

Originally Processed With FOIA(s):
S

FOIA Number:
S

FOIA MARKER

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

Record Group/Collection: Donated Historical Materials
Collection/Office of Origin: Frieden, Lex, Collection
Series: Related Materials
Subseries: Conferences

OA/ID Number: 52073
Folder ID Number: 52073-006

Folder Title:
ILRU [Independent Living Research Utilization] Conference '78

Stack:

Row:

Section:

Shelf:

Position:

TEXAS INSTITUTE FOR REHABILITATION AND RESEARCH

IN THE
TEXAS MEDICAL CENTER
1333 MOORSUND AVENUE
HOUSTON, TEXAS 77030

P. O. Box 20095
Houston, Texas 77025

Telephone
Area Code 713, 797-1440

July 1, 1978

Dear

The Independent Living Project is a research utilization project funded by the Rehabilitation Services Administration, and administered by TIRR. The primary purpose of this grant is to study independent living programs established for persons with physical disabilities and to develop a means of disseminating information about them. A major goal of the grant is to use this information to create a model training seminar that will be presented nationally to educate rehabilitation professionals, agency counselors and handicapped individuals about independent living.

To achieve this goal, this project needs recent information about existing, working independent living programs. Therefore, we are surveying all programs known to us. We would like very much to include information about your independent living program in our national sample.

In filling out this survey, please keep in mind that your responses will be held confidential. The only information that will be made public will be general summary statements drawn from the entire pool of responses.

Because the concept of independent living is so broad, and the goals of various programs are so diverse, parts of this questionnaire may not apply to your program. We would appreciate it if the person most actively involved in the operation of your program would complete as much of the questionnaire as applies to your program. It could take as little as 15 minutes to complete. We will be more than glad to share our summary data with you once the survey has been completed.

Please complete the questionnaire and return it by Aug. 1 to the Independent Living Research Utilization Project, TIRR, Annex, 105 Drew, Houston, Texas 77006.

Sincerely,

David M. Bailey
Project Coordinator

TEXAS INSTITUTE FOR REHABILITATION AND RESEARCH

IN THE

TEXAS MEDICAL CENTER

1333 MOURSUND AVENUE

HOUSTON, TEXAS 77030

P. O. Box 20095
Houston, Texas 77025

Telephone
Area Code 713, 797-1440

INDEPENDENT LIVING SURVEY

Name of person filling out survey _____ Date _____

Title or official capacity _____

I. IDENTIFYING INFORMATION

a. Name of project or program _____

b. Address of project or program _____

c. When did the program begin? _____

d. Size of community in which your program operates

- _____ less than 10,000
_____ 10,000 - 100,000
_____ 100,000 - 500,000
_____ greater than 500,000

e. Type of neighborhood surrounding the program

- _____ Urban central business district
_____ Urban residential
_____ Suburban residential
_____ Rural
_____ Isolated facility
_____ Campus-style arrangement
_____ Other (please specify)

II. POPULATION SERVED

a. Number of persons served per year

_____ 0-25 _____ 25-50 _____ 50-150 _____ 150-500 _____ 500+

b. Estimate approximate number of persons served in 1977 _____.

c. What is the average age of your service clients _____. What are the general range of ages served _____.

d. What are the proportions of your clients who are

male _____ female _____

Anglo _____ Black _____ Chicano _____ Other _____

from the immediate community _____, nearby cities _____, state _____,
nation _____.

III. LISTS OF SERVICES PRESENTLY PROVIDED

	<u>Primary purpose of program</u>	<u>Supplemental service</u>	<u>Number of clients served per year</u>	<u>Average number of days spent in programs per person</u>
Residential	_____	_____	_____	_____
Apartment registry	_____	_____	_____	_____
Attendant services	_____	_____	_____	_____
Attendant registry	_____	_____	_____	_____
Transportation	_____	_____	_____	_____
Vehicle modification	_____	_____	_____	_____
Para-legal	_____	_____	_____	_____
Peer-counseling	_____	_____	_____	_____
Family counseling	_____	_____	_____	_____
Medical treatment/ services	_____	_____	_____	_____
Out-patient services	_____	_____	_____	_____
Protective supervision	_____	_____	_____	_____
Community consulting and advising	_____	_____	_____	_____
Political lobbying and organizing	_____	_____	_____	_____
Advocacy	_____	_____	_____	_____
Social/recreational	_____	_____	_____	_____
Research	_____	_____	_____	_____
Communications (news- letters, etc.)	_____	_____	_____	_____
Information exchange, registry	_____	_____	_____	_____
Food preparation	_____	_____	_____	_____
Housekeeping	_____	_____	_____	_____

