"
- *Mary Ann Morrison*
Associate Professor in Physical Therapy
Marquette University
(UK, February — March 1984): "Extensive Study of British Approaches to the Rehabilitation of Adult Hemiplegia and Brain Damaged Individuals"
- *Michael Shinnick, Ed.D.*
Director of Rehabilitation
Facility Continuing Education Program
Auburn University
(Australia, March 1984): "MODAPTS and Workability: A Feasibility Investigation Regarding the Training of Facility Personnel"
- *Carolyn Vash, Ph.D.*
VP for Program Development
Institute for Information Studies
(Yugoslavia, May 1984): "A Study of the Yugoslavian Workers' Councils — Conceptual and Applied Utility for Improved Participatory Management in American Rehabilitation"

IEEIR Fellowship Reports Highlighted

"A Study of the Dutch National Policy toward the Handicapped" by Kenneth Nash, Director Joint Educational Program for the Deaf, University of Rochester, N.Y.

The purpose of this report is to summarize the findings of a six week study-trip to the Netherlands, sponsored by International Exchange of Experts in Rehabilitation. The intent of the study-trip was, first, to identify the major social, political and philosophical principles which form the basis of Dutch national policy for the handicapped; secondly, to analyze these policies from a case study perspective; finally, to identify trends which may influence Dutch policy in the next decade. Where appropriate, this report compares the Dutch and american policies and programs.

The report is partially based on interviews with selected members of parliament and officials of the Ministries of Health, Welfare, and Education. Much of the information is derived from discussions with handicapped citizens, leaders of organizations for the handicapped and special educators. In this report, special attention is

given to The Instituut voor Doven at Sint Michielsgestel.

The official Dutch hosts for this study-trip were Dr. J. van London, Director General, Ministry of Health and Mr. van Eindhoven, President, Instituut voor Doven at Sint Michielsgestel.

"Home Care Services for Severely Physically Disabled People in England and France (Case-Example: The Ventilator-Dependent Person)", by Allen Goldberg, M.D., Medical Director, Division of Respiratory Care, Children's Memorial Hospital.

What Dr. Goldberg's report of his study-visit attempts very successfully to do is:

- to analyze the operational programs providing home care services (personnel and technology) for severely physically disabled people which permit them to live at home
- to review the success factors and limitations of these programs
- to evaluate the effectiveness of these services in permitting severely physically disabled people to have productive lives

- to determine and elucidate elements of organization and operation that are adaptable to American national/regional/local and political/economical/social realities
- to analyze the system of information retrieval processing and dissemination

Dr. Goldberg has already done a considerable amount to implement some of the findings from his study-visit in France and England back here in the U.S.



Edited by DIANE E. WOODS

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FELLOWS AND FELLOWSHIPS 1982-1983

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"Differences in Japanese from American Patient Outcomes of Stroke Rehabilitation"

ALIKI COUDROGLOU, D.S.W., University of Arizona:

"Mainstreaming the Disabled/Social Policy Issues" — *Greece*

WILLIAM GELLMAN, PH.D., Council of Rehabilitation Affiliates:

"The Application of British Placement Experience to the U.S."

ALLEN I. GOLDBERG, M.D., Children's Memorial Hospital:

"Home Care Services for Severely Physically Disabled People in England and France Case-Example: The Ventilator-Dependent Person"

HARLAN HAHN, PH.D., University of Southern California

"The Issue of Equality: European Perceptions of Employment Policy for Disabled Persons"

JANE E. MYERS, PH.D., Ohio University:

"An Exploratory Study of Services for Disabled Persons in Industry (Including the Older Worker)" — *Japan*

KENNETH R. NASH, Ed.D., University of Rochester:

"An Analysis of Selected Education Programs, Rehabilitation Services and Social Policies for Deaf People" — *The Netherlands*

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"Enhancing Rehabilitation and Family Adjustment" — *The Netherlands*

HENRY WILLIAMS, NY State Mental Health System

"Village System in Nigeria: An Approach to the Rehabilitation of the Mentally Ill"

KENNETH R. NASH, Ed.D. Director, Joint Educational Program for the Deaf — University of Rochester

"A Study of the Dutch National Policy toward the Handicapped"

SPECIAL UTILIZATION EFFORTS BEING PLANNED

Each year the IEEIR holds utilization conferences on two out of five of the monographs being published during the project year.

