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MINI COURSE: BUILDING AN APARTMENT COMPLEX FOR THE HANDICAPPED

Readings:

Housing Authority Programs: Sections 8, 202, and 236
Small Business Administration: Sections 1&2 of the
Handicapped Assistance Loans
Dept. of Public Welfare Reports: Title XIX & XX
TRC Grant Guidelines
Laurie's book on Housing

Arrange meeting w/ :

Rodney Shaw - ILS
Rex Davidson - Independence Hall
Bob Geyer - consumer
Evelyn Thibedeaux - consumer
Will Clark - consumer
Bob Kafka - consumer
Jim Veerkamp - consumer
Cherry Albertson - DPW Homemaker Chore Service
Jean Cole - resource
David Stock - resource
Lex Frieden - resource
Mr. Hogan - Free Lives
Mr. Broncher - ILS
Richard Wilson - French Village

Agencies:

CETA
Small Business Administration
Volunteers in Technical Assistance
Retired Sr. Volunteer Program
Voluntary Action Center
HUD - Dallas & Houston offices
Jewish Community Center
Christian Home for the Aged

Write to:

- (1) Don Riel
Massachusetts
for information on Title XIX & Title XX sponsorship
- (2) Dave Williamson
HUD
Washington, D.C.
for information on community development programs
for the handicapped
- (3) Max Starkloff
St. Louis, Missouri
for information on a housing project he began
called "Paragrad"
- (4) Our Way, Inc.
Little Rock, Arkansas
for information on their housing project
- (5) Office for Handicapped Individuals
Washington, D.C.
request a copy of the OHI Resource Book
- (6) Jim Hayes
Coordinator of Handicapped Student Services
University of Texas at Arlington
Arlington, Texas
to request information on attendant management course
materials
- (7) Write to anyone you come across in the literature whose
projects seem comparable to what you want to accomplish.

General Assignments:

- (1) Begin and maintain a list of resources and summarize
what each resource has to offer.
- (2) Prepare a list of questions you hope to get answered
before each interview or telephone contact.
- (3) Write and mail your letters requesting various types
of information during the week of August 1st so that you will
receive replies during your participation in New Options.
- (4) Ask for as much written material as possible as you
talk with different people and/or agencies.

The Role of Vocational Rehabilitation
in Independent Living

IRI Prime Study Group I

Omaha, Nebraska

May 23-25, 1978

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Introduction to the Study on Independent Living

Independent living for rehabilitation clients has long been advocated by consumer organizations, professional organizations, and state rehabilitation agencies. Although independent living was never a formal objective, many individuals were able to achieve complete independence or independence of varying degrees as a result of rehabilitation efforts. Nevertheless, because these services were not available or were not provided due to many reasons, the rehabilitation gains attained by numerous individuals were ultimately lost.

Within the past several years, various organizations have initiated successful independent living programs for persons with severe disabilities. Pioneering efforts by agencies for the blind, the Center for Independent Living in Berkeley, California, and others have made, and continue to make, great contributions to independent living rehabilitation. These pioneers are to be recognized and commended for their involvement and contributions in an area so important to all people but especially those with severe handicaps. Additionally, because of their interest, concern, and efforts, consumers and professionals alike are seeking expanding independent living rehabilitation services, not only for those with vocational potential but also for persons for whom a vocational objective is impractical.

Such movements as centers for independent living have grown around the country. As a result, severely handicapped

individuals are seeking not only more involvement in their rehabilitation programs but are demanding expanded services, especially in the area of independent living. The groundwork has been prepared; and, now, vocational rehabilitation must go much further to meet the needs of individuals with severe handicaps as they strive to shake the dependency role for one of independence.

It seems certain that a formal program of some nature in the area of independent living rehabilitation will become a reality. Several events in the past few years support this observation:

(1) requirements of the Act of 1973 for a Comprehensive Needs Study (CNS) and (2) provisions for funding and implementation of special demonstration projects in the area of independent living. These projects, which will be discussed later in the document, have been designed to provide answers to the following questions:

1. What is the most efficient organizational arrangement for an independent living rehabilitation program?
2. What other programs and services can support an independent living program?
3. What services and/or additional services will be needed?
4. Who and what type of staff will be needed to provide the services?

Other significant questions which at this time have partial answers as a result of the demonstration projects are:

- ..Why should there be a discrete rehabilitation program for independent living?
- ..What services should be provided in such a program that are not now provided in existing social service, health, vocational rehabilitation, and related programs.
- ..Should the same services be provided to all severely handicapped people?

- ..What agency should provide the required services?
- ..Why can't handicapped people apply directly for services from the various existing programs?
- ..What people with what kinds of disabling conditions require special services for independent living?
- ..What should be the administrative setting for a rehabilitation program for independent living?

The preliminary data available in reference to these questions, as well as others, show much promise (e.g., some increase in employed clients and a reduced number of deinstitutionalized clients -- the Center for Independent Living in Berkeley reports that fifty-seven percent of those served are now independent, may have decreased transportation problems, and have fewer problems with assistive services.) However, more experimentation and research are needed before more definite answers to these and other issues are found.

Other issues of concern relate to expected outcomes, cost benefits, funding criteria, and accountability. Hopefully, these demonstration projects will yield answers and solutions. Much remains to be done in reference to housing, lowered interest rates on loans, transportation, removal of barriers, utilization of resources, etc. The program will be expensive, especially in the beginning of a rehabilitation client's independent living program, but over time may prove more economical than the present system.

Only time will reveal the final direction independent living programs will take; but, if agencies can begin to make decisions and investigate alternatives, when provisions are made for independent living rehabilitation programs, the programs can be implemented without long periods of delay.

Charges

The Institute on Rehabilitation Issues (IRI) National Planning Committee developed the following charges for the Prime Study Group on "The Role of Vocational Rehabilitation in Independent Living for the Severely Handicapped."

1. to provide information to assist vocational rehabilitation agencies in establishing independent living situations for the severely handicapped with consideration of legislation, attitudinal barriers within vocational rehabilitation and the community, innovative models, techniques, procedures, and other special problems;
2. to develop a resource document for rehabilitation agencies which will assist them in providing better independent living opportunities to severely handicapped clients; and
3. to develop a resource document to be used in the training of rehabilitation personnel to assist the severely handicapped individual to attain the greatest freedom in living independent in the community.

Some minor revisions were made in the original charges by the Prime Study Group but only for facilitating the development of the study.

Concepts of Independent Living Rehabilitation and Operational Definitions

The Rehabilitation Act of 1973 (Part D, Section 130(a)) states:

Section 130. (a) The Secretary shall conduct a comprehensive study, including research and demonstration projects of the feasibility of methods designed (1) to prepare individuals with the most severe handicaps for entry into programs under this Act who would not otherwise be eligible to enter such programs due to the severity of their handicap, and (2) to assist individuals with the most severe handicaps who, due to the severity of their handicaps or other factors such as their age, cannot reasonably be

expected to be rehabilitated for employment but for whom a program of rehabilitation could improve their ability to live independently or function normally within their family and community. Such study shall encompass the extent to which other programs administered by the Secretary do or might contribute to the objectives set forth in clauses (1) and (2) of the preceding sentence and the methods by which all such programs can be coordinated at Federal, State, and local levels with those carried out under this Act to the end that individuals with the most severe handicaps are assured of receiving the kinds of assistance necessary for them to achieve such objectives.

(b) The Secretary shall report the findings of the study, research, and demonstrations directed by subsection (a) of this section to the Congress and to the President together with such recommendations for legislative or other action as he may find desirable, not later than February 1, 1975.

For this IRI study, the following operational definition of independent living, as used by RSA, was accepted:

Independent living: to participate to the fullest extent possible in the normal day-to-day activities of everyday life.

The basic concept of independent living, then, is:

The ability of the severely handicapped person to participate actively in society: to work, to own a home, to raise a family, to acquire an education/training, and all other daily activities which will enhance his/her status as a contributing member of his/her community.

In the CNS, an independent living rehabilitation program is referred to as one:

which would provide comprehensive services to improve the ability of severely handicapped people to live independently or function normally within their family or community without reference to vocational goal.

The issue for state agencies may become one of providing services to handicapped individuals with and without vocational goals.

Purpose of the Study

The Prime Study Group has attempted to analyze independent living from the standpoint of the implications it has, or may have, for state rehabilitation agencies. As a result of questions related to organizational structure, funding, eligibility, and other factors which must be determined through Congressional action, it was possible only to project on many issues and implications. Nevertheless, independent living rehabilitation undoubtedly will become a reality; and, hopefully, through better awareness of the issues, state agencies will be prepared to assume whatever role they are assigned.

Many questions remain unanswered for state rehabilitation agencies in terms of an independent living rehabilitation program, but some groundwork is underway. The study has many limitations because of the many factors and impending issues involved. The Prime Study Group is hopeful, however, that this study will be useful to agencies as a basic manual for developing independent living rehabilitation programs (interfaced with existing independent living rehabilitation programs) and as a resource for in-service training of rehabilitation personnel.

REFERENCES

- U.S. Congress. Rehabilitation Act of 1973. Pub. L. 93-112, 93rd Cong., Cong. Report No. 93-391. Washington, D.C.: U.S. Printing Office.
- U.S. Department of Health, Education, and Welfare. Report of the Comprehensive Service Needs Study. The Urban Institute, Office of Human Development, Rehabilitation Services Administration, 1975.

UNIT I

HISTORICAL DEVELOPMENT OF THE INDEPENDENT
LIVING MOVEMENT

HISTORICAL DEVELOPMENT OF INDEPENDENT
LIVING MOVEMENT

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HISTORICAL DEVELOPMENT OF INDEPENDENT LIVING MOVEMENT

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INTRODUCTION

The Independent Living movement and its programmatic efforts are regarded by many as a new phenomenon on the rehabilitation horizon. However, interest in providing services that would assist the severely handicapped in achieving an independent lifestyle dates back several decades. As far back as the early 1950's, many states had introduced the concept of "mainstreaming" for the mentally retarded, and were providing half-way houses for the mentally ill. In 1959, legislation was proposed that would extend the benefits of rehabilitation to persons with severe handicaps, even when no vocational objective was obvious.

These bills contained titles relating to independent living rehabilitation services. The term "independent living rehabilitation services" referred to a variety of services which included but were not limited to: counseling, psychological and related services, physical restoration, and other related services, needed prosthetic appliances and training in such skills as would help maintain independent living.

In 1961 additional legislation was introduced which contained a title on "Independent Living Rehabilitation Services." These bills included, for the first time, an appropriation amount of \$15 million for the first year and \$25 million for the second year. The types of services proposed under this legislation were similar to those previously proposed in 1959. There were some further defining of services and change in emphasis. Such services as mobility and personal adjustment services were included. Also, the emphasis changed from just the mention of "maintenance" to more detailed discourse, for example, " ... maintenance needed to assure the availability of such services, and follow-up services to insure maintenance of rehabilitation gains." There was

also a shift from a limited discussion of preventing or reducing institutionalization to improving the lifestyle of the "seriously handicapped individual."

This removal of situation specific goals and the addition of the qualifier "seriously" handicapped were further evidence of the clearer portent of future legislative efforts.

All attempts at legislation were unsuccessful until 1973 when a breakthrough was established with the passage of the Rehabilitation Act of 1973. The Act made provision for a study of the comprehensive service needs of the severely disabled. Even though the Act failed to provide a formula grant program of Independent Living Rehabilitation (ILR) services for individuals with most severe handicaps, it did provide a legislative springboard for the development of a national policy on services to the severely handicapped. Also of significance were the provisions in Section 2 of the Act that gave priority for delivery of VR services to the severely handicapped.

The Comprehensive Service Needs Study, authorized in Section 130 of the Rehabilitation Act of 1973, revealed that programs serving the severely handicapped were inequitable, contained severe gaps in services, suffered from lack of coordination, and were not meeting the overall needs of the severely handicapped. The study concluded that there were still many unanswered questions and many unresolved issues that concern the provision of ILR services. In an attempt to address these issues, the Rehabilitation Services Administration (RSA), under the authority of Section 130 of the VR Act, funded five demonstration projects for the purpose of establishing and evaluating alternative ILR service delivery models.

Other concurrent efforts have been attempted and are now underway. These efforts are the result of the severely handicapped attempting to

their own problems. These community-based programs and centers have emerged almost simultaneously over the country. These programs utilize imaginative combinations of funding sources which include private, local, state and federal government assistance. These entities have provided much needed project funds usually given in the form of seed monies. With these funds the community-based, consumer-oriented programs have been able to explore and demonstrate methods for the delivery of independent living services.

In addition, some states have partially funded demonstration projects in alternative service delivery systems, utilizing VR Innovative and Expansion grant funds. Research and Demonstration grants have also been made for transitional living and other similar projects.

Evaluation of these various independent living efforts is not complete, and there remain many unanswered questions. It is clear, however, that independent living rehabilitation is a legitimate program. This is evidenced by the presence and success of the Section 130 Demonstration Projects, the consumer-oriented centers and the various existing state and nonprofit association operated programs. It is obvious that the need for these types of programs exist, and therefore, ILR should not be viewed as a futuristic concept, but rather as an idea whose time has come.

LEGISLATIVE HISTORY

1920 - 1971

The Vocational Rehabilitation program began in 1920 with the passage of the Smith-Fess Act (P.L. 66-236), and it traditionally has been the provider of services for the handicapped, although its mandate has been to serve only those handicapped individuals with a vocational potential. On the other hand, Congressional interest in addressing the problems of those handicapped individuals who have no vocational goal began to manifest itself as early as 1959.

During the period from 1959 to 1971, there were several attempts in Congress to enact legislation for special comprehensive rehabilitation services to improve the independent living of disabled individuals without regard to their ultimate employability. Emphasis in these early bills was on increasing the ability for independent living of the severely disabled, thereby reducing their dependence on public programs financed by public taxes.

In 1959, a bill (H.R. 361) was introduced (and reintroduced later in the year as H.R. 5416) that contained titles relating to independent living rehabilitation services.

Definitions in these bills were:

(a) The term "Independent Living Rehabilitation (ILR) services" means counseling, psychological and related services (including transportation) rendered seriously handicapped individuals and, in the case of any such individual found to require financial assistance with respect thereto, after full consideration of his eligibility for any similar benefits by way of pension, compensation, and insurance, such term shall include physical restoration and related services, including corrective surgery, therapeutic treatment, and hospitalization, needed prosthetic appliances and other devices which will contribute to independent living and training in the use thereof, and maintenance needed to assure the availability of such services.

(b) The term "handicapped individual" means an individual of employable age, as defined by regulations of the Secretary (of Health, Education, and Welfare), who is under such physical or mental disability as to require institutional care or attendance in his household continuously or for a substantial portion of the time, but who can be reasonably expected, as a result of rehabilitation services, to achieve such ability of independent living that he will no longer require such insitutional care or such attendance in his household.

In 1961, bills--authored primarily by the National Rehabilitation Association (NRA)--were introduced calling for a cooperative arrangement among state agencies administering public assistance, health services, social security and other programs, to provide independent living and ancillary services. To assure that attention given to this new program

would not detract from the traditional emphasis on vocational rehabilitation, the NRA recommended that the two concepts be segregated into separate programs.

These bills were opposed by the Administration. "The nature of the opposition was unclear, but persons involved in the process at the time recollect that the opposition was due to the inability of the DHEW to settle who might administer the provisions." (Comprehensive Service Needs Study, Urban Institute, 1975).

Although independent living rehabilitation services failed to achieve a legislative base, the need to serve severely disabled individuals was recognized. In 1965, amendments to the Vocational Rehabilitation Act provided for "extended evaluation" of disabled clients applying for vocational rehabilitation services. The governing concept behind this provision was that the process of extended evaluation could do much to help the severely disabled individual to improve--perhaps to the stage of employment.

1972

In 1972, a new bill intended to replace the expiring vocational rehabilitation legislation, was passed by Congress (H.R. 8395). This bill included comprehensive rehabilitation services and any other goods (including aids and devices) or services provided with funds under titles of the Act "that will make a substantial contribution to helping a handicapped individual to improve his ability to live independently or function normally with his family and community."

The bill included the following definitions:

A "handicapped individual" means any individual who has a physical or mental disability which constitutes or results in a substantial handicap to employment and can reasonably be expected to benefit from vocational rehabilitation services or comprehensive rehabilitation services.

"Rehabilitation" means the goal of achieving, through the provision of community rehabilitation services, substantial improvement in the ability to live independently or function normally within the family or community on the part of the handicapped individual who is not capable of achieving a vocational goal at the present time.

The purpose of the independent living provision in the 1972 bill was defined as:

... to assist the several States in developing and implementing continuing plans for meeting the current and future needs of handicapped individuals for whom a vocational goal is not possible or feasible, including the assessment of disability and rehabilitation potential, and for the training of specialized personnel needed for the provision of services to such individuals and research related thereto.

This legislation was pocket vetoed by President Nixon with the statement that the independent living measure would divert the vocational rehabilitation program from its basic vocational objectives, dilute the resources of the vocational program and impair its potential for continued achievements.

Congress made some changes in the vetoed bill--none affecting the independent living provisions--and in 1973 resubmitted it to the President. Again it was vetoed for the reason, among others, that it would dilute the resources of the vocational rehabilitation program or distort the program's objective by turning it toward welfare or medical goals. (Comprehensive Service Needs Study, Urban Institute, p. 10). Primarily, however, the bill was vetoed because the President's advisors felt the country could not afford a new program that would authorize \$30 million the first year and expand to \$80 million annually by the third year. Also questioned was whether enough was known about the needs of the severely disabled and about rehabilitation's ability to meet those needs.

1973 Rehabilitation Act

In 1973, a compromise between Congress and the Administration was reached. The provision in the 1972 bill establishing a formula grant program to fund

independent living services for severely disabled individuals without a vocational goal was dropped by Congress. On the other hand, the Administration agreed to conduct a study of the issues raised relative to serving the needs of severely handicapped individuals. The Rehabilitation Act of 1973 was then enacted. It contained a provision for the needs study in its Section 130.

Although the compromise bill dropped the provision for independent living rehabilitation services for handicapped individuals with no vocational goal, it established several important breakthroughs for the severely disabled. Priority in the delivery of vocational rehabilitation services to the severely disabled was mandated in the basic program. Title V--the "civil rights title for the handicapped"--contained some of the most important provisions regarding the welfare of the disabled. Sections 501, 502, 503 and 504 of Title V provided for affirmative action programs for the employment of the disabled within the federal government and by firms contracting with the government; for barrier-free work areas in such places; for the creation of the Architectural and Transportation Barriers Compliance Board; and for nondiscrimination on the basis of handicap for programs and activities receiving or benefiting from federal financial assistance.

1974 - Present

The Rehabilitation Act of 1973 was amended to include a broader definition of the term "handicapped individual". This was done in part to augment the implementation of Title V. It focused on major life activities rather than vocational objectives. It also authorized the White House Conference on Handicapped Individuals, which for the first time in history provided a national forum for the handicapped, including the severely disabled, to express their views and make recommendations for public policy to address their concerns.

Other Legislation Affecting the Independent Living Movement

Some of the major laws that have or will have positive implications for the severely disabled are as follows:

- o Education for all Handicapped Children Act of 1975 (P.L. 94-142), which calls for a sharply increased federal commitment to insure that all handicapped children receive full and appropriate educational services.
- o Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103).
- o Supplemental Security Income (SSI) amendments (among them, P.L. 94-566, P.L. 94-365, P.L. 94-569, and P.L. 94-585) extending SSI benefits to aged, blind, and disabled recipients in publicly operated community residences, and a new assistance program for SSI-eligible children.
- o Establishment of the Helen Keller National Center for Deaf Blind Youths and Adults by Section 305 of the Rehabilitation Act of 1973.
- o National Housing Act Amendments of 1975 (P.L. 94-173) Title I, which includes provisions for the removal of barriers, hazards and inconvenient features of housing for handicapped people, to be implemented by the newly established office of Independent Living for the Disabled (HUD).
- o Architectural Barriers Act of 1968 (P.L. 90-480) as amended by P.L. 94-541, pertaining to barrier-free design in federal buildings and facilities.
- o Federal-Aid Highway Act of 1973 (P.L. 93-87) as amended by P.L. 93-643, requiring access to public mass transportation facilities, equipment and services for elderly and handicapped persons.
- o Department of Transportation Appropriations Act of 1975 (P.L. 93-391) directing that none of the funds under the Act be available for purchase of mass transit equipment or construction of facilities unless they meet the requirements of the elderly and handicapped.

The failure to enact legislation that would provide a program of independent living rehabilitation services under the Rehabilitation Act has not prevented the federal-state vocational rehabilitation program from playing a significant role in the development of the Independent Living Movement.

Certain measures have been built into the program through the years that have increased the ability and authority of State vocational rehabilitation agencies to serve the severely disabled: the Innovation and Expansion program which had its origin in the Expansion grants program authorized by the 1954 Amendments to the Vocational Rehabilitation Act; the extended evaluation authority, authorized by the 1965 Vocational Rehabilitation Act amendments; the Individualized Written Rehabilitation Program and the priority for provision of services to severely disabled individuals mandated by the 1973 Rehabilitation Act. Also affecting the ability of the severely disabled individual to obtain services were measures contained in other legislation such as Medicare, Social Security, Title XX, and laws pertaining to the rights of the physically handicapped to public mass transportation services.

Finally, the concept of Independent Living Rehabilitation Services has changed over the years. Medical and rehabilitation technology has made such advances in the past two decades that many of those who would have been targets for ILR services in the 1960s are now routinely rehabilitated by the Vocational Rehabilitation programs. Advances in prosthetics, orthotics, communications and other technologies, medical science, and in the provision of services have vastly altered who can be vocationally rehabilitated.

COMPREHENSIVE SERVICE NEEDS STUDY

In the process of developing legislative proposals for Independent Living Rehabilitation Services, a number of issues were raised. To address these issues, Section 130 of the Rehabilitation Act of 1973 directed the Secretary of Health, Education, and Welfare to conduct a comprehensive study, including research and demonstration projects, of various methods of providing rehabilitation and related services to individuals with the most severe disabilities. Methods and services studied were those concerned with:

- a. the entry of such persons into programs under the Act that would lead to employment, or
- b. improvement in their ability to be independent of others in self-care and in functioning normally within their family and community if, because of the severity of their handicaps and other factors such as age, they cannot be rehabilitated vocationally. (RSA Annual Report, 1976)

The study investigated such key questions as: the national population of severely handicapped people, their characteristics, what their needs are, how their needs are being met, and the implications for policy if these needs were to be met more effectively.

