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INDEPENDENT LIVING

A Resource Manual

Edited and Compiled by
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ACKNOWLEDGMENTS

The primary objective of the Region IV short-term training project in Independent Living is to provide training and resource material to Region IV rehabilitation professionals who are (a) developing Independent Living Programs (ILP's), (b) using ILP's as a resource for their clients, and (c) operating ILP's.

To meet the objectives of the project, a regional short-term training project was developed in coordination with Emory University's Rehabilitation Research and Training Center, and the Independent Living Resource Manual was developed for initial presentation at the April 9-11, 1980 training program. After the program, the project will make this manual available to Regional IV rehabilitation personnel, provide technical assistance to persons involved in Independent Living (IL) planning, and conduct IL presentations to training programs and rehabilitation conferences.

Many people have contributed to the development of the resource manual. The following individuals were instrumental in the development and operation of the project. Martha Carrick of the Region IV Rehabilitation Services Administration Office provided valuable support and facilitation. Phyllis Stegall and Roger Decker, of Emory University Rehabilitation Research and Training Center, helped to shape the program format, and have been a joy to work with in coordinating the training program.

We appreciate the support of Laurel Richards and Lex Frieden, of the Texas Institute of Rehabilitation and Research, for their assistance in reviewing the manual, developing the program, and conducting training. Thanks to Pam Smith for her contribution to the initial project development. For her patience and hard work, thanks to Dixie Dawsey for her typing of the final manuscript. Thanks also to Mervyn Willoughby, Assistant Project Coordinator, for his significant contribution throughout the development of the manual.

This project would not have been initiated without the creative efforts of the following Independent Living grant writing committee: Alice Caruso, Carol Gardner, Michael Henderson, Sara Hoffman, Pam Smith, and Mervyn Willoughby.

Special thanks to Sara Hoffman, Project Coordinator, for her creativity and dedication to Independent Living. Without her efforts, the resource manual would not have evolved.

Michael Shinnick, Ed.D
Project Director
April 1, 1980

PREFACE

"Independent Living" means freedom from isolation or from the institution; it means the ability to choose where to live and how; it means the individual's ability to obtain the services necessary to carry out the activities of daily living that the non-disabled take for granted (Pfleuger, 1977).

The desire for independence is not new to our country. Self-control, autonomy, and national freedom were the "battle cries" that won a separation from England in 1775. Our world wars were as much crises over human values, as they were battles over lands and sea. In the decade just past there occurred another revolution of sorts, with the plea for equality between races raised up with a shouting voice and fists clenched in anger.

It seems as though the severely disabled are now waging a "war" of their own. However, their's is not a cry to battle but a desire for partnership with rehabilitation professionals, for the purpose of providing quality services. The disabled person of today sees himself as an expert in the fulfillment of his own needs and wants, and in many cases, is himself a professional who is working with other disabled individuals.

Title VII, of the 1978 amendments to the Rehabilitation Act of 1973, charges the Rehabilitation Professional with the responsibility of implementing Independent Living (IL) services. This piece of legislation is of special concern in rehabilitation. Among these concerns remains the fact that a limited amount of funding has been allocated for programs. Though the regulations have now been issued, adequate information has not been offered as to the provision of services and evaluation of programs. The concept of IL sparks both challenge and controversy.

Reconciling individual needs due to disability and the services which are appropriately sensitive is the challenge of Independent Living. It requires of us to remain prudent in the development and implementation of programs. It charges us to develop programs which are cost-effective and consumer-involved. And it may motivate us to preserve the belief in individual freedoms that we all enjoy, or could enjoy given the appropriate supportive services.

In order to meet this challenge, new directions must be taken in rehabilitation. The objectives of this resource manual attempt to reflect these directions, and the needs for information that they create. Definitions, concepts, and practical information is offered in the manual. It has, as its focus, outlines of strategies for the development and implementation of programs. In addition, resource materials are suggested which may be used for further analysis, planning, and research.

As the role of Independent Living in rehabilitation is relatively newborn, there appears to be a dearth of materials pertaining to evaluation of services and program impact. We have attempted to remedy this situation in several ways. Information has been provided which may assist in determining program success. Guidelines for policy development, program planning, outlines for training and curriculum development are presented. These areas are at the center of programming for Independent Living services. Philosophical and legislative issues explored in the manual may enable the professional to determine priorities for services rendered, eligibility criteria for participants, and program emphasis.

The objectives developed for this manual attempt to clarify the intent and focus of the information previously outlined. They are as follows:

1. To offer guidelines for state agency personnel and program planners in the organization and implementation of programs.

2. To provide teachers and trainers with information and suggested resources for the development of an Independent Living curriculum.

3. To present an annotated bibliography of Independent Living materials that may assist in planning, research, and program development.

As the Independent Living movement expands and becomes recognized as a viable service area in rehabilitation, there will be a need for information which will enhance the effectiveness of the administration and facilitation of services. This document may assist rehabilitation professionals in that endeavor, and in turn, the needs of the severely disabled may be met in a more meaningful and effective way.

Sara Jeanne Hoffman, M.Ed.
Project Coordinator

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INTRODUCTION

OBJECTIVE

To provide an overview of IL definitions, concepts, projects, and model programs.

SUMMARY

(1) Independent Living Glossary. Developed by Independent Living Research Utilization (ILRU), Houston, Texas. Reprint permission granted.

The glossary defines the following terms: Independent Living (IL), IL program, IL Center, IL residential program, and IL services provider. These terms provide for a basic understanding of Independent Living, which evolves from a review of relevant and current literature in the field.

(2) "Who is Severely Handicapped? The Need For A Workable Definition." Rehabilitation Brief, Vol. 1, No. 2, April 1978. Insert.

The purpose of the study was to insure that the phrase "severely handicapped" be specifically defined so that individuals who may qualify for rehabilitation services are accurately designated. This concern is especially important for those involved in IL services. This document exposes the difficulties in defining the severity of a disability for purposes of eligibility decisions and evidence of client gains.

Issues discussed include the use of a clearly defined coding system for level of disability, effective measures of functional limitations, the need for agreement of terms used, and training of professionals in assessment of disability.

Although this article is designed for vocational rehabilitation staff, information is provided which may stimulate an evaluation of the present VR system, and its ordained involvement with IL services.

(3) "IL: Movement and Programs." From ILRU Source Book, Houston, Texas, 1979. Reprint permission granted.

Independent Living programs provide the means by which severely disabled people can participate to the fullest extent possible, the normal day to day activities of life. Lex Frieden, Research Director for Texas Institute of Rehabilitation and Research, provides an overview of the movement toward the provision of Independent Living

programs (ILP's). An analysis of the various types of IL programs are discussed, which includes the Center for Independent Living in Berkely, California, and the Boston Center for Independent Living in Massachusetts. It is emphasized that the essence of a successful IL program is in direct consumer involvement and control over the implementation of services.

(4) "Independent Living Rehabilitation: Results of Five Demonstration Projects." Rehabilitation Brief, Vol. II, No. 9, October 26, 1979. Insert.

The Rehabilitation Act of 1973 provided for a study of severely disabled individuals across the nation. This Comprehensive Service Needs Study precipitated the establishment of six demonstration projects (one project has since been terminated), which would explore various facets of Independent Living services for the disabled.

This article offers a synopsis of the data collected as a result of those projects, and lists preliminary findings of the report.

Results are listed in terms of client needs: for equipment, transportation, services, architectural barriers removal, living arrangements, cost results and considerations, and household management skills.

From an assessment of those needs, it became evident that IL services are of benefit for severely disabled individuals. If these services are to be of high quality and are cost-effective as well, it is essential that similar benefits and avenues of inter-agency coordination be explored for purposes of continued funding.

(5) "International Efforts in Independent Living." Archives of Physical Medicine Rehabilitation, Vol. 60, October 1979. Reprint permission granted.

Several nations currently share a major concern for provision of services to severely disabled persons. The focus of this concern has been upon those services which promote maximum integration and independence of severely disabled individuals in the community. Recent efforts in this direction by governments, private citizens, and handicapped-consumer organizations in Sweden, The Netherlands, Denmark, England, Canada, and Australia are discussed. Developments in housing and environmental modification, transportation, and self-help training are reviewed for their potential interest to advocates and practitioners of rehabilitation for independent living.

A GLOSSARY FOR INDEPENDENT LIVING

developed by ILRU (Independent Living Research Utilization Project)

with grant support from the Rehabilitation Services Administration, US DHEW

revised May 1979

TIRR: The Institute for Rehabilitation & Research
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Independent Living Glossary

This selected glossary presents definitions of terms relating to independent living and kinds of independent living programs. Obviously, it is neither exhaustive nor comprehensive, especially since new terms are being created to describe new circumstances. However, there is a need to standardize the meanings of several key terms so that rehabilitation service providers, consumers, and others around the country will have a common frame of reference.

The definitions in the glossary were developed after a review of the relevant literature by the ILRU staff. The project's national advisory committee played a major role in this effort through group discussion of concepts and through written comments on early drafts of the definitions.

Independent living

Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of physical or psychological dependence upon others.

Discussion

Independence is a relative concept which each individual defines personally. Similarly, the concept of independent living is quite broad, subsuming many levels of functional independence.

Some severely disabled people view these varying levels of functioning as important distinctions of independence. For instance, certain activities not central to personal control of one's destiny or the day-to-day management of one's life are considered to be the essence of living independently. Some individuals perceive physical activities such as dressing oneself to be important examples of their ability to live independently. On the other hand, others view any extra time and energy spent dressing themselves as time and energy which could be spent more profitably at work. In fact, whether one performs these particular activities oneself or relies on the assistance of others has little to do with the amount of control one exercises over one's own life.

Independent living is not dependent upon programs that foster functional independence. Instead, it is based upon the individual's ability to choose and achieve a desired lifestyle and to function freely in society.

It should be stressed that not every person will be capable of achieving total independence in the sense described here. Some persons may not be able to or may not choose to exercise self-determination in certain matters. In such cases, the person may opt for or be restricted to a kind of modified independent living, limited independent living or semi-independent living.

Independent living movement

The process of translating into reality the theory that, given appropriate supportive services, accessible environments, and pertinent information and skills, severely disabled individuals may actively participate in all aspects of society.

Discussion

For years, some severely disabled individuals have lived comparatively independent lives by finding or making barrier-free residences and by securing attendant care, transportation, and other supportive services on an individual basis. In spite of these self-styled arrangements, programmatic and broadscale efforts to facilitate independent living were stifled by restrictive statutes, regulations, and an inadequate allocation of resources.

Historically, the independent living movement has been characterized by a great amount of consumer involvement

and consumer control. Also, the movement has been associated with expanding non-institutional residential alternatives for severely disabled individuals.

Independent living programs have always been seen as sources of specific information and referral. Developments in independent living probably reflect a lack of coordination of services which already exist in the community and gaps in the community-level service delivery system.

With the arrival of federal funds to support the development of independent living programs on a large-scale basis, many more programs designed to facilitate independent living by severely disabled people are likely to emerge in the near future.

Presently, approximately 35 programs may be classified as independent living programs. If one includes progressive group home projects, halfway houses, and other personal adjustment and mobility training programs in this census, there may be as many as 100 to 200.

Independent living program

A community-based program which has substantial consumer involvement, provides directly or coordinates indirectly through referral those services necessary to assist severely disabled individuals to increase self-determination and to minimize unnecessary dependence on others.

Services that an independent living program must provide or coordinate through referral are housing; attendant care, readers and/or interpreters; and information about goods and services relevant to independent living. Other services that are either provided or coordinated by

independent living programs include transportation provision or registry, peer counseling, advocacy or political action, independent living skills training, equipment maintenance and repair, and social-recreational services.

Note: Custodial care facilities and primary medical care facilities are specifically excluded from the definition of an independent living program.

Discussion

Independent living programs differ from one another in at least six primary areas: the service setting may range from residential to non-residential; the service delivery method may range from direct to indirect, or a combination of both; the helping style may range from non-handicapped to consumer; the vocational emphasis may range from primary to incidental; the goal orientation may range from transitional to on-going; and the disability-type served may range from single to many.

What kind of features an indepenedent living program has will depend on the needs of the clients served, the availability of existing community resources, the physical and social make-up of the community, and the goals of the program itself.

Conceptually, independent living program is generic--the most broadly defined term relating to organizations working with disabled individuals who wish to live independently. Several different kinds of independent living programs with specified purposes have been identified. Some of these are independent living centers, independent living residential centers, independent living transitional programs, and independent living service providers. The accompanying chart illustrates the relationships between these elements (see chart).

INDEPENDENT LIVING PROGRAMS: FOUR PRIMARY VARIATIONS

Conceptually, an Independent Living Program is generic -- the most broadly defined term relating to organizations working with disabled individuals who wish to live independently. Several different kinds of independent living programs with specified purposes have been identified. Some of these are: independent living center, independent living residential program, independent living transitional program, and independent living service provider.

What kinds of features an independent living program has will depend on the needs of the clients served, the availability of existing community resources, the physical and social make-up of the community, and the goals of the program itself.

INDEPENDENT LIVING PROGRAM	INDEPENDENT LIVING CENTER	INDEPENDENT LIVING RESIDENTIAL PROGRAM	INDEPENDENT LIVING TRANSITIONAL PROGRAM	INDEPENDENT LIVING SERVICE PROVIDER
Community-based	Community-based	Community-based	Community-based	Provides services useful for living independently
Consumer-involved	Consumer-controlled	Consumer-involved	Goal-oriented	
Provides/Coordinates:	Non-residential	Provides/Coordinates:	Time-linked	
Housing	Non-profit	Housing	Provides/Coordinates:	
Attendant Care	Provides/Coordinates:	Shared attendant services	Skills training in independent living	
Information	Housing	Transportation	Other services	
Other services	Attendant care	Other services		
	Peer counseling			
	Financial/legal advocacy			
	Community awareness and barrier removal programs			
	Other services			

Independent living center

A community-based, non-profit, non-residential program which is controlled by the disabled consumers it serves, provides directly or coordinates indirectly through referral those services which assist severely disabled individuals to increase personal self-determination and to minimize unnecessary dependence upon others. The minimum set of services that are provided by an independent living center are housing assistance; attendant care, readers, and/or interpreters; peer counseling; financial and legal advocacy; and community awareness and barrier removal programs.

Independent living residential program

A live-in independent living program that provides directly or coordinates through referral shared attendant services and transportation. Related services which increase personal self-determination and minimize unnecessary dependence on others may be provided.

Independent living transitional program

An independent living program that facilitates the movement of severely disabled people from comparatively dependent living situations to comparatively independent living situations. The primary service provided by these programs is skill training in such areas as attendant management, financial management, consumer affairs, mobility, educational-vocational opportunities, medical needs, living arrangements, social skills, time management, functional skills, sexuality, and so forth. Additional services may be provided. Transitional programs are usually goal-oriented and/or time-linked.

Independent living services provider

An organization which provides several discrete services which can be used to increase an individual's ability or opportunities to live independently. For example, a medical rehabilitation facility may provide out-patient services which are designed to maintain the physical health of a person who lives independently in the community. However, if the center does not provide or coordinate a full set of services including transportation, attendant care and so forth, it would be an independent living service provider rather than an independent living program. While an independent living service provider does not meet the criteria necessary to be classified as an independent living program, the services it provides may be used or coordinated by an independent living program.

REHAB BRIEF

BRINGING RESEARCH INTO EFFECTIVE FOCUS

Who is Severely Handicapped?— The Need For A Workable Definition

Vol I, No. 2

April 1, 1978

Mr. R. is an illiterate, black, 55-year-old laborer who recently developed arthritis in both knees. Previously he supported a family of four with his salary as an agricultural worker, the only job he has ever known. Now, unable to stand for the long periods of time required for farm labor, and seemingly unskilled for other work, Mr. R.'s employment outlook is grim.

Ms. S. lost both legs following an automobile accident during her second year of law school. Although confined to a wheelchair, she has returned to law school and has good job prospects upon graduation.

By many present medical and government agency standards, Ms. S. would be classified as severely disabled, despite her potential employability as a lawyer. On the other hand, Mr. R.'s arthritis would be considered only a moderate impairment, despite the fact that it keeps him from doing farm work, and that he might not qualify for vocational rehabilitation.

Obviously, in determining who is to be aided by vocational rehabilitation in these two cases, the degree of severity needs to be redefined. In addition to the disability itself, vocational and other conditions of the handicapped person's life must also be considered.

As these cases illustrate, factors beyond disability per se contribute to the severity of an individual's handicap. The VR community is faced not only with defining severe disability but also determining which additional factors contribute to the degree of disability. A Congressional mandate (Public Law 93-112) stated that "those with the most severe handicaps" should have priority for receiving VR services. To respond to these needs REHAB Group, Inc. was chosen to analyze the definition of "severe handicap" for the Rehabilitation Services Administration (RSA) of HEW in 1976.

Study Objectives

A major purpose of the study[1] was to recommend improvements in the definition of severely handicapped. Specifically, it sought to assure that the category be used accurately and reliably to qualify persons with priority for services.

The form of the initial RSA definition of severe handicap made the need for review, study, and redefinition inevitable. Along with this, administrative procedures and disability coding and classification practices needed to be developed that would lead to workable application of the definition.

Definition of Severe Handicap, 1973 Act

The definition of severe handicap as presented in Public Law 93-112 reads as follows:

Sec. 7(6) The term "handicapped individual" means any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided pursuant to Titles I and III of this Act.

Sec. 7(12) The term "severe handicap" means the disability which requires multiple services over an extended period of time and results from amputation, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, renal failure, respiratory or pulmonary dysfunction, and any other disability specified by the Secretary in regulations he shall prescribe.

Section 7(6) clearly states that in order for a person to be eligible for VR services, his "*disability must result in a substantial handicap to employment*." To be designated as severely handicapped, a person must have one or more prespecified medical conditions. Problems arising from the condition must also require multiple services. An individual may have a severe disability according to the definition, yet not be handicapped with respect to employment.

REHABILITATION SERVICES ADMINISTRATION • OFFICE OF HUMAN DEVELOPMENT SERVICE

DEPARTMENT OF HEALTH, EDUCATION AND WELFARE • WASHINGTON, D.C. 20201

METHODS

A National Advisory Committee, representing national and state leadership in rehabilitation, and a Technical Advisory Group (TAG) formed by REHAB Group, Inc. were advisors for the project.

To test the feasibility and limitations of the initial definition, state VR counselors and supervisors from four states worked as teams of three in their respective district offices. They reviewed and classified 393 cases. Half were selected by the severity standards of RSA and National Advisory Committee staffs. Counselors nominated another 30 percent as being difficult to classify. They randomly selected a final 20 percent. The severity ratings and classifications of the counselor teams, together with judgments of the TAG, provided detailed information about the inadequacies of the definition. Counselor reactions to the task pointed to the limits of the classification schema used.

RESULTS

Criteria for a New Definition

The definition in the Act and subsequent RSA guidelines were found inadequate. While one part of the Act asserts that a disability must result in substantial handicap to employment, another part would not deem the same condition a handicap. Regulations adding the requirement of functional limitations to employment and amending the disabilities list were among the agency instructions which experts and counselors think lead to variability in defining severity. If a new definition is to be used, these observations indicate it is important that

1) there be agreement among terms used in all documents,
2) the definition be distributed at the same time to all states, with a specified starting date for its use, and
3) all states discard all documents based on obsolete definitions.

Reactions of VR Agency Staff

- The classifications system lacks clarity in defining and identifying severely *handicapped* as opposed to severely *disabled* people.
- The key to an adequate coding system may be using a single code to represent the vocational handicap.
- The intent of the functional limitation criteria is unclear. Presumably, those listed in the RSA manual represent limitations to employment generic enough to apply to everyone. But, because no social/emotional variables are represented, the criteria do not apply well to any of the psychotic or psychoneurotic disorders classifications.
- Counselors do not often use functional limitation criteria. Apparently, part of the reason is that criteria are needed for the very cases to which existing ones do not apply. A second reason appears to be counselor beliefs that they will be judged as attempting to inflate their caseloads with severely handicapped persons if they use the functional limitation criteria.

Criticisms and Suggestions from Participating Groups

The National Advisory Committee reviewed the problems faced in reliably coding the severely handicapped. It noted that reliability is decreased by (1) a lack of sufficient or useful reports, (2) differences in timing or personnel assigned to coding by the various states, and (3) a lack of precise measures of functional limitation.

TAG saw additional limitations in existing practices. Among them are exclusive use of medical findings (while neglecting critical employability variables), inadequate medical reports, and the lack of key behavioral indicators to help clarify "gray" areas.

The Advisory Group deemed useless the requirement for multiple services because nearly all VR clients require several services. Thus, they claimed the definition of the 1973 Act is not explicit enough for VR personnel to identify the severely handicapped with sufficient validity and reliability.

Medical factors alone are insufficient for deciding who is severely disabled and will be a likely candidate for VR and future employment. Additional factors such as functional capacities, age, job experience, geographical location, and education must also be considered.

One staff suggestion for improving classification was to formulate a unique code based on degree of vocational handicap. The RSA staff thought the classification system could become usable if counselors became better trained in its use and learned how to collect the needed information.

Field testing conducted by teams of VR counselors and a Reviewing Panel revealed

- A high proportion of concurrence in disability codes;
- Variations among states in counselor-panel agreement rates;
- Less agreement in identifying secondary disabilities;
- No significant difference in disability coding agreement levels between "difficult" cases and others;
- Substantial agreement (78%) on the present severely handicapping conditions;

- The reviewing panel usually (72% of the cases) rejected attributing severity to any disability category;
- Severity status classification was less reliable with counselor-selected "difficult" cases.

The Counselor's Role

Obviously, the importance of the individual rehabilitation counselor in defining severity cannot be overemphasized. This is true in spite of the limitations imposed by the existing definition of severely handicapped and the coding system. The degree of effort and involvement a counselor contributes to placing clients in appropriate job situations has been used as one index of vocational handicap severity. Even if the multiple services criterion is dropped, counselor judgment will continue to play a key role in weighing the emotional and vocational rehabilitation needs of the client.

Research is being conducted to define "severely disabled" adequately, to measure its functional limitations, and to identify rehabilitation indicators.[2] New scales will aim at measuring more than just an individual's medically-related handicaps.

DEVELOPMENTS IN MEASURING FUNCTIONAL CAPACITY

Two approaches to objectively measuring functional capacity have stemmed from the work of medical rehabilitation research and training centers.

PULSES-Barthel Index

The PULSES-Barthel Index has proven to be one of the most efficient measuring scales yet devised. It includes such factors as self-care, mobility, general communication abilities, and psychosomatic capabilities.[3]

Recently Tufts University research staff have modified the PULSES-Barthel Profile to include a continuous scale. The modified scale is designed to measure an individual's need for professional and nonprofessional assistance in six broad areas:

P—Medical and/or nursing care required for physical conditions
U—Upper limb functional capacity in self-care activities
L—Lower limb functional capability in mobility activities
S—Sensory functional capability in communication
E—Excretory function control
S—Usual role and task performance capability

Each of the six functional areas is scaled from one to four to indicate mild to extreme disability. A total score of 21-24 indicates extreme disability, 16-20 severe disability, 12-15 moderate disability, 8-11 mild disability and 7 or less no disability. Additional indicators include functional limitations, communication impairment, home life status, family disruption, social activities, personal and social contact, employment, travel, socioeconomic achievement, and health care services.

Although used in many major rehabilitation centers, the index has not been applied extensively. Efforts are underway to develop training tools for implementing it.

Rehabilitation Indicators

New York University Institute of Rehabilitation Medicine has developed rehabilitation indicators (RI's) for use in obtaining and organizing large amounts of client function information. Underlying this development is an assumption that changes in client behavior can described objectively and serve as criteria for rehabilitation decisions.