A utilization conference is being planned to be held in Washington, D.C. on January 23, 24, 25, 1984 on the monograph by Ernie Young: *Societal Provision for the Long-Term Needs of the Disabled in Britain and Sweden, Relative to Decision-Making in Newborn Intensive Care Units*, which will be published in March '84.

The purpose of the conference is to bring together a group of 25-30 invited participants who are keenly interested in the topic, who will have read the monograph in manuscript form prior to the meeting and who are in a position to have an influence on policy and practice issues in rehabilitation in the U.S.

The monograph is based on the fellowship WRF IEEIR study-visit of Rev. Ernie Young, Ph.D. (Chaplain, Stanford University Hospital, Stanford University Medical Center) in Sweden and Great Britain where he spent two weeks in each country investigating the approaches and philosophies regarding intensive care procedures for premature, low-birth-weight and handicapped infants, as well as the subsequent services offered to disabled children and adults. He compares the approaches and philosophies (practices and policies) to those in the U.S. and makes some extremely important recommendations for policy makers as well as practitioners and parents here in the U.S.

A full agenda for the meeting is now being planned. Initially Rev. Young will present and clarify his ideas to the group then three or four respondents who will be selected will discuss their views. This will be done during the first morning of the 2 1/2-day meeting.

It is hoped that this meeting will be able to provide some new insights and move the discussion in the U.S. on the issues at hand to a position which will have an affect on policy decisions.

The other monograph for which utilization activities and seminars will be held is on Community-based Rehabilitation. It is being written by Antonio O. Periquet, M.D. of the Philippines. March '84 is the month during which we expect to hold meetings with Periquet and others in the U.S. interested in CBR.

OTHER NEWS

Rehabilitation International's World Assembly was held in the U.S. for the first time in fifteen years the week of October 16, 1983. The site of the meeting was the Department of State in Washington. Seventy-five delegates participated from 33 countries.

Rehab. International U.S.A. based in NYC and sponsor of REHABFILM held its seventh annual International film festival November 15-18, 1983 in NYC. Award-winning films from several countries were selected for viewing at this exciting event. ... A small international Symposium: "Effective Policies and Practices for People with Disabilities" is being arranged by University Centers for International Rehabilitation to be held in early May 1984. Some

WRF fellows and monograph authors will contribute at the meeting. An emphasis on economics and equity in relation to the disabled is planned. The meeting is by invitation-only; it is expected that conference proceedings will be available during the summer of 1984.

"The Visitors' Club...a chance for severely disabled persons to visit London..." one hotel involved with this membership club is **fully equipped** for people with severe disabilities. For more information, write to:

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(continued from page 1)

a reliance on others rather than self.

The Skibhus Project

In 1981, the town of Odense decided to attempt a pilot project to reduce the number of persons being admitted to nursing homes. Faced with the prospect of building more nursing homes despite funding cuts from the Danish government, the local Human Services Department called a conference of elderly, town officials and concerned professionals to discuss approaches to the problem. A consensus was reached whereby, Skibhus, one of 18 neighborhoods in Odense, would be the site of a pilot project to increase supportive services to the more than 90 % of the elderly who did not reside in nursing homes. Rather than continue to build nursing homes, which serve 6-8 % of Odense's elderly, a decision was reached to emphasize such things as improved access to transportation, shopping, housing, activities, and human contact, for the "at risk" or frail elderly. Additionally, the elderly were polled regarding their particular resources, expertise, needs, and interests.