The study had as one of its objectives:

... to investigate, seek out and determine the kinds, sources, approaches, and availability of existing and new services which could assist severely handicapped individuals to increase their capacities for independent living or more normal functioning in the community through the attainment of nonvocational rehabilitation services ...

(RSA Background Paper on Independent Living, 1977)

Findings of the Study

The study was extensive, and the body of information that it produced was vast. Among the findings of the study most relevant to this report were that the needs of the severely disabled differ widely from the needs of other handicapped persons and that simple expansion of existing vocational rehabilitation services in the states is not enough. These findings have dramatic ramifications for the federal-state vocational rehabilitation program. (CSN, 1975) Further, "... the study suggested the development of an ILR program as the most crucial decision area." (RSA Background Paper, 1975)

Subsequently, on the basis of the authority of Section 130 and the study, RSA funded five demonstration projects to investigate:

- o What organizational arrangements seem most efficient and effective for an Independent Living Rehabilitation (ILR) program?

- o What other programs and services can support an independent living thrust?
- o What services, especially what new services, may be required and who should provide them?
- o What manpower will be required and at what level can caseloads be handled?
- o What are the approximate likely achievements that will result from given levels of expenditures?
- o What would be the relative costs of seeking to achieve different types of results?
- o What limits should be placed on who is served?
- o Are there persons too severely handicapped to benefit even from ILR?
- o What are the objectives for an ILR program for which reasonable accountability can be maintained?

The Demonstration Projects

The demonstration projects, funded by RSA, were selected in such a fashion as to gather as much information as possible. Projects were funded that could address specific delivery issues as well as specific handicapped populations. Two projects were funded that concern themselves with medical-oriented physical restoration services.

Seattle

One of the projects is located in Seattle, Washington, at the University of Washington, Department of Rehabilitation. This project is involved with physically disabled clients during and after services of the rehabilitation facility. The project has housed with its staff a Vocational Counselor who is employed by the state rehabilitation agency. The project staff has found that a close working relationship between project staff and VR staff is a positive plus in the difficult task of job placement. The VR counselor also benefits by having firsthand knowledge of the client. The project experience has shown that referrals to VR counselors familiar with the client have a significantly higher probability of successful outcome than do referrals to other VR counselors.

Because of the difficulty in placing severely disabled persons in gainful employment, the project has found it necessary to utilize a more intense placement approach. When a client is felt to be ready, the staff arranges for vocational evaluation in the "job station program." The job station program allows clients to work in four to six different job situations for short periods of time.

An area of increasing interest and increased project activity will be the area of client advocacy. Recently, the State of Washington reduced the monthly fee that can be paid to an attendant for the delivery of attendant/chore services. The recent reduction in allowable payment for these services adversely affects the clients' independence, for without an attendant most disabled persons will have to be in a nursing home for the needed services or hospitalized because of lack of proper care. This is not only costly in terms of medical expense, but may also cause the individual to lose a job, give up hard-to-find housing, plus the mental debilitation that often accompanies reentry into institutional care.

The staff of the Seattle project will approach client advocacy from two directions. The major emphasis will be directed toward those areas viewed as most critical and most lacking: housing, transportation, and attendant care. In addition to "group advocacy", the project will also accentuate "individual advocacy." This approach is designed to impart advocacy skills to the client in such a fashion that, if needed in the future, the client will be able to advocate independently.

The project is moving toward more specialization in its service delivery. In the past, clients were randomly assigned to counselors; thus, a counselor dealt with various types of disabilities. In the future, each counselor will

work with only one type of client. This will create a situation in which the three counselors will work with 15 to 20 clients, all of whom have similar disabilities, and therefore are much more probable to have similar needs.

New York

The second project oriented to the role of a CMRC in ILR is mounted through the New York state agency and the Institute for Rehabilitation Medicine (IRM). This arrangement essentially tests both the coordination and case management aspects of a potential independent living program. While cooperative arrangements have existed between the two types of organizations, they have in the past been somewhat based on a straightforward limited purchase-of-service basis. The degree to which both can empathize with each other's orientation, budget and other constraints and work out specific mechanisms for integrated delivery of services remains to be seen. Primarily, clients are those with neuro-muscular diseases, such as muscular dystrophy, as well as a sample of other severely impaired persons.

The experience of this project has identified the following needs as those most critical to its clientele. They are: continuing health care, equipment for greater independence and life maintenance, physical therapy, rehabilitation counseling, ADL training, suitable housing, transportation, recreation, and in some instances, pre-vocational services and genetic counseling. The project has found it advantageous to develop an advisory panel which is composed of individuals concerned with availability of various community resources. As of January, 1978, 77 clients were either being considered for entry into or had become active project clients. Of these, 53 are in VR status 06, extended evaluation. To date, three clients have moved into regular VR programming. It is expected that another three to five will be able to do so in the next year.

Deinstitutionalization has been attempted with a small number of clients who have been long-term inpatients. Locating suitable residences, arranging for 24-hour attendant care, and ferreting out resources to cover the costs of such arrangements outside an institution are all considerations addressed by the project.

Transportation poses a severe mobility problem for clients in meeting treatment, training, recreational, and socialization needs. Driving evaluations have been conducted with 15 project clients, and the results document the technical and cost constraints of adapting standard vehicles to client use.

Because the clients of this project have diseases which are progressive in nature, the functional levels for these clients decline over time. This group will always require some type of service, and accordingly are thought of as long-term service clients, thus, the 18-month maximum duration for extended evaluation in the federal-state VR program may be insufficient for this severely disabled population. Indeed, several project clients have already exceeded this limit. One of the areas this project will emphasize is a clearer picture of the total cost involved in ILR. Often clients and their families are unaware of the costs involved in medical services, equipment, transportation, and other services provided by many sources through Medicare, Medicaid or donation. Yet such costs are part of the total requirements of the care and rehabilitation of the most severely handicapped.

The project will also be involved in taking a closer look at VR status 06 (18-month evaluation.) As mentioned, some of the project clients have exceeded or are approaching their 18th month of extended evaluation with continuation of evaluation services recommended. This observation suggests that the 18-month

maximum placed upon extended evaluation services in the federal-state VR program may be insufficient for the most severely disabled population.

Two projects are examining the feasibility of employing the state VR agency as the entity responsible for an ILR program. The Utah General Agency and Texas Blind Agency essentially ask, "If the ILR provisions had not been vetoed, how would the state program be operated?" The Utah project is designed additionally to look at certain aspects of potential demand for services while the Texas Blind project addresses the question of just how far one can go in serving the blind, multiply handicapped in the community.

Salt Lake City

The primary objective of this demonstration project is to provide specialized and timely programs that will include a full range of comprehensive rehabilitation services for a limited number of very severely disabled and handicapped people. There must be a significant effort made to assist the most severely disabled in improving the quality of their lives. Any approach to this task must focus upon individual needs with less regard for vocational potential and the individual's ability for utilizing routine and readily available rehabilitation services. Perhaps, most importantly, knowledge is needed on how to adapt special rehabilitation programs for serving the most severely disabled.

The progress and findings of this project are reflected in the alterations, additions and programmatic changes made by the project over the first few years. The project's original intentions were to work with individuals who had been denied VR services due to their severity who lived in and around Salt Lake City. In more recent months, however, most clients being accepted are those who are referred directly to the project. The project, through its experience,

has learned that clients who are referred directly to the project rather than through VR and then at some later date to the project show more rapid and meaningful progress.

The Utah project, as well as the other projects, has identified transportation, attendant care, and accessible, adequate housing as the most necessary and pressing needs of the severely disabled. In an attempt to alleviate the housing need, the Utah project has begun a transitional living center for its clients. The Utah project has renovated a small cluster of housing units (sixplex) which are accessible (barrier-free) and adequate for most of its clients. The purpose of the facility is to teach independent living skills to the severely disabled in order to prepare them for community living. Utah has experienced some recalcitrance on the part of landlords to allow structural modifications to accommodate the disabled person.

Transportation in Utah is another problem which tends to stem more from a lack of understanding on the part of the transportation agency staff than on inaccessible vehicles. Apparently some bus drivers will not pick up spastic cerebral palsy clients.

There is a problem with the availability of attendant services in Utah. Homemaker services, which include most housekeeping activities are provided through the state's Title XX program. The law in Utah makes provision for live-in homemakers (paid \$250 per month, based on 100 hours), however, it prohibits the homemaker from rendering personal assistance services, such as dressing and bathing. Technically, only home health aides under the direction of a Title XIX funded nursing agency can provide these services. Unfortunately, under the Title XIX program, these services cannot be delivered with the regularity and frequency these clients require.

This project has found it necessary to relate to medical and biomedical engineering resources. The project has employed an engineer on a half-time basis, not only for this purpose, but also to assist in adaptations of various devices and equipment for project clients.

In spite of the severity of disability which these clients possess, there have been some notable accomplishments. Twelve clients have been closed successfully. The criteria this project has followed in defining successful closures is as follows: (1) completion of the Individualized Written Rehabilitation Plan, a plan of services which outlines what services the client will be provided with, and the goal the client is striving to achieve, (2) maximum benefits attained in independent living; and (3) entry into the VR program. In some cases clients have been moved directly into competitive employment, and in most cases placements have been in sheltered workshops.

San Antonio

There are areas of reasonable concern about the state of knowledge regarding multiply handicapped blind persons. A blind cerebral palsied person, for example, must present more than the usual challenge to rehabilitation counselors.

This demonstration project provides a comprehensive milieu of services to test the feasibility of rehabilitation services to individuals who, because of their blindness and additional handicaps, are traditionally restricted from vocational rehabilitation services because of "handicap too severe." The purpose is to determine the individual needs of these persons, develop a program to meet these needs, and train these clients to live independently in their environments.

The present approach to serving blind citizens in Texas emphasizes a team approach, combined with assessments of the individual client's need--team members, include the rehabilitation counselor, rehabilitation teacher, placement specialist, the orientation and mobility specialist, the technical and consultive assistants and others. The utilization of this team approach has been expanded to deal with the special scope of this demonstration project.

This project is unique in that it serves a clientele quite different from most of the other projects. Where most projects are concerned with overcoming physical handicaps which result from the client's disability, the Texas project struggles to overcome experiential handicaps brought on by the client's sensory deprivations. The primary deficit (blindness) is further complicated by a secondary disability which may also be sensory (e.g., deafness), limb related or mental in nature.

The Texas project is quite active in client advocacy. However, their advocacy activity is most often of the group type. Most of these clients are viewed as being unable to successfully advocate for themselves. During the second grant period, this project involved 17 of its 20 clients in over 20 local organizations, societies and agencies.

Although the advocacy role of the agency is essential in securing services for its clients, the Rehabilitation Teacher is also an asset in securing these services. There are many societies and organizations, both public and private, that cater to specific disabilities. However, few of these entities employ staff who have had experience with the blind; therefore, many are reluctant to accept a blind-multihandicapped client even when the service to be delivered pertains to the disability an entity is staffed to serve. The teacher works both with the client and the staff while at the facility; this in-depth involvement will dissipate as both the client and the service agency staff feel comfortable with the situation.

Another important aspect of the teacher is in aiding a client to transfer what is taught at the service agency to the living situation. This is very essential for individuals who have visual handicaps. As well as aiding in learning and transfer processes, the teacher also has the abilities and responsibilities to teach many skills to the client themselves. Most often this is done in the particular environment in which the client lives, thus negating the need for client transportation or for transference of learned skills.

Since its original proposal, the project has amended its time of intervention. The project requested and received permission to work with clients during VR status 06. The Texas project felt that if it could intervene with blind multihandicapped clients during this extended evaluation, it could increase the probability of successful closures. This approach has been successful to date, and thus suggests an opportunity for ILR services within an existing VR program.

In attempting to deliver medically related services to blind-multihandicapped clients, especially those with limb impairments, it has become increasingly obvious that many need full-day programs, programs which provide therapies (physical, occupational, speech and recreational) as well as independent living rehabilitation. In the past, these types of services have been contracted for but have not usually been complete (all services cannot be procured at the same facility.) Many times the clients are returned home without any instructions for home activities. Irrespective of the results of therapy, this service usually lasts for three or four months and then is terminated.

One possible funding source for increasing the type of services outlined above is Title XX money. One of the varied service categories allowed under Title XX is the category entitled "Community Care for Aged, Blind and Disabled Adults." This program has five stated goals:

1. Achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency.
2. Achieving or maintainin self-sufficiency, including reduction or prevention of dependency.
3. Preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating or reuniting families.
4. Preventing or reducing inappropriate institutional care by providing for community-based care, home-based care or other forms of less intensive care.
5. Securing referral or admission for institutional care when other forms of care are not appropriate, or providing services to individuals in institutions.

A Title XX funded project is located in San Antonio and does provide many of the needed services. This facility works with chronically disabled and elderly persons. Most clients arrive in the morning and spend the majority of the day involved in therapeutic activity. At the end of each day, the clients are returned to their own living environments. Transportation is provided by relatives, volunteers and the Department of Human Resources.

It is felt that if the provision under which this service is delivered were expanded, many severely disabled would benefit. This service could be used to both prevent institutionalization and promote deinstitutionalization.

A major occurrence for this project was the granting of a supplemental award to enable the project to take a more in-depth look at the needs of the blind-mentally handicapped (emotionally ill) client. Due to this, the project will give priority to the Blind/MI when accepting new referrals.

Early intervention is a concept that has been touted by many, both in and out of the rehabilitation field. The project cites as an example the ability to mainstream the multiply handicapped if specialized services are

available to augment the process; e.g., intervention during VR status 06. An earlier intervention, then, might be expected to meet with more success, especially if one measure of success is the increased probability of employment.

Although vocational outcome is not by and of itself the only measure of success of a rehabilitation program, it is one easily recognized and understood. However, not much information has been gathered on the types of approaches used to place the severely handicapped. This issue and those noted above are of interest to this project and may receive more attention in the future.

Berkeley

The project at the Center for Independent Living (CIL), a consumer self-help organization, looks at the problems of the handicapped from a different theoretical perspective. They see the rehabilitation system as a network of public and private agencies in which several serious gaps exist. Psychological factors, for example, are often ignored as barriers to rehabilitation.

Established formal agencies, both public and nonprofit, often have traditions and limitations which result in gaps and occasional insensitivity to the needs and preferences of the disabled. There will always be those whose needs are such that no public agency can address them--it may take years to get a recently blinded or spinal cord injured person out of a depression and actively seeking to realize his maximum potential. Sex counseling, initiating lawsuits against landlords, and demanding action from public officials are some of the messy, controversial and essential activities for severely disabled persons.

There are questions about consumer self-help groups which need to be answered. They include: (1) How well does this approach work? (2) What does it cost? (3) What are the dangers as well as the opportunities? The CIL project is intended to clear up the issues surrounding this innovative, but controversial approach to service delivery.

One of CIL's major thrusts has been in the area of deinstitutionalization. A difficult problem for many institutionalized individuals is the accumulation of enough funds to move out of an institution. The individual receives only \$25 a month, which is supposed to cover personal needs; i.e., toilet articles, clothing, etc. This makes it extremely difficult to accumulate the necessary funds to move into an independent living situation.

The psychological adjustment is another difficult barrier to overcome. This is especially true for individuals who have been institutionalized since an early age. Most decisions made in institutional settings are made without consulting the individual which is affected by the decision. This lack of experience at participating in or making decisions adversely affects the individual when attempting to begin a life of independence.

The CIL project feels there are four critical issues to be dealt with in making this transition: (1) adequate and accessible housing, (2) adequate and accessible transportation, (3) adequate attendant care, and (4) counseling on how to organize and plan for these services. The first three services are available, if an individual has the knowledge and fortitude to persevere through the endless paperwork and the sometimes long delays. The fourth ingredient is rarely available, and thus the acquisition and retention of the first three is difficult.

It has been CIL's experience that attendant care is the most problematic of the four issues listed above. The initial problem is in finding adequately

trained attendants. This is not an easy task, partially because of the type of work and also because of the salary that accompanies the job. The problem is that of finding the quantity of attendants normally found to be necessary. Because a wheelchair individual needs attendant care only at various times of the day, and because salary for an attendant is based on hourly wages, most handicapped individuals utilize more than one attendant a day. A tertiary problem is finding replacements whenever an attendant is sick, takes a vacation, quits or is dismissed.

All of these problems require the disabled person to become a good supervisor/employer. Thus, a program such as CIL, provides a needed service for those wishing to increase their independence.

Finding adequate and accessible housing is always a problem for the disabled. CIL has found it necessary to provide a housing referral service which keeps a list of housing that meets the needs of the handicapped. Accessible housing is not a problem that is going away; on the contrary, it is a problem that requires constant monitoring.

Because of this, many disabled are restricted to what areas of a city or community they can live. Sometimes this creates hardships for those whose work is a considerable distance from where they live.

Transportation needs are being met with greater frequency than in the past. Many service delivery agencies provide accessible transportation to those who utilize their respective services. However, transportation for nonservice-oriented activities is not always readily available. CIL attempts to fill in these gaps through their van program. They also have an automobile alteration service which alters automobiles (mostly vans) for use by the physically disabled.

CIL will be moving toward a closer working relationship with various service delivery agencies. This is a departure from their previous posture of nonalliance with what was perceived to be the nonflexible recalcitrant system.

Another change involves the selection of clients from the Extended Evaluation category of the Department of Rehabilitation. Originally, CIL had as one of its objectives the election of clients who had been rejected by the Department of Rehabilitation on the basis of severity of disability. However, since CIL began their project, the state agency has changed its emphasis and now places priority on serving the severely disabled. The implications of this change in focus is that many people who formerly would have been rejected for services are now placed in Extended Evaluation status because of the uncertainty surrounding their vocational feasibility.

Preliminary Project Results

o Change in Independent Living Capability

The Barthel scale is an instrument which is used to measure the degree of disability possessed by orthopedically involved persons. This scale is administered at client intake, and then at the end of every 12 months. For those clients who are orthopedically involved and have been with the project for at least 12 months (N = 69), the average change in the Barthel Index was 14 percent. Given that an overwhelming proportion of project clients have been impaired for at least several years, a 14 percent increase in physical functioning is impressive.

o Employment

Only 4 percent of the original Section 130 project population were employed when the projects began. As of this date, 18 percent of the Section 130 population are employed, although some are not full-time employees, and some are working in sheltered employment situations. It is also important to note that over 10 percent of these severely disabled clients have subsequently been accepted as VR clients.

o Housing

The projects have been successful in deinstitutionalizing 45 percent of their original institutional population (17 out of 38 clients.) This has been accomplished through the use of transitional living facilities and through active efforts to provide the necessary services. The projects have experienced moderate success in assisting their clients in finding accessible housing. In meeting the housing needs of Section 130 clients, the projects have been successful in offsetting the cost of living independently by the use of various federal programs. These programs have included SSDI/SSI, the Food Stamp Program, Section 8 Program (HUD), and other similar programs. The Texas project, and recently the Utah project, have been involved in assisting clients in removing architectural barriers from clients' existing residences.

o Transportation

The transportation needs of the project clients have been reduced by over one-third from original stated needs. One project reduced its clients' transportation needs by two-thirds (CIL, Berkeley.) The increased availability of "Demand-Response Systems" (Dial-a-Ride, etc.) has been a big factor in this reduction. The projects' advocacy on behalf of their clients has also given their clients access to transportation systems that were heretofore unresponsive to their needs.

INDEPENDENT LIVING SERVICE DELIVERY MODELS

Variations of Models

In a review of federal programs providing services and financial assistance to the handicapped, the Comprehensive Service Needs Study found that they contain severe gaps in services, suffer from inadequate controls, and are operated with insufficient knowledge and resources (Urban Institute, 1975.)

The emergence over the past few years of many programs for the severely handicapped, all of which include some aspect of the independent living concept, represents an attempt by private concerns--with assistance by local, state and federal governments--to develop delivery of service models to fill the gaps. Many of these programs are consumer inspired and directed. They differ in the systems and services that they offer, but all have common elements: they focus

on the maximization of the severely disabled individual's opportunity for participation in all aspects of society, and they provide the broad range of services needed for this participation. Also common to these programs is their emphasis on advocacy of the rights of persons with disabilities and their provision for peer support.

Some variations in these programs may be identified. Among them are these:

1. Services provided in a non-residential setting vs. services in a residential model.
2. Services provided directly vs. services provided by referral to community services.
3. Services organized around commonly shared service needs vs. organizations serving one disability group.
4. Services based on professional service workers vs. a consumer approach to service delivery (or "peer counseling").
5. Vocational vs. nonvocational emphasis.
6. Provision of "traditional" services with an outcome objective vs. ongoing or permanent sustaining services.

Research and Demonstration projects, Rehabilitation Engineering projects, Innovation and Expansion projects, Special projects for Deaf Individuals, Special projects for Older Blind Individuals, and other specialized activities under the Rehabilitation Act have contributed to the content and development of the various independent living delivery models currently in operation.

Following are descriptions of some of the major programs providing independent living services for the severely handicapped:

Examples of Existing Centers and Programs

Center for Independent Living (CIL), Berkeley, California: One of the oldest and best known of programs providing ILR services is the CIL. Organized in 1972 as an outgrowth of the Cowell Residence Program for severely handicapped students at the University of California, Berkeley, the Center has provided a

model for other ILR programs in California and other parts of the country. It serves approximately 3,500 person who possess a broad range of disabilities.

The goal of the program is total integration of people with severe disabilities into community life. No residential facilities are available at the Center, but a full array of basic services, in addition to such specialized services as legal services and job placement, are provided.

Under grants and special funding from various sources, the Center directs a number of special projects. Two such projects are the Section 130 Demonstration Project, and the testing of the effectiveness and design of special equipment, sponsored by the Veteran's Administration.