RI's are also intended to define client strengths, limitations, goals, needs, and other variables relevant to rehabilitation planning.

Behavioral RI's describe the client's vocational/educational, independent living, social, polititalal/legal and economic functioning and skills. Environmental RI's describe other elements which support or hinder client attainment of goals.

Currently, the RI's are being tested in various rehabilitation settings with clients of differing disability types.

IMPLICATIONS FOR ACTION

- While guidelines for specific codes are helpful, counselor knowledge and skill in assessing a total client situation is critical. Guidelines make it easier to identify individuals who definitely do or do not meet severity standards. But the large middle area demands skilled counselor judgment.
- Much of the process of classifying level of severity could be turned over to computers for more precise application of decision rules. But judgmental review by professional staff would also be needed.
- Existing practices fall short of optimum performance because of inadequacies in functional limitation measurement.

- Assessment of severity limited to functional capacity for activities of daily living does not correspond to functional capacity for employment.
- Functional limitation needs to include measures of rate and endurance for the full range of activities required to travel to work and perform physical and mental tasks.
- If the counselor structures or guides the kind of vocational information to be gathered during the course of the medical examination, then the medical examiner will be able to examine the disability within the context of the individual's sociocultural, emotional, physical, and vocational capacities.
- The mere use of multiple services over an extended period of time is not a valid indicator of severe vocational handicap and should not be so used.
- Communications to field staff on coding should be consistent in content and timing.
- There should be agreement among terms used. All prior instructions on coding should be discarded.
- Counselors should be trained carefully in the use of codes. Supervisors should follow up on this training.
- Coding instructions should be field tested carefully prior to widespread distribution.

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Copies of the BRIEF are available from UF-RRI.

Prepared by Rehabilitation Research Institute • College of Health Related Professions

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IL: A history of the movement and model programs

The implicit theory behind independent living is that, given appropriate supportive services, accessible environments, and the information and skills necessary to benefit from them, severely disabled people can exercise self-determination and participate in all aspects of society. The theory is rather simply stated, but the concept is not particularly complicated.

For many years, some severely handicapped people have lived comparatively independent lives by finding or making barrier-free homes or apartments and by securing attendant care, transportation, and other supportive services on an individualized basis. Sometimes these arrangements were very imaginative, sometimes they were fortuitous, and most often they were circumstantial. In spite of these self-styled arrangements, programmatic and broad-scale efforts to facilitate independent living were stifled by restrictive statutes and regulations.

CIL/Berkeley

The most widely known, and perhaps the first effort at independent living for severely disabled people on a broad scale began in California. In the early 70's, a group of disabled students who had lived together in the Cowell Hospital Residence Hall at the University of California formed the Center for Independent Living (CIL) in Berkeley. Incorporated in 1972, CIL was established as a self-help, outreach program designed to expand options and alternatives available to disabled people throughout the community.

CIL now serves approximately 5,000 persons with many different types of disabilities from Berkeley and the surrounding community. With the goals of total integration or mainstreaming in mind, the Center provides several basic counseling services (e.g., family counseling, personal counseling, self-care counseling, etc.), attendant referrals and training, mobility training, wheelchair repair, transportation, and community advocacy. According to Pflueger, "these and other CIL services are designed to stabilize the environment of an individual with severe disabilities, thereby minimizing the handicapping aspects of disability and helping the person gain equal opportunity."[1] All of the chief administrators at the Center are severely disabled, as are a majority of its 105 employees. A private, nonprofit organization, CIL is supported by a variety of sources, including donations, project grants and contracts, and direct service fees. The facility where the Center is located primarily provides office space and work space for various programs.

Cooperative Living/Houston

At about the same time the disabled students in Berkeley were organizing CIL, a group of severely handicapped people in Houston, who were former patients at TIRR (The Institute for Rehabilitation and Research), realized the potential benefits of sharing services required to support independent living and began to plan the Cooperative Living Residential Project. Sponsored by TIRR and RSA, the project opened in 1972. Living in a barrier-free, dormitory-style building near downtown Houston, the Cooperative Living residents hired and managed their own attendants, arranged for their own transportation on a shared basis, and generally practiced the skills required in order to live independently. Most of the 40 people who lived in the project in its 3 years of operation as a research and demonstration project, began working or going to school while they lived there. The average number of residents in the program at any given time was 12.

Most people graduated from the Cooperative Living program in about 15 months and moved to more independent living arrangements in the community. Many of these people chose to continue sharing support services and formed their own corporations to provide independent living services. The organizations like Independent Life Styles and CLASP (Cluster Living and Shared Providers) exist in Houston today as independent entities. They provide and coordinate attendant care and transportation in specific residential settings such as apartment houses or condominium projects.

The Cooperative Living Project itself actually evolved into an independent living skills training program called New Options. New Options is designed to foster the integration of severely physically disabled people into their communities. The program, a 6-week transitional experience, provides information and skills required by handicapped people for them to live independently.[2]

Boston CIL

Modeling different aspects of both the programs in California and Texas, a group of people in Massachusetts established the Boston Center for Independent Living. The BCIL founders envisioned "a consumer-run, self-help community integrated with the able-bodied where severely disabled individuals could develop independent living skills."[3] The project opened in a theology building at Boston University which was adapted to be an accessible dormitory in 1974. Since then,

more than 50 people have participated in its programs.

Today BCIL provides supportive services for severely disabled people living in three types of environments. Some people whom the program serves live in a transitional-type facility located in an apartment complex in a Boston suburb. Others live in cluster housing—apartments adapted or modified for handicapped persons where attendants are on call. A few live independently in their own homes or apartments which they share with personal care assistants.

Other programs, such as Creative Living in Ohio and Atlantis in Colorado have been providing for some time services and coordinating community resources in a manner similar to those in California, Massachusetts, and Texas. More recently, programs supported by funding authorized in Section 130 of the Rehabilitation Act of 1973, by innovation and expansion grants from state vocational rehabilitation agencies, by universities, and by others have begun to expand opportunities for severely disabled people in other communities.

At this time, there are approximately 35 programs which might easily be classified as independent living programs. If one includes progressive group home projects, halfway houses, and other personal adjustment and mobility training programs in this census, there may be as many as 100 to 200. Most of these programs are located in urban areas. They typically serve fewer than 50 people at any given time. The primary client population is made up of persons with severe physical or developmental disabilities. They are most often private, nonprofit entities and are affiliated with various other voluntary and health service organizations. Their staffs may or may not be disabled themselves, although most programs give preference to hiring qualified handicapped people. Their budgets are small—usually on the order of $20,000 to $100,000. Financial support or funding usually comes from grants or donations. Additionally, some programs have begun to receive direct income for services rendered.

Typical service components

The universal service components of independent living programs seem to be residential services, including attendant care and housing or information about them and the provision and exchange of information required by severely disabled people who are trying to become more independent. Other major services provided may be transportation, peer counseling, independent living skills training, political advocacy, social and recreational services, health maintenance counseling, legal advocacy and financial counseling, and equipment repair and maintenance. It should be emphasized that every independent living program does not necessarily provide all possible independent living services. The focus, degree of involvement, or level of commitment of a program depends, naturally, upon the availability of existing community services, the physical and social makeup of the community, the needs of the program participants, and the goals of the program itself. Six major dimensions along which independent living programs are likely to differ have been outlined by Pflueger.[4] Each of these may be viewed as a continuum along which every independent living program will fall.

Basically, the variables are:

Service setting (residential-nonresidential). The setting in which services are provided will vary from strictly residential to totally nonresidential. Services may be organized around specific housing projects or they may be provided in a nonresidential service center.

Service delivery method (direct-indirect). Services may either be delivered directly by an independent living program or indirectly by referral to other service providers. The latter method is used mostly by programs which aim to coordinate existing services in the community. Many programs use a combination of service delivery methods.

Range of disability type served (single disability type-many disability types). Programs often vary as a result of the personal characteristics of the people they are trying to serve. Some programs focus on serving people with specific disability types while others are less specialized and serve people with a broader range of disabilities.

Service delivery style (non-handicapped-consumer). The image and feel of programs will vary from being paternalistic and authoritarian to being earthy and egalitarian. Programs which employ many disabled people and many nonprofessional or paraprofessional staff people will tend to be more oriented towards self-help than those programs which employ mainly nondisabled, professional people who adhere to staunch, academic backgrounds.

Vocational emphasis (primary-incidental). In some cases, programs may be seen as adjunct to or prerequisite to vocational involvement and training. On the other hand, they may be seen as independent from, though not necessarily exclusive of, vocational involvement.

Goal orientation (transitional-ongoing). Some programs are very goal oriented and transitional in nature. Their objective is to help people move from a level of dependence to one of independence. Other programs are designed to provide ongoing support for people who may already have reached a level of relative independence.

By assessing programs on the basis of these aspects, it is possible to describe quite clearly what may at first appear to be subtle differences between programs. For example, *Figure 1* shows how one might project the three programs described earlier.

By this analysis, it becomes apparent that while all three of these programs are similar in some respects, they also vary dramatically in some

ways. They are much alike in terms of helping style, service delivery style, or methods, and vocational emphasis. In contrast, they function in different settings, their goal orientations diverge, and their clientel or service constituencies differ. This is all in spite of the fact that they provide most of the same services.

Although the key variables may be identified, it is virtually impossible to say what makes an independent living program successful or not. There are, however, several key themes which seem to characterize the movement and which may signal success.

Historically, the independent living movement has been characterized by a great amount of consumer involvement and consumer control. This is more than likely due to the fact that the movement began during the late 60's—at the close of the Viet Nam era—when people all over America were beginning to seek more control over decisions which affected their lives. Also, the movement has been associated with expanding noninstitutional residential alternatives for severely disabled people. This emphasis probably reflects ties to earlier philosophical concepts of deinstitutionalization and normalization.[5] Many independent living programs are descendents of former halfway house projects or group homes.

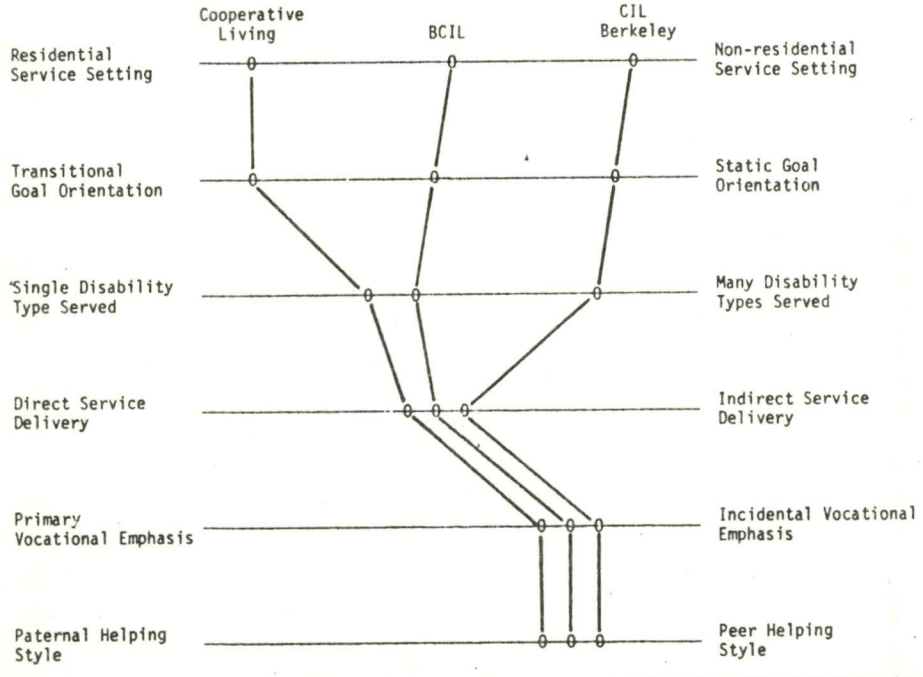
Finally, independent living programs have always been seen as sources of specific information and referral. This is partly a result of the fact that they usually do not have the resources to provide direct services. However, and more importantly, this presumably reflects a lack of coordination of services which already exist in the community, as well as basic inadequacies in those service systems when it comes to meeting the wide range and special needs of severely disabled people.

These historical precedents have not faded during the early development of the independent living movement. Consumer control and consumer involvement remain the essence of most successful independent living programs. With very few exceptions, all of the extant independent living programs or centers provide residential services, including attendant care or information about them. Information exchange and referral remain the basis of most programs and frequently are among the first services provided by new independent living programs.

Significant events

Several noteworthy events or progress markers stand out in the evolution of the independent living movement in addition to aspects of the founding of various programs. The funding of the Comprehensive Service Needs Study and its five ongoing demonstration projects authorized by the Rehabilitation Act of 1973 was significant from the standpoint that means were provided to study independent living on a wide-scale programmatic basis. The June 1975, *Report of the Comprehensive Needs Study* suggests that the

MULTI-DIMENSIONAL COMPARISION PROFILE OF THREE INDEPENDENT LIVING PROJECTS



development of an Independent Living Rehabilitation Program is a most crucial decision area. In October 1975, the first National Conference on Independent Living was held in Berkeley. This meeting, sponsored by RSA, brought together the leaders and developers in the field of independent living for the first time. It became clear, at this point, that independent living was a unique concept, distinct in many ways from more traditional approaches.

Innovation and expansion grant funds were first committed to systematically establish independent living projects by the California Department of Rehabilitation in 1976. During 1977, the independent living movement gained more recognition and momentum. It was the major topic of many national meetings. The White House Conference on Handicapped Individuals recommended that independent living become a national priority. The United States Department of Housing and Urban Development formally created an Office of Independent Living. HUD also promulgated regulations which legitimized support of centers for the handicapped by community development block grants.

In September 1978, the Second National Conference on Independent Living was held in Houston. Two months later, on November 6, President Carter signed the Rehabilitation Act Amendments of 1978. This legislation authorized for the first time a federal program to provide independent living services and support the development of independent living programs around the country.

Despite a relatively brief history and comparatively little data, independent living has established itself as a valid, programmatic concept in rehabilitation. It is clear now that many severely disabled people could work and live independently if they were supplied with supportive services to enable them to live outside of institutions. It is also evident that many severely disabled people, who are unable to work, are capable of substantial self-care and comparative social and psychological independence. Independent living programs may help severely disabled people make a transition from a state of relative dependency to one of comparative independence. Independent living programs may also provide the means by which severely disabled people can participate to the fullest extent possible in the normal day to day activities of life.

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REHAB BRIEF
Bringing Research into Effective Focus

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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.

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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

Project Location	*Staffing Patterns*	*Services Offered*	*Client Characteristics*	*Unique Characteristics*
NEW YORK conducted jointly by the Institute of Rehab Medicine and State Rehab Agency	VR counselor, physician, pyschologist, 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, pyschiatrist, 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 "similiar 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.

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International Efforts in Independent Living

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ABSTRACT. Tate DG, Jarvis RL, Juhr GD: International efforts in independent living. Arch Phys Med Rehabil 60: 462-467, 1979.

• Several nations currently share a major concern for provision of services to severely disabled persons. The focus of this concern has been upon those services which promote maximum integration and independence of severely disabled individuals in the community. Recent efforts in this direction by governments, private citizens, and handicapped-consumer organizations in Sweden, The Netherlands, Denmark, England, Canada, and Australia are discussed. Developments in housing and environmental modification, transportation, and self-help training are reviewed for their potential interest to advocates and practitioners of rehabilitation for independent living.

Providing assistance to severely disabled persons has become a universally recognized need. The concept of rehabilitation as a medical and/or vocational training process is being expanded to include provisions to help the severely disabled live and function more independently in society. In the United States the concept of independent living has been defined as the ability to do things physically alone, and to make independent decisions. This concept addresses the right of severely disabled individuals to participate to the fullest extent desired in the normal activities of daily living (ADL).[1]

A recent inventory by the Clearinghouse on the Handicapped indicates that currently there are approximately 74 Independent Living Center programs in the United States.[2] Handicapped-consumer groups have advocated that such programs should ideally offer a wide range of services: ADL, architectural barrier-free design, attendant services, coalition development, communications, community organization, consumer affairs information, economic support services, educational liaison, employment services, equipment repair, personal care and home health aides, homemaking, housing development and adaptation, independent living training, information services, mobility skills, outreach and recruitment, public relations, education, recreation, rehabilitation services, sex education, social services/state agency liaison, transportation and vocational liaison.[3] The majority of these services have been incorporated in the Rehabilitation Amendments of 1978 (PL 95-602), which mandate comprehensive services for independent living for severely disabled individuals.

Besides the United States, several other nations have been making significant efforts to provide assistance to severely disabled individuals. Many Western European countries, notably Sweden, Denmark, The Netherlands, and England, have since 1960 attempted to address the needs of such individuals in the areas of housing and environmental adaptations, transportation, and self-help training. Australia and Canada are among the non-European nations which have also been active in this endeavor.[4] This article reviews the most current information presently (1976-1979) available in the USA on independent living in the nations mentioned above.

Integrated living in the community has become an important concept in many of these countries, as a general drive is currently underway to move the severely disabled out of institutions. Obviously, the process of helping the disabled to become an integral part of the community will depend on the culture, attitudes, and economic and technical resources in the community where they live.[5]

SWEDEN

Sweden has been recognized as one of the most advanced countries in providing services for the severely disabled. For the past several years, the Swedish gov-

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ernment has designed and constructed housing and communities that integrate disabled and nondisabled persons.

The National Housing Board, which reports directly to the federal government, is responsible for the preparation and implementation of guidelines for the use of state loans and subsidies for housing. These guidelines are developed to insure accessiblity of public buildings. Assistance is available also to individuals who wish to make their homes more accessible and usable by handicapped persons.[4]

The National Board of Urban Planning has the responsibility to implement Swedish building laws. The Board insures that the mandatory requirements for accessibility in living units are developed and carried through completely.

Two attempts to improve living conditions for the disabled in Sweden are the Faltoversten and Husby projects. Faltoversten is a small, town-like project built on 3 levels. A subway station is located in the lowest level, while the middle level has a service and shopping center area. On the upper level are five 8-story apartment buildings totalling 536 apartments, including 50 units for the elderly and 14 for the handicapped. These 64 units communicate with a service unit on the shopping arcade level by means of an alarm system. All needs for food, clothing, shelter, medical care, social supports, and recreation can be met on site.

The Husby project, which consists of a large number of apartment blocks, is another integrated housing effort. Each building has 12 stories and contains 100 units. Housing for disabled individuals is interspersed with normal family housing, while housing for the elderly is in a separate building connected to a service suite near the town center. The site includes shopping and recreational facilities, all of which are completely accessible. As in Faltoversten, most units are very large, and are designed to accommodate disabled persons who can manage on their own most of the time and need only occasional assistance from staff attendants.

Perhaps the most developed effort toward integrated living in Sweden is reflected in the projects of the Fokus Society. Although the Society was disbanded in 1974 due to lack of funds, its pioneer concepts are valued by many in international rehabilitation.[4-8] These concepts were based on the principle that housing for the disabled should be located in regular residential areas near cultural, shopping, and business centers and in communities with relatively good employment opportunities and educational programs. Organized around a central directorate and a local executive committee, the Society included representatives of government, disabled-consumer organizations, local social, medical, and welfare services, and tenants.

Two Swedish research projects guided the development of the Fokus Society. First, a survey of the population and housing needs of severely disabled individuals aged 16-40 revealed that over 2,000 severely or moderately handicapped people could use adapted housing facilities. Second, a special task force including architects, rehabilitation experts, consulting engineers, and disabled individuals investigated solutions to providing the required housing. The task force considered buildings of 6-8 stories with 1 apartment on each story reserved for the disabled and other flats planned for nondisabled individuals as the best solution for integrated housing. It was the viewpoint of the Society that technology represented an important means of helping the disabled to function independently.[7] This was reflected by specific adaptations and modifications such as adjustable and detachable furnishings, technical devices to control panels, and extensive intercom systems in development of the housing project.

A special transportation system, "Fardtjanst," contributed to the success of the Fokus Society.[4] This system provided a dial-a-ride bus or taxi service for severely handicapped persons who could not use public transportation. Buses to transport residents for work, church, or recreation were available either free of charge or at the same fare charged the public for train or bus.

Employment had to be obtained outside of the housing area, on the open market, or in the sheltered workshop. Rent and personal services were paid by all tenants, disabled and nondisabled,[8] except that if a person's only income derived from a premature retirement pension, these services were free. The total monetary cost of a Fokus apartment, including rent and service, was approximately one-half that of care in a Swedish nursing home, despite the fact that most Fokus Society residents had severe disabilities such as cerebral palsy, muscular dystrophy, or spinal cord injury.

The Fokus Society was to be regarded as a complement to the work of the community. It demonstrated to the community that even the severely disabled could live a normal life if they received technologic and personal assistance when needed.

THE NETHERLANDS

The Netherlands has been concerned for many years with rehabilitation and housing for the disabled. Probably one of the most well-known projects throughout the world is Het Dorp (The Village), a community of 400 dwelling units built on 44 acres of wooded and hilly land near Arnhem, in eastern Holland.[6,8] Originally developed by a private nonprofit organization, the 1st buildings were erected in 1964, after more than 25 million guilders ($10 million) had been raised through a television and radio appeal.[4] The conception of the project and the basis of the appeal were to demonstrate that when inappropriate institutionalization is replaced by accessible facilities which promote self-care, the physically disabled can grow in independence, productivity, and self-esteem.

Het Dorp has been compared to a large, modern American motel complex. A mixture of 2-, 3-, and 4-story units is occupied by the handicapped residents, with each building carefully situated so as to be accessible from the outdoors. A system of elevators facilitates internal mobility. Contemporary design and warm colors impart a cheering impression.[4]

Floors of the buildings are organized in groups of 10 individual units, each of which is accessed via a single glass-panelled corridor, so that the units are approached as though on a sheltered street. Nine residents and 1 staff attendant comprise a living group, whose social contact is focused by its own large living-dining room, equipped with kitchenette. Three such groups share laundry-rooms, reading and music rooms, and facilities for guests and attendants for day and night. Marriages among residents have been more frequent than originally envisioned, necessitating the removal of walls between adjoining units.

At the onset of the project, interviews were conducted with disabled persons to determine their specific needs in construction and design of the buildings. As a result a sophisticated hardware approach has been implemented, making use of such conveniences as radio-controlled door-openers, electric wheelchairs, and specially designed kitchen and accessible bathrooms with modified shower, toilet, and washbowl.[7] Each unit is a self-contained apartment with separate outside door, mailbox, and bell, and a separate street address. Each resident has a telephone with an individual listing in the municipal directory.

Commercial and service facilities have been situated with 2 purposes in mind: to be accessible by the residents and to encourage interaction with outsiders, primarily the citizens of the nearby residential districts. Consequently, the majority of services, including medical clinic, library, management and administrative center, church, and theater are centrally located. At the periphery of the village, which is bordered by a 4-lane highway, are a gas station, restaurant, and shopping center. These facilities are also used by members of the outside community who, however, rarely venture into the central area or become involved with the daily activities of the residents. The villagers are able to travel to Arnhem, either in their electric wheelchairs (which frequently break down) or on small buses supported by the project. However, as cost of the bus service is prohibitive to those who have not previously contributed to social insurance plans and are thus not adequately covered, the amount of integration achieved has been less than initially intended.[4]

Het Dorp is financed by the Dutch government and provides support for residents unable to work. Those who can work are employed in the village workshops, which produce toys, clothing, ceramics, and braille and talking books.