It should be noted, that Skibhus was selected for the project due to its large number of elderly people and older housing. It was felt that if Skibhus could be made "elder-friendly" then more modern neighborhoods, with a lesser percentage of elderly could also.

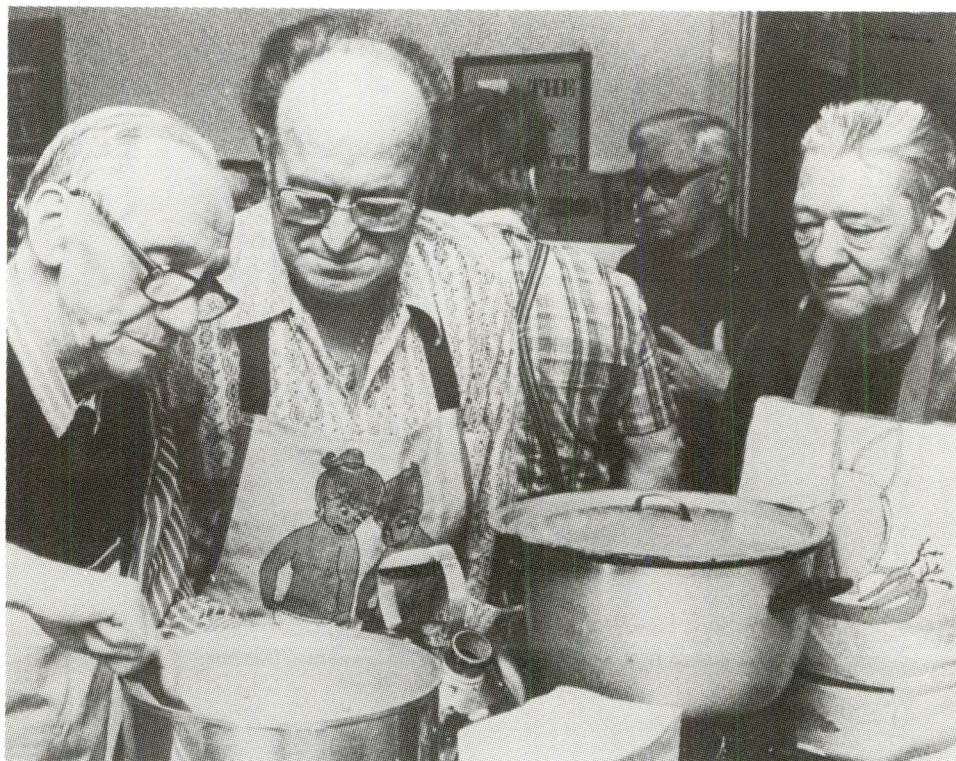
Help to Self-Help

The first organizational step was to list organizations serving the elderly, such as:

- Churches
- Civic Groups
- Fraternal Groups
- Social Groups

The leadership of these organizations were contacted and presented with the framework of the independent living model. After determining the interest level of these organizations, members were invited to a planning meeting. Following a discussion of the intended project, eight to ten representatives were elected to an Elder Commission, who were then charged with meeting with the municipality's social personnel. Based on their expertise and interests, Commission members assumed various job assignments, to establish and coordinate:

- Adult education services for the elderly
- Exercise programming
- Telephone chain (each person called by a member of the elderly chain, who in turn, calls the next person. Persons not reached are checked on)



- Neighbor chain — to exchange services, e.g., someone may help with shopping in exchange for a meal
- Secretarial services — for the neighborhood newsletter, correspondence, etc.
- Barrier assessment in homes and neighborhood
- Services assessment, e.g., shopping, transportation, etc. Home visitor programs

A chairperson was selected to handle the overall coordination of activities, public relations and outreach activities. The Department of Human Services provided the project with a social worker to aid in coordinating existing services with those planned by the Elder Commission. Various community programs agreed to open their facilities to aid the frail elderly.