Boston Center for Independent Living (BCIL): The Boston Center is a small nonprofit enterprise incorporating transitional living facilities, cluster housing and independent living for its clients. Its goal is to provide the severely disabled a base of operations that bridges the gap between institutionalization and independent living.

The BCIL was conceived in January 1974, and opened its doors in September 1974. The Center had its roots not only in the anger of "disabled individuals incarcerated" in public and private institutions, but also in the frustration of rehabilitation professionals who found the noninstitutional community inaccessible to clients and patients following rehabilitation.

To date, 50 individuals have passed through the program. In addition, other CILs have been established in Worcester and Amherst, Massachusetts, and in Bangor, Maine. Others are on the drawing board in Vermont, Rhode Island, Connecticut and S. E. Massachusetts, with BCIL input. (BCIL Report, 1977, Corcoran, Fay, Barthels, McHugh.)

Texas State Commission for the Blind: Some state Vocational Rehabilitation agencies in their efforts to serve the most severely handicapped have developed programs that provide prevocational skills training. Such programs could be viewed as models for the delivery of Independent Living Rehabilitation services within an existing vocational rehabilitation program. One such state agency is the Texas State Commission for the Blind. This agency has developed a continuum of services that successfully moves clients from dependent situations (institutions or private homes) to more independent living arrangements. Since the program utilizes Section 110 Basic Grant funds (Rehabilitation Act of 1973), all clients must have a reasonable expectation of employment. However, by making use of the extended evaluation provision, many severely handicapped clients are now given an opportunity to develop and display vocational potential.

The program progresses through a series of housing arrangements and utilizes various subsidy programs. The first community placement for most previously institutionalized clients would be in a transitional living facility. One such facility is an ICFMR-1 facility and is totally supported by Title XIX funds. The next step is the congregate living situation with individual apartment units. This housing arrangement is subsidized by Section 8 HUD housing allotments, SSI benefits and client income. The income is normally generated from sheltered workshop placement. A client can then progress to an individual living arrangement.

During this entire progression the client is being instructed in independent living skills, job related skills, mobility training, etc. The amount of agency instruction and involvement decreases as the client's independence increases.

CSAVR ATTITUDINAL SURVEY

Support by the VR state directors for Independent Living programs has increased in the past four years. In 1973, 60 percent of the directors favored these programs (NRA survey). In 1977, 92 percent were found to be in favor of independent living programs (CSA/VR Survey).

In response to questions in the 1977 survey, the state directors overwhelmingly favored the state VR agency as the primary component for the delivery of ILR services. Consensus on the relationship of such a program to the VR program was not obtained, however, nor was the question of funding agreed upon.

In regard to organization, 40 percent of the directors indicated that the ILR program should be an integral part of VR; 18 percent favored its being residual to VR; 14 percent favored separating the ILR program from VR; 13 percent favored a mix; 10 percent favored a precedent program; and the remaining respondents did not specify placement. However, in recent testimony before the House Subcommittee on Select Education, the Council recommended "a separate ILR program be established, with responsibility for administering the program located, by statute, in the State Vocational Rehabilitation Agencies."

With regard to funding an ILR program, 35 percent of the state directors believed the program should be authorized under a new section of the VR Act; 33 percent were for separate legislation; 9 percent indicated that ILR funds should come from Title I basic state grant appropriations; 18 percent favored a combination of funds; 2.5 percent favored funding from Title XX, and 2.5 percent did not specify a funding preference.

Seventy-seven percent of the state directors felt there should be no vocational objectives required for the program. The CSA/VR Task Force on

Legislation intends to use the survey results to aid the Council in reaching a final position on the issue of ILR programs.

FUTURE TRENDS

Policymakers are looking to these centers and service programs as possible models for expansion of services to the severely disabled.

Some formal evaluations of alternatives for service delivery systems are underway. Evaluation studies are being carried out by the Section 130 Demonstration Project. RSA has awarded a grant to identify the elements of the Innovation and Expansion grant funded programs in California that lend themselves to comparison and evaluation. In addition to the Section 130 Demonstration grants, RSA has funded a project to develop models and innovative methods of utilizing the services already available in state VR and other service agencies.

An independent living research utilization conference, sponsored by RSA, is being planned and will be conducted by the Texas Institute for Rehabilitation and Research in the summer of 1978 in Houston, Texas. This conference will bring together 30 - 40 persons with experience in the ILR field to develop a training program for providers of services to the handicapped. The training program will be designed to disseminate information on available ILR service programs, utilization of these services, and the development of new programs where none are now available.

While the centers and programs of ILR services have proven that the concept of ILR is valid and that severely disabled individuals, given a supportive environment, can live a dignified and rewarding existence, ILR is still an emerging field. Little is known, for instance, about the economics of ILR--the cost-benefits of providing ILR services, or the measurement of intangibles. More research is needed in these areas.

There is little doubt that new centers and programs will be developed. A coalition of ILR programs to reinforce their efforts is also a possibility.

While some of the ILR centers have imaginatively used a variety of funding sources such as Medicaid, SSI, and other payments and services programs to support their activities, it is clear they will need more government support if they are to survive and grow. A much needed step would be the adoption of a national policy regarding handicapped people.

SUMMARY OF SIGNIFICANT DEVELOPMENTS
IN THE INDEPENDENT LIVING MOVEMENT

At the present time both the Senate and House of Congress are considering how a rehabilitation program for Independent Living should be structured and financed. In hearings before the respective Committees of the two branches of Congress, proposals have been made that ILR be established and funded on a project basis, or that the ILR program be funded on a grant-in-aid basis to the various states. Neither branch of Congress has come forth with a bill that encompasses either a project basis or grant-in-aid funding.

In testimony before the two respective Congressional Committees, Mr. Humphreys, Commissioner of the Rehabilitation Services Administration, proposed to extend the present provisions of Section 130 and to increase the funding for projects under this authority.

UNIT II

IMPLICATIONS FOR STATE VOCATIONAL REHABILITATION
AGENCY ADMINISTRATION IN
INDEPENDENT LIVING

INDEPENDENT LIVING REHABILITATION

Implication for State Agency Administrators

Issues

1. Identify service agencies (and their funding sources) that provide services related to independent living rehabilitation and coordinating these resources in order to develop an integrated ILR program.
2. Identify personnel needs, training, and staffing patterns to accomplish ILR, utilizing where possible existing staff or recipients of services.
3. Re-educate service agency personnel in the philosophy and methodology of ILR.
4. Design an organizational structure that will and can take advantage of existing ILR services.
5. Design and implement ILR goals and objectives that are practical and realistic from the viewpoints of service agencies, communities, and individuals concerned.
6. Decide what service agency would be the proper agency to administer ILR.

Summary

ILR is a natural "next step" in the evolution of services to the severely handicapped. Providing ILR services to this group is difficult at its best; but to accomplish successful medical and vocational rehabilitation and then to see these efforts fail due to inadequate housing, transportation, and attendant care is frustrating to both clients and rehabilitation staff. Agency administrators are faced with many issues and concerns in arriving at a means and methodology that will provide ILR services at a price acceptable to the legislative body and taxpayers alike.

2.

Primary concerns deal with the identification of the many agencies that provide some ILR services, the design of an organizational structure to coordinate all resources for ILR, staffing needs, and in-service training in ILR philosophy and techniques.

The age-old philosophy that rehabilitation must have a vocational objective is no longer accepted by V. R. Administrators in providing services to the severely handicapped. Administrators will be challenged to reconcile this dichotomy, probably by providing parallel services where the severely handicapped can readily be transferred from a service that requires a vocational objective to one of ILR. A major question is: what would be the most appropriate organization to administer the ILR Program? It would seem that the Vocational Rehabilitation Agency would be the best suited for this task. Private agencies, such as centers for independent living, have been successful in providing ILR services and certainly must be considered. Since every service agency has a role to play in ILR, agency administrators will face a concern of major proportions in designing a package that will not within itself have the ingredients for self-destruction.

Changing Attitudes and Administrative Support

During the past twenty-five years, administrators of rehabilitation agencies have changed their attitudes toward ILR as a suitable objective for handicapped clients. This change can be attributed to the passage of the Rehabilitation Act of 1973 and the movement of consumers and their advocates for more involvement in the process with better and expanded services.

3.

A survey was taken in 1977 of state administrators of vocational rehabilitation to determine their sentiment regarding ILR issues. Results of this survey indicated that some eighty-eight percent favored the creation of an ILR program administered by vocational rehabilitation at both the state and federal levels.

The five options proposed for ILR in this study (of which the administrators were to vote on one) were as follows:

1. Integral part of VR-ILR, one of the many services of vocational rehabilitation.
2. Residual to vocational rehabilitation: vocational rehabilitation screens clients according to present eligibility standards and refers to ILR those clients who were ineligible because they were too severely disabled for vocational rehabilitation services.
3. Separate from vocational rehabilitation: create a distinct unit within the agency administering vocational rehabilitation.
4. Melange Program: no distinction between ILR and VR programs. Services to be provided as long as the individual has need of services regardless of income.
5. Precedent Program: the ILR program would be the evaluation arm and provider of ILR services to severely disabled before referring them on to vocational rehabilitation if eligible.

There was no clear-cut majority of opinion on the relationship of the ILR program to the vocational rehabilitation program. The analyst of this information concluded that perhaps the best approach to this question would be to let each state select the relationship best suited for its purpose or else set up demonstration projects to determine which of these five approaches would be most effective.

The Comprehensive Needs Study (1975) listed five approaches to

ILR:

1. Residual to vocational rehabilitation.
2. Separate from the present vocational rehabilitation program but administered by it.
3. A single program integrated into vocational rehabilitation.
4. Implementation by a non-rehabilitation agency.
5. In a separate but rehabilitation-related agency.

An ILR study (Pflueger 1977) compiled the experiences of several leaders in the ILR field with considerations to several alternatives to administering ILR services. The primary alternative is consumer-administered programs which draw on the contributions of the various agencies that by law can provide support to the severely handicapped. These varied consumer groups have gained recognition for the ILR movement and have created viable private organizations that are providing highly skilled comprehensive services to a number of severely handicapped individuals. Initially, these groups provided services primarily to the handicapped of a highly intellectual level. This concept has changed significantly as services have been expanded to all disability groups including the mentally retarded. Success by these consumer-based private organizations as a provider of ILR services demands that state agencies give serious consideration to their continued involvement, perhaps as copartners in this important area.

No doubt ILR will come. The when and in what form it will be implemented is a major concern for state administrators.

Legislation

Legislation will determine the role vocational rehabilitation will play in independent living rehabilitation. The emphasis placed on ILR, plus input from rehabilitation agencies in regard to future legislation, hopefully will provide regulations and guidelines that can be successfully implemented. Legislation and subsequent regulations will determine the organizational position of ILR along with personnel, facilities, and utilization of resources.

Major issues that legislation must address in addition to organizational structure are eligibility criteria and program objectives. One of the challenging aspects of ILR is the number of severely handicapped people who would be potential clients of this program. Persons in institutions, nursing homes, and in the home could conceivably become eligible for services. Some of these potential clients through ILR services could become employable. For many, however, it would not be practical to establish a goal of employment; nevertheless, they could benefit substantially from ILR services. It is conceivable that many potential clients would have disabilities of such severity that ILR services of various degrees could be of long durations. Thus, major decisions will be to determine the degree of severity of disability which would render the person eligible for ILR services and at what point these services can be terminated.

Establishment of goals and objectives is a necessity for any successful program. Therefore, identification of valid program

goals and objectives are primary administrative concerns. A vocational objective is a traditional goal of rehabilitation and one that loyal supporters may be reluctant to see removed from the traditional program. However, legislators and state administrators have indicated that an objective of ILR would be acceptable if suitable identifiable objectives were established for the program, or that the program be administered by a separate rehabilitation unit within the vocational rehabilitation agency. The ILR program must be prevented from becoming an institution that would restrict an individual's personal freedom but designed for both physically and mentally handicapped persons who could benefit from it with or without employment potential.

Funding:

ILR will be a costly program, especially in initial services to clients. However, if coordination of all the various ILR services provided by the numerous agencies and programs could be implemented in some manner, cost effectiveness could be gained. Fay (1977) states that:

"Cooperative efforts by rehabilitation professionals and disabled consumers have demonstrated that community-based ILR is a medically acceptable, cost effective, and personally rewarding alternative to institutional care for severely disabled individuals."

These centers utilize several methods of operation mentioned by Fay that merit serious consideration in funding plans by state administrators.

These methods are summarized as follows:

1. The use of severely disabled consumers to administer plan and implement programs of ILR.

7.

2. Uses a system of "mainstreaming" that is, placing the severely disabled in neighborhood housing with necessary modification assistance provided by existing funding sources.
3. These programs can be developed and put in operation in a short period of time and can be established in locations where needed without creating a large expensive administrative complex.
4. Consumer administrators can cross supporting agency lines easier and more effectively to secure funding support than could one agency.

The allocation of funds must also consider the number of severely handicapped who can benefit from ILR services. It will take time and experience to provide information on which to base a logical sum to support each ILR case. Some research is available regarding each of these considerations; however, until eligibility criteria for ILR is established, figures provided in these studies can serve only as tentative guidelines for state agencies.

In summary, ILR initially will require additional resources. Certain organizational and methodologies can be designed that will reduce these costs to a considerable extent. If ILR is to be successful, however, funding considerations must be given to the full ramifications and implications it has for housing, assistants, transportation, medical care, modifications of appliances, and systems for monitoring and evaluating the benefits and effectiveness of the program.

Personnel:

The ILR program, regardless of its final structure, will require adequately trained staff. Nevertheless, as a result of the Rehabilitation

Act of 1973 which mandated services to the severely handicapped, this problem may not be as acute as it seems. Rehabilitation staff have been involved with the severely handicapped, many requiring multiple and extended services which could be expanded to include ILR. Staff will have dealt with medical care, attendant services, transportation, and housing, which will be of importance to ILR programs. As a result, rehabilitation professionals recognize the need of ILR programs and will provide a cadre of experts in the field. In addition, consumers of ILR services could serve as consultants because of their knowledge of what services are needed and how to secure these services. Consumers could function as peer helpers, models, program administrators, as well as other positions with a minimum of specialized training. In fact, the utilization of the severely handicapped as ILR staff members could be one of the major benefits.

The personnel question cannot be settled until the questions of organization, eligibility, and funding are settled. No doubt specialized training will be required for personnel. Decisions will need to be made concerning the use of present vocational rehabilitation staff in serving both vocational rehabilitation and ILR clients. Rehabilitation counselors, vocational evaluators, adjustment specialists, attendants, as well as supervisory staff and program evaluators must be trained. Consumers can play an important role in providing expertise in the ILR field and must be considered in all levels of staffing.

Housing:

Many theories concerning housing have been advocated by various groups interested in ILR programs. These range from apartment complexes built

by incorporated private individuals with HUD support, private workshops with dormitory-type facilities, centers for independent living that utilize community housing, and the comprehensive rehabilitation centers using their facilities to teach independent living skills and then sending the disabled person into the home community to live.

Each of the above efforts has provided some degree of success. The centers for independent living have had a great deal of success in providing an opportunity for the handicapped person to live in the community with available necessary services. The housing or apartment complex, as well as sheltered workshops and rehabilitation facilities, will, without proper planning and supervision, retain or acquire the institutional atmosphere that ILR will be attempting to overcome. The centers for independent living work well for highly populated areas when fairly large numbers of severely handicapped live fairly close together. Attendant care will always be a problem and will be expensive where it is necessary on an individual basis, especially so for spinal cord injured or the completely paralyzed who must depend on attendants to provide care for all their activities of daily living. The person not functioning high enough intellectually to supervise his care can be a very expensive case to support in an independent living situation.

The independent living rehabilitation concept of total independence in a community setting is a worthy goal. Different types of housing situations will be necessary to accommodate the variety of disabled that will need to be served. There will always be a need for the institution and the nursing

home for those not able to participate in an ILR program. Every effort should be made, however, to provide the opportunity for those able to function in the independent setting to realize their goals.

Transportation:

Suitable transportation to accommodate the severely handicapped is a necessity for successful ILR. Development of a barrier-free public transportation system is far from reality, although giant strides have been made in some localities. Federal and state social service agencies have provided the means of transportation for the aged and severely handicapped but not to the extent to fulfill all needs. Private transportation is making some progress in services to the severely handicapped. Despite some gains, they are still inadequate and in many cases very expensive.

Severely handicapped themselves in some cases are providing transportation services in order to purchase vehicles fully equipped to transport disabled persons. In areas where there are large numbers of handicapped individuals, this idea is proving reliable and rewarding.

Progress in both private and public transportation systems is being made. However, in many instances, ILR will still need to provide transportation for the clients being served. This may be expensive. Efforts should be made to encourage public and private transportation to continue their development and ability to serve the handicapped as required by law. The ILR movement should never compete with them to the point of discouraging their services.

Architectural Barriers:

Legislation has been enacted in the past several years that has provided a blueprint and a mandate for eliminating architectural barriers. However, it does not remove the barriers that have been a life-time in building. No doubt this effort will be the most costly and time consuming part of the movement to bring the severely handicapped into the mainstream of society. The industrial complex cannot be torn down and rebuilt to correct past errors. This must be accomplished gradually. Yet, success in providing employment for the severely handicapped is more often than not prevented because of architectural barriers. The business man has a limit that he reaches rather quickly when he starts remodeling his plant to accommodate the severely handicapped. He must have support to do this job. Herein lies a major cost factor not only for ILR but for vocational rehabilitation in providing placement services especially for severely handicapped clients.

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UNIT III

IMPLICATIONS FOR THE PRACTITIONER IN PROVIDING
INDEPENDENT LIVING SERVICES

CHAPTER 4

ISSUE: The challenge for the rehabilitation practitioner in providing independent living rehabilitation services for the severely disabled individual.

OBJECTIVE: To examine the implications for the rehabilitation practitioner in the event the provision of independent living services for severely disabled individuals becomes a new responsibility of all vocational rehabilitation agencies.

SUMMARY: Though the concept of independent living services for severely disabled individuals is probably endorsed by most rehabilitation practitioners, the question of the responsibility for the provision of these services results in far from universal agreement. Rehabilitation without a vocational goal is considered heresy by some counselors who have long been inured with the belief that the goal of rehabilitation is employment. Assuming, then, that ILR (Independent Living Rehabilitation) ultimately becomes a new responsibility of VR agencies (and preliminary studies seem to point to the efficacy of this), one can envision a myriad of problems to be solved. Not only will an attitudinal change be necessary for those in VR opposed to such a move, but also those who favor such a program will be faced with a number of changes in caseload management techniques that will require their adaptation. Many of the techniques will involve merely an extension of current practices in rehabilitation. Others will involve a radical change, for example, a dramatic reduction in caseload size would be in store for the counselor solely engaged in providing independent living services for the severely disabled individual.

As always, when the legislation is passed and the programs are written, it falls upon the field personnel to put theory into action. No matter how carefully planned a program is, it is the field counselor who can make or break it. Attention must be centered, then, on how a potentially new program is going to affect the individuals who must wrestle with the problems inherent in any such massive proposal. This segment of the document will attempt to deal with those problems that presently loom as most significant. Certainly, not all will be affected similarly, but there are areas of concern that appear to be almost universal.

DISCUSSION: Even without knowing exactly how Congress will establish a nationwide program of independent living services for severely disabled persons, or how the Federal Administrative Agency will translate the legislation into guidelines and regulations, there is already enough information available from research and pilot projects to identify some items as being of concern to the rehabilitation practitioner:

Counselor attitudes: There is no question but that many rehabilitation counselors have long felt that there are a large number of referrals that cannot be served because of the fact that a vocational goal cannot be established. Even the use of extended evaluation does not come close to meeting client's needs, because once vocational potential is ruled out it means case closure. Indeed, were it not for the possibility

of homemaker, unpaid family worker or sheltered employment as legitimate vocational goals, numerous clients would be denied services because their potential for competitive employment is judged to be nonexistent. Few counselors would deny that they have had individuals referred to them who were severely disabled and were closed because of the apparent magnitude of the impairment(s) only to discover later that the client was gainfully employed. It could be argued that current rehabilitation practices precluded services that would obviously have resulted in a rehabilitation. Many counselors feel that the very people who could benefit most from rehabilitation services are denied these services because the "vocational" aspect, as it is now defined, is absent. With the advent of ILR, these counselors will have added incentives and resources to serve the most severely disabled individuals. The attitude, or philosophical bent, of these counselors would appear to be most receptive to the idea of ILR for the severely disabled. An added benefit would be that many of these individuals who were previously considered as not having vocational potential, would ultimately become employed in the competitive labor market.

Conversely, there are some counselors who cling steadfastly to the belief that vocational rehabilitation is just what it says, and that VR has no business becoming involved with the provision of independent living services. This is understandable because the pinnacle of rehabilitation efforts has always been employment for a handicapped individual in

a capacity in keeping with his maximum aptitudes and abilities. One can certainly detract nothing from this philosophy given the present framework of vocational rehabilitation. It has been the cornerstone of vocational rehabilitation since its inception. Whether these counselors can accept independent living as a rehabilitation goal in itself can only be speculated. No doubt many will change their present attitude, but for some it will not be easy. Be that as it may, attitudes will require change by some. It appears that this change in philosophy must be initiated at the very top if a venture into ILR by vocational rehabilitation agencies is to prove successful. If it can be shown to the reluctant that independent living is a realistic "vocation" in and of itself, attitudinal changes may come easier.

Service provision: Inherent in the term Independent Living Rehabilitation is the term comprehensive. In order to help a severely disabled person move from almost total dependence on others to maximum independence with regard to outside help, a rehabilitation practitioner will be required to have an intimate knowledge of the nature of various disabilities and their physical and emotional effects. A thorough knowledge of limitations as well as methods of treatment to restore an individual to maximum function must become an even more important part of the counselor's general fund of knowledge. At the very least he must know where to gain the information needed and must be able to interpret it to the client and others involved, including the client's family. Even after

medical treatment many clients know little about their impairments or how to cope with them. Frequently medical advice is minimal or is given at a time when the client is hardly in a frame of mind to absorb it. Certainly knowledge of this nature is assumed of the counselor even now though in reality some counselors possess only a superficial understanding of various disabilities and their effects.