Although Het Dorp appears to provide an opportunity for the severely disabled to live and work independently and to enjoy the outdoors, the project has been criticized because its design and size do not facilitate integration and interaction between handicapped residents and the surrounding community. Dutch government officials assert that these may be viewed as serious drawbacks and are not consistent with the current government policies, which encourage distribution of handicapped persons through integrated housing projects, with special convenience, accessibility, and safety provisions.[4] New experimental developments of single dwelling units are presently being established at different places throughout the country in contrast to collectively based units such as Het Dorp.

DENMARK

In Denmark, integrated living for disabled persons appears to be best demonstrated by the establishment over the past 15 years of a series of "collective houses" by the National Association of Disabled.[9] In 1971 this agency, through the Cripples' Building Society in Copenhagen, established 9 collective houses throughout the country, containing 1100 flats. Eight additional buildings with 900 flats were being planned and negotiations were in progress for 5 more buildings with 700 flats. The Danish strategy is to concentrate in collective houses those persons with severe physical disabilities who need clinical support and who are not managing in family housing.[9] As with the Fokus Society in Sweden, one of the primary objectives of the collective houses is physical and social integration with nonhandicapped peers.

The 13-story collective house at Hans Knudens Plads in Copenhagen, completed in 1959, was the first of its kind in the world, and exemplifies the collective house concept,[6] with 170 apartments adapted for the disabled. Integrated living with nondisabled peers is attained by virtue of the fact that one-third of the flats are reserved for the disabled, while the remainder house the orthopedic hospital nursing staff and the general public. In addition to a special nursing home for persons disabled by polio who require respiratory equipment, this collective house also contains a hostel for younger disabled singles, workshops, and a communal restaurant.

Essential differences between the collective house and the Het Dorp ethic have been observed. Where both agree that normal society has failed to cope with severely disabled people on their own, and that efficient clinical servicing is best achieved when the disabled population is concentrated, the collective house attempts integration with non-disabled persons, whereas Het Dorp opts for more segregation. One recent observation, however, has questioned the social integration that actually occurs in the collective house setting.[9]

In addition to the collective house concept the Danish government has developed other significant programs to promote independence of the severely handicapped. For example, as an incentive to adapt housing

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for the disabled, the Ministry of Housing covers the extra expenses of special equipment in the collective houses, and public loans are made available for the adaptation or conversion of apartments or houses as necessary. In addition, disability allowances are paid to those who cannot work, and a special grant is also paid to employed individuals who have serious medical difficulties, as an incentive to work despite troubles encountered in maintaining employment.[6]

Another meaningful experiment on the part of the Danish government has been the training and employment of a family member by the government to care for the severely disabled relative. The employed family member is given specific hospital training and is subsequently paid according to the family's financial status. This plan has proved effective both in keeping the family together and in saving public funds that would have been spent if the disabled person had required maintenance in a hospital or residential setting.[6]

ENGLAND

The movement for independent living in England has received much of its impetus from a publicity- and policy-wise handicapped-consumer organization, The Disablement Income Group, which mounted a very effective campaign culminating in the passage of the national Chronically Sick and Disabled Persons Act of 1970.[6] This Act made it mandatory for local authorities to (1) determine the number of disabled people in their community and assess their individual and collective needs; (2) provide an effective information service; and (3) extend the range of their services for the disabled. One of the major current lifestyle preferences of these consumers, according to surveys reported in a Design Guide of the British Centre on Environment for the Handicapped, was the desire to have the opportunity to choose their own home. Few felt that they would enjoy a special village like Het Dorp, while many regarded as ideal the principle of Sweden's Fokus housing.

New housing developments for the disabled in Great Britain reflected the aforementioned preferences of consumers. Custodial residential care in country mansions is being superseded by adapted housing within ordinary housing projects or adaptations to existing housing, with supportive services brought to the project or home. Some of the organizations and projects involved in this new direction are the Cheshire Foundation for the Sick and the Spastics Society.

The Cheshire Foundation for the Sick, a pioneer in providing residential care for the disabled, has recently pursued more innovative developments such as "breadwinner bungalows" for couples on the grounds of residential facilities, and ground-floor apartments for disabled students at Oxford who require personal assistance.

The Spastics Society has since 1952 provided sensitive, enlightened service to cerebral palsied individuals. Gradually shifting its focus from custodial care to integrated independent living, it now sponsors such resources as a traveling exhibit of aids demonstrated by an occupational therapist, toy libraries, weekend conferences including disabled persons and staff members, accommodations for severely disabled married couples, and a training college for professional and voluntary staff.[6]

The Spastics Society has also sponsored the Habinteg housing project, which provides integrated housing for elderly and disabled individuals in North London. Although the proportion of disabled residents is limited to 25%, all units are accessible. This project has been so successful that the Habinteg Housing Association has planned 26 additional projects throughout the country. Similar projects have also been privately developed by the Inskip St. Giles Housing Association and John Groom's Association for the Disabled.

Local government has also begun to play an important role in providing housing opportunities to the disabled and elderly who require noninstitutional ADL assistance, primarily in the form of sheltered housing. These facilities have been built and maintained by the housing authority, with the welfare authority contributing to the staff's salary.[10]

CANADA

In Canada direct responsibility for administration of health services lies primarily with the provincial and federal governments' Assistance Plan. The provincial and federal governments essentially share the costs of assistance to disabled persons. However, the local provinces have primary responsibility for eligibility and support determination and provision of vocational rehabilitation services.

Over the past decade significant efforts have been undertaken throughout the country to make the concepts of normalization and integrated living an integral part of service provision to the handicapped. Normalization implies that the handicapped are to be integrated into the social and economic stream alongside the able-bodied, and that facilities and resources are to be provided such that in the future the handicapped will cease to form a separate group.[11]

One significant development in normalization is represented by a demonstration project in Montreal, whose primary focus was to promote awareness of municipal, provincial, and federal governments to the "normalized" needs of the disabled, and ensure that the public sector provide appropriate resources to these persons.[12] Public agencies responsible for housing, welfare, home-care, education, manpower, and transportation have all provided significant input into the overall goals of the project. Since 1975 the Montreal Municipal Housing Bureau has regularly provided accessible and functional dwelling units in their high-rise projects. The redesign of social service and health delivery in Quebec has included proposals for decen-

tralized consultation and home services to disabled individuals living in the community. The Department of Education has adjusted student scholarships for the handicapped so that funds are available for living expenses to quadriplegic students outside an institution.

Numerous agencies throughout Canada have in the past few years been involved in the development of integrated living projects which provide disabled persons with comprehensive rehabilitation services. The Canadian Paraplegic Association, with a division in each of the provinces, for example, operates one of the world's largest comprehensive rehabilitation systems for the spinal cord injured. The Association supplies and maintains equipment, provides counseling, employment guidance, vocational training, educational supervision, and assistance with housing and home-care services. The Handicapped Resource Centre in British Columbia is another example of the cooperation and coordination of numerous agencies in the development of lifestyle alternatives for the physically disabled.

Numerous transitional homes and apartments to assist disabled persons discharged from long-term institutional settings have been established over the past 10 years. Examples are the Paraplegic Lodge in Vancouver, British Columbia; the Wheelchair Housing Centre in Winnipeg, Manitoba; and the Point Pleasant Lodge in Halifax, Nova Scotia.

The Cheshire Home Foundation, originally founded in England and chartered in Canada in 1971, operates numerous long-term group homes in Ontario and Saskatchewan to provide a normalized home environment for physically disabled adults. The way of life is as close to normal living as possible, with residents being free to come and go. Work opportunities are arranged where possible, and social activities are organized by the residents.[6]

AUSTRALIA

In Australia a stronger emphasis has been placed upon physical rehabilitation per se rather than upon the broader context of independent living. Although Australia, unlike the United States, has no legal provision which mandates specific services for the severely disabled, Australian consumers and professionals have been significantly influenced by the developments of the independent living movement in the USA.[13] The development and delivery of comprehensive rehabilitation services is primarily provided by the Commonwealth Rehabilitation Service with support from other government and nongovernment agencies in the areas of sheltered employment, activity therapy and training, and home-care services.

A network of independent living centers is being established across Australia to display and provide information about orthoses, prosthetic equipment, and aids to daily living. The 1st center was opened in 1977 by a voluntary agency, the Yooralla Society of Victoria. These centers emphasize display of information relating to physical aspects of disability. Services currently offered to severely disabled individuals appear limited, although some counseling is given in the areas of mobility, communication, self-care, home adaptations, and recreation.[13]

Because of the country's size and relatively small population, consumer activity tends to be fragmented and isolated. Thus the projected independent living centers seem an excellent vehicle for enhancing consumer involvement. Several programs have been established throughout the country to assist severely disabled persons to develop more independent lifestyles. In addition to establishing an independent living center, the Yooralla Society also provides a wide range of services and facilities to assist with rehabilitation. These include parent and family counseling, short-term care, vocational training, employment in workshops, activity therapy programs, recreation and accommodation programs.

The House With No Steps, New South Wales, initially established as a sports and social club for the handicapped in 1962, has evolved into a network of residences, workshops, and training centers. In 1966 the vocational training center was opened, providing an array of vocational and independent living services. In 1969 the project established 20 independent living units for individuals able to live without assistance.

The Phoenix Society, Inc, South Australia, provides employment under sheltered workshop conditions and, if opportunity exists, in the regular job market. It also offers professional assessment and training in areas of personal care, interpersonal competence, community survival, and work skills. Recreational, social, and cultural activities are also offered.

The Regency Park Center for Physically Handicapped Children, South Australia, exemplifies an integrated vocational training/independent living model which includes intensive training in those skills required to enter either open or sheltered employment. Emphasis of the program is upon frequent, on-going evaluation of progress, and integration of work, social, and interpersonal skill training.

CONCLUSIONS

The concept of independent living as applied to the international efforts reviewed here is probably best represented by the expression "integrated living" and has resulted directly from widespread movements for deinstitutionalization and normalization. These movements have only recently included the severely physically disabled, whose progress toward independence in noninstitutional communities requires significant environmental and housing modifications.

The extent to which various alternatives to institutionalization satisfy the needs and preferences of disabled persons has yet to be comprehensively evaluated. Likewise, the question of trade-off between degree of integration and adequate proximity to medical care

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cannot be expressed in a generally valid equation, but can only be weighed for each individual. Regardless of individual need and preference, presently available information indicates that community placements, even those requiring a full range of modifications and services, invariably prove to be less costly to the community than institutional placements. From this perspective it is possible that both handicapped consumers and the communities in which they live may benefit from further exploration of international activity in rehabilitation through independent living.

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FUNDING AND LEGISLATION

OBJECTIVES

1. To present an historical perspective on the Independent Living movement.

2. To examine methods of service delivery, goals, and program management from a Vocational Rehabilitation and Independent Living services perspective, in light of current legislation, PL 95-602.

3. To identify funding sources available which may be of benefit in the development of Independent Living programs.

SUMMARY

(1) "IL: A Legislative View." Kathaleen C. Arneson, American Rehabilitation, July-August 1978. Reprint permission granted.

Kathaleen Arneson, Director of Policy, Research, and Legislation for Rehabilitation Services Administration, offers a brief overview on the history of the Independent Living (IL). IL concepts are illustrated throughout a 20 year period of rehabilitation legislation. The developmental stages of the movement reflect a congressional concern for removing barriers of a social, environmental, and personal nature, all of which seriously affect disabled citizens.

(2) "Relation to Other Social Movements." Gerben De Jong, The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research. The University Centers for International Rehabilitation, Michigan, 1979. Reprint permission granted.

De Jong examines Independent Living as a social movement, analyzes the movement's expression through disability services, and considers the impact of IL and its implications for research.

In Section IV, IL is compared to other social movements, such as consumerism, civil rights, and deinstitutionalization. Each area is explored for its philosophical implications and influence for rehabilitation.

To live independently, De Jong suggests that the disabled person be involved with his or her family, an occupation, and civic duties, as well as avoid dependence upon various support systems. Until taxpayers witness a decrease in expenditures for human services, however, they will continue to view the severely disabled as incapable of community participation. There is a need for documentation of the benefits of IL programs to society.

(3) "Funding IL Programs." ILRU Source Book, Houston, Texas, 1979. Reprint permission granted.

The search for funding sources remains critical for the continuing operation of IL programs. These programs receive funds from any or all of these sources:

-donations, gifts, or contributions.

-payment of fees for services rendered.

-grants or contracts from public or private agencies, and corporations.

Certain types of competencies are required for the acquisition of funds. Imagination and good judgement are needed for developing support. Grantsmanship's skills are necessary so that support can remain for programming. This section offers a list of resources which have been utilized in funding IL programs. In addition, monies for supportive services and assistance, such as in transportation design are included.

Necessary to the maintenance of IL programs is the use of multiple funding sources, so that over-dependence on one grant does not occur. Center for Independent Living (CIL) in Berkeley, California depends upon 40 different sources for support. For further information on resources development, contact them at the following address:

Center for Independent Living
2539 Telegraph Road
Berkeley, California 94704
1-415-841-4776

(4) "Proposition 13: A Threat to the Growth of Independent Living." Robert H. Ruffner, Disabled USA, Vol. 2 No. 9, 1979. Reprint permission granted.

With the advent of Proposition 13 in California, it can be said that Federal funds for rehabilitation

programs may not always be plentiful and/or available for use. Independent Living Centers, however, play a unique role of bridging the gap between rehabilitation and independence, in offering services and support. These "missing link" type of services could possibly survive, and survive well, by adopting a for-profit stance.

There are several benefits for both the center and community if this kind of approach is used. Cooperation with small businesses may result in training disabled persons who can meet their affirmative action requirements. Increased financial support would provide for more services in the center, and in turn, vocational and social opportunities would be enhanced for participants.

This article advocates for exploration of various funding sources for IL Centers, ranging from private foundations to public industry. This approach to funding can insure continued support for programming, and a "longer life" for IL rehabilitation.

(5) "What's New About Independent Living?" Jean Cole, Archives of Physical Medicine Rehabilitation, Vol. 60, October 1979. Reprint permission granted.

The major purpose of this article is to examine important differences between independent living and traditional rehabilitation models of service provision, including comprehensive medical rehabilitation programs, state vocational rehabilitation agencies, and group homes designed to deinstitutionalize developmentally disabled individuals. The article is introduced by an overview of types of independent living programs in this country and their evolution. Goals, methods of service delivery, and program management techniques in independent living programs are contrasted with those of traditional models. Finally, trends that may develop as independent living become a standardized service entitlement are addressed, and the potential usefulness of some independent living concepts and methods in traditional rehabilitation programs are suggested.

IL: A Legislative View

Kathaleen C. Arneson

About 25 million disabled people are directly affected by P.L. 93–516 (the 1974 Amendments to the Rehabilitation Act of 1973), legislation which established the White House Conference on Handicapped Individuals. In this Act, Congress took action to help people with disabilities minimize their dependence and enhance their access to productive, participatory lives. It reiterated congressional concern for removing barriers of all kinds that inhibit the life styles of people with disabilities.

In one key provision, Congress stated that it was essential that recommendations be developed to assure that all people with handicaps be enabled to live their lives independently and with dignity. Further, it was stated that the complete integration of all handicapped people into normal community living, working, and service patterns be held as a prime national objective.

These clearly stated congressional objectives can be used as a starting point in the further evaluation of a National Policy on Disability for the 1980's. They also can serve as the basis for the development of new concepts and commitments for action on the part of government and other sectors of society in working through the next phases of national policy development and legislative action on "Independent Living" for people with disabilities.

As this paper is written, the 95th Congress, in the Spring of 1978, is considering proposed legislation to authorize today's version of that exciting and attractive (if somewhat elusive) term "Independent Living," a term which conjures up visions of physically restored people throwing away their crutches and striding off purposefully to work. Other pictures come to mind—the formerly homebound (perhaps a bed-ridden child with disabilities) now has been given special tutoring, has been physically restored and trained to eat in socially desirable ways, and is now being picked up every school day to go off to special education and regular classes. The vision might be of a newly blinded, older woman who is now able to bathe, dress, and otherwise care for herself without permanent attendant care because she has been taught the activities of daily living and has learned to cook and serve meals in her newly modified kitchen. Or, in your mind's eye, it might be the several young paraplegics who live together in a specially adapted house and who drive off to their jobs or classes in hand controlled cars or vans.

These examples reflect different concepts and views of "independent living" which have evolved over the past 20 to 25 years from the experience of many different individuals and programs. Within my own perspective of years reviewing and helping to develop federal legislation on rehabilitation, I have seen the concept develop, take on a variety of elements, and move through various stages, at times being expressed in legislation.

First—there was and is an emphasis upon aids to daily living. This is a "medical model" that is exemplified by teaching impaired people to attend to their personal needs (bathing, dressing, moving about, using the bathroom, eating, reading, going into and out of rooms and buildings, accessing to wheelchairs, cars, buses, and the like.)

The concept took form in legislation which emphasized "rehabilitation" as a legitimate objective of health services legislation and in state architectural barriers legislation which had the objective of making public buildings more "accessible" to people with functional limitations.

Second—"Independent Living" then began to take the form of an emphasis upon help through the provisions, as needed, of services within the familiar constellation of vocational rehabilitation services to severely disabled people who had no clear vocational potential. The rationale was that while an agency provided services to assess employability, it also would help the client gain facility in coping with the environment and, perhaps, ultimately prepare him for some level of vocational effort.

The action legislation which authorized this type of independent liv-

ing came through the provision of extended evaluation services, such as those under the Vocational Rehabilitation Act of 1965. The Congress also gave legislative expression to this emphasis in the Federal Architectural Barriers Act of 1968 and in the Urban Mass Transit Act Amendments of 1970 which mandated rights of disabled people to use public transit. Also, there were provisions in the 1964 public housing legislation referring to the need for housing for disabled people and the elderly.

Third—A new stage evolved in the early 1970's. It was the product of a coalescing of efforts to identify and advocate the rights of groups of severely disabled people who needed one or more of several comprehensive rehabilitation services over an extended period, sometimes for life. At this stage, the concept included the development of the person toward goals short of employment. These goals might have been deinstitutionalization, lessened dependence on family members or attendants for daily care, independence in homemaking, or the establishment of mobility within the community through driving adapted cars, and other similar goals that led to a more independent life style. The 1972 and the first 1973 Rehabilitation Act contained legislative proposals for comprehensive rehabilitation services to express this concept. The two Acts were vetoed.

Fourth—Another stage or expression of independent living involves self-help in the concept of services in centers for independent living. This often is typified by a physical structure (such as a rehabilitation center or residence) and a set of activities and services, often developed and managed by disabled people. The program involves peer group counseling, small business activity, community education action programs, and general advocacy functions. This concept was embodied in legislation introduced in the 94th Congress by Congressman Koch of New York. No action has been taken on the bill.

Fifth—The stage of "comprehensive services for the severely disabled" and models of independent living.

Congressional Initiative. The most significant legislation under consideration by Congress is S. 2600, introduced by Senators Randolph, Stafford, Pell, and Hathaway.

According to its sponsors, Title II of this proposed legislation would establish a new rehabilitation program. Its thrust would be to deliver comprehensive services to severely handicapped people who are identified as needing multiple, continuing, and probably lifelong services and treatment. They are also identified as perhaps having little or no vocational potential.

In contrast to other independent living legislative proposals, this bill includes, in Part A, a "rights" concept drawn from the current Developmental Disabilities Act. Similarly, the individualized plan of service has become part of the concept and program. The protection and advocacy systems developed for the developmentally disabled are extended to the larger population.

Part B authorizes a grant program to stimulate states to extend present services programs for the most severely disabled without vocational potential. States would have flexibility in service provision, but would have to develop a detailed, long range plan that would strive toward the goal of comprehensive services for all severely disabled people.

In developing new services, states would have to consider community living assistance, infant and preschool services, nonvocational social development assistance, and individualized case management.

The next section of the proposal, Part C, contains authorization to establish models. The independent living program encouraged by this section is residential in character and involves the development and demonstration of a continuum of alternative living arrangements (including group homes or other community living arrangements or facilities).

The Administration's Initiative. The Administration's 1978 proposal for independent living, testified to by RSA Commissioner Robert Humphreys, is an expansion of the independent living service projects program initiated as part of the Comprehensive Needs Study, undertaken in 1975 under the requirement of Section 130 of the Rehabilitation Act of 1973.

The Administration's proposal for 1979 is to double funds available and expand the number of current projects from 5 to 10. In 1980, this series of projects would be greatly expanded in number evaluated, and, hopefully, replicated in greater numbers of areas in 1981.

A companion series of community-based projects would improve local service delivery and modify architectural and attitudinal barriers.

These are some of the main ideas now being put forward in legislation under the "Independent Living" rubric.

By September 1978 (about the time of issuance of this edition of *American Rehabilitation*), we should know whence we shall go for the next 3 to 5 years in perfecting the Independent Living Rehabilitation Services concept.

Mrs. Arneson is Director of Policy Research and Legislation, RSA.

IV

RELATION TO OTHER SOCIAL MOVEMENTS

The movement for independent living has flourished at a time when several other complementary social movements have also developed. These movements include:

civil rights

consumerism

self-help

demedicalization/self-care

deinstitutionalization/normalization/ mainstreaming

While these movements share common values and assumptions, each arises from a somewhat different source in response to different social problems. Each has influenced the movement for independent living to one degree or another. The origins and ideology of the movement for independent living cannot be fully appreciated without noting the contributions of other social movements. The strategy here is to evaluate the nature and influence of each movement before considering their common ideological assumptions and the meaning of these movements for disability services and research.

Civil Rights

The civil rights movement of the 1960's has had an impact far beyond the racial minorities it sought to benefit. The movement made other disadvantaged groups aware of their rights

and aware of how their rights were being denied. During the initial stages, the movement was mainly concerned with civil rights as opposed to benefit rights. Civil rights include the right to vote, to hold elective office, to be tried by a jury of one's peers, and so forth. Benefit rights include the entitlement to income and medical assistance benefits, educational benefits, and other entitlements. The benefit rights issue was taken up later in the civil rights movement by the Poor Peoples' Campaign and by spin-offs such as the National Welfare Rights Organization.

The concern for both civil rights and benefits rights has spilled over to other vulnerable groups. In the area of mental health, patients have, in some instances, acquired the right to refuse treatment and to expect certain levels of care. In the area of child welfare, children have acquired new procedural rights that are slowly replacing the best-interest-of-the-child rule as the legal standard for adjudicating abuse and delinquency cases. Moreover, children are receiving rights to treatment and education under special education statutes.

The movement for independent living has been similarly concerned with both civil and benefit rights. The movement's interest in civil rights is reflected in Title V of the 1973 Rehabilitation Act prohibiting various forms of discrimination, particularly in the area of employment. However, the concern for civil rights has not stopped there. Persons with severe

mobility impairments are insisting that architectural and other environmental barriers in effect deprive them of their civil rights when these barriers prevent them from participating in the political life of the community. In like fashion, disabled persons have become aware that their benefit rights are prerequisites for living in a community setting. Without income assistance benefits or attendant care benefits, many disabled persons would be involuntarily confined to a long-term care facility.

The civil rights movement has not only had an effect on the securing of certain rights but also on the manner in which those rights have been secured. When traditional legal channels have been exhausted, disabled persons have learned to employ other techniques of social protest such as demonstrations and sit-ins.

The black movement that eventually grew out of the civil rights movement has had its own effect on the movement for independent living. According to the critique offered by the civil rights movement, racial discrimination was an American anomaly that could largely be removed through the enactment of new legal protections. The black movement saw the issue as one of racism that was central to the definition of white America and beyond the scope of simple legal remedies. The movement for independent living has come to recognize that prejudice against disability is rooted in our culture's attitudes about youth and beauty, and in the able-bodied

person's fear of vulnerability to physical disability. The black movement has inspired the movement for independent living to search more deeply for the sources of attitudes and behaviors toward persons with disabilities.