Results

Following a one year period, the Skibhus project was evaluated. The participants, town leaders and the Department of Human Services were asked about:

- ☐ changes making the neighborhood more "elderly friendly"
- ☐ improvements and quality of life for those "at risk"
- ☐ the number of nursing home admissions

Based on preliminary data, the decision was made to extend the project to all 18 neighborhoods of Odense. Perhaps the most significant finding was that nursing home admissions from Skibhus had been reduced by 15 % after the first year. Overall, the reaction to the project has been

extremely favorable on the part of the participants and the Department of Human Services. If future results for the entire town parallel those of Skibhus, no more nursing homes will be built. This will enable funds to be diverted to support programs designed to prevent or delay institutionalization.

Implications for the U.S.

Because we too are facing a need to provide services for the fastest growing segment of our population — the elderly — we should consider funding programs which follow the independent living model. If instead, we continue to build more nursing homes to meet the needs of the frail elderly, we risk wasting valuable human and monetary resources through "over-help."

People often worry more about "becoming a burden on others" than they do about aging, or even death. Informal support networks decrease that risk by increasing our ability to help ourselves. An increased emphasis on self-determination and the right to be consulted will strengthen the quality of life for our older population, in the same way that it will for our disabled population.

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REHAB BRIEF

Bringing Research
into
Effective Focus

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PEER COUNSELING: AS A MOVEMENT, AS A REHABILITATIVE SERVICE

"You can't *possibly* understand what I'm going through . . . *you're not disabled!*"

This sentiment has been voiced so often to rehabilitation professionals over the years that most readers can probably assign it to a dozen speakers within their own memories. You may have "sensed" such an attitude even when it was not said aloud. Whatever its validity, the message is a major force behind the development of peer-provided services in rehabilitation. Many people with disabilities—at least for a while as they learn to peacefully coexist with disability—have trouble believing that people who haven't experienced it could truly comprehend the implications. If understanding is absent, can genuine help be expected? What to do? Enlist the aid of providers who have that critical ingredient which spells "credibility" to those who feel and think this way.

Enter peer providers on the rehabilitation scene. The 1970s saw the germination and sprouting of the peer service approach. It was a natural part of the independent living/disability rights movement which took root and grew during the same period. Rehabilitation professionals weren't the only ones to see that people who've "been there" have a contribution to make. A discontented and increasingly active consumer constituency strongly agreed that people who've coped with disability could expand and improve the quality of such services as information and resource sharing, referral, skills training, role modeling, emotional support, self-exploration, problem identification, goal setting, action planning, and goal attainment monitoring.

Largely without benefit of validating research, peer services came into being in consumer-run independent living programs, professionally run rehabilitation agencies, educational institutions, and other settings. The movement grew rapidly for several reasons. It addressed the credibility problem. The range of apparent beneficiaries proved wider than expected—it includes service recipients, peer providers themselves, service programs, and entire communities. Perhaps most important, it appeared to be highly cost effective.

The numbers who could be served multiplied but the unit costs didn't.

By 1980 peer services had become sufficiently entrenched to prompt the Eighth Institute on Rehabilitation Issues (IRI) to select peer counseling as a focal issue. Through funding from NIHR and under the sponsorship of the Arkansas Rehabilitation Research and Training Center, the Prime Study Group undertook the charge. Briefly, this was to develop a resource document to help state vocational rehabilitation (VR) agencies and other organizations implement peer counseling programs as a way to broaden services to severely handicapped people.

The resulting document, titled *Peer Counseling as a Rehabilitation Counseling Resource*, edited by Rice and Pankowski (see sources below), states at the outset that "peer counseling" is a controversial, nebulous term. It was chosen over alternatives because it is used in the 1978 Amendments to the Rehabilitation Act, where it is listed among other services of independent living centers. A functional definition was developed by the Prime Study Group:

Peer counseling is help provided by a disabled person who has attained disability-related experiences, knowledge, and coping skills, and helps other disabled people and their significant others to cope with disability-related experiences.