To be most helpful to a client seeking to live independently it is imperative that the counselor have a broad knowledge of all of the possible needs of the severely disabled, not only the areas of functional limitations. The ability to use various community resources will be very important. The counselor may be required to assist the client in securing housing accommodations. He will thus be required to be familiar with the ongoing availability of apartments and other residences. He must know whether a particular residence is adaptable to the client because of the type of impairment involved. It may be incumbent of the counselor to intervene on his client's behalf for the removal of architectural barriers in the community, building modification, acquisition of medical and legal benefits the client may be unaware of but which could make life easier for him. He may be required to investigate for some clients sources of medication sold generically so the client can save money on prescription needs. Dietary planning is another area the counselor probably should be knowledgeable in so that client health can be maintained. The counselor will

most likely be required to assist some clients with budgetary matters so that those of limited income can survive economically. He will be required to arrange supportive services with the client such as occupational and physical therapy. A deeper knowledge of assistive devices and new rehabilitation technologies will be instrumental to good case management. Certainly arranging transportation will be an area of concern for the ILR counselor. Getting to and from medical services, shopping, and social activities is presently one of the major problems of the disabled. The availability and use of support services, such as epilepsy and multiple sclerosis groups, should be known by the counselor, as these groups have much to offer disabled individuals. Counselors will have to be aware of changes in service guidelines for these groups as they are often subject to funding availability which affects their activities. Often the counselor will be required to counsel family members on the needs of their clients. The counselor may become involved in encouraging local disabled citizen groups to lobby for improvements in local conditions in favor of disabled people.

In essence, to perform capably in providing effective independent living services, the rehabilitation practitioner's knowledge will have to be much more comprehensive than is generally required at present. There is no question that in some cases and for some clients many of the services described above are already being provided. Many services to homemakers

entail at least some of these services. Certainly, though, these practices aren't universal, and many, if not most counselors simply do not have the expertise gained through experience or training to be able to conduct their caseloads so that their clients in total can benefit from services of this type. It is obvious that if counselors are to provide these comprehensive services in a systemized fashion they will require far more broad and, at the same time, in depth, training.

Time constraints: Under present conditions, rehabilitation practitioners manage caseloads ranging from less than one hundred or so to as high as three hundred or more. Even counselors on the lower end in caseload size frequently lament the problem of too many job duties and too little time to perform them adequately. The use of the IWRP has not, in many areas, significantly reduced the ratio of time needed to devote to each case. If time is a factor in the present VR program, it would seem minimal in comparison to the amount of time needed to properly manage an independent living rehabilitation case. As mentioned above, these cases will require attention to many more details much more consistently than the types of cases now generally handled by rehabilitation counselors. Based on results of RSA pilot projects completed to date, it is felt that the maximum number of cases a counselor could handle in ILR would be around twenty-five, and, one study indicates, preferably as few as seventeen. Actual caseload size

would depend on many variables, such as geographic location of caseload, disability types, etc. It appears, then, that counselors engaged in this program will need to adjust ever more to quality of work rather than quantity. This fact would have to be recognized clearly by administrators and supervisory personnel as well. The production of "statistics" hardly seems appropriate as a measurement of performance. It seems feasible to devise criteria that would measure how effectively the counselor fostered client independence as a result of his case management. With the myriad of problems that will require solving by the counselor in seeking, with the client, the goal of independent living, there is no question but that the counselor will, as always, feel time constraints are a detriment to the kind of job performance he would like to exhibit. Job duties will differ in that each client will receive much more time and attention than now can be given. Many of the services will be the same but will be in greater depth, such as counseling and guidance toward adapting to the independent living situation. It appears that cases will be open for far longer periods of time than is the case at present. Counselor judgement of when to close a case will often be crucial to the success or failure of a particular case. If a case is terminated too soon the client may falter in his independence and become disillusioned. Conversely, the counselor must guard against fostering too much dependence on the client's part which could delay or eliminate the client's eventual independence.

Actually, counselor judgement as to assessing client needs and how they should be met will, no doubt, prove to be the pivotal factor in success or failure. The provision of independent living services will require a level of expertise not now possessed by some counselors. An individual who performs his job mechanically is undesirable under the present VR system and would be much more detrimental in the provision of independent living services for the severely disabled. Once again, proper recruitment of counselors and intensive training should be of primary importance if the proposed program is to work effectively.

Additional considerations for the rehabilitation practitioner:

It would appear that the most difficult problem adaptation would cause for counselors in the provision of ILR would be in those areas in which, unfortunately, he has had little training. The use of similar benefits is somewhat foreign to most counselors. The use of similar benefits will be prominent in ILR, and counselors must be properly trained in how to use them to the benefit of the client and the rehabilitation agency. State agencies should provide needed resource materials to counselors so clients can benefit from new technological advances in the rehabilitation field. The ability to recognize the need for in depth physical, social, and emotional evaluation will be needed. The counselor must be able to view the "whole" client and his world.

The ability to assess client potential will be instrumental to the ultimate success a client can achieve. Many will be able to go beyond what may be initially expected and can reach productive vocational lives.

Client attitudes is another area with which the ILR counselor will be required to deal. Many who will be eligible for independent living services will be those who were rejected by the regular VR program because they were too severely disabled. They may harbor negative feelings toward rehabilitation, and it will be necessary for the counselor to explain the reasons for their initial rejection and why they now are eligible to receive services. Even so, many will enter the program with reservations, and it will be the counselor's responsibility to convince them he has their best interests in mind. Furthermore, many severely disabled individuals may be fearful of leaving an institutional setting or an uncomfortable situation because previous treatment caused almost total dependence on others. Convincing a client who is willing and desirous of living independently but who is afraid to move because he fears failure that he can succeed will be a difficult task for the counselor. Also, advising a client that independent living is contraindicated because of the severity of disability or other reasons may be even more difficult. Effective counseling abilities will be imperative if negative client attitudes are to be changed to those of a positive nature. If the counselor is not convinced his recommendations are correct, he cannot expect the client to have

confidence in his suggestions.

There are, indeed, many unique challenges in store for rehabilitation practioners in the event Independent Living Rehabilitation becomes reality. It will be an opportunity for counselors to have a central role, from start to finish, in the rehabilitation of severely disabled individuals. They will need the "tools", in the form of funding, training, and administrative committment if they are to be successful. Even if these requirements are met, the rehabilitation practioner will be required to posess initiative, intuition, organization abilities, and medical knowledge beyond what is now required. He will often have to be an advocate for his disabled clients, and he will have to know community resources that are available to benefit the client and how to maximize them in partnership with the client. Above all, he must posess empathy for the people whose lives he will be affecting so intensely.

IMPLICATIONS:

1. If Independent Living Rehabilitation becomes a reality, many of the present attitudes in Rehabilitation will not easily accommodate such a program. Basic attitudinal changes will be necessary, at all levels, if such a program is to effectively be carried out.
2. Rehabilitation practioners will be required to have increased knowledge in many areas not presently emphasized, for example, barrier removal and active advocacy of rights for the disabled.
3. Caseload size will be dramatically reduced, calling for increased personnel to handle the expected increase in the number of referrals.

4. New methods of counselor performance evaluation will be mandatory as ILR casework will be radically different from the present system.
5. Increased funding will be necessary in order for counselors to properly provide ILR services.
6. Intensive training of rehabilitation practitioners will be imperative, not only initially, but in an ongoing manner.
7. Only the most experienced and professionally most capable counselors should be given ILR caseloads because of the increased difficulty in managing such cases.
8. An intimate knowledge of community resources and similar benefits will be required of the rehabilitation practitioner, as this would reduce costs of the program and permit services for larger numbers of clients. Local office training programs could emphasize this, inviting various service provider representatives to the local office to discuss their programs. Their cooperation would greatly enhance the successful operation of ILR caseloads, and they would also be a valuable referral source.

UNIT IV

THE ROLE OF THE CONSUMER IN
INDEPENDENT LIVING

UNIT V

INDEPENDENT LIVING REHABILITATION SERVICES
WITHIN THE REHABILITATION PROCESS

Independent Living Rehabilitation Services Within the
Existing Vocational Rehabilitation Process

ISSUE:

Because of the existing mandate in rehabilitation legislation to serve the severely handicapped on a priority basis, the state vocational rehabilitation agency must be involved in ILR type services to enable the individual who is severely handicapped the chance to move positively to a successful vocational goal.

OBJECTIVE:

To explore the provision of ILR type services within the existing vocational rehabilitation service delivery system.

SUMMARY:

The charge that vocational rehabilitation should provide a broader scope of rehabilitation services is not new because of the necessity of looking at the totality of the problems and conditions faced by the person with a severe disability. These comments about providing ILR services within the existing VR authority and capability are in no way intended to infer that current VR service delivery systems have appropriate legislation, funding, existing staff, or any other total capability to provide ILR per se. This is simply an attempt to explore the prospect of a vocational rehabilitation agency providing more complete rehabilitation services to the severely handicapped.

DISCUSSION:

Rehabilitation legislation in 1973 clearly mandates services to the severely handicapped on a priority basis. The entire issue of

independent living rehabilitation (ILR) is entangled with the equally broad issue of services to the severely handicapped. The objective of VR services is "employability". The eligibility criteria remain:

- 1) "The presence of a physical or mental disability which for the individual constitutes or results in a substantial handicap to employment; and
- 2) A reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability."

If comprehensive VR services are provided, ILR services are a necessary part of the VR process. Can an individual work without an appropriate place to live? Can an individual work without reliable and appropriate transportation to his place of employment? Can an individual work without appropriate social skills? Can an individual be a legitimate 26 closure without appropriate independent living skills?

In the majority of cases, and more especially with the severely handicapped, skills and environments for independent living are prerequisite to vocational performance. Many of the ILR skills, as commonly perceived, are the same skills as those needed for employment stability. Call these ILR skills pre-vocational skills, skills necessary for employment, or whatever you like. The result is the same---ILR is, can and must be a part of effective VR casework.

Agencies specifically serving the blind have historically and traditionally provided a comprehensive service system approach. Immediately after the primary goal of sight preservation and/or restoration comes rehabilitation to the least restrictive living environment and the most productive employment. This vocational rehabilitation process by design includes ILR services. Basically,

any service that may benefit the individual in terms of employability is offered.

The overriding principle here is that ILR can and is being provided in the existing VR process, but Utopia has not yet been reached. Vocational rehabilitation received only 2% of the federal money directed to the disabled during fiscal year 1973 and this trend seems to be continuing. A service delivery system can do only "x" amount of things with "x" amount of money. Inflation continues to eat away at available resources. As more costly services are needed for longer periods of time by the severely handicapped, fewer clients will be served due to available resources. This equates to more and more handicapped individuals falling through the cracks. Utilizing the VR process most effectively and to its fullest, which includes ILR type services, will not solve the problems of independent living rehabilitation needed by the severely handicapped. Professional staff and administrative attitudes remain as barriers, but these can be overcome given the necessary training and time.

The information presented below is presented as food for thought and to assist the VR professional in establishing intermediate goals and objectives (as related to ILR) through proper utilization of VR 06 status and the IWRP.

I. Diagnostic Assessment

The diagnostic assessment period can be described as the most important part of the rehabilitation process. Other parts of the process will evolve from the quality of information gathered and decisions made during this initial period. It is during this period that the counselor must begin to identify those ILR services that will be needed for the client to proceed through the rehabilitation

process.

For many years ILR services have been provided through the rehabilitation program. The priority of services for severely disabled has increased the need for ILR services within rehabilitation. Much of the information reviewed here is basic to most counselors' knowledge and skills, but it will be necessary for counselors to review some of the basic knowledge and to improve upon the skills. Provision of more comprehensive and better quality services will be the key to ILR within the rehabilitation process.

The securing of a complete social history will be an important first step. The following are suggested items to be included; however, some items may vary according to the particular client.

1. Identifying data
2. Source of referral; reason for referral
3. Present illness
History of present illness; date of injury or onset of illness
Client's description of disability and how it has affected his life
4. Previous medical history
Complete history of previous illness or injuries; names of physicians, dates of hospitalization
5. Personal & family history
Parents' background; parents' occupations; number of brothers and sisters; cultural climate of home
6. Education
Highest grade completed; vocational or pre-vocational courses or training; affect of disability or illness on school progress; record of school grades, psychological tests, and other pertinent information from school setting; participation in school activities; location of school
7. Work history
Kinds of work; length of each job; relationship with employers and other employees; kind of work liked best; relationship with supervisors; specific skills for use in future employment; attitude toward work

8. Present family relationships and economic situations
Marital status; persons in immediate household; sources and adequacy of financial support; affect of handicap on relations among family members; standard of living; evidences of harmony or discord in family; family's willingness to assume supportive role in rehabilitation process; if married, attitude of spouse
9. Personality and habits
Interests; hobbies; social activities; personal habits; leader or follower; personal appearance and manner; evidence of emotional problems
10. Planning for independence
Attitude toward rehabilitation process and goal of independent living and employment; clarity of goals; identification of current obstacles, i.e., education, training, barriers, transportation, employment opportunities, review attitude toward work; review attitude toward disability; assessment of level of income needed to achieve independence.

The above outline includes suggestions and is not intended to be comprehensive. Item 10 is not an integral part of most social histories but must be considered basic in the assessment of the severely disabled client.

Through careful evaluation of the complete social history, the counselor should be able to identify those support systems that can facilitate the client's movement through the rehabilitation process. Services may need to be provided to assist in some of these areas. Support systems that will be critical in the success of the rehabilitation program are:

1. Medical
Does the client have a physician and/or medical facility assuming responsibility for coordinating his treatment program?
2. Family
Is the family supportive of the client moving toward independence?
3. Financial
Does the client and/or family have the resources to provide for basic support while the client participates in a rehabilitation program?

4. Psychological/Social

Does the client's social relationships and activities contribute positively to the goals of the rehabilitation process?

5. Housing

Does the client reside in an appropriate living situation with environmental support as necessary?

6. Transportation

Does the client have access to the necessary transportation resources for follow-through with a program?

7. Communication

Does the client have access to appropriate communication systems?

8. Advocacy

Does the client have access to appropriate advocacy support?

Having addressed the above issues, the counselor determines the client's eligibility based on existing criteria. If there are some questions regarding feasibility for a vocational objective, extended evaluation will be appropriate. During this process, it may be helpful for the counselor to address some of the following questions.

1. Motivation - Does the individual aspire to be independent in the mainstream of the community?
2. Intelligence - Does the individual have the general intelligence to understand both the rehabilitation system and the options that may be available?
3. Survival skills - Has the individual acquired the specific survival skills that will enable him to maintain rehabilitation gains?
4. Self-confidence - Does the individual have the self-confidence to move from the "womb-like" hospital, rehabilitation center, or family setting into the "risk-filled reality" of a training facility, employment setting, apartment, or other independent living situation?
5. Community Support - Does the individual have the support of family and friends and significant others in moving toward independence?
6. Expectations - What are the client's expectations of the agency, institutional, and community options that are available?

7. Goal oriented - Is the individual goal oriented or just "drifting"?
8. Decision making - Problem solving - Is the individual able to make decisions? Is the individual able to solve most of the problems involved in everyday living?

In reviewing these issues and questions, the counselor should be able to define the ILR services that will be needed within the VR process. Many of these services may be provided in extended evaluation.

3a "It is quite possible that intermediate goals to be achieved during the extended evaluation process may require many services that are not vocationally relevant." In many cases, issues of independent living need to be solved before employment potential can be assessed.

3b "Extended evaluation should be widely used to provide flexibility in approaches and to encourage change and innovation."

Counselors will need to evaluate their own attitudes, values, and skills during this period. As a part of this self-assessment, counselors may need to ask:

1. Do I believe that the client can achieve a greater level of independence? Or do I perceive the client's handicap as a totally negative situation?
2. Am I comfortable in supporting the client's move from dependence to independence?
3. Do I have any needs to keep my clients dependent on me?
4. Can I deal comfortably with the client's personal concerns that must be discussed if ILR services are to be provided?
5. Does my own self-image and body-image interfere with my developing a positive relationship with the client?
6. Do I believe that my client is entitled to the highest level of independence possible?
7. Am I comfortable with the ups and downs, with the growth and setbacks?
8. Am I resourceful enough to work with clients who need ILR services?

9. Am I comfortable with progress that may be slow and difficult to measure?

II. Planning

During this phase of the process, the counselor and the client will work together to develop the IWRP. Many of the intermediate objectives will have been identified during the diagnostic phase. The vocational goal must be established and appropriate services identified for goal attainment.

Some of the goals and services may be directed in the following areas:⁴

1. Attendant Management - Methods of locating, training and supervising attendants.
2. Financial Management - Programs of financial assistance, counseling on money management.
3. Mobility - Exploration of various modes of transportation, both public and private; evaluation of devices needed for ambulation; specific needs such as transfer training or mobility training.
4. Home Management - Adaptive techniques and/or equipment to facilitate independent housekeeping.
5. Medical Needs - Self-directed care, routine medical maintenance, health maintenance, education, emergency care plans, resources in the community, therapy (speech, occupational, physical).
6. Living Arrangement - Evaluate current situation and identify options; rearrange environment to improve capabilities.
7. Communication - Improve on communication skills, verbal, written, and telephone; learn assertiveness. Identify specialized communication devices.
8. Leisure Time - Identify social relationships and/or groups; spectator activities, participant activities, hobbies.
9. Problem Solving - Problem identification and method of solution; community resources.
10. Equipment - Identify assistive equipment needs; selection, operation, care and maintenance of necessary equipment.
11. Activities of Daily Living - Personal hygiene, feeding, bathing, dressing.

12. Sexuality - Sexuality and disability, dating, role expectations.
13. Mental Health - Identify problems, and resources for help; explore peer counseling.
14. Facilities - Identify client need and resources in community.
15. Educational - Vocational Opportunities - Exploration of educational and vocational programs; range of employment opportunities.
16. Rights - informed consent; right to service; discrimination.

These areas of concern can be addressed at many points in the rehabilitation process. In some cases, it will be appropriate to deal with many of these issues in extended evaluation. If this has not been done, however, the counselor must address these goal possibilities during the planning phase. All of these suggestions relate directly to independent living for the severely handicapped. It will be noted that many of these ILR pre-vocational services have been provided, and must continue to be provided, as a part of the rehabilitation process.

It is important to note that the vocational rehabilitation counselor may be the professional person who can best look at the whole person and the totality of the problems being faced as the client moves toward independence. This approach will be necessary to avoid fragmentation.

III. Service Provision

The client and counselor together have agreed upon the intermediate objectives, the vocational goal, and the services to be provided. The counselor continues to have an important role as the client moves toward independence. The following are some areas to be considered.

Case Management

3c "The nature, quality, and full completion of services rendered, should be under the careful scrutiny of the vocational rehabilitation

counselor." Because of the number of complex issues that must be addressed in working with the severely handicapped, it is natural that many problems will occur during this period. It will be a time of growth and change for the client, and it will also be a time of stress. The client and professional working together in problem solving will be of great importance in the client's successful completion of the rehabilitation program. Counseling and guidance will be a continuing important service throughout this process as well as periodic evaluation and revision of the service delivery program.

Resource Utilization and Coordination

No one agency can provide all the services needed to assist the client in the rehabilitation process (this is especially true for the severely disabled). The counselor has a key role in coordinating the resources available. Linkages with other agencies are essential, and should lead to a team effort which is focused on agreed upon goals.

Support Systems

During the diagnostic phase, several support systems were identified as important to the client's successful completion of a program. During the service provision period, there should be a regular evaluation of the support systems. This will assist in identifying problem areas that need intervention.

Independent Living Issues

Is the client coping well with his/her daily activities and schedule? Is the client relating well to family, friends, colleagues, etc.? Is the client appropriately assertive in his/her interactions? Is the client getting his/her needs met? Is the client becoming more self-confident and independent? Is the counselor supporting the client

in his/her decision making? Is the counselor reinforcing independence and not dependence? Is the client continuing to be goal oriented? Does the client have some additional needs such as training, transportation, housing, equipment, etc. that must be met before employment?

Program Revisions

Progress may not be constant. The client may have ups and downs during this period. Changes may be needed in the vocational goal. Some of the intermediate objectives may need to be altered, or additions may need to be made. Flexibility is the key in working with the severely handicapped. The counselor should be open to any changes that are indicated in assisting the client in achieving his goal. The counselor's way of responding to temporary setbacks may directly affect the client's ability to solve problems in the future. The counselor will need to assist the client in maintaining perspective so that temporary setbacks are not interpreted as failure.

IV. Goal Attainment

The counselor's responsibility in job development and placement is of great importance as the client approaches this phase. In many cases, job modification will be needed. ^{3d}"Job development for the severely handicapped will demand dedication, effort, cooperation, and understanding on the part of the employers and will require the development of unique expertise by vocational rehabilitation workers."

This may be a frightening time for the client. It may appear that many of the support systems that have been present during the program are going to suddenly disappear when employment begins. The counselor will need to help the client evaluate once again the status of the support systems needed for independent living to be a reality.

In some cases, the goal may have been "homemaker" rather than

employment in the community. Many ILR services can be provided to enable a person to function in the home as long as the counselor works within the existing rehabilitation guidelines.

Whatever the goal, the client will need follow-up services so that the placement can be evaluated. Problems need to be addressed so that the success of the placement is not jeopardized. Supportive counseling may be extremely important to the client during this period.

The key to successful attainment of the goal, however, lies with the client. The client's motivation to success and to be self-sufficient will be all important. ⁵"If he doesn't believe in himself and believes the counselor 'brought' him through the rehabilitation process, it is going to show in the job interview. He may have been able to fool his doctor, his counselor, and himself about having an adequate self-concept, being job ready, and being highly motivated. He probably won't fool the prospective employer."

V. Post-Employment Services

⁶"Post-employment services are provided after clients have been determined to be rehabilitated to assist those in need of such services to maintain employment. The concept recognizes that an individual may need certain vocational rehabilitation services following rehabilitation in order to maintain his employment and prevent the breakdown of rehabilitation results.

Counseling and guidance are as essential during the post-employment service period as they are during other phases of the vocational rehabilitation process and constitute the core service by the counselor around which all other post-employment services are provided.