Consumerism

The parameters of the consumer movement are hard to define. It is a movement that affects nearly all social classes and groups. The movement is most personified by Ralph Nader but also includes public interest lawyers representing various disadvantaged groups. The movement embraces both the person who devotedly reads Consumer Reports and the person who campaigns for new consumer protection legislation. Because the parameters of the movement are hard to define, a more profitable venture here would be to briefly evaluate the movement in terms of its ideology---consumerism, and in terms of its expression in disability policy.

Basic to consumerism is a distrust of seller or service provider. It is up to the consumer to become informed about product reliability or service adequacy. Consumer sovereignty has always been the hallmark of free market economic theory. In practice, however, it is often the professional who has been sovereign.

With the rise of consumer sovereignty, professional dominance in disability policy and rehabilitation is being challenged. In vocational rehabilitation, for example, the professional counselor does not necessarily have the final

word in case planning as he/she once did. Instead, the Rehabilitation Act of 1973 provides for an "individualized written rehabilitation plan" (IWRP)[17] to be drawn up jointly by client and counselor. Outside vocational rehabilitation, the movement for independent living has spawned new advocacy centers to advise disabled persons of their legal rights and benefits. With the awareness generated by the movement for independent living, the disabled person with several years of disability experience is often better informed about governmental benefits and regulations than his/her professional counterpart in the human services system.

Self-Help

The self-help movement embraces a large variety of groups: from the Female Improvement Society to Alcoholics Anonymous (Withorn, 1977: 221). There now appears to be a self-help group for almost every conceivable human condition or problem---alcoholism, drugs, gambling, death, homosexuality, child abuse, women's health, old age, sex, neighborhood crime, cigarette smoking, child birth, and of prime interest here, physical disability (Back and Taylor, 1976; Hurwitz, 1976; Levy, 1976; Reisman, 1976; Withorn, 1977). Self-help organizations view themselves as mutual aid groups that serve as adjuncts or as valid alternatives to established human service

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[17] See Sections 101 (a) (9) and 102 of the Rehabilitation Act of 1973 (P.L. 93-112).

agencies (Durman, 1976; Levin, 1976; Sidel and Sidel, 1976; Tax, 1976; Withorn, 1977). Self-help groups usually address problems and needs not responded to by other institutions in society.

Among disabled persons, centers for independent living have become the primary self-help unit. The various centers seek to serve both as an adjunct to the present human service system and as an alternative service provider. As an adjunct to the system, the centers at times serve as conduits for funding human services such as attendant care. As an alternative to the system, the centers may provide peer counseling and advocacy services not provided by mainline human service organizations.

The self-help movement is fueled by the same distrust of professionally dominated services mentioned in our discussion on consumerism. Self-help organizations are intended to give people the opportunity to exercise control over their own lives and the services they use. They are the knowledge-giving, awareness-providing organizations that help to confer sovereignty on the consumer.

Demedicalization/Self-Care

"Demedicalization" is a trend that is challenging the dominance of medical professionals in selected spheres of human life. The trend is supported by well-known critics such as Ivan Illich (1976) who have expressed the concern that

too many social problems and life conditions are being unnecessarily "medicalized."

Over the last several decades, an increasing number of behaviors considered sinful or criminal have come to be considered illnesses (Coe, 1978; Fox, 1968 and 1977; Freidson, 1970; Mechanic, 1973; Pitts, 1968; Twaddle, 1973; Zola, 1975). Alcoholism and mental disorders, for example, have been removed from the categories of sin or crime and are now labeled illnesses. Some have even begun to call child abuse a "disease." Similarly, life events such as birth and death now almost always entail a considerable degree of medical intervention.

Many have begun to react to the excesses of medicalization and have urged that certain conditions and life events be demedicalized. One example is pregnancy and childbirth. Some urge that pregnancy be removed from the category of illness and that childbirth be supervised by a midwife rather than a physician. Another example is death (Blauner, 1966; Buckingham, et al., 1976; Kalish, 1965; Kron, 1976). "Death with dignity" is the phrase being used for allowing the terminally ill to die at home rather than in a hospital wired to the latest array of monitoring devices.

Implicit in the argument for demedicalization is the assumption that individuals can and should take greater responsibility for their own health and medical care. In many ways, demedicalization is an extension of the self-help

movement to the fields of health and medical care. In some quarters, the demedicalization trend is referred to as the self-care movement. The movement goes beyond the keep-fit, watch-your-weight, stop-smoking, and drink-less campaigns of the recent past. The self-care movement encourages people to administer their own treatment for minor health problems and to avert potential complications arising from chronic health conditions.

The movement for independent living is very much a partisan in the medicalization/self-care debate. At issue for the movement for independent living is the extent to which the management of disability should remain under the aegis of the medical care system once medical stability has been substantially obtained. Today, most public policy with respect to disability requires some type of professional medical presence, whether that be in the acute stages of disability, in the determination of eligibility for income maintenance benefits, or in long-term institutional care. The movement for independent living asserts that much of this medical presence is both unnecessary and counterproductive.

Central to the goals of the movement for independent living is the belief that the management of medically stabilized disabilities should be demedicalized. Disabled persons are insisting that the management of their disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the lives of disabled

persons is said to entail behaviors on the part of both medical practitioners and disabled "patients" that induce dependency and thus are in conflict with rehabilitation and independent living goals.

The Medical Model

To understand how these behaviors arise, it is helpful to turn to the concept of the "medical model," a loosely used concept that often varies with the context in which it is discussed.[18] As used here, the medical model consists of the following assumptions and role expectations in the provision of medical care:

> The physician is the technically competent expert.
>
> Medical care should be administered through a chain of authority wherein the physician is the principal decision maker, i.e., accountability for the care of the patient is centered on the attending physician.
>
> The "patient" is expected to assume the "sick role" that requires him/her to cooperate with the medical practitioners caring for him/her.

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[18] The term, "medical model," is used in at least two ways: (1) as a set of criteria to determine whether a particular form of social deviance should be defined as a "medical problem" (Veatch, 1973), and (2) as a set of assumptions and behavioral expectations considered typical or normative in the provision of medical care. The second use of the term is the one employed here.

The concept of the medical model is strangely absent from much of the medical sociology literature. The concept is more often discussed in the psychiatry literature (e.g., Siegler and Osmond, 1974), in part because psychiatry operates at the boundaries of medicine where it is not always clear whether a form of social deviance or mental aberration should be labeled a medical problem.

> The main purpose of medicine is the provision of acute/restorative care.
>
> Illness is muted primarily through the use of clinical procedures such as surgery, drug therapy, and the "laying on of hands."
>
> Illness can only be diagnosed, certified, and treated by trained practitioners.

Like most models, this version of the medical model is a rather rigid construction of what is supposed to exist and happen in the provision of medical care. The model does not attempt to be exhaustive; it focuses primarily on those elements that can also help us understand what the demedicalization of disability is all about.

Before evaluating the role expectations of the medical model, it is worth noting some of the model's other features that have been unpalatable to the movement for independent living. One important reason for demedicalizing disability, the movement implicitly argues, is that many of the assumptions of the medical model do not fit or apply to the needs of disabled persons. For example, the model's emphasis on acute/restorative care is not in keeping with the needs of long-term disabled persons well beyond the acute phase.[19] Likewise, once beyond the acute phase and living independently, disabled persons are not in need of surgery, drugs, or the

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[19]Working with chronically disabled patients who have little or no hope for full recovery (in the conventional sense) is considered by most medical practitioners to be less glamorous and less rewarding than the heroic life-saving and health-restoration activities involved in acute care.

laying on of hands that characterizes clinical medicine. Disabled persons often develop sufficient familiarity with their disability in order to adequately monitor their medical treatment. Hence, experienced disabled persons are often not in need of the diagnostic, certification, or treatment services of medical professionals.

The Sick Role

The movement for independent living has been particularly critical of the behavioral expectations of the medical model as defined in the sick role. The sick role in this context has a very specific meaning. The concept of the sick role, as originally formulated by Talcot Parsons (1951: 428-79), is considered the single most important concept in medical sociology. By understanding the requirements of the sick role we can gain a better insight into the position advocated by the movement for independent living.

The sick role consists of two interrelated sets of exemptions and obligations:

> A sick person is exempted from "normal" social activities and responsibilities depending on the nature and severity of the illness.
>
> A sick person is exempted from any responsibility for his/her illness. He/she is not morally accountable for his/her condition and is not expected to become better by sheer will.

These exemptions are granted conditionally. In exchange:

> A sick person is obligated to define the state of being sick as aberrant and undesirable, and to do everything possible to facilitate his/her recovery.
>
> A sick person is obligated to seek technically competent help and to cooperate with the physician in getting well.

The sick role is intended to be a temporary one. But for the long-term or permanently disabled person there is no immediate recovery in the sense of being restored to one's original physical condition. Because the disability is often an irrevocable part of his/her existence, the disabled person, as a result of the sick role, begins to accept not only his/her condition but also his/her own very personhood as "aberrant" and "undesirable." Moreover, he/she begins to accept the dependency prescribed under the sick role as normative for the duration of his/her disability. Thus, the sick role removes from the disabled person the obligation to take charge of his/her own affairs.

The Impaired Role

This critique of the sick role is affirmed in the concept of the "impaired role" articulated by Gordon (1966) and by Siegler and Osmond (1973). The impaired role is ascribed to an individual whose condition is not likely to improve and who is unable to meet the first requirement of the sick role,

the duty to try to get well as soon as possible.[20] Occupants of the impaired role have abandoned the idea of recovery altogether and have come to accept their condition and dependency as permanent. In the words of Siegler and Osmond (1973: 56), the impaired role "carries with it a loss of full human status:"

> ...the impaired role does not require the exertions of cooperating with medical treatment and trying to regain one's health, but the price of this idleness is a kind of second class citizenship.

The impaired role is not a normative one or one prescribed by the medical model, but is a role a disabled person is allowed to slip into as the passage of time weakens the assumptions of the sick role.

The impaired role is fictionalized in Thomas Mann's (1927) Nobel Prize-winning The Magic Mountain, a novel about patients living at the Berghof, an international tuberculosis sanitorium for the well-to-do. Here patients abandon the sick role for the impaired role. Siegler and Osmond's (1973: 53) description of the impaired role at the Berghof is informative:

> The impaired role has a lower status than the sick role, but life at the Berghof is so luxurious for these wealthy patients that they do not care. It is true that no one takes them seriously, and their life

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[20] Others (Kassebaum and Baumann, 1965; Safilios-Rothchild, 1970; Segall, 1976; Twaddle, 1969) have also acknowledged the limitations of the sick role as a theoretical construct and have suggested the need to develop alternatives to the sick role concept for the patient/person with a chronic illness or disability.

> is ordered for them by the resident physicians, but in return for this child-like status, they are allowed to spend their days as children do, playing card games, taking up hobbies, having meals served to them, "playing" with each other, or, most often, doing nothing at all.

Mann's fictionalized account of the Berghof presents us with one variant of the impaired role as it is found in a particular institutional setting. His account provides us a glimpse of the tendencies toward child-like dependency inherent in the impaired role.

The movement for independent living rejects the behavioral expectations created by both the sick role and its derivative, the impaired role, by saying that the disabled do not want to be relieved of their familial, occupational, and civic responsibilities in exchange for a child-like dependency. In fact, this "relief" is considered tantamount to denying the disabled their right to participate in the life of the community and their right to full personhood.[21]

Deinstitutionalization/Mainstreaming/Normalization

The dependency creating features of the medical model and the impaired role are most pronounced in institutional settings. Institutions are self-contained social systems

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[21]Safilios-Rothchild (1970: 73-81) has proposed the concept of a "disabled role" or a "rehabilitant role." This role requires the individual to resume "normal" social roles within the limits of his/her physical impairment. As Sifilios-Rothchild (1970: 80-81) suggests, the rehabilitant role is an ideal social role often undermined by the rules and regulations present in the institutional environment in which rehabilitation is supposed to take place.

that allow house staff and various practitioners to exercise a substantial measure of social control with little outside interference.

Prolonged institutionalization is known to have harmful effects (Corcoran, 1978: 63):

> Patients are encouraged to follow instructions, rules and regulations. Compliance is highly valued, and individualistic behavior is discouraged. The "good" patient is the individual who respectfully follows instructions and does not disagree with staff. On the other hand, the patient who constantly asks for a dime for the pay phone, a postage stamp, or a pass to leave the institution on personal business, tends to be treated as a nuisance or labeled "manipulative." Patients do not make their own appointments, keep their own medical charts, or take their own medications. Responsibility for these things is legally vested in the institution. Yet on the day of discharge, the patient is expected suddenly to assume control of his own health care and life decision making.

The trend to deinstitutionalize is one that cuts across many disabling conditions. The best known deinstitutionalization effort is the community mental health movement which has allowed many individuals---often with the use of psychotropic drugs---to leave institutional confinement or remain in the community. Similar examples can be found in other areas such as geriatric care and juvenile corrections.

The deinstitutionalization movement has been backed by the political argument that institutional care is expensive and that community care will save taxpayer money. Proof of this argument has been hard to establish, especially when

studies overlook the ever present tendency of institutions to increase utilization to meet capacity.

Severely physically disabled persons and their advocates are latecomers to the deinstitutionalization thrust. This is understandable. Unlike mentally impaired persons or ex-offenders, their disability is more difficult to conceal. Moreover, the deinstitutionalization of the severely physically impaired requires substantial environmental or architectural modifications not required by others.

The movement for independent living has adopted many of the same money-saving arguments for deinstitutionalization used by other groups. The only problem is that many of these arguments are beginning to wear thin with representatives of the taxpaying public who have not witnessed any significant decrease in human service expenditures. As latecomers to the deinstitutionalization thrust, severely physically disabled persons are less likely to benefit from the money-saving argument. Public cynicism about deinstitutionalization may prove to be yet another barrier to independent living.

Closely related to the deinstitutionalization movement are the concepts of normalization and mainstreaming. These two concepts have been discussed mainly in connection with developmentally disabled children and young adults. At one time it was thought that the interests of disabled children were best served by confining them to institutions or segregating them into special education classes. Now, the thinking is that a

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disabled child or young adult becomes more "normal" when "mainstreamed" with his/her able-bodied counterpart. However, normalization goes beyond mere deinstitutionalization. According to Dybwad (1973: 57), it assumes that:

> normal on our earth is trouble and strife, trial and tribulation and the handicapped person has the right to be exposed to it. Normalization...includes the dignity of risk....

Hence normalization takes deinstitutionalization one step further to include the possibility of failure---a fact which the deinstitutionalization movement has not always been prepared to accept.

The dignity of risk is what the movement for independent living is all about. Without the possibility of failure, the disabled person is said to lack true independence and the mark of one's humanity---the right to choose for good and evil.

Common Properties

We have argued that the movement for independent living represents the convergence of several contemporary social movements or trends. The movement for independent living is like a chemical solution consisting of different but compatible and mutually reinforcing elements. Our analysis here has attempted to distill the solution down to its component elements to better understand the social chemistry that makes up the movement for independent living.

However, our analysis can be taken a couple of steps further. We can also understand the movement for independent living by

examining the properties common to the movements we have discussed. These common properties or denominators provide us the clues to the movement for independent living's basic ideological commitments. These commitments are the focus of the following section:

Funding IL programs

Funding continues to be a crucial aspect of independent living planning for many reasons. It will probably be necessary to obtain office space, to buy equipment, to hire personnel, or to continue operation and maintenance of a facility or office. Funding may come from any one or a combination of several different sources, depending on its intended use.

Income to support independent living programs generally comes from three basic sources: donations, gifts, or contributions; payment of fees for services rendered or space utilized; and grants or contracts from public or private agencies and corporations. State and federal government grants or contracts have been the two most commonly used sources of support. Donations from community groups and individuals often resulting from fund-raising events and projects have also been a major source of funding. Income from direct and third party payment of fees for services has been less frequent, but there seems to be a trend towards utilization of service charges as a means of program support.

Program sponsors need to use imagination and good judgment in order to develop and maintain support and funding for programs. In addition to good management skills, proposal writing and grantsmanship skills are needed by people who run independent living programs to insure continued funding.

This chapter contains tables and bibliographical lists designed to provide information and stimulate ideas about obtaining funds for independent living programs. Included are:

- Table One: Resource matrix of federal programs which successful independent living programs have used to support the delivery of their services;
- Table Two: Service matrix of federal programs which may provide direct support for supportive services;
- Table Three: Annotated listing of federal programs which could be used to assist independent living programs; and
- Bibliography of books and articles related to identifying appropriate funding sources and to increasing grantsmanship skills.

Table one: Resource matrix

Federal programs being used to support ILPs

At the Second National Conference on Independent Living held in Houston in September 1978, nationally recognized leaders in independent living met to discuss funding available to support independent living. Representatives of 16 independent living programs (ILPs) identified funding sources successfully being used by their respective programs. This information has been compiled in a Resource Matrix, in which federal, state, and local funding sources are listed across the top and ILPs are listed down the left hand side. The matrix allows the reader to identify specific IL programs that have used any given funding source successfully. An explanation of abbreviations is given on the back of the matrix.

When possible, the matrix is cross-referenced with the Annotated Registry of ILPs in the United States. Program profiles in the registry describe key features such as service setting (residential or non-residential), service delivery (direct or indirect), service delivery style (non-handicapped or consumer), vocational emphasis (incidental or primary), goal orientation (transitional or ongoing), disability served (single or many), target disability type, and a list of specific services provided. The registry and matrix together allow the reader to cross-reference ILPs on the basis of program characteristics or funding base.

The ILRU project plans to update the matrix whenever possible, so the staff would appreciate receiving information regarding funding techniques not included herein or programs which are successfully using some combination of funding sources.

Table 1: Resource matrix

	State/Fed. VR Grants	State/Fed. VR Fees for Services	Dev. Disabilities Grant	Title 19	Title 20	Food Stamps	CETA	VISTA	HUD	UMTA 16B2	Revenue Sharing	Special Grants (Foundations, Corporations, Individuals)
CIL (Center for Independent Living-Berkeley)	Local, state, regional, national		•	Medicare state supplement	Chore services		Title, I, III, IV	•	CDBG	•	•	Local corp., foundations, C of C
BCIL (Boston Center for Independent Living)	I & E	•		•			•		Sec 8			
Creative Living-Columbus, Ohio	•								236 Sec 8			•
Worcester Area Transitional Housing (WATH)-Worcester, Mass.												
New Options-Houston	R & T Center, Federal R & D	•										
Genesis/Atlantis/VISTA-Denver												
Univ. of Washington-Seattle	I & E, Research							Protection & advocacy group				
Houston CBFL (Coalition for Barrier-free Living)							•	•	CDBG			
CLASP -Houston		•		Home health medical services	Chore services, management funds	•			Sec 8			
Independence Hall-Free Lives Goodwill Industries-Houston		•			Chore services				236			Goodwill subsidy
UCP -Pittsburgh	Day program	•	•		Life skills prog., Attd. care, transportation		•		Sec 8	•	Community develop. for accessibility	•
Nat'l. Para. Foundation (SW Mass., NE Mass., Vermont, New Hamp.)	I & E	•	•				Title II, VI		CDBG 202, 707, 689			•
Independent Living Program-Detroit			•				•			•		
Bronx Developmental Services			•	•	•	•			Sec 8			
Independent Lifestyles-Houston		•			Chore services							•
Southwest Center for the Hearing Impaired-San Antonio	I & E				•		•					•

List of Abbreviations

State/Fed. VR Grants—State and Federal Vocational Rehabilitation Grants
- I & E—Innovation and Expansion Grant
- R & T Center—Research and Training Center
- Fed. R & D—Federal Research and Demonstration Grant

Dev. Disabilities—Developmental Disabilities

CETA—Comprehensive Employment and Training Act

VISTA—Volunteers in Service to America

HUD—Department of Housing and Urban Development
- CDBG—Community Development Block Grant

UMTA—Urban Mass Transportation Administration

Special Grants
- Local Corp.—Local Corporations
- C of C—Chamber of Commerce

Table 2: Service matrix

Federal programs which can provide direct support for IL services

Federal program	Services for which federal financial participation is available																
	Core services							Other services									
	Meals			H'keep.		P/Care											
	Congregate meals	Home-delivered meals	Food stamps	Chore	Homemaker	Home-health aide/services	Personal care	I & R	Transportation	Counseling	Legal services	Social services (general)	Health-related, health-supportive	Preventive	Screening and evaluation	Voc. & rehab. serv./devices	Housing services
Title XX, Social Security Act	●	●		●	●	●	●	●	●	●	●	●	●	●			●
Food Stamp Program	●	●	●														
Sec. 16(b)(2), UMTA									●								
Reduced Fares, UMTA									●								
Medicare						●											
Medicaid (basic required services)						●	●		●						●	●	
Community Development												●					●
Revenue Sharing												●					

Adapted from Suzette Ashworth, *et. al*, *Well-Being in Old Age: Essential Services*, and George Beall, *Congregate Housing for Older People*.

Table 3: Federal programs for IL

Annotated listing of programs which could be used by ILPs

Program title	Administrative jurisdiction	Principal beneficiary	Nature of assistance/benefits	Financing
Income				
A. Income security, disability, and retirement programs				
1. OASDI—Social security	Federal	Eligible retired or disabled workers and their dependents	Direct cash benefits and automatic eligibility for Medicare hospital insurance	Payroll taxes (personal contributions)
2. Veterans programs				
a. Compensation to veterans with a service-connected disability				
b. Pensions for veterans with nonservice-connected disabilities				
c. Pensions for widows and children of veterans	Federal	Categorical, low income, and other requirements	Direct cash and in-kind benefits, and automatic eligibility for certain other veterans programs	Open-ended federal appropriations

Adapted from Suzette Ashworth, *et. al*, *Well-Being in Old Age: Essential Services*, and George Beall, *Congregate Housing for Older People*.

Table 3 continued. . .

Program title	Administrative jurisdiction	Principal beneficiary	Nature of assistance/benefits	Financing
B. Income supplement programs				
1. Supplemental Security Income (SSI) Program	Federal-state	Low income and other categorical requirements	Direct cash benefits, automatic eligibility for benefits from the Title XX and the Senior Community Service Employment Programs, and eligibility, depending on state of residence, for Food Stamp and Medicaid programs	Open-ended appropriations from federal general revenues, state supplementation where applicable
2. Lower Income Housing Assistance Program (Sec. 8)	Federal	Low income and other categorical requirements	Project grants to certain housing owners, subsidies to cover the difference between family contributions for rent and the unit rental	Annual federal appropriations
3. Rent Supplement Program (Sec. 101)	Federal	Low income and other categorical requirements	Monthly payments to owner of housing (nonprofit, cooperative or limited-dividend organizations) on behalf of low-income tenants	Annual federal appropriations
4. Food Stamp Program	Federal-state	Low income and other categorical requirements	Direct cash benefits in form of purchase of food coupons worth more than purchase price. Coupons used for food commodities, home-delivered meals, and congregate meals in a Title VII nutrition project setting	Open-ended federal appropriations, personal contributions
5. Reduced fares, Urban Mass Transportation Act, as amended	Federal	All elderly or disabled persons with access to mass transportation so funded by UMTA	Direct cash benefits. Mass transportation systems receiving UMTA funds for either capital or operating expenses must charge elderly and handicapped persons no more than half-fare during off-peak hours	Open-ended federal appropriations, personal contributions

Table 3 continued. . .