An IRI task was to review the state of the art. The Prime Study Group acknowledged a dearth of controlled research and relied heavily on data maintained by the Independent Living Research Utilization Project in Houston. From these, they identified and described *six* models of peer counseling programs used in various settings for differing purposes.

MODELS OF PEER COUNSELING

1. **The CONVENTIONAL Approach.** Peer counselors are *paraprofessionals*, supervised by a professional counselor who functions as a case manager. They typically have good working knowledge of human service delivery systems, counseling abilities, and good communication skills. They may or may not

have college degrees. In-service training is often provided. Most contacts occur in private offices, weekly or bi-weekly, and encompass a wide range of personal issues. Peers are typically salaried, full-time employees. This model is used most frequently in independent living programs today. It suits densely populated urban areas because of transportation needs and high service demands which call for more structured programs.

2. The FIELD Approach. Peer counseling is often delivered in the client's residence because of transportation problems, medical complications, fear of the outside, or overprotective guardians. Peers tend to have strong consumer backgrounds and little formal education. They are often volunteers or part-time employees. Supervision is generally less than in the Conventional model; programs are more flexible. This *outreach* model is used extensively in rural programs and in urban outreach to institutionalized populations.

3. The REHABILITATION Approach. Former state VR agency clients provide peer counseling through consulting contracts with the agency. They usually have substantial academic backgrounds. The approach is highly structured with well-defined recording, scheduling, supervision, and case review requirements. Counseling often relates to vocational concerns but may cover personal issues. Peers usually work part time on an hourly wage scale. The motivating effects of their role modeling and help in meeting prevocational needs have been noted.

4. The INSTRUCTIONAL Approach. In a highly structured group process clients are given information and taught skills by peer tutors. Peers are selected for skills, experiences, and academic training. They may work full or part time, conducting 10-15 training sessions per week for groups of three to eight. Under supervision from a project director, they have considerable freedom to plan and conduct the sessions. Role modeling is a frequent function. This model is used in rehabilitation facilities, independent living centers, and colleges. It is often combined with Conventional and Field models, usually in metropolitan areas.

5. The INFORMATION AND REFERRAL Approach. This is a straightforward method of giving clients timely information about service and equipment needs. Peers may have personal experience to share, and may specialize in such areas as attendant care, transportation, communication skills, or architectural accessibility. Face-to-face client contacts are few in number and lead to linkages with other community resources. Program structure and supervision vary; in some programs, records on all contacts and follow-up are required.

6. The COMMUNITY Approach. This model focuses on improving the quality and quantity of help available within the natural networks of a community instead of referring individuals to specific services. It is characterized by interaction among friends, family members, and significant others. The trend is toward formal training for identified natural helpers. A few independent living programs try to encourage its use by identifying helping networks in the community. It often occurs in group living situations as information is passed through a "grapevine." Peers are usually volunteers.

NEEDED CHARACTERISTICS

The possession of disability-related experiences is an important trait that sets peer counselors apart from other helpers. It is a necessary prerequisite to serving as a role model but is not sufficient by itself. To be effective, the person must have the interest, commitment, time, energy, skills, and personal qualities essential to good helping relationships. The latter undergird good interpersonal and communication skills and include:

- **Empathy**—the ability to grasp another's feelings, experiences, goals, and accurately convey this understanding to the person.
- **Respect**—caring, warmth, and positive regard for another, communicated through nonpossessive interest and acceptance.
- **Genuineness**—honesty with oneself and others, and humanness, integrated into one's personality.
- **Concreteness**—the ability to guide discussions into personally relevant material, in specific terms, to help another conceptualize experiences in manageable ways.
- **Self Disclosure**—appropriate, timely sharing of personal experiences, thoughts, feelings, and attitudes to model effective self-exploration and problem solving.
- **Immediacy**—concentration on the "here and now" of the relationship to foster direct dealing with the impact of each on the other.
- **Confrontation**—the ability to focus on discrepancies in another's communications and "call it like it is" in a facilitative manner.