Some post-employment services, however, required by a particular handicapped individual to maintain himself in employment may not fall

within the scope of vocational rehabilitation services. This might include an attendant or homemaker to assist the handicapped individual to dress, prepare meals and do other tasks in the home which the handicapped individual cannot do alone. While the State vocational rehabilitation agency cannot provide continuing attendant or homemaker services, specific arrangements for obtaining such services should be included in the post-employment services program for that individual utilizing other agencies and resources, including those of the handicapped individual. It is imperative that the counselor explore and make full use of all resources and benefits available to the client in planning post-employment services, just as is required in planning and providing all of the vocational rehabilitation services that lead to the client's preparation for and placement in employment."

IMPLICATIONS:

- 1) More monetary resources for services must be made directly available to VR agencies (only "x" amount of work can be done with "x" amount of money).
- 2) More monetary resources for training staff in the ILR needs of individuals with severe handicaps and skills to provide comprehensive services must be made available directly or indirectly to VR agencies.
- 3) Goal directed services with measurable outcomes for ILR must be established to further and maintain the credibility of vocational rehabilitation.
- 4) Increased and more effective use of post-employment services must be implemented.
- 5) More effective methods to integrate ILR and VR services in a timely fashion must be developed.
- 6) More effective use of extended evaluation to give clients and counselors knowledge of new alternatives for successful independent living and employment must be developed.
- 7) Acceptance of ILR within the VR process must be fostered by demonstrated success (see #3 above).

- 8) Re-examination of the concept of vocational rehabilitation closure may be necessary (multiple services over an extended period of time).
- 9) An increased use of similar benefits may be necessary (multiple services over an extended period of time).
- 10) Understanding that for the severely handicapped habilitation may be necessary prior to the traditional rehabilitation.
- 11) Appropriate supportive services for the severely handicapped such as transportation and living environments must be developed.

Footnotes

1. The general outline and some of the content of the social history is taken from:

"An Introduction to the Vocational Rehabilitation Process"

John F. McGowan

Thomas L. Porter

U.S. Department of Health, Education, and Welfare

Revised 1967 p. 75 - 76

2. Most of the content of this section is taken from:

"Housing Alternatives for Individuals with Spinal Cord Injury"

Frederick A. Fay

Tufts - New England Medical Ctr. Rehabilitation Institution

Number 7, Second printing, October, 1977

page 2

3. Critical Issues Involved in the Rehabilitation of the Severely Handicapped:

IRI Publication

Arkansas Rehabilitation Research & Training Center

University of Arkansas, April, 1974

3a - p.94; 3b - p.94; 3c - p.76; 3d - p.108

4. Information Memorandum

RSA-IM-77-87

Subject: Independent Living

Dept. of Health, Education & Welfare

Office of Human Development

RSA

Washington, D.C. 20201

Most of this section is taken from p.1 of this document

5. American Rehabilitation

September - October, 1977

"Self Employment for Severely Disabled People"

P. 6, Edward J. Coletti

Footnotes (con't)

6. Program Regulation Guide

RSA-PRG-75-9

Subject: Post-Employment Services

Chapter 1543

Dept. of Health, Education & Welfare

Office of Human Development

Washington, D. C. 20201

The content of this section was taken from pages 1-3 of
this document

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1. "Critical Issues Involved in Rehabilitation of the Severely Handicapped", First Institute on Rehabilitation Issues, Arkansas Rehabilitation Research & Training Center, University of Arkansas, April, 1974
2. "Report of the Comprehensive Service Needs Study". The Urban Institute, June, 1975
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4. "Independent Living". Institute for Research Utilization, Susan Stoddard Pflueger, December, 1977.
5. Title 45 CFR, Chapter IV, Part 401, "The State Vocational Rehabilitation Program", November 25, 1975.
6. Public Law 93-112, 93rd Congress, H.R. 8070, September 26, 1973.
7. "An Introduction to the Vocational Rehabilitation Process", John F. McGowan, Thomas L. Porter, U.S. Department of Health, Education and Welfare, Rev. 1967, p. 75-76.
8. "Housing Alternatives for Individuals with Spinal Cord Injury", Frederick A. Fay, Tufts - New England Medical Center Rehabilitation Institution, Number 7, Second printing, October, 1977, page 2.
9. RSA-IM-77-87, "Independent Living", Department of Health, Education, and Welfare, Office of Human Development, RSA, Washington, D.C. page 1.
10. American Rehabilitation, September - October, 1977, "Self Employment for Severely Disabled People", p. 6, Edward J. Coletti
11. RSA-PRG-75-9, "Post-Employment Services", Department of Health, Education & Welfare, Office of Human Development, RSA, Washington, D. C., pages 1-3, June 6, 1975.

UNIT VI

INDEPENDENT LIVING REHABILITATION
THROUGH SPECIAL PROJECTS

INDEPENDENT LIVING REHABILITATION THROUGH PROJECTS

It has been suggested that one method of initiating a nationwide rehabilitation program for independent living be through the mechanism of discreet projects funded for a specific duration from earmarked funds appropriated under the Rehabilitation Act.

Advocates of this approach suggest that the project method will provide the flexibility needed to establish alternative service delivery systems to determine what systems work or don't work or their relative efficacy, and how the resources of various programs such as Medicaid, Title XX, VR, HUD, Social Security, etc., can be meshed to maximize existing services and prevent unnecessary duplication and waste.

In testimony before the Congressional Committees on rehabilitation, support for the project approach comes from several sources. Among these are the following:

1. From an evolutionary point of view, the obvious next explosive area for rehabilitation research will concern itself with the service delivery system to meet the needs of those who may not have vocational goals. So-called "independent living services" have created a Tower of Babel, with a confusion of definitions and programs. Sec. 130 just does not have the funding to do the job. What is needed is some form of new project grant authority with some substantial funding to experiment with different service delivery systems in a variety of settings. Should the VR agencies do this? CIL's? How much would it cost? May I remind the Committee that the Comprehensive Needs Study indicated that the 10 million severely handicapped individuals have some \$21.5 billion spent by some 85 federal programs in their behalf --- yet an infinitesimal amount of that goes for rehabilitation. In these days of "can't afford" a small percentage of that \$21.5 billion spent not to warehouse but to rehabilitate might pay handsome economic as well as personal dividends.^{1/}
2. As Dr. William Spencer noted in his testimony of June 20, 1977, before the Senate Subcommittee on the Handicapped, a number of programs currently exist which are necessary to achieve independent living. They include programs for housing, transportation, social services and medical care. They are insufficient, however, because there are enormous gaps in service due to eligibility requirements, lack of

^{1/} Testimony of James H. Garrett, Ph.D., Vice President, World Rehabilitation Fund, before House Committee on Select Education, April 10, 1978.

some services in some localities, and lack of coordination between agencies that provide services.

Despite the urgency of these unmet needs, we cannot recommend that overall financing for a comprehensive program of independent living rehabilitation be made at this time. Instead, a pilot phase is needed to work on questions of program and policy.

We agree with Dr. Spencer that a variety of demonstration programs are needed to explore ways of organizing and providing services to the severely disabled. Federal funds should be appropriated to allow from 20-50 model programs to be developed throughout the country. Diversity should be encouraged with respect to location, constellation of services and style of organization.

Some diversity would also be possible with respect to clients served, but we recommend, at least during the pilot phase, that the target population be working-age adults with severe physical and/or sensory disabilities. In our opinion, these are the individuals who have the greatest need for independent living services and who have received the least assistance in the past. Limiting the demonstration programs to these participants will also make comparisons between programs and evaluation of outcomes more feasible.

A number of organizations should be eligible to apply for center grants. The few independent living programs already in existence have been started by various sponsors; by state departments of vocational rehabilitation, consumer groups, research and training centers and private, nonprofit organizations.

Such wide-ranging experience should be valuable in searching for clues about the types of programs which are most successful. While we would be reluctant to set quotas to ensure continued diversity, it should be recognized that some groups, by virtue of training, experience, and resources, are better equipped than others to compete for funding. The demonstration projects should include some initiated and largely run by consumer groups. They should also include some from rural areas and some from each major section of the country.

Regardless of sponsoring organization, every demonstration program should require extensive consumer participation in planning, operation and evaluation of the programs. The need for this requirement is obvious just to fulfill the basic intent of independent living programs. Another result of consumer participation should be to intercept the misguided

efforts of organizations which may be tempted to leap into this area solely because of the availability of government funds. We have already seen the unfortunate results of some housing projects for disabled people, built on cheap land, far outside of urban areas, which completely disregarded the need for accessible public transportation, medical services, shopping facilities, and the like.

This brings us back to the importance of a system for evaluation of the demonstration projects. As Dr. Spencer recommended, an evaluation design should be required for each center. Uniform data should be collected on needs, services provided and services missing, costs, outcomes, etc. These should provide a data base for a report to the President and the Congress. They should also provide gradual accumulation of knowledge about the characteristics of successful and unsuccessful programs which can be used to identify more uniform requirements for independent living programs in the future.

It should not be expected, however, that evaluation of the demonstration programs will lead to definition of a single "best" format for independent living programs. Various individuals are comfortable in different kinds of settings, and even the same individual may need different settings and services at different stages of his or her life. As another example, a model which works well in an urban environment may need considerable modification in a rural area.

The research will be important, however, in identifying the parameters common to all effective independent living programs.^{1/}

3. There is no comprehensive rehabilitation service program that serves disabled people for whom vocational goals cannot be established, but for whom a related goal of greater independence in living could be developed. Certain elements of such a program are in place today in some communities, especially for people who can qualify for public assistance and medicaid, but no general comprehensive program is available.

The goal of more independent living has always been an integral part of and is a by-product of the delivery of vocational rehabilitation service. It has come to mean the ability of the severely disabled person to participate actively in society;

^{1/} Working Paper Prepared by Nancy Crews, Ph.D., Committee on Social and Environmental Aspects of Rehabilitation in Independent Living for the American Congress of Rehabilitation Medicine.

to own and manage a home; to raise a family; to exercise the rights and responsibilities of non-disabled people. In summary, it means to participate to the fullest extent possible in the normal day-to-day activities of everyday life.

In achieving this goal (as in working toward vocational rehabilitation) it is necessary to provide a full range of services.

Services are planned with the individual, are coordinated and provided singly or in combination, as needed.

Independent living rehabilitation is not new to the rehabilitation system. Advances in independent living have been achieved by hundreds of thousands of people already served by the State-Federal program. It can be assumed that many who did not reach the optimum goal of employment and were "closed", not rehabilitated, were very much improved in their capacity to cope with responsibilities of personal and community living. Perhaps agencies and counselors should be given greater credit for these achievements of their clients.

As a matter of planned service outcome, agencies for the blind, both public and voluntary, have for many years furnished some components of an ILR program to their clients. The authority for extended evaluation in the Rehabilitation Act has also been used as a means to upgrade and later to evaluate disabled clients whose vocational potential has been difficult to predict. The agencies in Alabama and Texas using non-Federal funds have been providing independent living activities.

We propose project grants for independent living building on the experience and on the findings of Section 130 projects now underway.

Our proposal includes a series of community-based projects to be conducted by VR State agencies and other public, private, and voluntary agencies.

The projects would give us an opportunity to assess the impact of this initiative. An important consideration would be the capacity of the people served under these projects to develop vocational potential as a result of independent living rehabilitation services.^{1/}

^{1/} Testimony of Robert R. Humphreys, Commissioner, Rehabilitation Services Administration before Subcommittee on Select Education, House Committee on Education and Labor, April 12, 1978.

A suggested legislative base for this project approach is the addition of a new section to the Rehabilitation Act which provide for grants to or contracts with public or nonprofit private entities to pay part or all of the costs of projects to provide comprehensive services to assist severely handicapped individuals, and handicapped individuals who without such assistance would continue to be institutionalized, to live independently and function normally to the extent possible. Services provided under each project would include, as appropriate, the services described in Section 103 of the Rehabilitation Act and other services needed, including transportation services, attendant care and accommodations to and modification of living spaces. No project would be funded for a period in excess of five years. All projects would be evaluated to determine their effectiveness.

There is no way of knowing at this time what legislation, if any, pertaining to independent living rehabilitation might be enacted by the Congress. Nor is there any indication, at this time, of the legislative format of the Administration's proposal to Congress in this area. However, it would seem advisable that State rehabilitation agencies give thought to the criteria and standards they will employ in establishing and conducting independent living rehabilitation projects or in establishing working relationships with projects established by and to be operated by organizations and agencies outside the state VR agency, should the Congress establish a nationwide program for independent living rehabilitation along the lines described above.

It is vitally important that certain elements be incorporated into these criteria to assure, among other things, that the individuals served by the project are those persons who are severely disabled and determined to be so by objective measures; that the proposed services are essential to the needs of the individuals to be served and are not duplicative; that the organization of the project, the service delivery method, staffing, funding, etc., is sound and focused to achieve the ends for which the project is designed; that the individuals served by the project or their representatives have significant roles not only in the development of the project but in its continuing operation; that the preparation and maintenance of an IWRP on an appropriate IWRP form(s) is an integral part of the project; that adequate measures are included in the project for assessing and reporting each client's progress, including client self-reporting, reporting by a relative or friend closely associated with the client as well as counselor reporting; and that proper relations are established with other human services programs including vocational rehabilitation to assure maximum use of their services and resources.

The highest standards must apply in the operation of these projects to assure quality and prompt services to the individuals for whom the projects are designed, and the provision of reliable data and findings on which the Administration and the Congress can best determine the form and content of an independent living rehabilitation program for the future.

In the initial years of a rehabilitation program for independent living, irrespective of whether the program is administered within the

existing vocational rehabilitation framework or on a project basis, the primary quest will be for innovative ways of making readily available (through existing programs where the required service exists or if it doesn't exist by creating the needed services) the variety of services and assistance that will enable severely disabled people to live and function independently within the community in living arrangements and in a life-style of their choice.1/

In conducting their statewide studies of rehabilitation needs, required by Section 101(a)(15) of the Rehabilitation Act, State VR agencies may wish to include the collection of information and data for the development of a reservoir of innovative programs or projects to be initiated when the enabling legislation and funds become a reality. Organizations representing handicapped people should be included in this survey and planning process, as such organizations may very well be the best qualified to administer a particular project or service in a specific community. In any event, they can provide advice and guidance based on experience, that will give added dimension and depth to the survey and planning process.

It is important that the principles and practices that have proved successful over time in the vocational rehabilitation program be made an integral part of the operation of the independent living rehabilitation project. This includes complete involvement of each client in the development of his/her individualized rehabilitation program, recording of this program in writing on an IWRP form that spells out intermediate goals as well as the end goal and the resources to be utilized and steps to be taken in achieving the intermediate goals and the end goal. Also, it is essential that accurate records be maintained on costs, both costs defrayed directly by the project and the value of services received from other programs, for as the BCIL Report indicates so long as the program offers a cheaper alternative to institutional care then it will have continued public support.2/

Existing programs offer a variety of services that can be utilized in a rehabilitation project for independent living. Among these programs are vocational rehabilitation, Medicaid, Medicare, SSI and SSDI, HUD and state and local housing authorities, Veterans Administration, CETA, Title XX, R&T Centers, Rehabilitation Engineering Centers, BEOG and state scholarship programs, Blue Cross-Blue Shield, Mental Health Clinics and Labor Union programs. Often the benefit or service a program can offer may not be apparent or may not have occurred to the administrators of the program as

1/ Some may wish to live in residential Center for Independent Living, either transitionally or permanently; some may wish to live in housing complexes with special accommodations--architectural, transportation, a pool of personal care assistants and exercising attendants, etc.; others may wish to live with their families, or independently in accessible apartments with or without a personal care attendant.

2/ The BCIL Report, R&T Center No. 7 Tufts-New England Medical Center, July 1977, p. 27.

being possible under the program's regulation, as, for example, the payment of Personal Care Assistants under the Massachusetts Medicaid Program.^{1/}

In the design of a project, it would be well to examine thoroughly all programs that might contribute to attainment of the project goals, and explore with the administrators of these programs the specific needs of the people in the project and what services the other programs can offer. If the project is to be operated by an organization other than the VR agency, the VR agency should provide assistance to the sponsoring organization in this exploratory work.

Should the rehabilitation program for independent living be established on a project basis, it is likely that there will be a common data collection system. It will be important, therefore, that the reporting system for each project be well developed and efficiently operated. In its review of projects, State VR agencies will need to give particular attention to this aspect of the project, especially the quality of staff responsible for the reporting function. Also, it would be well to give thought to the measures that might be employed to measure client progress in the project. Numerous studies have been made on outcomes measures in the vocational rehabilitation program. Many of these studies measure changes in clients' physical and psychosocial functioning as well as their vocational functioning and potential. Review of the various methods and measures employed in these studies in the areas of physical and psychosocial functioning is suggested. It would seem particularly important in any rehabilitation program for independent living that the client report what he or she perceives to be the results of participation in the project. A well designed form should be developed for this purpose. Consideration should also be given to periodic reporting by an individual who is close to the client, so that comparisons and correlations can be made between the counselor's report, the client's report and the third party report in the interest of securing as true a reflection of the projects' results as is possible.

The basic requirements and guidelines for domestic research and demonstration projects under the Rehabilitation Act are set forth in RSA Manual Section 4010. (Program Regulation Guide RSA-PRG-76-24 of February 10, 1976.) These requirements and guidelines would be applicable to rehabilitation projects for independent living.

^{1/} The BCIL Report, R&T Center No. 7 Tufts-New England Medical Center, July 1977, p. 27.

UNIT VII
EVALUATION

Ralph D. Reese, Jr.

EVALUATION

ISSUE: How can evaluative measures be developed and utilized to insure the effective and efficient operation of an independent living rehabilitation program?

OBJECTIVE: To provide a "state of the art" summary of efforts to establish performance outcome measures that will adequately access a severely handicapped individual's progress toward independent living.

SUMMARY: An Independent Living Rehabilitation Program regardless of the level of funding whether operated on a project basis or fully integrated into state VR agencies as a service delivery system for severely handicapped individuals must have an evaluation component built into it that will accurately measure progress as well as the lack thereof and success as well as failure in Quality of Life areas leading to personal, social, and economic (vocational where possible) independence.

DISCUSSION: Traditionally the term "Independent Living" has been used to refer to the aids to daily living, the wheelchairs, arm braces, specially designed housing, etc., that offered the severely disabled person the ability to care somewhat for his own survival needs. Today the term goes beyond survival needs to include the broad range of services that help the handicapped person move into the mainstream of society.¹

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When those active in the movement today use the term "independent living", they are referring to the ability of the severely handicapped person to actively participate in society--to work, have a home, raise a family and generally share in the joys and responsibilities of community life. They are referring to the social services that we all take for granted but that may be denied to the handicapped person because of architectural and attitudinal barriers.

"Independent Living Rehabilitation" means programs providing rehabilitation services to the severely handicapped enabling them to live independently.

The elements which constitute "Independent Living Rehabilitation" (ILR) for one person may not be at all similar to the elements necessary for another person. Each severely disabled person faces different problems and will require services targeted to his or her unique and distinct problems. However, as generally practiced today, ILR programs provide counseling and direct services in some, if not all, of the following areas: Peer, Group and Family Counseling - locating and arranging special counseling services; Attendant Management - methods of locating, training, and working with attendants; Technological Aids and Devices - locating and securing needed aids and devices; Financial Management - programs of financial assistance, money management; Consumer Affairs - issues of

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public concern affecting the handicapped; Advocate Services - locating persons and groups that may serve as an advocate for the individual; Legal Services - information on legal rights and where and how to seek legal advice; Mobility - Orientation and mobility training, exploration of various modes of transportation, both public and private; Educational - Cultural - Vocational Opportunities - exploration of educational and vocational programs and cultural activities, range of employment available to persons with various disabilities, rehabilitation engineering services; Home Management - adaptive techniques of housekeeping; Medical Needs - self-directed care, routine medical maintenance, emergency care plans, physical and other therapies, sight and hearing conservation services, resources in the community; Living Arrangements - adaptive housing, comparison of living situations and supportive services; Social Skills - learning skills to enhance communication and assertiveness, exploring personal feelings about common concerns; Leisure Time - spectator activities, participant activities, hobbies; Functional Skills - rearranging the environment to improve capabilities, self-analysis of personal techniques, assistive equipment needs; Problem-Solving - problem identification and methods of solution; and Sexuality - sexuality and disability dating role expectations.²; Protective Services - insuring a safe

and secure life situation.

EVALUATION OF INDIVIDUAL OUTCOME

Medical and rehabilitation technology has made tremendous advances in the last few decades and we are now able to help persons with even the most severe disabilities to the point of independence. As ^{we} develop ILR programs, we must incorporate into them measures that accurately evaluate the "independent living gain" that accrues from the provision of ILR services.

It is generally recognized that vocational outcome is much easier to measure than independent living outcome. Even so, the status 26 vocational rehabilitation closure has not properly measured the degree of difficulty and accomplishment of VR clients with varying disabilities and vocational goals.

The status "26" closure prior to the Rehabilitation Act of 1973, and to an ever lessening degree even today at the policy making end of the administrative hierarchy has served vocational rehabilitation quite well as a very easy to defend measure of program success and resource utilization. Rehabilitation Services have been supported quite generally by all political ideologies (liberal to conservative) for over fifty years based in part on the easy measurability of X-number of successes (status "26" closures). Many other

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social programs have suffered from an inability to demonstrate clearly and concisely to Congress and the American public the effects of their programs. The status "26" closure was actually developed for this very purpose back in the 1920's to provide state VR agencies with a mechanism to indicate how Federal funds were being spent. As Vocational Rehabilitation has grown and expanded, the successful case closure ("26") has incorporated less than gainful employment into its purview and ever so gradually has become less descriptive of program objectives.