Program title	Administrative jurisdiction	Principal beneficiary	Nature of assistance/benefits	Financing
Health programs				
A. Medicare, Title XVIII, Social Security Act				
1. Part A. Hospital insurance	Federal	Part A—All OASDI and railroad retirement beneficiaries	Reimbursement for service to various categories of service providers, primarily for inpatient hospital and certain post-hospital services under Part A and physician services and other services under Part B	Part A—Payroll taxes (personal contributions)
2. Part B. Supplementary medical insurance	Federal	Part B—All eligible persons who elect to enroll		Part B—Premiums and general revenue funds
B. Medicaid, Medical Assistance Program, Title XIX, Social Security Act	Federal-state	Low income and medically needy, as determined by federal and state standards	Formula grants to states; state matching funds required; federal share ranges from 50% to 83%. Payments made to certain providers of medical services according to state-established reimbursement schedules	Open-ended federal financing with state and state-local supplementation
Social services				
A. Supportive services				
1. Title XX, Social Services Program, Social Security Act	Federal-state-local	Low income and other categorical requirements	75% federal formula grant to states for a wide variety of social and other services designed to achieve certain goals generally supportive of reducing social dependency of low-income persons, including elderly and disabled. Restrictions on use of funds in certain settings. Some support available for limited meals program, not part of full nutrition regimen	Annual federal appropriations

Drafting a grant proposal

1. Statement of need
   - A. Identify the problem.
   - B. Explain why it is worth solving.
   - C. Describe activities in this area—
     1. Your program's.
     2. Results of literature review.
2. Client group
   - A. Define client group.
   - B. Describe role in planning.
   - C. Project number of beneficiaries and program cost.
3. Objectives
   - A. List objectives.
   - B. Translate into behavioral terms.
4. Strategies
   - A. Outline basic procedures.
   - B. Present step-by-step plan.
   - C. Describe program specifics.
   - D. Explain involvement of other agencies, etc.
   - E. Emphasize program innovations.
5. Staff
6. Budget
7. Evaluation
8. Dissemination

Table 3 continued. . .

Program title	Administrative jurisdiction	Principal beneficiary	Nature of assistance/benefits	Financing
2. Community Food and Nutrition Program, Title II, Economic Opportunity Act of 1964, as amended	Federal-local	Low-income persons	Supplementation of larger food programs of other agencies, and of projects which will increase the production of food	Annual federal appropriations
3. General Revenue Sharing, State and Local Fiscal Assistance Act	Federal-state-local	All needy persons in jurisdictions utilizing such funds	Formula grants to state and local governments to be utilized to deal with community problems, including use for social services for poor, aged, or disabled	General revenues
4. Community Development, Title I, Housing and Community Development Act of 1974	Federal-state-local	All needy persons in areas so developed	Federal community development block grants for designated purposes, including services supportive of other community development activity, removal of material and architectural barriers which restrict the mobility of elderly and handicapped persons and creation of centers for the handicapped	Annual federal appropriations
5. Sec. 16(b) (2), Urban Mass Transportation Act of 1964, as amended	Federal	All elderly or disabled persons with access to such UMTA-funded transportation systems	Capital grants and loans to private nonprofit organizations to plan and design mass transportation facilities to meet the special needs of the elderly and the handicapped	Annual federal appropriations
B. Employment and Rehabilitation programs				
1. Rehabilitation Act of 1973 (as amended)	Federal-state	All persons with disabilities within limits of available funds and according to certain predetermined criteria	Rehabilitation services of all sorts including counseling, vocational training, attendant care, and so forth	Annual federal appropriations
2. Comprehensive Employment and Training Act of 1973 (CETA)	Federal-state-local	Categorical and income requirements	Subsidized employment for those qualified, provided through formula and project grants with specialized uses	Annual federal appropriations

Proposition 13: A Threat to the Growth of Independent Living

PROPOSITION 13 IS CREATING new challenges for centers for independent living across the United States. What began as a California phenomenon has swept across the country, imperiling government funds which have helped to keep these centers in business. Two centers, one in Berkeley, California, and the other in Boston, Massachusetts, are actively exploring prospects for survival.

Berkeley, the oldest and most firmly established independent living center, faces an imminent cut off of local government funds. This would effectively wipe out most of the direct services which the Berkeley center now offers to about 5,000 disabled people each year.

Boston, a much smaller operation, is heavily dependent on sole-source funding from a Massachusetts government agency. Boston finds that its funding, too, is on the line. Fund cuts everywhere are the order of the day, and the centers are reassessing their sources of money, and looking for new ways to continue their existence.

"We simply cannot continue to rely on government grants, local, State, or federal," says a senior staff member at the Berkeley center. "It's a new situation, and one which we are evaluating. Here at Berkeley, we're seriously considering setting ourselves up as a private enterprise. We're going to learn how to be entrepreneurs!"

Move over, General Motors?! Well, with Berkeley's success in attracting grants and launching new programs and services, becoming a moneymaking proposition may be well within its scope.

Already, it has a successful computer training program with a 98 percent job placement rate at the completion of each nine-month training course. This computer training program has 90 San Francisco Bay area firms on its advisory committee, and the committee firms serve as sources of placement for persons in the training program. The center believes that subcontracts, using these firms as a nucleus, are a distinct possibility.

It has not escaped the attention of the Berkeley center staff that businesses involved with the advisory committee are very interested in meeting affirmative action requirements as they apply to disabled people. There are many other such firms in the Bay area which would be equally interested in meeting their affirmative action requirements. The Berkeley center could utilize this interest, helping these firms meet their needs, and, at the same time, help itself obtain some hard money for providing these services.

The Small Business Administration, with its low-cost loans to minority businesses, including those owned and operated by disabled people, is another potential source of money. The Boston center is preparing an application for these funds, and the Berkeley center is considering the same approach.

Berkeley is far ahead of Boston in the wide range of services and activities it offers, as well as the fact that recently the Berkeley center purchased its own building. Located four curb-cut blocks from the University of California's famed Sproul Hall (remember, that's where the 60's student revolution began,) the Berkeley center building is spacious and well-sited for any number of business ventures.

Berkeley is already in the business of training people who go on to open and staff other independent living centers. Berkeley "graduates" are now involved in centers in San Diego, Santa Rosa and other locations.

Would a new for-profit business stance damage the centers' vital "missing link" role? It seems unlikely, as the goal of both the Boston and the Berkeley centers is to integrate disabled people into society and help maintain this integrated independence.

It would seem likely that future profits of an independent living center's entrepreneurial effort would be ploughed back into the center's activities. This in turn would generate more disabled people into jobs—either within the centers or on the outside. As a result, the profit-making angle has strong appeal.

The "missing link" aspect of the independent living centers also needs more reliable funding. The "missing link" refers to the centers' roles in bridging the gap between rehabilitation and independence. Too often, the federal-State rehabilitation program will assist a disabled person with adaptive devices, occupational and physical therapy, an education, and then, "graduate" the disabled person from its rolls.

It is at this point that the centers step in and help the newly rehabilitated person locate housing, find a job, or prepare realistic job skills. They also provide needed peer counseling (your problems are not unique), repair wheelchairs, and outfit vans. They advise people about government benefits which may have been denied, and they provide counseling on drug and alcohol problems. The centers are also invaluable sources of social contacts and activities, all designed to help foster independence in society.

The Berkeley center is already filling these "missing links" between rehabilitation agencies and independence for the disabled person. If the Berkeley center can do this with federal-State rehabilitation agencies, why shouldn't it play the same role with private industry, which needs to meet affirmative action requirements, by locating, training, and placing disabled people at industry expense?

Additional funds for the "missing link" may also be available through public school systems, universities, and other private and public groups which are now under the gun to meet varied affirmative action requirements. The "missing link" concept can move in many ways to help many people.

The Boston center is applying for status as a member agency of United Way, a major fund raising source for private, nonprofit, helping agencies This is another potential alternative source of funding.

At the present time, independent living centers are still operating independently and relying upon the wits of their staffs and advisors to raise monies, provide services, etc. As the movement grows, and more independent living centers are founded, perhaps the time is not far off when the centers will pool resources and form an "association" which could play a vital lobbying and fund raising role for all centers. Although each center has its own constituency and its own particular problems, a sharing of common goals (such as the need for money) may be another answer.

Is the day far off when an association of these dynamic and creative independent living centers will be sponsoring a money-raising telethon? If the centers do opt for this route, hopefully, we'll be witnessing a telethon that bears no resemblance to those underway at the present time. Telethons may be an effective way of raising needed money, and centers for independent living need money. No potential source of funds is going to be overlooked.

But before the centers get to that point, there are the ever present sticky issues: The Social Security Disability Insurance (SSDI) cut offs which prohibit disabled people from earning more than a certain small amount before they lose their SSDI payments and their Medicaid benefits, the still elusive national health insurance, and need for income tax deductions for unusual expenses associated with severe disability.

The creativity of independent living centers has already been demonstrated. The challenge of Proposition 13 is serving to spur new directions, new sources of funding, new dynamics for all centers.

—Robert H. Ruffner

Mr. Ruffner is the director of Communications at PCEH.

"What's New About Independent Living?"

Jean A. Cole, PhD

ABSTRACT. Cole JA: "What's new about independent living?" Arch Phys Med Rehabil 60: 458-462, 1979.

• The major purpose of this article is to examine important differences between independent living and traditional rehabilitation models of service provision, including comprehensive medical rehabilitation programs, state vocational rehabilitation agencies, and group homes designed to deinstitutionalize developmentally disabled individuals. The article is introduced by an overview of types of independent living programs in this country and their evolution. Goals, methods of service delivery, and program management techniques in independent living programs are contrasted with those of traditional models. Finally, trends that may develop as independent living becomes a standardized service entitlement are addressed, and the potential usefulness of some independent living concepts and methods in traditional rehabilitation programs are suggested.

Since passage last fall of the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978 (PL95-602), I have met with many persons interested in independent living at 5 bi-regional meetings around the country. At every conference a frequent comment has been "Independent living as described in the new legislation is really nothing new. . . our agency (or facility or program) has been providing these kinds of services all along."

The issue of whether independent living really is something new deserves serious reflection. This addition to the field of rehabilitation challenges each of us, whether part of a state agency, medical or vocational facility, program for developmentally disabled persons, or voluntary association, to rethink our goals and to question whether our actions actually foster the kind of independence of handicapped individuals that we all subscribe to philosophically.

In the past few years the growth of independent living has been dramatic. Five or 6 years ago only a handful of independent living programs had been developed, largely by groups of young disabled university students in scattered areas such as Champaign-Urbana, Berkeley, Houston, and Boston. At that time a few demonstration efforts in independent living were being funded with federal grants or state Innovation and Expansion money. As the efforts of pilot projects gained recognition, regional level planning for independent living began to emerge in some parts of the country including California, New England, Michigan, and Colorado. With passage of the Rehabilitation Amendments of 1978, independent living officially became a standardized service entitlement, available in theory to handicapped citizens in all parts of the country.

MODELS OF INDEPENDENT LIVING

To contrast independent living with more traditional programs of rehabilitation service, it may be useful to begin with an overview of current independent living organizations. The Independent Living Research Utilization Project at The Institute for Rehabilitation and Research (TIRR)[1] conducted a national survey of such programs in 1978 and identified about 60 to 70 in the United States. An independent living program can be defined as a nonprofit program which is controlled or substantially influenced by disabled consumers and which provides a constellation of services including attendant, reader and/or interpreter provision or referral; peer counseling; financial and legal advocacy; housing provision or referral; and community awareness and barrier removal programs. In addition to these comprehensive programs, there are numerous smaller organizations that provide one or a few services related to independent living.

Each independent living program is different from the others in terms of services and patterns of organization, but 3 major models can be identified. One is the community-based service model designed after the Center for Independent Living in Berkeley. The other 2 models differ from the first in that they provide residential facilities, one for relatively extended periods and the other on a brief transitional training basis.

Some of the oldest and best-known examples can further clarify these models.

The Center for Independent Living (CIL) in Berkeley, California, is the prototype of the community-based program. It was probably the first organization operated by disabled consumers to be established in the United States. CIL is not a residential program, but a multifaceted program of referral services, support services, and research and advocacy projects directed toward removing architectural and attitudinal barriers. The goal of the organization is total integration of people with severe disabilities into community life by providing various kinds of counseling, independent living skills training, and other supportive services. Whenever possible, existing community resources are used, so CIL also refers many people to agencies that

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From The Institute for Rehabilitation and Research, Houston.

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provide such assistance as vocational counseling, training and financial support.

The Boston Center for Independent Living[2] (BCIL) is a well-established example of a residential program. BCIL was founded in 1974 as a consumer-run self-help community where severely disabled individuals could develop independent living skills. Since then it has evolved into a nonprofit corporation that coordinates 3 different forms of independent living in the Boston area. Since its inception BCIL has made transitional living facilities available to interested severely disabled individuals. The program includes skills training to prepare participants for independent living in the community. For participants with more developed independent living skills who desire a more private lifestyle, BCIL has located an apartment building that makes cluster housing available in modified apartments with a pool of personal care assistants. BCIL has also been working to locate facilities and funding for individuals who wish to share an accessible apartment with a personal care assistant and live independently.

New Options in Houston[3] is an example of a transitional training program that provides information and first-hand experiences to prepare participants for independent living in a short period of time. The residential program includes a 6-week cycle of instructional modules emphasizing the skills needed to live and work with a minimum of assistance.

Participants can enhance their personal, physical and functional skills through the New Options Program. They learn to work with personal care assistants, are introduced to educational and vocational opportunities and alternative living arrangements, and experience the community through fieldtrips. New Options also has an extensive independent living research project which is used to trace the influence of the program on former participants.

Just under half of the respondents to the Research Utilization Project survey fit one of these comprehensive models. The remainder were classified as "Independent Living Service Providers"—organizations that offer one or more relevant services, but that fail to meet the criteria for a comprehensive independent living program.

More than 50% of all respondents provided the following services:

Independent living skills training	71%
Transportation	67%
Residential provision/registry	62%
Attendant services/registry	60%
Social/recreational services	57%
Financial counseling	52%
Community counseling services	52%
Peer counseling	52%
Client advocacy services	51%

There was no discernible pattern in the combinations of services, suggesting that the needs of the program clientele are diverse and heavily influenced by existing community services and support. The rank ordering of services suggests their relative significance to the programs and participants. Independent living skills training, transportation, and residential provision or registry are the 3 services most frequently offered by the responding programs. It is interesting to note, however, that when the programs were asked directly to rank services in order of importance they chose independent living skills training, residential provision/registry, and attendant services provision/registry.

DIFFERENCES BETWEEN INDEPENDENT LIVING PROGRAMS AND TRADITIONAL REHABILITATION MODELS

Independent living programs differ from most traditional rehabilitation programs with respect to their goals, their methods of service delivery, and their style of program management.

Goals

The Independent Living Research Utilization Project at TIRR has made a substantial effort to distill from published literature and from personal contacts with leaders in the field a concise statement of what independence means in the independent living movement. The answer seems to include 2 essential elements: 1) assuming responsibility for directing one's own life, and 2) participating actively in the day-to-day life of the community. These 2 elements constitute fundamental goals of the services provided by all successful independent living programs.

On the surface these goals seem to correspond to the stated purposes of traditional programs in the field of rehabilitation, including, for example, comprehensive medical rehabilitation programs, state vocational rehabilitation agencies, and group homes designed to deinstitutionalize developmentally disabled individuals. However, thoughtful examination demonstrates that in most cases these traditional programs say to their clients "We are here to help you become more independent. . . so long as your definition of independence agrees with our definition." In most medical rehabilitation programs, independence is defined as maximum physical functioning. In state vocational rehabilitation agencies, independence is defined as being employed. In group homes, independence is defined as group living in a community setting. This statement is not intended to suggest that comprehensive medical rehabilitation programs focus exclusively on physical functioning or that vocational rehabilitation agencies focus exclusively on employment. The fact remains, however, that the funding bases of these medical and vocational rehabilitation programs dictate a preponderant emphasis on goals within their designated domains. The movement to deinstitutionalize developmentally disabled individuals has likewise placed primary emphasis on group living as the major alternative to institutionalization.

In contrast, independent living programs say to their clients "You choose your own goals and lifestyle." Acceptable choices may include deciding to learn to dress oneself OR choosing to save time and energy by having an attendant assist with dressing; deciding to seek job training and eventual employment OR choosing not to work; deciding to live in a residence shared with other handicapped individuals OR choosing to live in a regular apartment within a typical neighborhood social system.

This insistence on client self-choice rather than incorporation of the client into a set of goals established by program managers, service professionals, or funding mechanisms constitutes a fundamental difference in basic ideology. The sources of these differences in ideology are examined by DeJong[4] and Varela.[5]

Methods of Service Delivery

Achieving the 2 fundamental goals of independent living, self-direction and active participation in the community, often entails styles of personal interaction and methods of service delivery different from those typically found in traditional rehabilitation settings. Letting clients select their own goals, make decisions, and take risks is often easy to verbalize as a program philosophy and difficult to adhere to in practice. In the New Options transitional living project, for example, staff members often find it difficult to watch program participants make what staff feel are unwise decisions and experience negative consequences. However, learning from mistakes is a process all persons experience as they assume adult roles. Determining the boundaries of risk that can be supported by staff in an independent living program is a difficult issue that requires careful consideration for each client.

Allowing clients to assume responsibility for managing their own lives is also difficult at times because their self-management skills may not be well-developed. It is often tempting for a rehabilitation professional to make arrangements, coordinate resources, or solve problems on behalf of clients because the professional can accomplish these tasks much more quickly and easily. The greater skill of the professional is often due to the fact that the client has never had opportunities to practice. Independent living programs place great emphasis on allowing and expecting the handicapped person to function as autonomously as possible, even though progress may initially be slow and laborious and greater creativity may be required from staff.

These issues of client self-direction will undoubtedly assume even greater significance as independent living programs expand from their early focus on highly intelligent physically disabled university students to include developmentally disabled clients and others who may have less intellectual capability and background experience in making decisions, assessing reasonable risks, and dealing with problems and crises on a day-to-day basis. Brown[6] alludes to this concern in working with a new population of clients whom he terms "less ready" for assuming the responsibilities of independent living.

The emphasis on a philosophy of client self-direction has led to the development of several new types of staff roles in independent living programs. Perhaps the most widely discussed of these is the role of peer counselor. Peer counselors often function as role models, educators, advisers, sources of emotional support and friendship, contact brokers, and in some cases as therapeutic counselors. The possible development of a therapeutic relationship between peer counselor and client is an issue of serious concern to many persons in the rehabilitation field because peer counselors do not necessarily have formal training or experience in using therapeutic counseling techniques. In some independent living programs such as the New Options project, therapeutic counseling is done only by persons with professional training.

An important consideration in the concept of peer counseling is the meaning of the term "peer." In many programs a peer is strictly defined as a person with a disability similar to that of the client. In my opinion the essential issue is rather the development of a counselor-client relationship in which the counselor does not impose his or her opinion based on formally acquired expertise on the client. In such a peer relationship the counselor and client jointly define goals and make plans, with the client in a position of control over decisions.

Another nontraditional role frequently utilized in independent living programs is that of personal care assistant. This role differs from that of aide or nurse in a health care setting in that the personal care assistant is directed by the handicapped individual.

In addition to new types of staff roles, another major difference in the service delivery strategies used in independent living programs is a commitment to the functioning of handicapped persons in actual community settings that maximize the inclusion of the handicapped individual as a regular member of society. This means avoiding segregation of handicapped clients in special places that isolate them from the general public. This issue leads proponents of an independent living philosophy to disagree strongly with the practice of placing handicapped individuals in special group residences built specifically for them. Such residences, whether group homes for developmentally disabled clients or special residential accommodations for physically handicapped persons, tend to create a "separate but equal" environment that decreases opportunities for full inclusion in society.

Program Management

A final important area of difference between independent living and traditional rehabilitation models is the substantial involvement of consumers in the operation of independent living programs. In some programs

"substantial involvement" is formally defined to mean control of the board of directors and reservation of certain staff positions for consumers. In other cases "substantial involvement" may be less formally defined but still include an important influence of consumers on the policies and service delivery style of the program.

Consumer involvement in the management of independent living programs has followed an interesting evolutionary course. As most independent living programs began, they were developed and managed with great personal commitment and contribution of time and effort by a small group of very competent disabled individuals. Now that these programs are growing and independent living is becoming a standardized rehabilitation service, the management of programs will inevitably require more formalized procedures and sophisticated management skills. The need to provide management training for consumers to run independent living programs was articulated at the Second National Conference on Independent Living in Houston in September 1978. Making technical assistance available to independent living programs is now required in the state planning sections of the new Rehabilitation Amendments of 1978. The further development of independent living programming will thus provide unique opportunities to observe various ways of integrating consumer participation and professional managerial methods in program management.

WHAT CAN WE LEARN FROM INDEPENDENT LIVING PROGRAMS

The previous section has pointed out some of the basic differences between independent living programs and traditional rehabilitation models such as medical programs, state vocational rehabilitation agencies, or group homes. Careful reflection on these differences may prompt us to raise important questions about our comfortable and familiar ways of doing things. Perhaps there are useful lessons to be learned about the way client goals are defined, about service delivery styles and roles, and about overall program management. This is not to suggest that all rehabilitation programs should be operated like independent living programs. There are many reasons why this is neither desirable nor workable. But the emergence of a successful new strategy of rehabilitation offers many valuable opportunities to examine and explore our own philosophies and actions and to adopt what seems genuinely useful into other contexts. There are traditional rehabilitation programs in the country today that are now experimenting with incorporation of some independent living methods into traditional service delivery mechanisms.[7] This trend of incorporating useful new ideas and strategies will hopefully continue and expand. It is also important that in traditional rehabilitation programs we seek a real understanding of the purposes and concepts of independent living and become familiar with the services typically provided by independent living programs. This depth of understanding is essential if we hope to form good working relationships with independent living programs to work cooperatively in assisting handicapped individuals function as full members of the community.

FUTURE ISSUES AS INDEPENDENT LIVING BECOMES A STANDARDIZED SERVICE ENTITLEMENT

The Rehabilitation Amendments of 1978 offer great opportunities but also pose serious concerns for the future evolution of independent living in this country. With formalization of planning and control on a statewide basis and generalized entitlement to services will come issues of program accreditation, eligibility determination, standardization of the case management and monitoring functions, and bureaucratic elaboration. Some of these changes can perhaps be anticipated through the experience of states and regions that have already developed "second generation" programs.[6,7]

Many important challenges continue to face the independent living movement, including ways to serve rural populations and ways to meet the needs of previously unserved groups such as persons with head injuries who may lack some of the self-management and decision-making skills of the physically disabled students in early programs.

It is important as we seek to foresee and manage changes that many of the strengths developed by independent living programs be preserved. These include the ability to be genuinely responsive to goals and needs as defined by the client, flexibility to coordinate existing community resources efficiently, and an innovative spirit that fosters a variety of creative solutions without premature closure on adopting one way of doing things.

Acknowledgment: My thinking about independent living has been shaped to a large degree by several colleagues at TIRR, and I am grateful for their support and assistance. These persons include Mary Ann Board, Lex Frieden, Laurie Gerken, Barbara Holden, Laurel Richards, William Spencer, MD, Jane Sperry, and David Stock. My views are also based on extensive interviews with many handicapped individuals living independently in Houston. The opinions expressed in this article are my own.

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CONSUMER INVOLVEMENT

OBJECTIVES

1. To examine the role of consumer involvement in the development and implementation of Independent Living programs.

2. To provide an analysis of the problem areas and benefits of a working relationship between consumer and state agency personnel.