The document asserts that these and other core communication skills can be developed through training and practice, and that paraprofessional helpers can become very effective without extensive training in psychological theory.

Peer counselors must adhere to certain ethical principles:

- following the rules of the organizations in which they work;
- abiding by confidentiality and record-keeping policies;

- knowing their limits and seeking help when needed;
- operating in accord with their established job descriptions;
- distinguishing between giving support and acting as "rescuer" and avoiding assumption of clients' responsibilities;
- guarding against advising or dictating specific courses of action;
- respecting clients' often differing value systems; and
- being self-aware when efforts to be open to others' feelings about disabilities bring back personal grief or anger and when seeking help.

After describing what peer counseling is and does, the resource manual addresses administrative concerns. Interested program-responsible people may benefit from reviewing these portions of the original document. The remainder of this BRIEF offers highlights from a more recent document which further clarifies the status of peer counseling as a developing rehabilitative service.

A HISTORICAL OVERVIEW

In 1983, Robert Akridge, of the Arkansas Rehabilitation Research and Training Center, prepared a state-of-the-art review of "Peer-provided Rehabilitative Services" for the 1984-5 Volume of the *Annual Review of Rehabilitation* (see sources below). He begins by indicating that there is still very little rigorous research-based information to guide peer service program decision making. That which does exist on peer helper technology was developed mainly in educational settings. He reviews this and other bodies of research which claim relevance to peer-provided rehabilitative services. From this broad perspective, he chronicles the dynamics and social context of their evolution.

The development of competency-based training of helping professionals and the widespread use of paraprofessionals led to identifying basic helping skills. Growth of the paraprofessional movement laid the foundation for peer counselors and facilitators. This reinforced a related trend of teaching adjustment or coping skills directly to clients. The skills-training orientation helped demystify the biological, behavioral, and social sciences, and increased public awareness of them. Public awareness accentuated the de-institutionalization and disability rights movements, and the general mushrooming of mutual/self-help groups. The civil rights and women's movements and experimentation with participatory management styles in work organization all represent efforts to democratize the culture. This is reflected in consumer involvement legislation and client assistance programs within social and rehabilitation services.

According to Akridge, human service agencies are in a state of shock from shrinking financial resources,

growing needs for service, greater demands for accountability, and marginally effective technical-professional support. Use of peer-provided services is being widely advocated as a cost-effective means of coping and, perhaps, improving human services.

THE COUNSELING PROCESS

Systematic training in helping skills for professional counselors emerged partly as a result of researched-based evidence that *affective skills* (e.g., empathy, genuineness) are essential to "helping" and not "hurting." The findings show that such skills can be taught and measured; and regardless of counselors' theoretical backgrounds or other techniques used, their success stems largely from their effectiveness in affective skill areas. This prompted the training of paraprofessionals to use these skills. Paraprofessionals found them useful in their own lives and taught them directly to clients.

Akridge notes that those who are underserved by the traditional disability-related service delivery system are likely to have trouble establishing trusting relationships with professional helpers. However, personal defensiveness must be reduced if the growth process of exploring, understanding, and acting is to be stimulated. He concludes that peer providers offer the rehabilitation profession a potential resource for reaching out to the underserved since they are perceived as emotionally, socially, and culturally closer. He believes they can be trained to contribute to the counseling process and serve as bridges to rehabilitation professionals.

TRAINING PEER COUNSELORS

Helping, like most other life tasks, is an interpersonal process requiring effective communication. Good reception involves empathic understanding and the ability to convey that understanding. Good expression involves straightforward, assertive messages. Research shows that training people in assertiveness increases their empathy and vice versa. Also, among counselor trainees, anticipatory anxiety about being evaluated (using physiological and self-report measures) has been found to account for nearly half of the variation in communicated empathy during a session. These findings suggest that it is wise to train peer counselors in affective skill areas.