At the service delivery end (Counselor/Client end) of the administrative hierarchy the status "26" closure (with the possible exception of very early in the life of the VR Program when it was small, its mandate limited and its services few) has never served adequately to provide corrective feedback that would improve individual counselor and client performance toward the goal of client success. This has become increasingly the case as the VR Program has expanded, its services increased and the definition of client success has changed. Initially client success was measured by employment in the competitive labor market. Today sheltered employment, homemaker, unpaid family worker, etc., are a part of the purview of successful client outcome. Terminology

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in VR eligibility has changed from services leading to gainful employment to services that may benefit an individual in terms of employability. While the traditional parameter of change has been whether or not a client gets a job, the Rehabilitation Act of 1973 with its emphasis on serving the more time consuming and expensive severely disabled client has called for outcome measurement to measure changes in economic, physical, and psychosocial functions, as well as vocational functioning and potential. The need to develop an outcome measurement in Vocational Rehabilitation that measures these four main areas of client change appears to compliment the need for an adequate outcome measure for an Independent Living Rehabilitation Program.

The development of an accurate individual ILR progress and outcome measure that is reliable and valid but also quantifiable and relatively easy to administer appears to be the key to accessing individual client benefit, as well as project and/or program effectiveness. Such a measure, if generally accepted, would be an essential element of an Independent Living Rehabilitation Program of national scope.

Other important considerations for a national ILR Program would include incorporation of the "Individualized Written

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Rehabilitation Program (IWRP)" approach to client/significant other involvement in the development and provision of ILR services. It is imperative that the client and/or appropriate representatives of the client are involved from the outset in helping make decisions on when, where, how and what type of ILR services are planned and provided as well as in the establishment of reasonable and potentially attainable ILR short and long range objectives. After all, who can better assist in these critical determinations than the client and/or his representative(s)? It is essential that jointly established short and long term objectives be as specific and objectively measurable as possible in order to insure that the effects of a national ILR program on its clientele can be objectively demonstrated. This will be critical to establishing the integrity of such a comprehensive and far reaching program in the eyes of lawmakers and the general public.

Consideration should be given to building into whatever individual outcome measurement device(s) is (are) finally developed for a national ILR program the capacity to measure individual outcome through the eyes of the consumer and/or his appropriate representatives as well as the professional(s) involved in the ILR service provision.

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Perhaps an averaging of the scores of outcome measurements completed by the professional(s) and the consumer and/or ^{her} his representative(s) will lead to a more objective assessment of success in those areas that, out of necessity, will have to be measured by somewhat subjective means.

Certainly, consumer (client) involvement in the planning and provision of ILR services and the establishment of short and long range clearly definable and objectively measureable ILR objectives is to follow the lead of Vocational Rehabilitation by developing an "Individualized Written Independent Living Rehabilitation Program (IWILRP)" for each ILR client using the same principles of client involvement that are now being used for Vocational Rehabilitation clients. Including the client and/or appropriate representative(s) in the measurement of individual outcome is another step in involving the client in all areas of the individualized ILR Program.

When reviewing the literature on any subject in an effort to develop a state of the art discussion, the risk is always present that what is reviewed and discussed has changed and is therefore outdated. Therefore, the following discussion of outcome measures should be reviewed with this in mind.

OUTCOME MEASURES FROM COMPREHENSIVE MEDICAL REHAB CENTERS

It appears that the advent of Weed's Problem-Oriented Medical

Record was the first step in a series of significant changes that are occurring today in medical care. The traditional medical history and physical examination format is inadequate for obtaining ⁱⁿformation about a rehabilitation patient's future status. Weed's concept of developing a more organized approach to the medical record has revolutionized medical record keeping and is now routinely taught in many medical schools. It has also encouraged the development of "Activities of Daily Living" (ADL) scales which are used in conjunction with the problem-oriented medical record to measure functional status and progress over time.⁷

A survey of the literature from Comprehensive Medical Rehabilitation Centers (CMRC's) indicates that most have developed "Activities of Daily Living Evaluation forms" to meet their individual needs, but there is no one such form that is widely accepted and used. The purposes of these ADL scales are: (1) to objectively describe a patient's functional status at a given point in time; (2) from sequential evaluations to measure improvement or deterioration in functional status; (3) to monitor functional status to reinforce progress to the patient and those working with him; (4) to enhance communication of patient information between health care facilities and personnel; and (5) to promote comparability of clinical observations in medical

rehabilitation research.⁴ Donaldson⁴ at Tufts New England Medical Center identified and cross tabulated the variables in twenty-^{five} ADL scales and thereby devised an ADL evaluation which contains all the self-care and mobility variables commonly used by other scales as well as a few additional variables of special interest. The categories for rating the patient's functional status have definite objective criteria. The data can be punched directly from the form onto punch cards and can be processed by a computer using a program which has been devised to generate a Kenny self-care score, a Katz index rating, and/or a Barthel index rating should a single expression of ADL status be desired.

The Urban Institute in its Comprehensive Needs Study which focused on a description of the needs of the most severely handicapped beyond what is the traditional rehabilitation scope today indicated that a method which focuses on measuring functional limitations appears to have the greatest number of advantages since it is reliable, valid, and relatively easy to administer. In its comprehensive medical Rehabilitation Center survey the Urban Institute used functional performance level as the primary indicator of severe disability. Functional performance was measured at three points in time; upon admission to the project, upon end of the active provision of services, and at some period after, preferably one year.

Two major scales were utilized to measure physical functioning:

- (1) The PULSES Profile scale, developed by E. Moskowitz and C. McCann and modified by Carl V. Granger, M.D.; and
- (2) The Barthel Index, developed by F. I. Mahoney and D. W. Barthel and modified by Carl V. Granger. They found both the modified PULSES and the modified Barthel to be reliable measures of critical functional performance.

The PULSES Profile scale measures the need for professional and non-^{pr}professional assistance in six broad areas:

- P - The medical and/or nursing care required for the physical condition.
- U - The upper limb functional capability in self-care activities
- L - The 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 these functional areas is scaled with values of one to four. A subscore of three or four indicates assistance from another person is either frequent or necessary on a daily basis. A total score of 21-24 indicates extreme disability (scoring threes or fours in all areas); 16-20 severe disability; 12-15 moderate to severe disability; 8-11

mild to moderate disability; and 6-7 no disability.⁵

The Barthel Index measures the ability to function independently. It is divided into two subscales: "self-care" and "mobility." The Barthel Index contains nine "self-care" items which are considered basic to individual's ability to care for himself and six additional "mobility items" which pertain to the ability to move around without assistance. Items which are considered more important, such as ability to eat without assistance, are weighted more heavily than less important items like grooming. The Barthel Index has five categories which measure the extent of dependency in self-care and mobility:

Score

- 0-20 Totally Dependent
- 21-61 Severely Dependent
- 62-90 Moderately Dependent
- 91-99 Slightly Dependent
- 100 Independent

Barthel self-care items are:

- A. Drinking
- B. Eating
- C. Dressing upper body
- D. Dressing lower body
- E. Putting on brace or artificial limb

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- F. Grooming
- G. Washing or bathing
- H. Controlling urination
(bladder continence)
- I. Controlling bowel movements
(bowel continence)

Barthel Mobility items are:

- A. Getting in or out of chair
- B. Getting on or off toilet
- C. Getting in or out of tub or shower
- D. Walking 50 yards one level
- E. Walking up or down one flight of stairs
- F. If not walking:

Propelling or pushing wheelchair

Scores are derived from the Barthel scale, which assigns weights to each item on the Barthel Index.⁵ The Barthel Index is reasonably sensitive to changes in the individual's functioning, it is applicable to a general rehabilitation population, it has been researched to some extent, and it has a mechanism for scoring. These same comments can be made regarding the PULSES Profile.

The Barthel Index was originally used in clinical settings to evaluate a patient's state of independence before treatment,

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and his status when maximum benefit had been obtained.

As such, it provided a measure of an individual's progress toward independent living. Environmental factors such as availability of help (E.G., for dressing, eating), architectural barriers or presence of special devices (e.g., stairs, grab bars, ramps, etc.) can influence the Barthel score, since an individual who can perform the activity alone, even with the help of special devices, receives a perfect score; therefore, the score must be construed as the interaction of the person's physical condition with environmental conditions.⁶

The Functional Limitations Scale was developed as a supplement to the Barthel Index. It covers eleven (11) other important areas of daily living:

Functional Limitations	can do with no difficulty		can do with some difficulty		cannot do at all		undetermined or not applicable	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
1. Operating household appliances								
2. Taking medicine								
3. Getting in or out of bed								
4. Sitting for more than an hour								
5. Lifting or carrying weights of about 10 pounds								
6. Stooping, bending or kneeling								
7. Reaching with both arms								

15.

8. Using hands and fingers
9. Using the telephone
10. Operating a TV, radio, or stereo
11. Admitting visitors to your home

Impairment on these items would indicate that, at a minimum, it would be more difficult or require more time to perform daily household activities (e.g., cooking, cleaning, lifting items) and to maintain communication with others (e.g., admitting visitors, using a telephone, etc.). Items on this scale are scored more stringently than the Barthel. On the Barthel, a perfect score is possible if the person can perform the task independently, regardless of difficulty involved, whereas on the functional limitations scale, respondents indicate whether they can do the task "with no difficulty," "with some difficulty," or "not at all." Thus, the major contributions of this scale are that it expands the areas of daily living covered by the Barthel and permits finer discriminations of the degree of functional impairment.⁶

Medical rehabilitation efforts to standardize a measurement of functioning in disability has had a history of endless versions of scales without general acceptance of any one. Consequently, the incentive to do the extensive development work necessary for a universally satisfactory instrument is lacking. It is probably safe to say that no present functional

classification system, no matter how well known, has sufficiently detailed instructions for usage. A list of items, even with full definitions is not enough. The conditions for assessment need to be spelled out: the type of equipment, detailed task descriptions, how many attempts are given before judging success or failure, what sort of time limits (however generous) should be used, etc. A review of the medical models reveals they have many limitations when applied across disability groups. For example, they are not sensitive to the limitations nor do they measure the change of the sensory impaired. Furthermore, the medically developed functional measurement scales are too complex to be easily completed by a counselor, would require an excessive amount of time for completion, are not easily interpreted by non-medical staff, would require intensive in-service training for counselors, and are designed to primarily measure physical functional performance, leaving vocational, economic, and even psychosocial variables yet unmeasured. They have been used on a project basis (Section 130 Projects, etc.) primarily because of the lack of an alternative measure that can adequately measure functional improvement.

A project was funded in October 1974 for the Institute of

Rehabilitation Medicine at New York University Medical Center to develop "Rehabilitation Indicators" which are to be designed as "A Method for Enhancing Accountability and the Provision of Rehabilitation Services." Four types of Rehabilitation Indicators (RI's) have been developed: Status RI's describe statuses such as "living arrangement" and "employment status"; Activity pattern RI's describe recreational, self-care, educational and other activities selected by the client in day to day living; skill R.I.'s describe behavioral "tools" that constitute client strengths and problems (e.g. "walking up/downstairs", "reading a newspaper"); and environmental RI's describe aspects of the physical, social and personal environment that act as barriers to and/or supports in clients reaching their goals.

Using Rehabilitation Indicators within rehabilitation settings will not require adoption of any one approach or methodology, such as a goal attainment model. Goal attainment models as well as other approaches to rehabilitation service provision can all benefit from use of Rehabilitation Indicators. RI's were not developed with only the present State-Federal VR system in mind, so flexibility of usage approaches has been built in.

Rehabilitation Indicators form a non-jargon language that

promises to communicate well with many types and levels of participants in rehabilitation efforts. Varying types of clients (those with MR, psychiatric, physical and sensory impairments), varying types of services providers (counselors, nurses, psychologists, physicians, aides, OT's, etc.) and types of service settings (hospitals, State-Federal VR agencies, workshops, mental health centers, etc.) can use the same language to discuss rehabilitation goals, needs, entry criteria problems addressed by differing rehabilitation services, etc.

Rehabilitation indicators have three major purposes that they have been developed to address:

- a. Improving accountability for rehabilitation efforts by expanding the number of behavioral dimensions defined as important to the client's information base (e.g. vocational, social, independent living and other dimensions) and by increasing the objectivity of the information base.
- b. Improving the provision of rehabilitation services through improvement of information that is used in forming individual rehabilitation plans and rehabilitation program plans.
- c. Providing a tool that can be used to define operationally "disability" and "needs".

EXAMPLES OF REHABILITATION INDICATORS1. STATUS RI's

s40. Housing Arrangement

- s400 House, # rooms
- s401 Apartment, # rooms
- s402 Hotel room, # rooms
- s403 Half-way house (short-term placement)
- s404 Hostel, long-term group living
- s405 Institution (e.g. developmental center, hospital): ward arrangement (▷ 4 persons)
- s406 Institution: semi-private room
- s407 Other housing, # rooms

2. ACTIVITY PATTERN RI's

- A15 Household business (away)
- A150 shopping for groceries
- A151 shopping for other merchandise
- A152 banking, paying bills, accounts
- A153 obtaining services: cleaning, shoe repair, etc.
- A154 obtaining and/or using credit cards

3. SKILL RI's

03.00 Showers/bathes

- 03.01 Draws water at regulated temperature
- 03.02 Enters/leaves shower or bath
- 03.03 Soaps and rinses entire body
- 03.04 Dries entire body
- 03.05 Leaves bathing area clean and neat after use

4. ENVIRONMENTAL RI's

E09 Transportation

- 090 Public buses
- 091 Public trains, subways
- 092 Public taxis
- 093 Airplanes
- 094 Van, disability-modified, public
- 095 Van, disability-modified, private
- 096 Private automobile, modified
- 097 Private automobile, unmodified

PROJECT PRINCIPALS: This project is co-directed by Leonard Diller, Ph.D., Wilbert Fordyce, Ph.D. and Durand Jacobs, Ph.D. The Project Coordinator is Margaret Brown.

The Rehabilitation Indicators Project whose purpose is to develop a generic language that can be used to describe a rehabilitation client's capacities, behaviors, and relevant social or physical environment is one of the most comprehensive efforts ever undertaken to develop criteria for outcome measures. This long-term research effort could be potentially quite relevant to the outcome measurement dilemma.

The most promising area for exploration in new methods of outcome measurement in Vocational Rehabilitation and one that appears to be equally promising for an Independent Living Rehabilitation (ILR) Program nationwide is the weighted closure. Designed to reflect the reality that some clients are more difficult to serve, requiring more time, effort and expertise, and the coordination of varying resources within a community to reach the successful outcome is a tailored requirement for any individual outcome measure in an ILR Program.

The following weighted closure and case difficulty indexes acknowledge that rehabilitation gain may be made on more than the dimension of placement, and so in addition to

weighting certain factors using a computational process that allows for differences in case difficulty, there also is provision for "points being awarded" for gains the client may make in psychosocial functioning, physical functioning, and economic independence.

NEW OUTCOME MEASUREMENT EFFORTS IN VOCATIONAL REHABILITATION

The base of the evaluation problem in Vocational Rehabilitation lies in the closure system which allows one credit for each client closed "rehabilitated." The range of outcomes covered by the closed rehabilitated category (e.g. '26' closure) is so large that the closure requirements often seem arbitrary. At the same time, many valuable services are provided that improve client destiny for clients who are closed in the not rehabilitated categories. This lack of adequate outcome measures in Vocational Rehabilitation has restricted effective program evaluation, development and management. The closure categories so weakly reflect the goals of VR, that they inhibit their achievement. The inability of the VR closure system to distinguish easy from difficult cases, the lack of information provided, and the ^{am}ambiguous nature of the closure categories have destroyed the system's utility for program evaluation.⁸

OKLAHOMA SERVICE OUTCOME MEASUREMENT FORM:

Assuming that measures of case difficulty and client change could be formulated, Oklahoma's Rehabilitation Agency approached the Rehabilitation Services Administration for funding of such a project. Funds were made available (EV-3-71) and the Service Outcome Measurement Project began June 16, 1971. The project was designed to develop a measure of which would reflect the relative difficulty of cases and measure client change in the physical, educational, psychosocial, economic and vocational areas.⁹ These broad initial purposes were given prerequisites in order to develop an administratively feasible measure of case difficulty and client change. In general, these prerequisites were:

- 1) Change should be measured for all clients regardless of closure status.
- 2) The measure should require no changes in the service delivery system.
- 3) The measure should not require sophisticated electronic data processing equipment.
- 4) The measure should be easily interpreted.
- 5) The measure should require little in-service training for the counselor.
- 6) The measure should not require more than ten minutes of the counselor's time per case to administer.

23.

- 7) The measure should yield reliable information when used by different agencies, programs and counselors.
- 8) The content of the measure should reflect the real world concerns and goals of vocational rehabilitation.

To meet these criteria, the project staff developed the Service Outcome Measurement (SOM) Form. The original version was composed of routinely collected demographic data and 23 five-point rating scales. All scales had anchoring definitions affixed to each of the five points in the individual scale. The employment orientation of Vocational Rehabilitation provided the general framework for the development of the scales. Emphasis was placed on the client's functional ability in relation to employment. The original instrument was subdivided into six (6) areas:

1. Difficulty
2. Educational Status
3. Economic/Vocational Status
4. Physical Functioning
5. Adjustment to Disability
6. Social Competency

Area scores consisted of the sum of the ratings for the items in that area divided by the number of items in the area. A total score was computed by summing the area scores.⁸

The SOM Form was later reduced to a shortened version as the result of a factor analytic study performed on 1,945 SOM Forms collected as pretest data for a field test of the SOM Form (Westerheide, Lenhart, and Miller, 1974). This version termed the factored version, of the SOM Form contains 17 five-point rating scales with anchoring definitions at each of the levels within the individual scales. The seventeen scales are grouped into five factors. These factors and the scales are:

Factor 1 - Economic/Vocational Status

- A. Weekly Earnings
- B. Work Status
- C. Primary Source of Support
- D. Dependency of Client on Others for Financial Support

Factor 2 - Physical Functioning

- A. Mobility
- B. Physical Independence for Tasks other than Mobility
- C. Work Tolerance
- D. Prominence of Vocationally Handicapping Condition

Factor 3 - Psycho/Social Functioning

- A. Identification with Worker Role
- B. Compatibility of Employment Expectations with Client's Personality and Physical Condition
- C. Client's confidence as a worker
- D. Decision-Making Ability

Factor 4 - Family Relationships

- A. Role in Family
- B. Family Support

Factor 5 - Education

- A. Current Vocational Level

- B. Years of Academic Education
- C. Language Facility

The score for each factor is the average for the scales in the factor and the Total Score is the sum of the scores for the factors.

The "General Instructions for Raters", the "Service Outcome Measurement Form (Factored Version)" and a brief explanation of each of the scales can be found in the Appendix of this publication (See Appendix).

The Project Staff tells us that the outlook for the use of these or a similar set of rating scales seem quite good. The Service Outcome Measurement (SOM) Form has demonstrated (1) good reliability, (2) solid internal structure, and (3) a substantial and stable relationship to counselor ratings of Global Case Difficulty, time and effort, and the severity of client's handicap, while at the same time, staying within the confines of administrative necessity. Finally, it is recognized that the stability of client change scores are essential aspects of outcome measures for an agency as large and varied as Vocational Rehabilitation. The SOM Form does show stability across all groups. Project staff feels that the form has held up well throughout extensive field testing and while it may not be the final answer to outcome measure, it is a solid start. The form is a base that can

be worked with and improved. Scales can be added or subtracted from the form on the basis of field experience without unduly interfering or confusing the evaluation systems built around it.⁸

The Oklahoma Service Outcome Measurement Form may be a flexible enough instrument that it can be modified by the addition and/or deletion of scales in order to make it applicable to an Independent Living Rehabilitation Program of national scope without unduly interfering with the evaluation systems built around it. It also may have the capacity to allow the client and/or significant other(s) to participate in the measurement of his/her individual outcome. If the SOM could demonstrate this much flexibility and given its built in prerequisites for administrative flexibility (requires no more than 10 minutes to complete, easily interpreted, etc.), it could have promise as a future individual outcome measurement form for a national ILR Program.

The following discussion of various outcome resources (under exploration for potential use in Vocational Rehabilitation) were selectively excerpted from the Institute for Research Utilizations December 1977 publication of "New Directions in Rehabilitation Outcome Measurement." They were selected for their potential applicability to an Independent Living

Rehabilitation Program.

FLORIDA DIFFICULTY INDEX:

This index has four basic elements: Amount of time client was in the rehabilitation process (statuses 10-26); Average case service cost; average number of case services provided; and Sermon's Composite Case Difficulty Index. These factors for a given client are compared against annual averages and a composite difficulty score computed. In experience with this scale, it has been found to agree closely with counselor estimates of case difficulty.

GOAL ATTAINMENT SCALING:

Developed by the Program Evaluation Resource Center in Minneapolis, this technique is applicable to a wide variety of human service activities. It is a procedure for identifying behaviorally defined goals and outcomes for clients on a simple scale ranging from most unfavorable outcome to best-anticipated outcome. Each problem or goal area is identified by the counselor, often with input from the client, and weighted as to importance in the overall counseling process. Simple mathematical procedures are provided for weighting and for computing total outcome score.

Goodyear and Bitter (1974) report a study of the use of GAS at a rehabilitation hospital in Colorado. They concluded

that GAS was a useful technique for measuring client change as a result of rehabilitation counseling services conducted in a rehabilitation setting. The Research Utilization Laboratory at the Jewish Vocational Service in Chicago has produced a manual (1976) for applying GAS in rehabilitation settings. It includes both step-by-step training in how GAS works and some concrete examples of how the approach can be applied with VR clients. Further information on GAS in VR settings (e.g., how it relates to the CARF standards) is given in the January 1977 issue of RUL's Lab Notes.

The RUL manual includes a most interesting rationale used to select GAS as the preferred approach for responding to some of the problems in outcome measurement we have noted in this paper. Management-by-Objectives approaches were rejected because no real structure for measuring client progress was included. Some computerized systems for mapping progress and measuring cost-benefit were rejected because they seemed complicated, inflexible, and too costly. The RUL staff also felt that other available case difficulty weighting systems were not well-enough developed at this time to permit one of them to be selected. GAS was chosen for several reasons:

1. It can be used to measure a client's progress, a counselor's skill development, an agency's efficiency, or any number of things.