3. To identify methods to be utilized in initiating consumer involvement policies within a facility.

SUMMARY

(1) "The Prevalence of Disability and the Movement's Constituency." Gerben De Jong, The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research. The University Centers for International Rehabilitation, Michigan, 1979. Reprint permission granted.

De Jong provides an analysis of the target population for IL services, the severely physically disabled. This information can promote an awareness of "who" this constituent is, his needs, and his contributions to the development of the IL movement.

Recent national statistics are reviewed, and it is noted that the IL constituency comprises less than 10% of the nations' total population. These figures are based on a definition of disability which looks only at the need for personal care or assistance in mobility, and limitations in ones' "major activity" which is employment.

There are other groups, however, which are not directly related to the core constituency, who have had a significant influence upon the movement. These groups include disability professionals, special interest groups, peer counselors, and coalitions for disabled persons.

The movements' constituency seems to be hard to define. However, the support is there for services to continue to expand, as more professionals become involved, and as more consumers become professionals. IL programs may also develop to the point that other types of disabilities can be served, such as the elderly, or those with a degenerative disease, such as multiple sclerosis.

(2) "Rehabilitation Consumerism: Confrontation or Communication and Cooperation?" Andrew S. Adams, Journal of Rehabilitation, January-February 1976. Reprint permission granted.

Both the professional and the consumer have as a common goal, to promote maximum personal and economic independence for disabled individuals. Professionals in rehabilitation need not view the consumer movement as a "threat." The disabled can ably assist professionals in policy making, articulation of client goals and objectives, and the organization and promptness of services.

The disabled are no longer perceiving themselves as "clients" to whom decisions are made for them, but as able participants in the decisions and processes which shape their own future. It is time that professionals in our field recognize disabled individuals as fully functioning adults whose contribution can be invaluable in the rehabilitation process.

(3) "Independent Living Programs: The Role of the Able-Bodied Professional." Sheldon Berrol, Archives of Physical Medicine Rehabilitation, Vol. 60, October 1979. Reprint permission granted.

The Independent Living Program movement was created by the disabled community. It has established a broad coalition of diverse disabilities functioning to provide services on a broader scale than has been traditionally offered by the rehabilitation community. The effectiveness and the strength of the movement lies in the consumer control. The able-bodied professional can provide expertise, balance, and a vital link with established rehabilitation programs. The integrity of the independent living program movement can only be maintained and developed if these basic concepts are respected.

(4) "What You Always Wanted to Know About Sexuality and Handicapped People . . . Now You Can Ask." Susan Knight, Disabled USA, February 1980. Reprint permission granted.

A peer couselor can offer a unique degree of credibility and specific information to his client which stems from personal life experiences with a disability. The able-bodied professional who is empathetic and supportive, and possesses the skills necessary for counseling can be of equal benefit.

Disabled and able-bodied couselors need to acquire clear and direct information on problems relative to the

disabled. This can be acquired through professional training and contact with other disabled persons.

(5) "Models for Consumer Involvement/Policy Development Consultation." Consumer Involvement/Policy Development Consultation: A Resource Manual for Staff Development Personnel and Rehabilitation Trainers, B. Douglas Rice, Arkansas Rehabilitation Research and Training Center, Arkansas, 1979. Reprint permission granted.

One of the major concerns addressed in the Rehabilitation Act of 1973, and subsequent amendments is the expanded role of the consumer in rehabilitation services. These sections from the Consumer Involvement Manual highlight the essential factors involved with the implementation of consumer-related policies. These factors include the following:

- -elimination of defensive attitudes by both the agency and consumers;
- -continuous effort to inform and educate the public, including consumers, in preference to agency policy, procedures, regulations, limitations, restrictions, and services.

Specific procedures to be utilized in policy development are briefly described. Advantages and responsibilities are outlined for both the consumer and state agency personnel. It is emphasized that not only should consumers have access to information on agency policies and regulations, but that they have a "right" to be trained in appropriate professional areas. In return, the agency receives various benefits. They will receive relevant information on the problems that disabled persons encounter. A more meaningful and affective relationship between client and agency can occur through the mediation and insight offered by the consumer.

(6) Consumer Involvement in the Massachusetts Rehabilitation Commission, Elmer C. Bartels, 1979. Reprint permission granted.

Elmer Bartels, Commissioner of Rehabilitation in Massachusetts, presents a position paper on consumer involvement within the rehabilitation agency. The major purpose of the consumer involvement program is to improve the agency's service delivery system. Difficulties in its implementation as perceived by the consumer and by agency personnel are explored. In response to those problem areas, Bartels discusses the benefits of the program for both parties concerned.

The agency has utilized a wide variety of models at all levels of management in the implementation of consumer strategies. These methodologies are outlined in this paper and program objectives are developed. Examples of methodologies include serving as advisory board members for developing/implementing agency policies and assisting in problem-solving for difficult cases involving disabled clients.

An outline of training sessions for both agency personnel and consumers is presented. State-wide plans and objectives for implementing a consumer involvement program are documented. As these plans develop, techniques for implementation will be refined, analyzed, and data will be collected. For more information please contact:

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(7) "Peer Counseling." Gwen Chandler, Presentation delivered to participants attending Facility Training in Work Adjustment Services, Region IV, Auburn University, Auburn, Alabama, 1980.

Ms. Chandler, former Miss Wheelchair Alabama and student at Auburn University, examines the role of peer counseling in Independent Living programs. Drawing on her personal experience with a disability, Gwen voices the need of her peers for relationships with well-adjusted, independent disabled persons. This approach can foster positive feelings on the part of counselees, as they recognize that their counselor is not only empathetic to their particular situation, but has probably had similar experiences as well.

Characteristics of effective peer counseling are indicated. Various strategies for implementing a program are recommended. Suggestions for the training of counselors are briefly outlined. Peer counseling can meet the needs of disabled persons which are not being met as programs or supportive services are withdrawn or no longer made available.

II

THE PREVALENCE OF DISABILITY AND THE MOVEMENT"S CONSTITUENCY

The movement for independent living has always counted the "severely disabled" as its primary target group or constituency. But who are the severely disabled? How many are there?

Results from National Survey Data

One common method used to define and measure severe disability is the inability to work or to carry on one's major activity. Based on results from its 1974 Health Interview Survey (HIS), the National Center for Health Statistics (NCHS)

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[1]An extensive literature has developed exploring and defining the nature of social movements (Ash, 1972; Cameron, 1966; Gerlach and Hine, 1972 and 1973; Gerschwender, 1968; Gusfield, 1969; Herbele, 1951; Hopper, 1950; Howard, 1974; McLaughlin, 1967; Meadows, 1943; Obuscall, 1973; Toch, 1965; Turner, 1969 and 1970; Warren, 1977; Wilkinson, 1971; Wilson, 1972; Zald and Ash, 1966; and Zygmunt, 1972).

estimates that 3.3 percent or 6.8 million of the nation's population are unable to carry on their major activity, as shown in Table 1, below. Going across different age groups, about 0.2 percent of all children[2], 2.6 percent of all working age adults, and 17.1 percent of all the elderly[3] are unable to carry on their major activity.

If we expand the definition of severe disability to include those who are able to carry on their major activity but are limited in amount or kind of activity, the number of severely disabled persons increases appreciably. Based on the same Health Interview Survey (see Table 1 again), combining the two most activity restricted groups, 10.6 percent or 22.0 million of the nation's population would be classified as severely disabled.

By focusing on limitations in a person's major activity, the Health Interview Survey uses a "social role" definition of disability. This definition points up a problem that has been of interest to those involved in the movement for

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[2]For children the inability to carry on one's major activity would mean the inability to play or go to school.

[3]It is unclear what "limitations in major activity" mean for the elderly. The Health Interview Survey evaluates the elderly in the same manner as working age adults: whether or not a person is limited in their ability to work. (For the definitions of disability used by HIS see National Center for Health Statistics (1976: 35-37). Asking an elderly person whether they are able to work seems increasingly inappropriate the more a person is removed in age from participating in the labor force and when the usual kind of work remains unspecified. Moreover, an elderly person's ability to work remains untested in a society that demands mandatory retirement.

TABLE 1

Percentage Distribution of Total Population[a] by Degree of Activity Limitation and Age Group United States, 1974[b]

Degree of Activity Limitation	Total Population (N=207.3 million)	Age Group		
		Under 17 yrs. (N=63.0 million)	17-64 yrs. (N=123.6 million)	Over 64 yrs. (N=20.7 millio
With no activity limitation	85.9%	96.3%	85.9%	54.1%
With activity limitation	14.1	3.7	14.1	45.9
Limited but not in major activity	3.5	1.8	3.9	6.6
Limited in amount or kind of major activity	7.3	1.7	7.6	22.1
Unable to carry on major activity	3.3	0.2	2.6	17.1
Totals	100.0	100.0	100.0	100.0

Source: National Center for Health Statistics (1976:11, Table 1).

[a]Noninstitutionalized civilian population.

[b]As estimated by the Health Interview Survey, 1974.

independent living. The social role definition of disability has a large environmental component: limitations in one's major activity depend in large part upon the presence or absence of environmental barriers. These barriers---such as physically inaccessible places of employment and community services---and not the physical impairment itself, may determine whether a person is limited in his/her major activity.

A less environmentally biased definition of severe disability is the physical functioning definition of disability. This definition focuses on the ability to move certain limbs or the ability to be independent in personal hygiene and mobility.[4] Needing help with personal care is generally considered the most restrictive level of physical functioning in large national surveys and is sometimes used as an alternative definition of severe physical disability. As noted in Table 2, about 1.2 percent of the child age population,[5] about 1.2 percent of the working age population, and about 7.7 percent of the elderly population need some assistance from another person with personal care. If these percentages were applied to the current age distribution, about 3.6 million would need some assistance from another person with their personal care.

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[4]Even the performance of these activities can be limited by environmental constraints.

[5]Since very young children require help with personal care on a regular basis, the 1972 Ohio State Survey (cited in Table 2) considered only children who required extra help with personal care because of a physical, mental, or emotional problem.

TABLE 2

Number and Percentage Distribution of Population[a] Needing Some Help From Another Person for Personal Care and Mobility by Age Group as Estimated by Various National Surveys United States, 1966-68, 1972

Survey and Age Group	Needs Help From Another Person With Personal Care		Needs Help From Another Person With Mobility[b]	
	Number (thousands)	Percent[c]	Number (thousands)	Percent[c]
Social Security Survey, 1966	1,259			
18-64 yrs.	1,259	→ 1.2%	1,851	1.8%
Social Security Survey, 1972*				
20-64 yrs.	1,534	1.4	2,619	2.4
20-34 yrs.	217	0.5	597	1.4
35-44 yrs.	209	1.0	414	1.9
45-54 yrs.	391	1.7	581	2.5
55-64 yrs.	716	3.8	1,028	5.4
Ohio State Survey, 1972				
Under 18 yrs.	858[d]	→ 1.2	na	na
18-44 yrs.	372[d]	0.5	442[d]	0.6
45-54 yrs.	na	1.4	na	2.6
55-64 yrs.	na	2.7	na	5.2
45-64 yrs.	837[d]	2.0	1,612[d]	3.8
18-64 yrs.	1,254[d]	1.1	2,149[d]	1.8
65-74 yrs.	na	3.0	na	8.5
Over 74 yrs.	na	9.1	na	16.7
Over 64 yrs.	1,046[d]	5.2	2,298[d]	11.5
All adults	2,510[d]	1.8	4,934[d]	3.5
Health Interview Survey, 1966-68				
Over 55 yrs.	1,747	4.9	na	na
55-64 yrs.	363	2.1	na	na
Over 65 yrs.	1,385	→ 7.7	na	na
65-74 yrs.	499	4.4	na	na
Over 75 yrs.	886	13.4	na	na

TABLE 2
(continued)

Survey and Age Group	Needs Help From Another Person With Personal Care		Needs Help From Another Person With Mobility[b]	
	Number (thousands)	Percent[c]	Number (thousands)	Percent[c]
Health Interview Survey, 1972				
Under 17 yrs.	na	na	81	0.1
17-44 yrs.	na	na	229	0.3
45-64 yrs.	na	na	663	1.6
17-64 yrs.	na	na	892	0.7
Over 64 yrs.	na	na	1,374	6.9
All adults	na	na	2,226	1.6
All ages	na	na	2,348	1.1

Sources: Haber (1970:19, Table 1), Burdette (1972:13, Table 1; 31, Table 17 Posner (1977:12-13, Table 1), Nagi (1973:IV-16, Table IV-8; 1975:39, Table 9, Nagi and Luken (1975:10, Table 5), and National Center for Health Statistics (1972:3&15, Table 1; 1974:16, Table 2).

[a]Noninstitutionalized civilian population.

[b]In the Social Security Survey, those requiring help with mobility overlappe with those requiring help with personal care, i.e., the person requiring help with both activities would be counted twice. In the Ohio State University Survey, those requiring help with mobility did not overlap with those requiring help with personal care, i.e., these two groups are mutually exclusive. In the Ohio State University Survey, those needing help with personal care were considered more dependent than those needing help with mobility (Nagi, 1973:IV-13). Since the Ohio State University Survey classified people into their most dependent category, it is possible to compare the two surveys in terms of needing help for personal care, but not mobility.

[c]Percent of each age group.

[d]Based on extrapolations of Ohio State University Survey data to Census data Since the age distribution in the Ohio State Survey was slightly different than the age distribution for the nation as a whole, the numbers of each age group are not additive.

The percentage of the population needing help with mobility varies from about 2.0 percent of the working age population to about 7.0 percent of the elderly population. None of the five surveys reviewed here[6] report data on childhood mobility.

In pinpointing the movement's constituency from these national data, two additional factors need to be considered. First, those who are dependent in personal care and those who are dependent in mobility are overlapping groups; the statistics are not additive. Second, national survey data do not provide any indication as to how much assistance an individual or group needs in personal care or mobility. Since the movement for independent living is primarily concerned about persons who need substantial assistance with personal care or mobility, these national statistics suggest that the movement is focused on a relatively small percentage of the nation's population.

Core Constituency

However, the movement's core constituency is even more limited than that suggested by these national data. The movement has concentrated its energies on a relatively few major disability groups: those with spinal cord injury, muscular dystrophy, cerebral palsy, multiple sclerosis, and post-polio disablement. These five groups indeed comprise a very small but not insignificant portion of the nation's population.

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[6]The five national surveys reviewed here are listed in Table 2.

Moreover, the movement for independent living has concentrated its energies on a selected age group: the older adolescent and younger working age adult. The emphasis on this narrow age range is, in part, a function of the disabling conditions mentioned above. For example, spinal cord injury is most common among males during their late teens and early twenties when they are most likely to participate in disability-prone activities. Multiple sclerosis generally becomes evident during one's twenties. Cerebral palsy and muscular dystrophy are developmental disabilities and thus are already evident during a person's childhood years. Those with a post-polio disablement are the senior members of the independent living movement.

The emphasis on the younger adult is also a function of the communities where the movement has taken root. The movement for independent living has been most active in large academic communities containing critical masses of university-aged persons. Free from some of the more demanding familial and economic responsibilities, this age group is often better able to organize around major social issues.

Notably absent from the movement's constituency are older persons with severe physical impairments resulting from stroke or other degenerative conditions. While the movement's philosophy may have direct relevance to older disabled persons, the movement has focused its concern elsewhere. The movement's present age bias is one that cannot last indefinitely. Medical science is not only enabling severely disabled persons to

survive initial trauma but is also enabling severely disabled persons to live longer. Thus, as the movement's initial adherents grow older we can expect the movement to enlarge its present age focus.[7]

Disability Professionals and Special Interest Organizations

There is another part of the movement's constituency that deserves mention here: the disability professionals and special interest organizations. The disability professionals include physicians in physical medicine and rehabilitation, physical therapists, occupational therapists, nurses, rehabilitation counselors, and disability researchers. The commitment of these professionals to the movement varies widely and generalizations cannot be made except that the movement is increasing its number of adherents. The special interest groups include organizations such as the National Paraplegia Foundation, the Easter Seal Society, and various professional and voluntary associations. Again, the commitment of these organizations varies widely from chapter to chapter.

In defining the movement's constituency one should not overlook the overlap between disabled "consumers" and disability

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[7]Also absent from the movement's constituency and leadership are racial minorities. Disability statistics indicate that racial minorities have a higher prevalence of disability than do their white counterparts (DeJong, 1977a: 53; U.S. Bureau of the Census, 1973b: 239, Table 52). The absence of racial minorities deserves special analysis. Given the similarities between the civil rights movement, the black movement, and the movement for independent living (see pages 20-22), one would think that the movement for independent living would attract disabled persons from racial minorities.

professionals. Many disabled persons are themselves disability professionals. The participation of able-bodied professionals in the movement can to some degree be explained by the influence and the consciousness-raising impact of their disabled professional peers.

The movement's strength comes, in part, from linking the interests of its primary disability groups with the interests of other disability groups, especially on issues of common concern. The issue of architectural barriers, for example, is one that unites other mobility impaired groups, even though its greatest effect is on the core disability groups represented in the movement for independent living. Coalition building through organizations such as the American Coalition of Citizens with Disabilities (ACCD) has enabled the movement to enlarge its constituency around specific issues.

Difficulties in Definition

We may conclude that the movement's constituency is hard to define. National survey data enables us to identify that portion of the population most likely to come within the scope of the movement's concern. While we can identify a core constituency, there are many other interested parties---professionals and special interest groups---who have come to recognize the movement and have joined forces to one degree or another (Figure 1). Moreover, common interests with other disability groups enables the movement to extend its influence beyond the boundaries of the core disability groups.

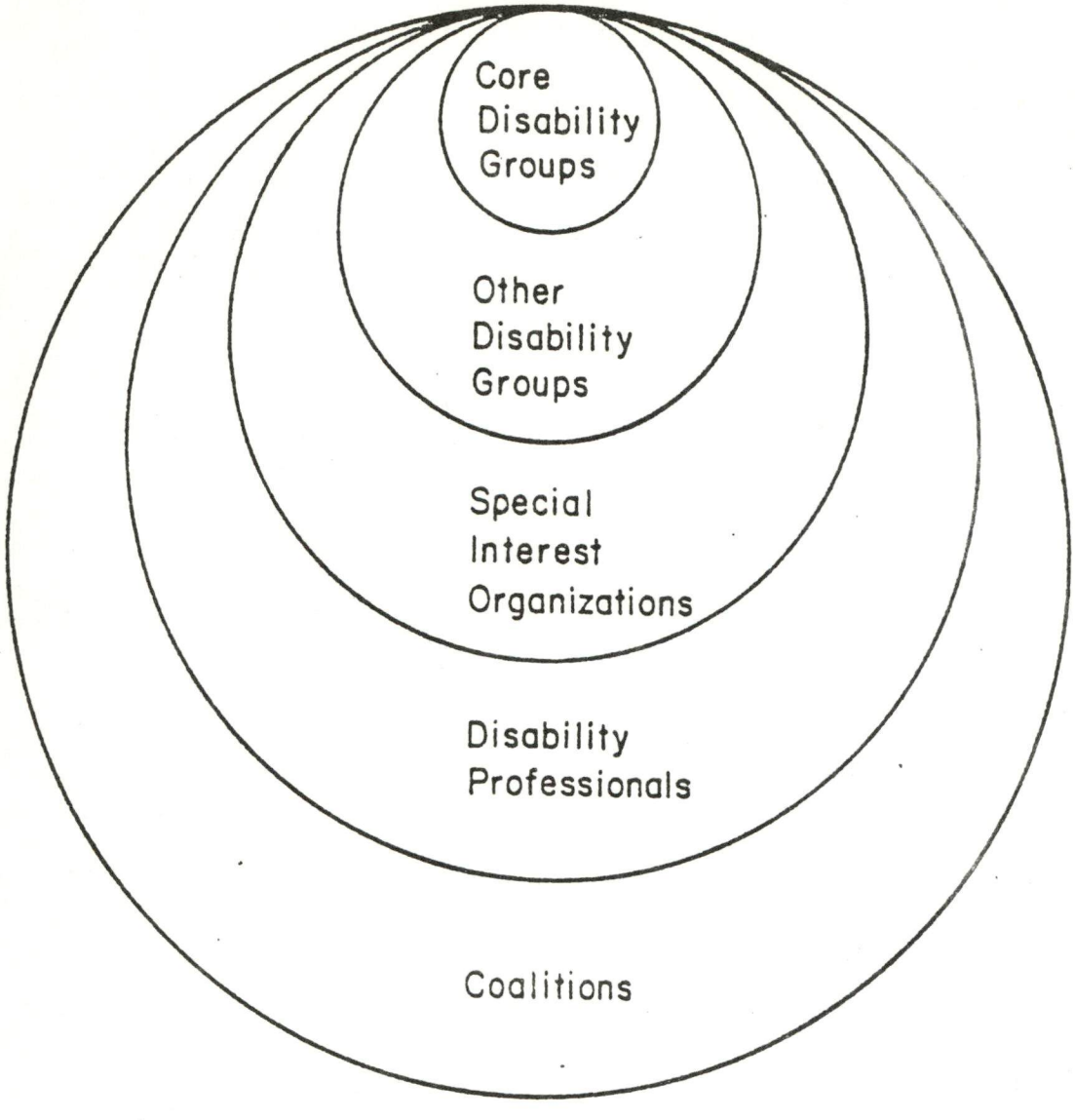

Figure 1. The Movement for Independent Living's Constituency

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The movement's constituency is defined not only by who participates, but also by what it advocates. The movement's constituency, in some respects, extends to others who do not actively participate but who nonetheless come under its consciousness-raising spell and thus become informal advocates of the movement's philosophy and ideology.[8] In subsequent sections we will be exploring in greater depth the movement's philosophical and ideological commitments.

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[8]The problem of constituency definition is similar to that in the women's movement. The constituency of the women's movement is not limited to its most active participants but in a sense also includes women and men who have come to accept the movement's values and can be expected to vote and accept a life-style in keeping with those values.

Andrew S. Adams

Rehabilitation Consumerism Confrontation or Communication and Cooperation?

Address by Commissioner Andrew S. Adams, Rehabilitation Services Administration at the Annual Meeting of the National Rehabilitation Association in Cincinnati, Ohio, on Tuesday, October 14, 1975.

The prominent role of NRA in the system of delivering rehabilitation services—historically, now, and in the future—commands my respect and the appreciation of all. I could spend hours discussing the current RSA developments and the ambitions we have for the future of rehabilitation services. On other occasions I anticipate we will be considering the strong part NRA will surely play in these developments. I want to make a few general comments and then dig into the concern of this session.

First of all, I bring you greetings from our new Secretary. I have had meetings with Dr. Mathews, and he has already shown firm support for our programs. I also want to mention our Assistant Secretary for Human Development. Stan Thomas has demonstrated strong support for the rehabilitation of the disabled, as he has for the aged, the native Americans, the run-a-way youth, and the disadvantaged children.

While this forum is not the occasion for an update on all the new developments in RSA, I do want to briefly report to you the latest figures in carrying out the mandates of the Rehabilitation Act of 1973 and Amendments of 1974. Nationwide, we continue to provide more resources to severely handicapped Americans. With your determination and resourcefulness, this past year we rehabilitated 325,000 disabled people—of which 119,000 were seriously disabled. This is a significant jump from the year before. I remain confident that, despite the economy and our limited resources, the results of rehabilitation will continue to be greater. With your continued support, the physically and mentally disabled in our great country will live and work taller and taller.

This session has the specific purpose of focusing on one important and timely concern which affects all of us. The title assigned in the program reads: "Rehabilitation Consumerism: Confrontation or Communication and Cooperation."