About 75% of the independent living centers responding to a 1983 mail questionnaire reported sending at least one staff member to at least one off-site training program in the two-year period studied. On-site training, ongoing or as needed, was reported by 82%. Such training is conducted by in-house staff (55%) or by staff plus outside consultants (39%). The topics emphasized are the counseling process (40%), disability-related experience (40%), and peer-service program management (20%).

MARKETING PEER SERVICES

Additional surveys show that 89% of the state VR agency directors consider peer counseling to be of prime importance in independent living programs, but lack of acceptance by practicing professionals is a major impediment to their use and refinement. Rehabilitation center clients and attendees at a national independent living conference were most supportive of the concept; vocational instructors and recreation staff in rehabilitation centers were intermediate in their support; and rehabilitation center counselors were least supportive. In view of the evidence supporting the facilitative role of informal leaders among client groups and of demonstrations that selected clients can be trained to increase their facilitative functioning, Akridge posits a continuing need to market peer services to the rest of the rehabilitation community.

IMPLICATIONS

The data are not yet in specific to the efficacy of peer services in rehabilitation. However, numerous findings support the utility of peer and mutual/self-help approaches with other populations, and none suggest that disabled people are such "a breed apart" that markedly different findings should be expected for them. Careful, though not scientifically controlled, observations suggest substantial benefits accruing not only to clients but to peer counselors (one learns best by teaching), service-delivery programs (always cost conscious), and communities (which enjoy more self-sufficient disabled constituencies). It seems reasonable, then, to guess that peer service has a valuable role to play, to use it, and meanwhile to gather data. Thus can we better define the role, its scope, the best ways to integrate it into the total service system, and identify pitfalls to avoid.

Counseling, per se, is undeniably a professional-level skill. It seems natural that professional counselors would be more skeptical than people in other disciplines about the value of nonprofessionals' counseling efforts. This may reflect professional ego, but it reflects also the insiders' intensive familiarity with what is required when counseling gets tough. The term "peer counseling" may begin by being inaccurate and end by subverting the practice into wrong directions. The peers' functioning seems more akin to that of a *coach*. In sports or the performing arts, coaches are drawn from the ranks of older-and-wiser players or performers. They use their experientially derived skills and knowledge to coach less experienced souls across common ground—which may be rough terrain. They demonstrate, observe, and give

feedback as learners practice. Perhaps solidifying this functional distinction in a term such as "peer coaching" would help in the marketing. The coaching function, which can only be done by experienced "players," might be more eagerly embraced as a vital addition to the service system.

SOURCES

1. Akridge, Robert. "Peer-provided Rehabilitation Services." *Annual Review of Rehabilitation*. In press. New York, New York: Springer Publishing Co.
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3. Mathews, S.A., Pittman, J.L., and Mathews, R.M. *Peer Counseling Directory*. Lawrence, Kansas: Rehabilitation Research and Training Center on Independent Living, University of Kansas, 1983.

Source No. 2 is available from the Publications Department, Arkansas Rehabilitation Research and Training Center, P.O. Box 1358, Hot Springs, AR 71902. (\$4.00)

Source No. 3 is available from the National Rehabilitation Information Center (NARIC), 4407 8th Street, N.E., Washington, D.C. 20017. (Please write to NARIC for price information.)

SUGGESTED READINGS

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Evans, J., and Livneh, H. "Peer Counseling: A Training Program." *Journal of Rehabilitation* 48, No. 1 (Jan.-Feb.-Mar. 1982): 52-55.

Harriman, M.A., and Garfunkel, M.A. "Value of Self-Help Groups in Spinal Cord Injury Rehabilitation: Model Systems." *Science Digest* 26, No. 3 (Fall 1981): 26-33.

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