2. Scales are completely individualized, to reflect realistic possibilities for each client or operation you want to measure, rather than predetermined requirements.
3. GAS does not determine the methodology you use to reach the goals that are chosen.
4. GAS can generate numerical progress scores if desired, but it can also be used more informally.
5. GAS can be used as a communication tool with clients, between agencies, with clients' families, or within an agency.
6. GAS does not have to be used with every client. It can be used with a random sample, with clients selected because they might benefit from its structure, with clients referred from a particular source, or those chosen by some other criteria.
7. GAS has been thoroughly tested in the mental health field, and there have been extensive studies made of it by its originators.
8. GAS is compatible with Management-by-Objectives, can be computerized if desirable, and fits into other systems easily.

CASE DIFFICULTY INDEX (SERMON, 1972):

Sermon's Case Difficulty Index is based on data about what percentage of cases in different disability classifications do not get rehabilitated, statistically converted into a difficulty factor for each individual case closure. In assessing counselor performance, the Case Difficulty Index is used to develop two additional measures of counselor performance. The Total Weighted Closure Index is designed to measure total counselor effort represented by the number

of successful closures obtained by the counselor. It is a "Quantity tempered with difficulty" measure of counselor performance. The Average Weighted Closure Index measures the average difficulty of all cases successfully closed by a counselor regardless of the volume or actual number of cases closed. It is concerned not with measuring quantity of production but intended to provide a quality measure of counselor performance. The advantage of this index is that it is simple and adjustable to changing conditions. It currently is in use in New Jersey, Florida, and Minnesota.

PATTERN-PROBABILITY APPROACH (BONGE, 1975):

This approach involves computing a probability index of expected case difficulty based on predictions from biographical variables. The probability index can be used to weight case closure (e.g., to give extra credit to counselors for success with cases the "statistics" say are especially challenging).

It is evident from a review of the Vocational Rehabilitation weighted closure and case difficulty indexes that all have significant shortcomings for application to an Independent Living Rehabilitation^{ation} Program. For one thing none of them measure functional status as comprehensively as will be necessary with this population of most severely disabled individuals.

For a brief and yet quite pointed description of problems and gaps in Vocational Rehabilitation research refer to Chapter VI of Thomas E. Backer's, Ph.D. "New Directions in Rehabilitation Outcome Measurement." This is one in a series of publications by the Institute for Research Utilization (719 Delaware Avenue, S.W., Washington, D. C.) published in December 1977 and dealing with Emergency Issues in Rehabilitation.

IMPLICATIONS:

There appear to be four main areas of client change which should be measured by whatever instrument is developed:

Vocational Functioning and Potential

The degree to which a client has demonstrated capacity to appraise realistically his/her own vocational potential in light of inherent limitations, and to exhibit the physical and emotional endurance necessary to achieve vocational objectives.

Economic Independence

The degree to which the client can function independently in society without reliance on public support for maintenance of income and other related social services.

Physical Functioning

The degree to which a client demonstrates the capacity for reduction of symptoms, improved physical tolerance, development to fullest practical extent of compensatory mechanisms,

increased endurance, and emotional adaptation to disabling conditions.

Psychosocial Functioning

The degree to which a client demonstrates social and psychological adaptability which serve to enhance feelings of security, adequacy, functioning capability, emotional stability, and social interaction.

Any individual outcome measurement instrument developed to service an ILR Program national in scope and administered by Vocational Rehabilitation should attempt to meet the following criteria which are a modification of what Westerheide, Lenhart, and Miller (1974) applied to the development of the Oklahoma Service Outcome Measurement Form:

1. Change should be measured for all clients regardless of closure status;
2. The measure should not unduly complicate or change the ILR service delivery system;
3. The measure should not require sophisticated electronic data processing equipment;
4. The measure should be easily interpreted;
5. The measure should not require extensive inservice training;
6. The measure should not require more than ten minutes of the counselor's, the client and/or major significant other(s) time per case;
7. The measure should yield reliable information when used across agencies, programs, and counselors; and

8. The content of the measure should reflect the real world concerns and goals of the Independent Living Rehabilitation Program as seen through the eyes of the professional(s) and the consumer and/or his/her appropriate representative(s).

Finally, it should be recognized that Independent Living as an emerging concept, that has developed through community based projects with support under the Rehab Act and other support and whose parameters are still being defined is a comprehensive effort at serving human needs of the most severely disabled of our population. As such, it is an emerging program that cross cuts many factors. Therefore, until the parameters of such a program, national in scope, become more defined and observable the development of specific evaluation criteria will be difficult. There is a large gray area between what has been done on the vocational side and the medical models. Hopefully, this chapter has provided food for thought and will encourage future efforts and research in this gray area.

Ralph D. Russo Jr.

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GENERAL INSTRUCTIONS FOR RATERS

The purpose of the Service Outcome Measurement Form is to document the type of severity of the client's problems and show the changes in the client's level of functioning that have occurred during the rehabilitation process. Items from the R-300 have been used whenever possible to facilitate filling out the form. However the bulk of the form is counselor ratings of the level of client functioning in various areas.

All scales are five-point ratings with anchoring definitions. The definitions given must be viewed as levels of functioning in relation to employment. The definitions are designed to eliminate as much as possible the problems encountered in the good, fair poor type of ratings.

A second consideration to be kept in mind is that the client's employability is the attribute being rated. This orientation may seem vague in some of the psychological and social scales, however, it should be remembered that minimum levels of functioning in areas such as family relationships and decision-making must be main-

tained or personal affairs become employment problems.

Also, it is important to remember that the client's present level of functioning is rated.

Each scale is listed in the next section with a paragraph on the nature of the scale and what it is trying to measure. The rater should first carefully read the definitions of each level, then the paragraph below. Then, he should reread the level definitions in reference to the explanatory paragraph. It is imperative for the reliability of ratings that different raters and users be working within the same framework. By carefully going through this Manual, many of the problems inherent in rating scales can be eliminated before they begin.

The Practice Exercises are designed to help the rater check his understanding of the scales. The scales and the explanatory paragraph should be read carefully before you attempt to complete the Practice Exercises.

Note on Scoring

The scoring of the SOM Form is quite simple. The score for the individual factor is the average score for the scales in the factor. For example, the factor

one score would be scales IA,+IB.+IC.+ID. divided by four while the factor five score would be scales VA.+VB.+VC. divided by three. The total score is the sum of the five factor scores.

Change scores for the factors and total score can be derived by subtracting the posttest scores from the pretest scores. These raw change scores were used in the analysis of the field test (Westerheide, Lenhart, and Miller, 1975). The raw scores were used in this study in order that the information provided by the study would be consistent with how the form would be used in the everyday rehabilitation setting, where data processing capabilities may be limited. There exists several statistical manipulations that can be applied to different scores that may be desirable in special studies, but they require substantial data processing support. If these manipulations are employed, subsequent reports should indicate that the resulting change scores are different from the scores used in the original validation of the instrument.

SERVICE OUTCOME MEASUREMENT FORM
(Factored Version)

Counselor: _____ Client: _____ Date: _____

1. _____ Status
2. _____ Reason for Closure (only if other than 26)

Factor 1 - Economic/Vocational Status

A. Weekly Earnings

- _____ 1. \$100.01 per week and above
- _____ 2. \$ 70.00 per week to \$100.00
- _____ 3. \$ 50.01 per week to \$70.00
- _____ 4. \$ 10.01 per week to \$50.00
- _____ 5. \$ 10.00 per week and below

B. Work Status

- _____ 1. Wage or salaried worker (competitive labor market) or self-employed (except BEP)
- _____ 2. Wage or salaried worker (sheltered workshop) state agency managed business enterprise (BEP)
- _____ 3. Homemaker, unpaid family worker, not working student
- _____ 4. Trainee or worker (non-competitive labor market)
- _____ 5. Not working other

C. Primary Source of Support

- _____ 1. Own Earnings
- _____ 2. Dividends, Interest, Rent, and Savings
- _____ 3. Family and friends, or non-disability insurance (Retirement, Survivors, Annuity, Etc.)
- _____ 4. Disability and Sickness Insurance (SSDI, Workmen's Compensation, Civil Service, Etc.)
- _____ 5. Public Assistance, Private Relief, or Resident of Public Institution

D. Dependency of Client on Others for Financial Support

- _____ 1. Completely Independent
- _____ 2. Approximately 25% of income comes from sources other than own earnings
- _____ 3. Approximately 50% of income comes from sources other than own earnings
- _____ 4. Approximately 75% of income comes from sources other than own earnings
- _____ 5. Totally dependent on sources other than own earnings

Factor 2 - Physical Functioning

A. Mobility

- _____ 1. Totally Independent
- _____ 2. Ambulatory, but somewhat restricted or with minimal use of devices
- _____ 3. Ambulatory with major devices, as unassisted wheelchair or blind (cane)
- _____ 4. Ambulatory only with assistance of another person, as assisted wheelchair
- _____ 5. Completely homebound

B. Physical Independence for Tasks Other than Mobility

- _____ 1. Totally Independent
- _____ 2. Minimal assistance required
- _____ 3. Dependent for one major or several minor tasks
- _____ 4. Dependent for several major tasks
- _____ 5. Constant need for attendant services

C. Work Tolerance

- _____ 1. Minimal restrictions to type of work client can do
- _____ 2. Occupations limited to light physical activity but able to work full-time
- _____ 3. Sedentary work low stress, or close supervision required; but able to work full-time
- _____ 4. Unable to work full-time because of mental or physical condition
- _____ 5. Current disability status precludes employment

D. Prominence of Vocationally Handicapping Condition (Including Mental and Emotional)

- ___ 1. Hidden and cannot be directly observed
- ___ 2. Hidden and would only be observed episodically
- ___ 3. Noticeable only after a period of interviewing, or only slightly noticeable
- ___ 4. Marked and obvious, noticeable at once and continually manifest
- ___ 5. Marked, obvious, and continually manifest and will be repugnant to most employers

Factor 3 - Psycho/Social Functioning

A. Identification with Worker Role

- ___ 1. Client feels personal need to be independent, and do his share
- ___ 2. Identity to worker role developing or deteriorated somewhat since disability but wants to work
- ___ 3. Weak identity to worker role, little idea of day-to-day work demands
- ___ 4. Client has adjusted to being dependent; talks of working but is unconvincing
- ___ 5. Client strongly identifies with handicap and clings to dependent role

B. Compatibility of Employment Expectations with Client's Personality and Physical Condition

- ___ 1. Client seems ideally suited for the work he desires
- ___ 2. Client's employment expectations are reasonable, although not ideal
- ___ 3. Client has no ideas concerning possible vocational goals, or his ideas are more "day dreams" than employment expectations
- ___ 4. Client's employment expectations are very, unrealistic and impractical
- ___ 5. Client's employment expectations are so totally unrealistic and impractical, counselor must work with other professional persons, agencies, or institutions before client can proceed in the rehabilitation process

C. Client's Confidence in Himself as a Worker

- ___ 1. Highly favorable, client's self-confidence inspires confidence from others
- ___ 2. Client believes he can and will be a good employee in spite of his handicap
- ___ 3. Client feels he will become a fairly good employee but exhibits little initiative
- ___ 4. Client excessively timid or shows unimpressive over-confidence
- ___ 5. Client can never see himself as being able to hold a job

D. Decision-Making Ability

- ___ 1. Takes strong active role in decision making
- ___ 2. Slow to make decisions but makes his own decisions
- ___ 3. Wants others to make decisions but will take some part in decision-making process
- ___ 4. Others make decisions for him and manage his personal affairs
- ___ 5. Will neither help make decisions nor take action on help from others; counselor must work with other professional agencies, persons, or institutions before client can proceed in the rehabilitation process

Factor 4 - Family Relationships

A. Role in Family

- ___ 1. Assumes appropriate role
- ___ 2. Assumes appropriate role but some counselor reservation
- ___ 3. Participates in familial affairs but evidence of underlying ambivalence toward family
- ___ 4. Refuses to assume appropriate role
- ___ 5. Conscious effort to disrupt family

B. Family Support

- ___ 1. Good; family shows great deal of understanding of client; very supportive and helpful
- ___ 2. Moderate; although not ideal, support is adequate
- ___ 3. Fair; support given but is inappropriate; evidence of underlying ambivalence on the part of the family
- ___ 4. Poor; support given but there is definite indifference on the part of the family toward client or his rehabilitation
- ___ 5. Very poor; family definitely non-supportive, strong opposition

Factor 5 - Education

A. Current Vocational Level

- ☐ 1. Professional, Technical and Managerial
- ☐ 2. Licensed or certified trades and crafts, or other highly skilled work
- ☐ 3. Semi-skilled and clerical
- ☐ 4. Unskilled
- ☐ 5. Disability status precludes employment

B. Years of Academic Education

- ☐ 1. 16 years or above
- ☐ 2. 13-15 years
- ☐ 3. High School Graduate or G.E.D. certificate
- ☐ 4. 8 years or above
- ☐ 5. less than 8 years

C. Language Facility

- ☐ 1. Reads and writes well; has no trouble understanding and communicating common vernacular and could learn to use technical language
- ☐ 2. Reads, speaks, and writes adequately; has no particular problem filling out employment applications, or holding job interview
- ☐ 3. Reads, speaks, and writes adequately for job applications and interview, but speaks slowly and may have some difficulty with other than simple written instructions. Totally deaf or blind (reads braille)
- ☐ 4. Reads, speaks, and/or writes poorly, and will have difficulty interpreting even simple written instructions
- ☐ 5. Almost complete lack of language, functionally illiterate, extremely small vocabulary

EXPLANATION OF SCALES

FACTOR 1 - ECONOMIC/VOCATIONAL STATUS

A. Weekly Earnings

- ☐ 1. \$100.01 per week and above
- ☐ 2. \$ 70.01 per week to \$100.00
- ☐ 3. \$ 50.01 per week to \$70.00
- ☐ 4. \$ 10.01 per week to \$50.00
- ☐ 5. \$ 10.00 per week and below

In this scale, simply check the appropriate range for the client's weekly earnings

B. Work Status

- ☐ 1. Wage or salaried worker (competitive labor market) or self-employed (except BEP)
- ☐ 2. Wage or salaried worker (sheltered workshop), state agency managed business enterprise (BEP)
- ☐ 3. Homemaker, unpaid family worker, not working student
- ☐ 4. Trainee or worker (non-competitive labor market)
- ☐ 5. Not working other

The levels in this scale correspond with the R-300 codes. Level 1 is composed of codes 1 and 3; Level 2 being codes 2 and 4; Level 3 being codes 5, 6, and 7; Level 4 being code 9, and Level 5 being code 8. If a client is "not working student" (Level 3) but is living off summer earnings and/or part-time work, he can be rated at Level 1 only if his own earnings are his primary source of support.

C. Primary Source of Support

- ☐ 1. Own Earnings
- ☐ 2. Dividends, Interest, Rent, and Savings
- ☐ 3. Family and friends, or non-disability insurance (retirement, survivors, annuity, etc.)
- ☐ 4. Disability and Sickness Insurance (SSDI, Workmen's Compensation, Civil Service, etc.)
- ☐ 5. Public Assistance, Private Relief, or Resident of Public Institution

Primary Source of Support refers to largest single source of income regardless of the amount it contributes to his total income. Level 1 and Level 2 are self-explanatory. Level 3 includes not only family and friends, but also non-disability related insurance; that is, the reason the client is receiving benefits has nothing to do with his disability. Level 4 is disability or sickness insurance of all types, while level 5 relates to those clients who are dependent on public or private relief agencies or residents of public institutions.

D. Dependency of Client on Others for Financial Support

- ☐ 1. Completely Independent
- ☐ 2. Approximately 25% of income comes from sources other than own earnings
- ☐ 3. Approximately 50% of income comes from sources other than own earnings
- ☐ 4. Approximately 75% of income comes from sources other than own earnings
- ☐ 5. Totally dependent on sources other than own earnings

A) This item seeks a finer measure of the client's financial independence than can be inferred from "Weekly Earnings" alone. Financial independence refers to the client's ability to provide for himself without relying on others. If a client receives money from an outside source such as a relative, dividends, etc., but the client could live on his own earnings, he would be classified as "Completely independent." If the client must rely on non-monetary support such as free child care or medicine, he would be classified in the appropriate category relative to the approximate amount these services would cost the client if he could afford to pay for them himself. Homemakers and unpaid family workers at closure will be rated as completely dependent, if unpaid.

FACTOR 2 - PHYSICAL FUNCTIONING

A. Mobility

- ☐ 1. Totally independent
- ☐ 2. Ambulatory, but somewhat restricted or with minimal use of devices
- ☐ 3. Ambulatory with major devices, as unassisted wheelchair, or blind (cane)
- ☐ 4. Ambulatory only with assistance of another person, as assisted wheelchair
- ☐ 5. Bedridden

Ambulatory has to do with the person's ability to move about in a limited area such as a shop, office building, school, or hospital. "Totally Independent" would be checked for a person who moves about with normal speed and agility for a person of his age. "Ambulatory, but somewhat restricted or with minimal use of devices" would be a client who walks slowly, uses a brace, cane (not blind), limps, or an appliance that does not have the bulk of a wheelchair or walker. "Ambulatory with major devices, as unassisted wheelchair" refers to larger devices, blind (cane) or several smaller devices (as double leg braces and crutches), but retains the aspect of independence from help from other people, which distinguishes level four "Ambulatory only with assistance of another person." "Bedridden" refers to a client who for all practical purposes is confined to bed, or homebound to the extent that he cannot physically leave his home, hospital, or nursing home. This level does not include persons institutionalized for behavioral reasons.

B. Physical Independence for Tasks Other than Mobility

- ☐ 1. Totally independent
- ☐ 2. Minimal assistance required
- ☐ 3. Dependent for one major or several minor tasks
- ☐ 4. Dependent for several major tasks
- ☐ 5. Constant need for attendant services

Physical Independence in this category is exclusive of the area covered by the item of "Mobility." This item covers activities of daily living, self-care activities, writing, reading, and other basic skills. To rate this item, the rater should rate the problem in terms of minor being a small inconvenience, and major tasks being a significant periodical inconvenience to the employer or coworkers.

C. Work Tolerance

- ☐ 1. Minimal restrictions to type of work client can do
- ☐ 2. Occupations limited to light physical activity but able to work full-time
- ☐ 3. Sedentary work, low stress, or close supervision required; but able to work full-time
- ☐ 4. Unable to work full-time because of mental or physical condition
- ☐ 5. Current disability status precludes employment

Work Tolerance refers to limitations as to the types of work a client can do and the time the client can stay on the job. The first three levels refer to limitations as to the type of work the client can do. If the client can do only sedentary work, increasing severity is reflected in the time a client can stay working. In reference to mental disabilities, a client who could work a regular full-time job but requires low stress, close supervision, or other special job conditions, would be rated at level 3, "Sedentary work, low stress, or requires close supervision, but able to work full-time."

D. Prominence of Vocationally Handicapping Condition (Including Mental and Emotional) Handicap Is:

- ☐ 1. Hidden and cannot be directly observed
- ☐ 2. Hidden and would only be observed episodically
- ☐ 3. Noticeable only after a period of interviewing, or only slightly noticeable
- ☐ 4. Marked and obvious, noticeable at once and continually manifest
- ☐ 5. Marked, obvious, and continually manifest and will be repugnant to most employers

How obvious the handicap is should be rated as it might be noticed by a potential employer. The last definition might be considered as handicaps that would preclude saleswork or occupations involving a much public contact.

FACTOR 3 - PSYCHO/SOCIAL FUNCTIONING

A. Identification with Worker Role

- ☐ 1. Client feels personal need to be independent, and do his share
- ☐ 2. Identity to worker role developing deteriorated somewhat since disability but wants to work
- ☐ 3. Weak identity to worker role, little idea of day-to-day work demands
- ☐ 4. Client has adjusted to being dependent; talks of working but is unconvincing
- ☐ 5. Client strongly identifies with handicap and clings to dependent role

The client's attitude toward dependency and the worker role is rated from a personal need to be independent to a total life style and personal orientation built around the dependency caused or excused by the disability. The second level differentiates clients who are in the process of solidifying their identity to the worker role and clients who formerly had a strong worker identity which has weakened somewhat since the onset of the disability; however, the clients at the third level have developed at best only a weak identity as a worker and is differentiated from level 2 by either the absence of the development of a positive work identity or the absence of a basic worker identity. Clients at level 4 have adjusted to being dependent and may talk about working; however, this seems only for the benefit of the counselor and is unconvincing. Level 5 is distinguished by the intensity and more total involvement of the client with the dependency role.

B. Compatibility of Employment Expectations with Client's Personality and Physical Condition

- ☐ 1. Client seems ideally suited for the work he desires
- ☐ 2. Client's employment expectations are reasonable, although not ideal
- ☐ 3. Client has no ideas concerning possible vocational goals, or his ideas are more "day dreams" than employment expectations
- ☐ 4. Client's employment expectations are very unrealistic and impractical
- ☐ 5. Client's employment expectations are so totally unrealistic and impractical, counselor must work with other professional persons, agencies, or institutions before client can proceed in the rehabilitation process

Compatibility of employment expectations with personality and physical condition covers not only the area of realistic understanding of the physical limitations of the disability, but also the understanding of personality strong and weak points in relation to employment. The first level refers to individuals who have realistic concepts of their strengths, limitations and themselves, as differentiated from clients having a reasonable vocational goal, but not as well integrated with aptitudes, abilities, and interests. Also, the second level would cover a vocational goal which seems reasonable to the counselor; however, he has some reservations. The third level pertains to clients having no firm ideas as to what they should do or clients who state unrealistic employment

expectations which the client gives when questioned closely. The fourth level deals with the client who not only has unrealistic and impractical goals, but also believes they are realistic resulting in a significant barrier to the client's rehabilitation. A client should not be placed accordingly in the last level unless his unrealistic outlook is symptomatic or a larger loss of contact with reality. In this case, the counselor will be acquiring short-term therapy or be working simultaneously with a mental institution or mental health agency.