I am here because I have a very strong interest—both professionally and personally—in the successful implementation of consumerism in rehabilitation services. It represents one of the highest priorities among the current issues. And I am here because the subject is of immediate concern and warrants the strong direct attention of the Commissioner of RSA. And you know, your Commissioner represents both the consumer and the provider.

Consumerism is not an issue about which we can achieve effective resolutions by being "for" or "against" in the abstract. In the field of rehabilitation, consumerism is a range of specific processes and events in which the relationship between service providers (the professionals) and disabled persons (the consumers) may be one of confrontation *or* of communication and cooperation. This is as true of the individual relationship between a VR counselor and an individual in need of services as it is of the relationships between groups representing various consumers and institutions administering various services. And it is a potential or immediate concern in every rehabilitation organization—whether the membership includes balanced combinations of consumers and professionals or predominant membership of one category.

From my vantage point, I see numerous examples of confrontation and of communication and cooperation between providers and consumers of rehabilitation services. While I generally hope for a movement toward more and more situations where the resolutions are achieved through communication and cooperation, there are appropriate times for confrontation as an initial process to stimulate dialogue and represent interests.

consumerism

It is my intention today to present some of the facets and perspectives which may help us to deal with the issue of consumerism within the field of rehabilitation. But, I want to state at the outset that I believe the fundamental truth is that professionals and consumers in rehabilitation are basically on the same side. I see us together pursuing a worthy mission to promote the maximum personal and economic independence of disabled persons who constitute one of every eleven Americans.

The genesis of consumerism has its roots in the human constitution. People invariably have a supreme interest in shaping their own destiny—in making their own choices about the things which most directly affect their lives. Taxation without representation was an issue raised by consumers. A long series of unresolved abuses stimulated the confrontation of the American Revolution. Consumerism is the basic process through which Americans cooperatively choose their future. The elective process assumes that most of the people most of the time can make a judgment which is in their collective best interest.

In the commercial market place, it is primarily the consumer who decides which products and services are appropriate and cost effective. As consumers we sometimes need the services of independent evaluators and various consumer advocate groups to deal with the complexities of the modern scene, but our choices do shape the stock market, the supermarket shelves, the professional services we receive, and most other commercial transactions. In recent years consumer organizations have made some progress in safety, warranties and guaranties, deceptive advertising and other areas.

Direct participation by consumers in government services most directly effecting various categorical groups manifested itself in the experience of the poverty program when "maximum feasible participation" turned out in some cases to be what Daniel Patrick Moynihan called "maximum feasible misunderstanding." Corrective Congressional action and subsequent consumer participation structures in the fields of health, community development, transportation planning, community mental health centers, and many more areas demonstrate the national perspective: namely, involvement in government processes and programs by representatives of the persons most directly affected is an extension and current manifestation of our national understanding of democracy.

In RSA we do not regard consumer involvement as an additional workload burden nor as a burr under the saddle. Consumerism, as well as professional personnel standards, is the law. And I am charged with administering it. For example, participation by consumers of VR services in the development of each State plan is a mandated procedure. (Section 101(A)(18)—P.L. 93-112 i.e., 1973 Rehabilitation Act) Moreover, in carrying out evaluation on behalf of the Secretary of HEW, I am required whenever possible to obtain the specific views of persons participating in and served by programs and projects assisted under the Act, about such programs and projects (Section 401(c)). [See also Section 405(a).] Consumer involvement is not only mandated in relationship to programs and projects, it is specifically required by law in every individual case. Individualized written rehabilitation plans are not optional. Failure to perform this requirement, as has been reported in some instances, it not only a violation of federal law, but a disrespect for the essential truth that individuals rehabilitate themselves, with the assistance and genuine understanding of persons who are professionally skilled in the various aspects of rehabilitation service.

I cannot resist saying something else which comes to mind in relationship to individualized plans. My understanding of the kind of relationship between a handicapped person and a rehabilitation counselor which is absolutely necessary for both results and professional integrity is that among the processes, the counselor will genuinely listen and perceive "where a person is." He will not make quick assumptions or proceed on the basis of his or her own personal values and priorities. The counselor will, to the best of his or her abilities, perceive the unique set of problems and the unique potentials, and attempt to bring to bear the variety of skills and services which will help each person to help himself. I see the relationship as one of high integrity and trust.

In that regard, and without commenting on any specific cases (some of which are in the courts) I believe you share my outrage for the few situations where records have apparently been falsified—where persons with real needs have been closed out. That kind of action has no place in the rehabilitation movement, and I believe that the millions of us who are professionals and/or consumers speak with one voice in expressing our displeasure. Moreover, to the degree that such actions may have been motivated by the numbers game or quota systems, it is an abuse of appro-

priate planning and evaluation techniques. I would personally rather report a drop in our achievements than to turn away persons in need, or compromise our integrity to reach targeted objectives. And to the degree that consumism and professionalism in rehabilitation helps to root out such abuses, it has my unequivocal support—and, I believe, it has yours too.

Having said that consumerism in rehabilitation is a manifestation of the democratic processes, that it is the law, that it emanates from the basic human desire to participate in our own destiny, and that essentially individuals rehabilitate themselves with the assistance of professionals, I want to add that consumerism in rehabilitation is a *movement whose time has come.* And, I rejoice in that reality. I see groups of persons in wheelchairs visiting Congress, presenting their case. I see organizations of handicapped persons pressuring institutions for the removal of barriers and taking transportation systems to court to achieve access. Every rehabilitation program at the State and National levels, and every rehabilitation organization of professionals are experiencing the efforts of disabled persons as consumers, moving to participate in the decisions that affect their lives.

As professionals in the field, we do not need to regard this movement in our time as essentially threatening. While there may be abuses and mistakes, it is a snowball picking up weight and size as it moves amongst us. And the results include the potential of expanding our insights and strengthening the rehabilitation mission throughout our society. Professionals can embrace the consumer movement without conceding their integrity or acceding to the excesses and strategic judgment differences which may exist. A healthy tension can be maintained which, like the federal check and balance system, will serve the greater good of all. I see this healthy tension every week in various meetings and in the development of RSA programs. The General tendency is for consumer representatives to raise the *output* questions; namely, can persons who receive VR services function better, live better, move around better, cope with their environment better. Can they sustain their personal and economic independence; can they earn a living and fulfill their unique potential? At its best, consumerism does not represent itself as professional in the fields which require extensive training and clinical experience, nor does it expect to generate the detailed answers to the questions of *how* we can best operate programs of service. But it does participate in the *what* questions, in the decisions regarding alternatives, and in the policy choices. And, it does add the sense of urgency and importance which represents the genuine self-interest of disabled persons.

Consumers keep us professionals honest because they are not impressed with sophisticated systems or substantial input resources, unless they deliver. More and more they do not regard themselves as "clients" to whom something is done, but as full participants in the decisions and processes which shape their own future. I am convinced that consumerism in rehabilitation does not want to "throw out the baby with the bath." There is high respect and appreciation for professional skills and judgment and a desire to pursue the kind of courses which assure that such respect continues to be merited.

I anticipate that consumerism will expand itself in a broad variety of ways including:

A) Participation on agency boards, planning committees, policy and practice formulations, and program evaluation, particularly with regard to outcomes.

B) Staffing, consulting, or volunteering in rehabilitation agencies and facilities on an operating level.

C) Increased availability of consumer advocacy personnel within programs.

D) Increased pursuance of rights, benefits, responsibilities, goals, objectives, and accountability processes.

Some of the operational techniques and results of individual consumerism will include:

A) Increased client orientation to services, procedures, practices, and limitations, i.e., rights and benefits.

B) Individual choice among services and objectives.

C) Increased respect for the uniqueness, dignity, privacy, and sensitivities of the client.

D) Increased and continuous opportunities for the client to articulate problems and needs.

E) Increased opportunity at all times for self-determination, whenever humanly possible.

F) Carefully explained referral when another program or service is indicated, with appropriate assistance.

G) Intensive understanding of client expectations and programs or service expectations.

H) Careful distinction between rights and privileges as they relate to services under the law or statutes.

I) Promptness, efficiency, and organization of needed services.

J) Consumer involvement in developing the case plan.

K) Clarity and availability of client information obtained.

L) Appropriate sharing of data on client progress or problems.

M) Case evaluation translated into client self-evaluation.

N) Job satisfaction.

O) Leadership role of counselor to prevent or resolve problems.

P) Extended client interest beyond legal agency requirements.

However consumerism emerges in each particular context, it is something which deserves our strong interest.

In RSA I have placed top priority on developing a "Consumer Involvement System" that provides for maximum involvement and cooperation of consumers and their organizations. I strongly urge that this be emphasized at the State and local levels. I am positive that a well thought-out and planned CIS can capitalize on confrontation, open communications, and foster cooperation so that consumers and providers can be "singing out of the same hymn book."

Independent Living Programs: The Role of the Able-Bodied Professional

Sheldon Berrol, MD

ABSTRACT. Berrol S: Independent living program, role of able-bodied professional. Arch Phys Med Rehabil 60: 456-457, 1979.

• The Independent Living Program movement was created by the disabled community. It has established a broad coalition of diverse disabilities functioning to provide services on a broader scale than has been traditionally offered by the rehabilitation community. The effectiveness and the strength of the movement lies in consumer control. The able-bodied professional can provide expertise, balance and a vital link with established rehabilitation programs. The integrity of the independent living program movement can only be maintained and developed if these basic concepts are respected.

The disabled movement which emerged in the early 1970s had its origins in the civil rights movements, the free speech movements, and college activism in the mid- and late 1960s. This social ferment provided a fertile breeding ground for the development of self determination in the disabled minority. In reflecting on their own experiences with traditional rehabilitation service delivery models, disabled activists concluded that they were not sufficiently visible or involved in the rehabilitation process. There existed at that time the medical rehabilitation model and the vocational rehabilitation model. It was evident that no system was present to bridge the gap between the two.[1]

The disabled had clearly experienced multitudinous barriers to psychosocial integration into the able-bodied community. They had experienced the architectural barriers, the educational barriers, and the attitudinal barriers which had been given lip service only at that point. More significantly, however, there was the almost total absence of services designed to allow one to integrate into the community.

The basic premise of the movement is that the disabled should be integrated as fully as possible into their communities, and that the needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services which do not necessarily include medical or vocational rehabilitation. An innovative feature of the movement is the premise that independent living for the severely disabled is not

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only feasible, but is their basic right even in the absence of vocational goals. The independent living movement established the concept of a coalition of persons with disabilitites working toward a unifying goal of permitting an individual, regardless of impairment, to participate to the maximum extent possible in normal activities of everyday life.

The independent living movement was created and nurtured by the disabled community, and the successful programs are governed and directed from within this community. There have been several attempts to establish independent living programs under the aegis and guidance of medical rehabilitation institutions, state vocational rehabilitation programs, and single disability volunteer agencies. The majority of these programs have not achieved the success of consumer based organizations.[2]

Traditional rehabilitation programs are directed by administrative and governing boards that are primarily concerned with a positive public image, a need for service development and cost effectiveness. These goals are frequently barriers to the aggressive advocacy necessary to an independent living program (ILP). Few institutions would provide a visible advocacy image in the face of potential adverse publicity.

The development of the ILP requires the identification of service deficiencies. The basic premise is the expansion of existing services to meet the needs of the individual. Traditional rehabilitation models are primarily concerned with the development of new services. The ILP movement has demonstrated a more effective expenditure of dollars in securing services from existing community agencies. A realistic fear of the ILP movement is the open attempt at assimilating the programs in an effort to gain increased funding for the institution.

The disabled community must have a primary role in the disposition of monies created by new legislation or the basic premise of self determination as a primary motivating factor will be eliminated. This would presage the demise of the ILP movement. The able-bodied professional can provide expertise to the program, but cannot provide the essential motivation or role modeling necessary to initiate progress toward independent living.

In the past, professionals have had a limited view of the potentials of the severely disabled, and we have unfortunately defined limits for various disability categories. For example, many textbooks are available that set limits for spinal cord injured patients depending upon their levels of injury. However, we have all seen exceptions to each of these limitations. How many more exceptions would there be if we did not daily define such limitations? In fact, as professionals, we need to help our patients redefine their expectations upward.

The able-bodied professional working with an ILP needs to believe in the philosophy of self-determination and to promote the basic dignity of worth of each individual. Services need to be developed that will allow for upward mobility and access to the community at large. Traditional rehabilitation models have defined programs around dependency rather than independence and the direction for change must occur with the aid of the rehabilitation professional. It is essential that a major thrust be directed toward balancing the opportunities for the able bodied and the disabled as the latter emerges into the status of the professional. It is unfortunate that within the field of rehabilitation many professionals have a distorted view of disability by never having worked with or for people who present successful disabled role models.

We must not confuse the concept of transitional living with the ILP. The development of basic living skills in a transitional facility requires professional development. The acquisition of independent living skills, however, requires the development of community resources, a variety of potential living situations, and the facilitation of adaptive coping and confrontation strategies. These issues can best be addressed by skilled peer professionals unhampered by institutional pressures.

The able-bodied professional must participate in promoting the expansion of services to the disabled. Changes in local services, such as the disastrous limitations of attendant care responsibilities in California, has significantly altered the ability of the disabled to purchase services with existing dollars. Yet no professional organization lobbied the legislature or the governor; only the disabled were heard from. To develop a true collaborative relationship, we, as able-bodied professionals, must speak out publicly for those we serve.

In summary, the able-bodied professionals must provide leadership in their areas of expertise without dominance, they must provide services, they must be active advocates, they must share their unique skills, and they must provide training. They must assure that there are the same opportunities to develop positive role models as are available to the able-bodied population. For successful involvement in the development of an independent living program, the able-bodied professional must allow the direction of the ILP to occur from within the disabled community, reflecting the unique needs of that community and its members.

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What You Always Wanted to Know About Sexuality and Handicapped People . . . Now You Can Ask!

The scene takes place in a counseling room at the Sex and Disability Unit of the Human Sexuality Program in San Francisco.

Three people are seated, talking with each other. Two of these people, a man in a wheelchair with a quadriplegic spinal cord injury and a woman with cerebral palsy, are the "counselors." A man, also in a wheelchair, who has been paralyzed from the waist down for the past five years, is the "client." The three people are gathered for the first time to decide if what the client wants in the way of information and feedback is what these counselors can provide.

As the scene opens, the client has just finished talking about how difficult it has been for him to develop relationships with women since his injury. He has described his frustration and dismay at not being taken seriously by women he finds attractive.

The counselor in a wheelchair begins to talk about some of his own experiences of feeling isolated and scared. He also speaks briefly of some of the ways he asserts himself with women and how well they work, sometimes.

While he is relating this, the woman in our drama begins to have misgivings. She has heard him share this information before, and even though it is valuable, she believes he is setting himself up for the client to discount. By sharing his own experience so early in the session, the client has a perfect opportunity to respond: "But that's not me!"

Instead the client is smiling and saying: "You know, I've said these same things to a lot of people and they've all tried to cheer me up. You're telling me what you do . . . Well, I just can't say you don't know what you're talking about. If you can meet women, maybe I can too."

IT'S TIME FOR TRUE CONFESSIONS. I admit that I was the female

counselor in the scenario. What impressed me in the preceeding scene was the realization that the man who had come to us for assistance was so simply and eloquently able to sum up one of the major goals of the Sex and Disability Unit.

This goal, to enable a number of disabled people to provide accurate sex information in an empathetic manner to other disabled people, is the core of our philosophy. This idea of consumer-based sex education, though not a new one, had a particular evolution I would like to describe. The process may be of help to people doing similar work in the future.

I met Robert Geiger, M.D., in 1972 when he was lecturing to medical students at the University of California, San Francisco, about the effects of spinal cord injury on sexuality. I was in college at the University of California at Davis, doing an independent research project on sex and disability. (This project was funded by the National Sex Forum, San Francisco.)

We were both "one of a kind" in those days when "Sex and Disability" was a nonentity, except in the hearts and minds of many disabled people who were aware that the rest of society didn't see us as sexual beings. When we met, Bob was contributing much of his free time to various rehabilitation centers, spreading the word that disabled people are sexual beings, and getting lots of strange looks from people in the medical profession.

Bob and I spent a lot of time discussing the potential impact of a sex and disability education movement. We discussed not only the impact on disabled people but on people in the helping professions as well. Very early in our debates, Bob introduced me to the concept of the "ringer."

Basically, he believed that anything he said to a group or audience about sex and spinal cord injury needed to be presented in relation to the experiences of disabled people themselves, particularly if there were any people with disabilities in the audience.

What he had developed was an amazingly effective educational tool. After speaking to a group, and then answering questions, he would take a question and address it to a spinal cord injured person in the audience. This approach not only gave participants some firsthand information, but also raised the status of disabled participants from being specimens under study, to colleagues with information and experience to share.

Even before I met Bob, I had been interested in finding out more about the sex and social information needs of people like myself with cerebral palsy, and others with congenital and early-onset disabilities.

"One of the major points made by many people with all types of disabilities was the need to inform health professionals that disabled people are sexual beings."

In the early 1970's, the development of information on sex and spinal cord injury was still in its infancy. But, through Bob's work, and the work of other places such as the program in Human Sexuality at the University of Minnesota, there was the beginning of awareness among persons in the helping professions. Professionals were learning that a person who becomes disabled as an adult will frequently have sexual concerns, and a need for information both during and after the rehabilitation process.

The experience of many people with life-long disabilities is one of being treated as asexual all of their lives, and little attention from the medical professions has been paid to this problem. Both Bob and I felt that both groups (those congenitally disabled, and those disabled later in life,) had a right to have their sexual and social needs addressed.

In the fall of 1973, through funding to the Human Sexuality Program made possible by the national office and the San Francisco affiliate of the United Cerebral Palsy Association, we were able to begin to assess the needs of people with cerebral palsy.

Through flyers and press releases distributed throughout the Bay Area, we asked adults to meet with us and to describe what it had been like for them growing up with cerebral palsy.

How did other people relate to them socially and sexually? How did they feel about themselves as social and sexual people? What ideas did they get from their families when they were small about their potential to have both sexual and social relationships, to raise families, etc.? What information did they now have about sex and how did they obtain it? The results of this counseling study are published elsewhere ("Sexuality of People with Cerebral Palsy," *Medical Aspects of Human Sexuality, March 1975).*

What I think is important to this discussion is that in gathering information we sought out the "experts" themselves, the people with the particular disability and life experience. In fact, I repeatedly said, "The reason we are asking you to speak with us is because we don't have the information. By you and others telling us about your individual experiences, we hope to develop a program that will assist not only you, but all of us with congenital disabilities."

One of the major points made by many people with all types of disabilities was the need to inform health professionals that disabled people are sexual beings. Not only our program, but others throughout the country have used panels of disabled persons as people rather than "patients."

One of the most exciting experiences I still encounter in educational sessions was having an able-bodied participant come up to me and say: "You know, until I heard you and these other people speak, I thought I'd kill myself if I ever ended up in a wheelchair. But hearing all of you say that life goes on and that it can still be worthwhile and even fun (much less sexy!) makes me feel better. I don't have to worry so much about the future, and maybe being disabled isn't such a tragedy after all."

Yes, Virginia, there is life and often love after disability . . . which brings up the question of "Who really needs the disabled sex educator?" Is it mostly the disabled person?

I think a disabled "peer" counselor can add a unique degree of credibility

and specific information because of his or her personal experience. However, I know able-bodied people who, because of their personal empathy and professional skills, are also excellent sex and disability educators. It seems that a disabled person can benefit from contact with either of these.

I personally feel that the people who *really* need disabled educators and counselors are able-bodied. The able-bodied helping professional, the family member of the disabled person, and the person on the street are all in need of getting clear, correct information on sex and disability. They should get this information from disabled people who exemplify and exhibit the social skill and comfort with sexual issues that is so lacking in most persons, regardless of physical abilities.

Whether giving a presentation, counseling, consulting, or just engaged in a casual conversation, the disabled person who is competent, and who is sexually and emotionally self-aware does much to demonstrate that disabled people are sexual.

This image should not be misconstrued as the "Super Gimp" who works an 80-hour week and would rather be dead than admit that he or she feels scared and/or helpless at times. Instead, we need people who acknowledge both their strengths and limitations, and who are comfortable about themselves. Only by being human will others begin to see us that way.

After the three years with the "Sexuality and Cerebral Palsy Project," Bob and I, and disabled colleagues who worked with us in conferences and workshops, decided that our next step toward gaining sexual and social rights would be to train people to provide sociosexual education and counseling.

We wanted to reach two specific groups: 1) disabled people, (and able-bodied persons who have significant personal and/or professional relationships with disabled people), who could become educators and counselors; and, 2) teachers and parents of disabled children, who could teach accurate and effective sex and social skills education in the classroom and at home.

The first group could have an effect on the able-bodied and disabled adult population. The second group could provide children with the information and encouragement that might facilitate a more fulfilling and enjoyable adolescence and adulthood. We wrote two grant proposals to cover both groups, and both were funded.

The "Training Project in Sex and Disability" funded by the Division of Manpower Training, National Institutes of Mental Health, has trained 28 people over the past three years to become educators and/or counselors (depending on their individual skill level) in sex and disability.

This half-time, one-year training program gave these people exposure to specific information about sexuality, social skills development, and various disabilities and medical conditions. Additionally, all of the people, 70 percent of whom are disabled, worked during their training in either a community agency serving the disabled or in a hospital setting.

"But hearing all of you say that life goes on and that it can still be worthwhile and fun (much less sexy!) makes me feel better."

They gained experience doing in-service training and community education with a wide variety of professional and consumer groups. One of the major findings from their community work was that disabled persons with sexual and social concerns do not, for the most part, need "psychotherapy" to deal with their issues. Instead, education and information-sharing in an empathetic manner, either individually or in a group, supplies the support most need to make their lives more fulfilling.

By exploring their own feelings about disability and life concerns during the training process, these people have been able to assist both disabled and able-bodied persons in finding solutions to their questions about sex and disability.

Our second group, teachers and parents, have been reached by conducting "Family Life Education Training" workshops for 300 people throughout the country. This is done through a grant from the Bureau of Education for the Handicapped. Much of the teaching and small group facilitation in these courses has been provided by disabled teachers. These staff members have done much to assist workshop participants, (most of whom are able-bodied, and deal with young disabled people), in seeing that disabled people can grow up and form satisfying social and sexual relationships.

A future goal of the Sex and Disability Unit, contingent on funding, is to give priority to teachers and parents of students who are either hearing or visually impaired. These groups of students are distinctly different from each other, and from persons with physical disabilities, in problems they face with their particular sensory impairment. But, they are similar in the experience of lacking social and sexual education during school years.

It is our plan to provide accurate information and encouragement to teachers and parents utilizing a staff composed of deaf or blind teachers. In this way, participants will gain a positive outlook about the social and sexual potential of their students.

What I have described is how one program, the Human Sexuality Program in San Francisco, has approached the topic of sex and disability. By utilizing the people most affected, disabled people, we hope to have a lasting effect on society and the disabled people who are a part of it.

I believe it is our humanness and our ability to love that can bridge the gap called "difference."

—Susan Knight

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Models for Consumer Involvement/Policy Development Consultation

A. Introduction

1. There are several CI/PDC models agencies may choose to follow:
   a. Each model should be evaluated in terms of appropriateness for the agency. The agency should:
      (1) Study characteristics of each model.
      (2) Let the consumer advisers state their opinions on each model.
      (3) Have a reasonable trial period (optional).
      (4) Adopt the best model(s) that will meet the legal requirements.
   b. **No one method** works for every state agency. Choose the method or methods best for yours.
2. One staff person should have responsibility for CI/PDC:
   a. He/she will be a representative from the State Rehabilitation Agency's administrative structure.
   b. Getting the program started will be this individual's responsibility.
   c. This person will give the program the time it deserves.
   d. He/she will provide leadership for the program.
   e. This staff member will be a catalyst-advocate for agency, for consumer.

B. The Models

1. Consumer Advisory Committee
   a. Make sure there is a balanced and adequate representation from all consumer groups and providers of Vocational Rehabilitation Services.
   b. Most state agencies have used this method and feel comfortable with it.
   c. Regional and/or District Advisory Committees:
      (1) These committees are in addition to the state advisory committee.
      (2) They deal with local policy and administrative matters.
      (3) Supervisors of the district or regional offices can serve the adviser position(s) for these committees.
      (4) Selected members from these committees could be sent as delegates to the state advisory committee.
      (5) The State Consumer Advisory Committee/State Agency must assess and address issues presented to them by the Regional Committees. Feedback must be provided to ensure their continued involvement in CI/PDC.
2. Forums and Open Meetings
   a. A series of meetings conducted at scheduled intervals in the state capital (or other parts of the state).
   b. An **adequate** and **balanced** representation of all consumer groups and providers of Vocational Rehabilitation Services is required.
   c. The written State Plan should explain how to obtain a balanced and adequate representation.
   d. All participants should be notified and sent materials well in advance of scheduled meetings so that:
      (1) They can review all proposed programs, program changes, current practices, etc.
      (2) They can present items (in advance) to be included in the agenda.

e. Next to Advisory Committees, State Agencies have utilized forums the most. As a result, they feel comfortable with this method.

3. Opinion/Attitude Surveys
   a. Advantages:
      (1) Surveys can reach large numbers of people in a relatively short period of time.
      (2) It is economical, if done by telephone or mail.
      (3) Sometimes, it is the **only** way to obtain the desired information.
   b. Disadvantages:
      (1) This method permits neither an exchange of views nor the in-depth deliberations that can take place in the other models.
      (2) Great skill is required in preparing the survey questions and statements to reduce to a minimum different interpretations of the questions.
      (3) The follow-through in informing those polled of the survey results may require considerable effort (depending upon the number and location of the people polled).
   c. In all probability this approach should not be used on a permanent basis, since the other methods are more effective and involve direct contact between consumers and state agencies.
4. Other Models
   a. Closed-circuit television
   b. "Hot Lines" (Telephones)
   c. Your own ideas
   d. Expect new and different approaches in the future.

Consumer Rights and Responsibilities

A. Consumer Rights

1. Client Orientation: Exploration of roles, expectancies, responsibilities, and counselor/client relationships.
2. Local level Advisory Groups: Understanding of the role and function of the local rehabilitation office, agency staff, and services.
3. Agency Training Activities: Consumers participating in training programs should be provided with adequate information; be encouraged to participate in program planning; be reimbursed for travel, per diem, and other expenses.
4. State Office Level: Policy development consultation can only be provided by clients who are well informed, trained, and provided adequate resources. This is especially true in areas of budgeting, priorities, programs, services, etc.
5. In summary, consumer advisers must have access to information to which they are entitled and to agency policy, procedures, regulations, and limitations.
6. **Consumers must be trained.**

B. Consumer Responsibilities

1. Responsibilities to the state agency and to their constituents.
2. Recognizing and understanding the legal mandate and budgetary limits of the state agency to which they are providing policy development consultation.
4. Willingness to work with the state agency constructively and consistently over a sufficiently long period to effect desired changes;
4. Devoting whatever time and effort is required to gain a clear and comprehensive understanding of the policies and procedures of the state agency.
5. Dealing with problems as issues and not in a personal or vindictive manner;
6. Willingness to be concerned with a broad range of issues and to view program proposals when indicated in terms of benefiting all disabled people and not necessarily one group of handicapped people;
7. Keeping their constituency informed about state agency policies and programs and their role in the development and implementation of these policies and programs.

C. Consumer Organizations' Responsibilities

1. The consumer organizations must recognize and understand the legal mandate or mission of the agency with which it is dealing.
2. Policy and procedures of the agency must be understood by the consumer.
3. Consumer organizations, as represented by leaders, must be willing to work with an agency, constructively and consistently over a sufficiently long period to effect the desired changes.
4. Representation from a consumer organization should be broad enough to meet the needs of its constituency.
5. Problems must be dealt with as issues, not in a personal or vindictive manner.
6. The consumer organization must keep its members informed about agency responsibilities and policies.

Advantages of Consumer Involvement/Policy Development Consultation

A. Advantages of CI/PDC for the Consumer

1. Consumers will become more familiar with the mission and regulations governing the agency.
2. Consumers will be able to guide their constituents to the agencies which can most appropriately deal with their specific problems.
3. Consumers have initiated many projects designed to help themselves (e.g. New Options, the Center for Independent Living (CIL), Berkeley, California). As one of the pioneers, CIL initiated self-help groups, peer counseling, consumer advocacy, and other programs for consumer assistance. As a result of the efforts of CIL, similar projects are being developed and operated by consumer groups across the country.

B. Advantages of CI/PDC for the State Agency

1. Greater efficiency
2. Fewer clients will be mis-directed to agencies that cannot meet their needs
3. Consumers can become "agency" advocates
4. Legislative changes (due to consumer advocacy)
5. Fund-Raising enhanced due to positive consumer advocacy and involvement
6. Will keep staff informed on contemporary problems of the handicapped
7. Improves client-counselor relationships
8. Feedback from clients
9. Evaluation tool that can augment the quota and cost-analysis methods now used
10. Receive new insights and ideas which can lead to innovation
11. Builds morale of agency staff: Agency personnel are frequently better motivated after working directly with consumers. Being able to see the results of services and developing meaningful rapport will increase a sense of purpose and dedication on the part of agency workers.
12. Increased client morale due to increased self-esteem and the opportunity to contribute.
13. Consumers may become rehabilitation professionals: Such professionals provide valuable insight for agencies.
14. A proper CI/PDC program will include feedback not only from clients and service providers but from all segments of the population.

I. Background

Consumer Involvement constitutes one of the three developmental objectives within the Client Services Division for FY 1979. Momentum for this Program has been provided by a number of sources including the Vocational Rehabilitation Act of 1973, State and Federal Mandates for Consumer Involvement, an Innovation and Expansion Grant with Tufts-New England Medical Center on Consumer Involvement, and numerous contributions over the past decade on citizen participation in human services. Much of the rationale for the Agency's Plan on Consumer Involvement has been drawn from these resources and activities. (See list of attached readings for further reference.)

As a position statement for Consumer Involvement in the Agency, this paper identifies where we have been and where we intend to go.

The Consumer Involvement Program will implement this position throughout the State.

II. Definitions

1. Consumer

   a. An individual who is a past, present, future, or potential client

   b. A parent or guardian of a handicapped individual

2. Consumer Representative

   An elected or appointed individual who represents a group of handicapped individuals or parents of handicapped individuals.

3. Involvement

   a. Any activity which utilizes the ideas and suggestions of consumers or consumer representatives for policy development consultation

   b. Any activity which impacts upon the delivery of service system in a positive manner

   c. Any activity which finds Agency staff working with consumers to improve the environment surrounding handicapped individuals

III. Purpose

The major purpose for the Consumer Involvement Program is to improve the Agency's service delivery system. The Rehabilitation Services Administration requires each state agency to actively incorporate into its policy making structure the views of individuals and groups who are:

1. recipients of vocational rehabilitation services, or, as appropriate, their parents, guardians, or other representatives;

2. providers of vocational rehabilitation services; and

3. others active in the field of vocational rehabilitation (Rehabilitation Services Manual, 525.02, 1975)

By working cooperatively with individuals in these categories, Agency staff will be able to develop more extensive resources in the community. Issues of concern for handicapped individuals may be addressed so that the overall environment surrounding disabled citizens may be improved. This cooperative relationship should foster an atmosphere where mutual advocacy will further the cause of those served while it improves the capacity of the Agency to carry out its mission

IV. Assumptions

Several basic assumptions must be made before an effective Consumer Involvement Program is to be implemented.

1. MRC wants input and feedback from consumers on the service delivery system.

2. Consumers want to give input and feedback to the Agency.

3. Roles for interaction among participants are clearly defined.

4. All participants in Consumer Involvement activities recognize that such an evolutionary effort will require a commitment from everyone for a period of initial development and future implementation.

5. MRC is committed to an enduring Consumer Involvement Program.

V. Difficulties

These assumptions must be seen in the context of perceptions and concerns on the part of staff and consumers alike. Only then can a clear understanding of the appropriate action for implementation of the Program be gained.

The following are some examples of concerns and perceptions commonly held by consumers:

1. It is difficult to make an impact on any bureaucratic process or institution.

2. Agency staff may appear to have a condescending attitude toward those people they are helping.

3. The Agency's Consumer Involvement activities may appear to be only token efforts at placating consumer advocates.

4. The Agency may wish to take away benefits from those consumers who express unpopular opinions.

5. There may be limitations in finances, time, and communication facilities (e.g., interpreters for the deaf and Spanish speaking) on the part of the Agency as well as consumer participants.

6. Agency staff and consumers may have philosophical differences on the ability of non-disabled persons to deliver rehabilitation services.

Those difficulties as perceived by Agency staff may include:

1. Consumer Involvement takes too much time and money.

2. Cross-disability representation is impossible.

3. Consumer Involvement provides an additional atmosphere of confrontation.

4. This atmosphere may lead to consumer control, thus, lowering the status and power of the professionals.

5. Consumers lack knowledge in the rehabilitation system.

6. Limited professional experience in and exposure to consumer involvement provides too great a risk for doing something wrong.

VI. Benefits

The following list of reasons for the Program's development lends perspective to the task at hand.

1. Consumers can contribute an important resource in those areas where rehabilitation professionals may need technical assistance. Consumers can provide new ideas for more effective service delivery through experience gained by living with their own disabilities.

2. Public support for Agency policies and practices can be gained when consumers understand the responsibilities and limitations of the Agency.

3. Reward to Agency staff can increase as a result of cooperative relationships with consumers.

4. Increased reward can also be experienced by the client population being served.

5. Additional advantages have been listed in Chapter 25 of the Rehabilitation Services Manual. They are:

   a. increased awareness of client needs;

   b. realistic insights as to how various aspects of the state vocational rehabilitation program are functioning and how they might be improved;

   c. establishment of better working relationships between the agency and clients, providers and other individuals and organizations active in rehabilitation in the state;

   d. better information sharing and clearer understanding of the state agency's mission, goals and objectives;

   e. increased and more effective advocacy for the state agency's programs and its program needs; and

   f. establishment of a mechanism to permit continuous external feedback from all segments of the population on current and proposed operations and plans.

VII. Methodologies

The Agency has utilized a wide variety of models at all levels of management in the implementation of Consumer Involvement. It is important to recognize how extensive the practice of Consumer Involvement activities is within the Agency at this time. Many of the models used have become an established part of the Agency in their own right. The list includes the following:

1. When a counselor and a client negotiate the Individualized Written Rehabilitation Plan (IWRP) a form of consumer involvement takes place. As an extension of this process the Ombudsman is assigned to work with client complaints on individual cases. Administrative Review of cases and the Fair Hearings process provide clients and client representatives an opportunity to pursue their complaints within the System.

2. Another model whereby an individual consumer (not necessarily a client) may become involved is through Individual Policy Consultation (IPC). Some uses of this model include:

   a. assist in interviewing and hiring new personnel

   b. participate in staff training

   c. assist in developing solutions for difficult cases

d. assist in contacting and developing relationships with local agencies and groups

e. discuss issues of a specific disability group

f. review and comment on Agency policy stands.

3. Consumers become involved when they enter into group counseling, peer counseling, Job Seeking Skills Groups, Self-Help Groups, Job Clubs, or any other group activity sponsored by the local area office.

4. Agency staff have also become involved with groups outside the Office sponsored by consumers. This gives an added perspective on consumer issues not available at Agency run activities.

5. Consumers have participated in Area Strategy Planning Team (ASPT) hearings.

6. For approval of Innovation and Expansion Grant funding the Agency requires that each group have a Consumer Involvement component, thus insuring the support of consumer run service programs such as those, for example, at Boston Self Help Center, Worcester Area Transitional Housing, and the Stavros Foundation.

7. The Information Center for Individuals with Disabilities at the Central Office has been set up and run by the Inter-Campus Committee for Handicapped Students (ICCHS) which is a consumer group.

8. The newsletter, Consumer - Rehab. Link, is run by consumers who report on issues important to the handicapped community around the state.

9. Statewide consumer conferences on vocational rehabilitation have been organized by Tufts-New England Medical Center and the American Coalition of Citizens with Disabilities.

10. Advisory Councils have taken form in over a dozen area offices and at the Central Office. The local Councils have worked to ensure that services provided by the Agency respond to the needs of the disabled population in the area. The Advisory Council at the Central Office meets with the Commissioner to address policy issues affecting the Agency on a statewide level.

11. Partnership-Advocacy groups have been generated out of attempts to serve the needs of participating consumers on Advisory Councils. When the most important concerns of handicapped people in a given area do not include vocational rehabilitation service delivery or policy stands, then a group of consumers may find that, with

the assistance of Agency staff, different problems can be addressed. For instance, transportation, accessibility, housing, and public education for the handicapped community have been addressed in such groups. MRC staff offer assistance to consumers on the problems of priority in their area. Thus, a form of partnership has been developed for the purpose of advocating for a better living environment for MRC clients and disabled people in general.

Regardless of the model chosen as a valid form of Consumer Involvement, it is important to recognize how to differentiate models. Only a clear definition of the roles of the participants can keep a breakdown in communication from occuring.

VIII. Plans

Within the context of the second administrative goal "To assure consumerism", the following is a list of objectives which are to be met for the development of a coherent statewide Consumer Involvement Program. Attached to each objective are the activities by which each objective can be achieved.

1. Involve consumers in policy development consultation, encouraging direct contact with consumers, direct input and feedback, and mutual accountability.

   a. Continue utilization of consumer input through Advisory Councils.

   b. Continue utilization of consumer input through Individual Policy Consultation.

2. Participate with consumers in the community on projects of mutual concern.

   a. Continue to form Partnership-Advocacy relationships with those consumers interested in improving the environment of disabled people.

   b. Maintain close working relations with consumer groups and coalitions.

   c. Assure the continuance of a newsletter which publishes material of interest and concern to agency personnel and the consumer community.

3. Assure some form of Consumer Involvement activities at all levels of the Agency.

   a. Adequately fund and staff Consumer Involvement at the local, regional and central levels.

   b. Encourage staff efforts to contribute creatively to Consumer Involvement activities (e.g., development of new models of Consumer Involvement).

c. Experiment with the implementation of Regional Advisory Councils where and when appropriate.

d. Implement a logical link between the Central Office Advisory Council and the Area Office Advisory Councils in order to achieve statewide, cross-disability representation on the Central Office Advisory Council.

e. Institute permanent guidelines governing the implementation of Consumer Involvement activities defining the issues of: payment for consumer participation, Advisory Council structure and procedure, rights and responsibilities of consumer participants as well as Agency staff.

4. Formalize training in Consumer Involvement for Agency staff in the areas of model development (process) and communication skills (sensitivity).

a. Conduct statewide and regional training sessions for a combined group of Agency staff and interested consumers.

b. Provide forums for Agency staff to trade ideas, concerns, and philosophies in regard to Consumer Involvement in order to keep the topic alive and to keep the sophistication of Consumer Involvement activities growing.

5. Conduct an ongoing evaluation component as a part of the Consumer Involvement Program.

6. These objectives and activities will be utilized in formulating specific statewide, regional, and area office plans both long and short range.

PEER COUNSELING

Consumer Involvement is a big part of independent living programs. From the planning stages to the actual provision of services disabled people are involved. One form of this involvement, is peer counseling.

To me, no segment of any independent living program is more important than peer counseling. Peer counseling means disabled people serving as information providers, resource persons, sounding boards, and role models for other disabled people. Not only is peer counseling important, but it can be cost-effective for a facility. It does require effort and planning.

Five years ago when I became a paraplegic, I really didn't consider myself "disabled." Lets say, five years ago when I found myself unable to walk, to control some of my body functions, to get in and out of most buildings, to reach canned food at the supermarket - when I found myself disabled in all these important areas of my life - the thing that I wanted the most was to talk with someone I felt knew the feelings I was experiencing.

I wanted to talk with a woman who was in the same boat I was, but who was rowing with agility and speed. I wanted to meet a woman who was in a wheelchair and had been long enough to have put her life back in order. Maybe you think "If that was what you wanted why didn't you go after it." I don't know why I didn't simply ask somewhere to find such a woman - I didn't. I kept thinking, "All these people are trying to help but they don't understand." I wanted "peer counseling," but I didn't even know such a thing existed. Actually, I was so uninformed that I associated counseling only with psychiatry.

I did not find a peer counselor until almost two years after I became disabled. I can't describe to you how thrilled I was to find her. I was so hungry to know all about her life, her methods for coping with everyday annoyances and difficulties, and especially, her ways of coping with feelings. The million feelings, fears, and discomforts associated with being disabled.

I asked such questions as, "How do you get your chair in and out of the car?" I wanted to see if she knew a better way than I had devised. "Do you travel alone, or stay in motels by yourself?" At that time I had not spent a night alone since becoming a paraplegic. I was afraid. "Do you date?" I was real interested in anything she could tell me about dating. You'd think a woman who had been married for 11 years would know how to relate to men, but my experience had been as an able bodied teenager and then an adult wife. Now that I was a disabled divorced woman, I felt totally unprepared to cope with dating. I asked her, "Do you feel less of a woman?" and "How do you feel when people stare." The most important question I wanted answered was, "Are you happy now - is it okay after 5 or 6 years; does the pain of being 'different' lessen?" All of these questions were ones I desperately needed answered by a relatively well adjusted disabled woman.

The benefits of my encounter with that woman three years ago are still with me, and I've been given the opportunity since then to serve in a similar role for other disabled individuals. I have been asked by counselors, friends, and families of disabled individuals to get in touch and share my experiences. I have functioned as a sounding board, resource person, role model, friend, or in short, "peer counselor." All my experience in this area has been as an unpaid volunteer. This is one approach that is not utilized to the fullest. Of course I was paid with

"warm fuzzies." Another approach could be to set aside monies in an independent living program to pay peer counselors.

If peer counseling is to be part of an independent living program, where to begin needs a little discussion. Of utmost importance is finding the right people. There are such people everywhere. But what are you looking for in a peer counselor? I think four characteristics are important. First and of great concern should be the person's outlook on life. A positive outlook is vital; a peer counselor who accentuates the positive. I don't mean that the negative aspects of the disability should not be dealt with but that more emphasis should be placed on the positive aspects of daily living.

A second characteristic is independence. They should be independent to their fullest limit possible. That doesn't mean living alone and functioning as an island. For a quadraplegic, it could mean living in an apartment with attendant care, doing volunteer work, and singing in the choir on Sunday. If that is that person's optimum independent functioning and they are at that level with a positive attitude, then they have met the first two requirements.

A third characteristic should be love - a healthy love for other human beings - whether able bodied or disabled. If the wrong people are chosen, peer counseling sessions can turn into "We disabled get a raw deal from able bodies." A person with a "chip on their shoulder" towards able bodies could be disasterous for the counselee. On the other hand, a person uncomfortable with his own disability could use his peer counselor status to prove his superiority over the counselee. I guess what I'm saying is he needs to love others, and this love is only possible if he loves and is comfortable with himself.

The peer counselor that I see as "perfect" is positive, independent, and loving - but that's not all - I see one more characteristic as necessary. He should be outgoing.

By outgoing, I mean having a desire to share in conversation. A person can be positive, independent, and loving, yet find it quite tramatic to converse with others about personal subjects. They will need to be open and be willing to share aspects of their own life.

Now that we have decided on what we are looking for in a counselor, we need to decide on where to look for them. Local active organizations, such as disabled groups, civic groups, and service clubs could be utilized. Accepting resumes, interviewing and building up a file of interested individuals and their specific disability is another alternative.

Some of these people will be available during the day and can come to a facility for group sessions or individual interactions during the workday. Others would be available during evening hours. Developing a weekly or bi-weekly evening group might be feasible, or counselors could remain by telephone to answer unexpected calls or address needs for assurance and support. Some would be willing to make home visits. Some would be unable to leave their own home. I think limiting peer counselors to people who are unable to be mobile is failing to utilize every resource available to us. There are homebound people who possess all the characteristics that are important in a peer counselor. I know one such person who might be termed as an invalid. He is blind, and totally unable to move, except for his mouth and one finger. He developed a rare muscle disease at age 7

and at age 33 is confined to his bed. He is sharp, alert, compassionate, and great to talk to about lots of subjects. He has a special phone hook-up so he can talk to Birmingham from his home in Athens, Alabama. He has classes, by phone, with the University of Alabama at Birmingham. If I were in charge of an Independent Living program in Alabama, I would provide him with a state-wide hook-up, and a list of counselees. I figure he could reach out to the home-bound who could function independently someday, and be a source of sunshine to those who couldn't get out in the sun.

There are certain areas that a disabled person needs another disabled person to really cover. Number one is feelings. I believe that you can't know what it is like to have a physical disability if you are able bodied. You can sit in a wheelchair and try to experience it, but you are only "sitting" in a wheelchair. Just sitting in a wheelchair isn't the problem, it's the million feelings you experience as a disabled person that is the problem. I was blindfolded one day for half an hour to get an idea of blindness, but I didn't get close. I knew I could "take off my blindness" at anytime that it became too inconvenient. I can't take off my paralysis. I feel what it is to be paraplegic.

I can't feel what it's like to have a limb missing, a facial disfigurement, or a bent and twisted body. But I do have one thing in common with people who have these handicaps. This concerns how society views us. We are seen as different, abnormal, inferior, or strange. Because of this commonality between all disabilities, I can understand when a young man with facial disfigurements talks to me about his desire for normal relationships with the opposite sex. I can understand when a young woman with no arms talks about how she wants to be seen as a "real woman." I'm not saying "the only good counselor is a disabled

counselor." However, I do feel disabled counselors can be uniquely successful for two reasons. Their experiences, and the counselees' feeling that "here is a person who knows what I'm saying because he has been there."

After finding peer counselor candidates, there remains the task of training them. Perhaps a ten hour course in empathic responding, resource availability, and counselor orientation would be in order. A training program could serve two purposes; to provide the counselor with needed skills and information, but also to give him a sense of pride and loyalty to the program. Developing a handbook for peer counselors would be advisable to cover such topics as confidentiality, ethics, and other important aspects of a counseling relationship relevant to peer counseling.

The fourth phase of peer counseling development involves the setting up of a schedule for services. This would change and differ, with the particular case load and type of facility. Needless to say, after you locate, choose, and train your peer counselors, you use them.

The main weakness in all programs for the disabled is that the programs end, and the disabled person is on his own. His disability doesn't end, but his support services do after a time. I see peer counseling as a "net." The occupational therapist, physical therapist, evaluator and rehabilitation counselor are like firemen who rescue the person from the burning building, but they aren't going to hold him in their arms for life. Peer counseling can help build a "net" the disabled person can fall into, when the professional services are no longer made available. I see peer counseling as having an on-going natural development, as it has for me and others I know.

I hope that I haven't given you the idea that I think the only type of consumer involvement should be in peer counseling. I think the disabled can and should be involved in all phases of an Independent Living Program, from planning the program, to serving in key positions in the provision of services. I love the idea of consumer involvement, and hope that it will become a reality and not just an idea or an isolated event.

GWEN CHANDLER