C. Client's Confidence in Himself as A Worker

- _____ 1. Highly favorable, client's self-confidence inspires confidence from others
- _____ 2. Client believes he can and will be a good employee in spite of his handicap
- _____ 3. Client feels he will become a fairly good employee but exhibits little initiative
- _____ 4. Client excessively timid or shows unimpressive over-confidence
- _____ 5. Client can never see himself as being able to hold a job

This item deals with self-confidence and self-concept in terms of the client's perception of himself as a worker or ability to get a job done. The first level refers to those clients who can take initiative and inspire others to have confidence in him. The counselors often have clients who "talk a good stick" but leave the counselor with many reservations, or the counselor feels the client is trying to put something over on him. This client reaction is equivalent to excessive shyness and timidity and should be rated in level 4. Levels 2 and 3 fall in between being differentiated by the amount of initiative the client feels he can take. Level 5 refers to those clients who are self-deprecating to the extreme, and as a result of this feeling of failure, the client will probably leave any job he is placed on at the first bit of rough going and feel he has proved what he has known all along--that he is destined to be a failure.

D. Decision-Making Ability

- _____ 1. Takes strong active role in decision making
- _____ 2. Slow to make decisions but makes his own decisions
- _____ 3. Wants others to make decisions but will take some part in decision making process
- _____ 4. Others make decisions for him and manage his personal affairs
- _____ 5. Will neither help make decisions nor take action on help from others; counselor must work with other professional agencies, persons, or institutions before client can proceed in the rehabilitation process

Decision-making ability refers not only to making decisions but implies acting on these decisions. Also implied is the ability to manage his own affairs. The first level deals with the client who meets his problems head on, makes his own decisions, and needs information and financial help rather than counseling; whereas, a client on the second level may seem overcautious, but maintains his independence. At the third level, a client looks for an easy way out of the decision-making process and maintains possibly only a veto power in this process. At the fourth level, the client does not make decisions, must be led and prodded to take any action. At level five, the client's immobility in taking any action and making decisions necessitates work with an outside agency such as a mental institution, mental health clinic, or the counselor must plan for therapy from outside professional resources before the client can proceed in the rehabilitation process.

FACTOR 4 - FAMILY RELATIONSHIPS

A. Role in Family

- _____ 1. Assumes appropriate role
- _____ 2. Assumes appropriate role but some counselor reservation
- _____ 3. Participates in familial affairs but evidence of underlying ambivalence towards family
- _____ 4. Refuses to assume appropriate role
- _____ 5. Conscious effort to disrupt family

The appropriateness of the client's role in the family can be a difficult area to rate because of variations in age, sex, race, and physical and emotional conditions of the other family members. The distinction between Level 1 and Level 2 is made basically on how the rater feels about his judgment. In these two levels, the client seems to assume the appropriate role for his particular

family situation, but Level 2 represents a somewhat guarded judgment. Level 3 has the client participating in family affairs, but only at a superficial level when it seems unjustified by the family's reaction to the client, while in Level 4 not even superficial participation is present. Level 5 refers to clients actively trying to disrupt the family, and may be seen as a psychiatric problem. Remember that the appropriateness of the role the client plays is what is being rated and, in some instances, a client who is uninvolved with his family, may, because of the emotional climate at home, be rated on Level 1 or 2. Persons other than biological parents may be rated as family if they perform the family's function in relation to the client. If the client has no immediate family, rate him at Level 2.

D. Family Support

- ☐ 1. Good; family shows great deal of understanding of client; very supportive and helpful
- ☐ 2. Moderate; although not ideal, support is adequate
- ☐ 3. Fair; support given but is inappropriate; evidence of underlying ambivalence on the part of the family
- ☐ 4. Poor; support given but there is definite indifference on the part of the family toward client or his rehabilitation
- ☐ 5. Very poor; family definitely non-supportive, strong opposition

Family support is rated not only by whether support is given, but also whether it is appropriate or not. By rating the item in this manner, the rating is intended to reflect the understanding of the client by his family as well as the presence of active support. The client's family can be every bit as unrealistic about the client's disability and capacities as the client himself. At the first level, the family is very involved and shows a good understanding of the client's situation. In Level 2, the family support is still adequate, but does not show the quality in understanding of the client and/or appropriateness of the support that exists at Level 1. The third level refers to the family who wants the client to live up to their expectations, which are out of touch, either high or low, with the client's capabilities. The fourth level represents superficial support that only serves as a cover-up for underlying indifference. At Level 5 the family offers active opposition and wants to keep the client dependent on the family. If the client has no family, place him at Level 2, because he does not have the positive effect of a supportive family. Persons other than biological parents may be rated as family if they perform the family's function in relation to the client.

FACTOR 5 - EDUCATION

A. Current Vocational Level

- ☐ 1. Professional; Technical and Managerial
- ☐ 2. Licensed or certified trades and crafts, or other highly skilled work
- ☐ 3. Semi-skilled and clerical
- ☐ 4. Unskilled
- ☐ 5. Disability status precludes employment

Current Vocational Level refers to the type of job the client could or is presently holding, that is the job the client is presently capable of holding. Level 1 is professional (doctors, lawyers, educators, counselors, etc.), highly technical (engineers, architects), and managerial (managers, accountants, officials). Level 2 is skilled labor. These occupations are usually licensed or certified by federal, state or local governments or a trade association; however, exceptions to this rule of thumb must be made in certain cases such as farmers or farm workers who may fall at any level, and certain types of secretaries whose work and salary may place them in Level 2 or Level 1. Level 3 relates to semi-skilled occupations that require a minimum of training at least at entry level jobs. An apprentice would be rated at Level 3 until he receives his journeyman's license. Level 4 is unskilled labor and work which requires no formal training over two weeks or only a short on-the-job orientation period is required. At Level 5 the limitations imposed by the client's disability prevent him from maintaining employment. If the client is unemployed but could perform unskilled labor, rate him at Level 4 or the appropriate level for the job he could presently perform. Remember the client's current vocational level is being rated, not his expected level after services.

B. Years of Academic Education

- ☐ 1. 16 years or above
- ☐ 2. 13-15 years
- ☐ 3. high school graduate or GED Certificate
- ☐ 4. 8 years or above
- ☐ 5. less than 8 years

This item reflects the number of years of training the client has had in formal academic schools. If a high school diploma or GED Certificate was received, check level 3. In cases of mentally

retarded, special education, or learning disabilities class, the approximate grade level attained should be checked. If a BA or BS degree has been granted in under 4 years, rate the client at Level 1.

C. Language Facility

- ____ 1. Reads and writes well; has no trouble understanding and communicating common vernacular and could learn to use technical language
- ____ 2. Reads, speaks, and writes adequately; has no particular problem filling out employment applications, or holding job interviews
- ____ 3. Reads, speaks and writes adequately for job applications and interviews, but speaks slowly and may have some difficulty with other than simple written instructions. Totally deaf or blind (reads braille).
- ____ 4. Reads, speaks and/or writes poorly, and will have difficulty interpreting even simple written instructions
- ____ 5. Almost complete lack of language, functionally illiterate, extremely small vocabulary

This item deals with basic language skills needed on the job. The first level covers not only very fluent clients, but also any client who can express himself clearly even if client's vocabulary is not large. The second level is for clients whose use of language is adequate for job interviews, filling out applications, and making business telephone calls and following most written instructions. Clients rated in level 3 would have difficulty interpreting complex instructions and would be limited to low level office work. A client at level 4 would have a great deal of trouble filling out job applications and holding a good interview; on the job, he may have trouble following even simple written instructions. The last level refers to clients who have extremely limited verbal as well as written vocabularies.

UNIT VIII

STAFF TRAINING

CHAPTER 8: STAFF DEVELOPMENT

TOPIC: Staff Training

OBJECTIVES:

1. To present guidelines for designing training programs for vocational rehabilitation personnel in the area of Independent Living Rehabilitation.
2. To present information unique to independent living rehabilitation that will assist the staff development personnel and other rehabilitation personnel in the development of training programs.
3. To identify resources which might be used by staff development personnel to increase the effectiveness of training programs in the area of independent living rehabilitation.

SUMMARY:

It is the intent of the staff training chapter to present resources that can be utilized by the vocational rehabilitation agency to enhance the effectiveness of training efforts in the area of independent living rehabilitation. The extent to which these resources will be used by the agency are influenced by the (1) available training resources in the state, (2) knowledge base of the staff in the area of independent living rehabilitation and (3) state of the art of independent living rehabilitation in a particular state/area. However, there are characteristics unique to independent living rehabilitation which can be integrated into an effective training session through use of appropriate resources. It is these characteristics that are highlighted in the following sections.

DISCUSSION

Whenever a mandate for change in target population, policies, and procedures, or agency mission occurs, along with it comes either an overt or covert message for staff development/training. Change brings with it uncertainties, anxiety, and concern on the part of staff as to how the change process will affect their role within the agency, and more critically, how it will affect their day to day operations. Independent Living Rehabilitation, because of its complexity, and at times almost overwhelming number of components - e.g. housing, transportation, legal, advocacy, peer counseling, self-care, presents to the staff a challenge in terms of coordinating and delivery within an already complex system. The challenge is not unsurmountable, and through well planned training sessions, solutions can be presented to the staff.

The complexity of Independent Living Rehabilitation, presents to the training officer, the necessity to draw on a variety of resources both from within and outside of the agency. Some recommended resource groups are:

- consumers - severely disabled, residents of independent living programs, peer-counselors, members of the agency advisory board.
- health providers - physiatrist, occupational therapist, physical therapist, rehabilitation nurse.
- counselors - those who are involved in servicing the severely disabled in both rural and urban settings, counselors assigned to university settings.
- project directors of the 130 projects - directors of pilot programs in independent living rehabilitation.

--other agencies - blind agency staff, development disability advisory groups, state housing authority, state transportation agency, Easter Seals, United Cerebral Palsy.

--other professionals - lawyer with interest/expertise in law for handicapped, financial expertise, community government officials.

Since much of the success of Independent Living Rehabilitation is dependent on the active involvement of the consumer (client) as well as the innovativeness of the provider (counselor), it is important that these two resource groups be actively involved in the planning and presentation of the training session. Both resource groups are able to provide workshop participants with practical, how-to-do-it or not-do-it information that is the essence of Independent Living Rehabilitation. Such questions as what is peer counseling? How does a counselor set up peer counseling within their district office? What are the important components of Independent Living Rehabilitation that a counselor and/or consumer group must address? Where does the counselor document Independent Living Rehabilitation? Can be addressed by either the consumers or providers or both.

The training session also needs to provide opportunities for the administrative staff to acquire information. Of concern to them are such issues as the cost/benefit of providing Independent Living Rehabilitation, the outcome evaluation mechanisms used in the pilot projects, the various methods that Independent Living Rehabilitation programs have established, or the professional skills of counselors who are delivering ILR services. Because Independent Living Rehabilitation is multi-faceted, it requires interaction at the administrative level, between agencies involved in housing,

transportation, third-party reimbursement, and the rehabilitation medicine community. Identification by administrative staff from the various agencies as to where their agency fits into independent living rehabilitation is an important component of a successful independent living rehabilitation program. Through the training sessions, administrative staff has the opportunity to develop agency strategies, based on both consumer and counselor input, for the implementation of an independent living rehabilitation program.

CONTENT:

Based on its particular training needs in the area of independent living rehabilitation, the state training officer will develop a training plan for his/her state agency. Specific components of the topic area, because they form the core of a knowledge base, should be included in all staff training sessions on independent living rehabilitation. They are:

1. Information: definition of independent living rehabilitation, history,
"State of the Art"
2. Legislation: Rehabilitation Act of 1973
3. Components of independent living rehabilitation: existing models
4. Role of Consumers
5. Implications for V.R.: administration, counselor, other rehabilitation
personnel

Content of any training program, depends upon several considerations,
such as:

- analysis and evaluation of training needs
- planning and committee(s) review
- establishing goals and objectives (outcomes) (results)
- program design and schedules
- selection of faculty/consultants

--program implementation

--program evaluation

--follow-up

In order to make any training program on independent living rehabilitation as effective as possible, it is necessary to involve the severely disabled consumer both in the planning and implementation phases. Involvement of counselors who have been serving independent living rehabilitation clients in the complete training cycle, which also serve to enhance the impact of the training session.

Intended in the development of this IRI manual, is that it be used for staff development. Because of the rapid increase of written material in independent living rehabilitation, the training officer will need to update themselves on the status of recently published materials. Three additional IRI documents will provide the training officer with related resource materials - "Critical Issues Involved in Rehabilitation of the Severely Handicapped;" "Vocational Rehabilitation for the Severely Handicapped Homebound;" and "Consumer Involvement."

IMPLICATIONS:

1. Independent living rehabilitation is a reality. The need for staff training is a pressing one to ensure the timely delivery of appropriate independent living rehabilitation services, and to develop a positive attitude toward independent living rehabilitation.
2. The support of top and middle management is a definite necessity for effective training programs in independent living rehabilitation.
3. All levels of rehabilitation staff should be involved in the training program if effective independent living rehabilitation services are to become a reality.

4. The content and methods of training should be practical, realistic and innovative in reference to service models, to independent living rehabilitation resources, and to the community resources.
5. Maximum and innovative use of resources such as consumers, counselors, peer-counselors, other governmental/service agency staff, legal lawyers, should be made to enhance the practical aspects of the training session.
6. Appropriate funds should be provided by state rehabilitation agencies, who have the prime responsibility for independent living rehabilitation service delivery, for training their staff in the knowledge and skills needed to effectively provide independent living rehabilitation services.

Training Plan: Independent Living

Goals: *To provide participants with an understanding of the development of the concept of Independent Living.

*To give participants the opportunity to explore the implications of Independent Living in existing vocational rehabilitation programs for the severely handicapped.

*To review the success of Independent Living Projects.

*To consider the role of consumers in Independent Living.

Time	Content	Outcome	Method	Materials	Individuals Responsible Individuals Responsible	Evaluation
8:30-10:00	Introduction of Independent Living Concept and why participants have been selected to attend. (Necessary housekeeping activities, registration forms. Pre-Test)	Participants will understand why they have been selected to attend this program. Pre-Test will tell training director what they now know.	Lecture	Registration Forms Slide-Tape Presentation	State Director Staff Development Director	Rating Scale
10:00-10:15	Break and Informal Discussion					
10:15-11:45	Historical Development of Independent Living	Participants will be able to trace the conception and birth of the IL movement and why it will be important in the future.	Discussion Between Director of Field Services and the Staff Development Director	Handouts Overhead IRI Publication	Director of Field Services/ Staff Development Director (with ample time for questions from participants)	Pre-Test/ Post-Test
11:45-1:00	Lunch					
1:00-2:45	Implications of Independent Living	Participants will be able to identify the implications of Independent Living at the State Level as well as the Local Level.	Panel Discussion	Blackboard Overhead IRI Publication	State Director Director of Field Services Supervising Counselor	Pre-Test/ Post-Test

Time	Content	Outcome	Method	Materials	Individuals Responsible	Evaluation
2:45-3:00	Break and Informal Discussion					
3:00-4:30	Potential Problems and Solutions at the Local Level. Charge given to Each Group by Staff Development Director.	Participants will be able to relate the content of the above program components to their local districts and will be able to explore their own feelings about IL.	Small Groups (arranged by geographical distribution)	Resource Persons for each group	Staff Development Director plus Resource Persons	Rating Scale
4:30-6:00	Attitude Adjustment Hour					
DAY 100 8:15-9:00 A.M.	Each Small Group Reports Its Findings.	Participants will be able to explore potential problems and solutions existing in their districts.	General Session		Group Reporters	Rating Scale
9:00-10:00	Independent Living Through Funded Projects.	Participants will understand what projects have been able to accomplish in IL.	Lecture	IRI Publication Overhead	A Project Director or a local expert.	Pre-Test/Post-Test
10:00-10:15	Break and Informal Discussion					
10:15-11:15	The Role of the Consumer in IL.	Participants will be given the chance to view the concept of IL through the eyes of consumers.	Panel Discussion	Overhead IRI Publication	Knowledgeable Consumers	Pre-Test/Post-Test
11:15-11:45	Participant Commitment	Participants will be given the chance to see what their role will be in developing IL.	Lecture	Overhead	State Director	
11:45-12:00	Post-Test					

Key Ingredients:

- *-program is short (1 and 1/2 days) thus allowing participation of top through bottom agency staff with little disruption of client services...State Director, Supervisors, Counselors should be able to get away from their office for two days.
- *-program makes use of a variety of presentation methods (lecture, panel discussion, small groups, etc.) but does not overdo the small group approach. Participants should feel that they learned something worthwhile.

Independent Living
Slide-Tape

DRAFT

1. Some two hundred years ago the founders of our country declared their independence knowing full well that potential problems their action might cause. Uncertain of what lay ahead they met together to sign their names to a document that would change the course of history.
2. Today that same spirit is evident in another group of Americans. Like their fore-fathers, they too realize the potential problems their actions may cause. And yet, they too look for independence.
3. The type of independence they seek is not unlike that sought two hundred years ago. Today their battle is a protest against segregation and discrimination as well as an affirmation of their right to share fully in the joys and responsibilities of our society.
4. There is then a new movement afoot in America and throughout the world for that matter. It is a movement of people with special needs -- the aged, the severely handicapped, the developmentally disabled and the mentally ill.
5. Remember the demonstrations in the Federal hallways a few years ago? We became quite accustomed to seeing the cities burn a number of years ago but there was a special shock in seeing many people with different disabilities joining hands together in their battle to pass Section 504. With their help the final signatures were placed on action to insure independence. Two hundred years later than in Philadelphia.
6. Now another segment of the movement is gaining popularity across the country. Simply stated it is called "Independent Living".
7. Just what is Independent Living?
8. Reading the limited literature that in press one finds many definitions and concepts surrounding this term. Yet they all have a common core. Let's look at a few of the definitions being considered.

9. First, there is the concept of Independent Living as physical modifications or aids to daily living. We are all familiar with this concept with the special tools and equipment developed over the years that enable individuals to become independent. The major goal of these devices is to give the disabled individual the equipment that will insure survival.

10. the United States Department of Housing and Urban Development has established a new Office of Independent Living that concerns itself with special housing needs of the severely handicapped.

11. There is another concept of independent living that is developing in the state/federal vocational rehabilitation programs across the country.

12. As it stands now individuals are eligible for services in vocational rehabilitation agencies only if as a result of the services rendered there is a good chance that the person will be able to return to work.

13. If the rehabilitation counselor cannot make this determination the disabled person is not eligible for services and must seek assistance elsewhere.

14. Many people, both inside as well as outside the state agencies have long argued for a separate program for individuals who might not be expected to return to employment. The same level of service would be offered to both groups regardless of what outcome was expected.

15. One potential argument for those advocating this position is found in that fact that state agencies have discovered that a rather high percentage of those individuals declared ineligible or closed "not rehabilitated" because of severity actually found employment within six months after leaving the agency.

16. It therefore stands to reason that some of those individuals served under the Independent Living program of vocational rehabilitation might actually be closed "rehabilitated" later in the regular VR program.

17. A final way of looking at Independent Living focuses on attitudes and on the rights of severely handicapped people. This independent living movement includes consumers and professionals who advocate change in general attitudes and provision of service that individuals with disabilities need in order to take part in the full richness of community life.

18. This last concept enhances the belief that people with disabilities have the right to services that enable them to be equal and independent members of the community.

19. Thus, although we have looked at three differing views of what has been called Independent Living it is evident that a common thread runs through each. The final definition is not ready now and may never be for the concept changes as barriers are overcome and new needs are identified.

20. It is also interesting that governmental agencies are not the only ones interested in Independent Living.

21. Consumer run organizations have been into Independent Living for quite a number of years. Most recently there are developing a number of Centers for Independent Living that attempt to coordinate and complement services provided by government.

22. There are a number of differences existing between each of the projects but most are based on the new meaning of independent living that has emerged, combining physical modification services, rehabilitation and consumer rights into a comprehensive network of service for the person with a severe handicap.

23. There are sufficient differences existing between the many efforts that the provisions of the Rehabilitation Act of 1973 called for a evaluation of five demonstration projects to investigate:

24. What organizational arrangements seem most efficient and effective for an Independent Living Rehabilitation (ILP) program?

25. What services, especially new services, may be required and who can provide them?

26. What manpower will be required and at what level can caseloads be handled?

27. What are the approximate likely achievements that will result from given levels of expenditures?

28. What would be the relative costs of seeking to achieve different types of results?

29. What limits should be placed on who is served?

30. Are there persons too severely handicapped to benefit even from ILR?

31. Once the result of these studies is known professionals will have a better understanding of what is needed and how much it will cost to be involved in the project approach to independent living.

32. At this time it is not clear what direction independent living will take within state vocational rehabilitation agencies. Some argue that it is only a matter of time before legislation will create an independent living component within the state agencies.

33. Should that occur, what will Independent Living Rehabilitation look like?

34. Let's project not two hundred years but only two years in the future of vocational rehabilitation in the United States.

35. It really will not be that much different than it is today. For, whether we will admit it or not, many vocational rehabilitation counselors are already deeply involved in independent living programs.

36. When a counselor accepts a client under the concept of extended evaluation he is really making use of independent living components to determine if services will enable the individual to return to competitive employment.

37. The counselor can provide a vast array of services without declaring the individual eligible. There is no need to determine an employment objective at this stage of the game. Services are provided to determine if the individual is eligible.

38. Under the new program in independent living in two years the counselor would provide the same array of services but would not be required to list an employment objective for the client being served.

39. No vocational goal might be hard to swallow for the "traditional rehabilitation counselor" but there would still be the regular VR program where clients would be served on the basis of eligibility.

40. Transfers between programs would be easy with the result that there would be fewer "failures". It is not uncommon for rehabilitation counselors to become somewhat discouraged when one of their clients cannot work even after every effort has been made. There is no doubt whatsoever that the client received real benefit from the services provided. Under today's system there is no credit awarded to the counselor who closes an individual unless that person is working.

41. Under the new system a counselor working in the independent living component would be able to develop an Individualized Written Rehabilitation Program on any client who needed services. Should that same client then make the necessary progress to be considered employable it would be a simple matter to transfer to a vocational rehabilitation counselor who would assist in placement.

42. State agency programs working with the blind have more experience than those regular program agencies and can attest to the worth of an independent living program.

43. There is little doubt that these concepts will change and evolve over the years. Yet the time has come for all rehabilitation professionals to study the emerging concept on independent living for there is no return once independence is realized.

44. The signatures are on the document.

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APPENDICES