	<u>Primary purpose of program</u>	<u>Supplemental service</u>	<u>Number of clients served per year</u>	<u>Average number of days spent in programs per person</u>
Financial Support	_____	_____	_____	_____
Financial aid or counseling	_____	_____	_____	_____
Mobility training	_____	_____	_____	_____
Independent Living Skills training	_____	_____	_____	_____
Wheelchair or equip- ment repair	_____	_____	_____	_____
Vocational educational counseling	_____	_____	_____	_____
Vocational training	_____	_____	_____	_____
Vocational placement	_____	_____	_____	_____
Sheltered workshop	_____	_____	_____	_____
Other (please specify)	_____	_____	_____	_____

Please rank the three services or functions that are the most important descriptors of your program.

1. _____
2. _____
3. _____

Would you consider your program to be primarily

- a. residential _____ or non-residential _____
- b. single service _____ or multi-service _____
- c. vocational _____ or non-vocational _____

Is the dominant focus of your program primarily

- a. self help _____ or professional treatment _____
- b. to provide physical care _____, information _____ or counseling _____

IV. CRITERIA FOR PARTICIPATION

a. Admission criteria

restricted by type of handicap? yes____ no____

If "yes," what types of handicap_____

restricted by level of independent living? yes____ no____

If "yes," please explain_____

restricted by sex? yes____ no____

restricted by financial capability? yes____ no____

restricted by vocational capability? yes____ no____

restricted by religion? yes____ no____

unrestricted, open admission? yes____ no____

unrestricted but limited by available space/facilities? yes____ no____

Length of waiting list_____

Are there any other admission criteria? _____ If so, please explain

Please describe your most typical service client.

b. Who determines criteria for admission?_____

c. Who handles application procedures?_____

d. What are the criteria for discharge/graduation?

medical stability_____

psychological stability_____

level of independent functioning_____

set program cycle_____ length of cycle_____

vocational placement_____

participant/client decision_____

financial constraints_____

other_____ (please explain)_____

none_____

e. Who decides to discharge/terminate/graduate participants?_____

f. From what sources do you receive referrals?_____

What proportion of your clientel are referred?_____

g. To what other organizations or groups do you make referrals?_____

Please estimate the number or proportion of your clientel that you refer elsewhere?_____

V. ORGANIZATIONAL OR MANAGEMENT STRUCTURE OF THE PROGRAM
(Please check all descriptors that apply)

Private, profit_____

Non-profit_____

Cooperative_____

Unincorporated_____

Association_____

Club_____

Hospital affiliate_____

Name of hospital_____

University affiliate_____

Name of university_____

Church affiliate_____

Name of church_____

Business affjliate_____

Name of business_____

Health care facility affiliate_____

Name of health care facility_____

State agency affiliate_____

Name of state agency_____

R & T center affiliate _____

Name of R & T center _____

Other (Please specify _____)

STAFF BREAKDOWN

	full time	part time	adjunct or advisory (volunteer professional)	volunteer full time	volunteer part time	number handicapped
board of directors	_____	_____	_____	_____	_____	_____
executive director	_____	_____	_____	_____	_____	_____
professional counselors	_____	_____	_____	_____	_____	_____
professional therapists	_____	_____	_____	_____	_____	_____
peer counselors	_____	_____	_____	_____	_____	_____
aids and attendants	_____	_____	_____	_____	_____	_____
drivers	_____	_____	_____	_____	_____	_____
cooks	_____	_____	_____	_____	_____	_____
housekeeping	_____	_____	_____	_____	_____	_____
bookkeeping	_____	_____	_____	_____	_____	_____
secretarial	_____	_____	_____	_____	_____	_____
research	_____	_____	_____	_____	_____	_____
physician	_____	_____	_____	_____	_____	_____
other _____	_____	_____	_____	_____	_____	_____

Total number of full time, paid employees _____

Total number of part time, paid employees _____

Total number of volunteers _____

Approximate monthly payroll _____

Do you have any physical structures, facilities, space?

owned _____ rented _____ leased _____ borrowed _____

Size of facility (approximate square foot) _____

Please estimate the approximate area devoted to the following settings:

1. Residential _____
2. Single family dwelling(s) _____
3. Multi-family house(s) _____
4. Apartments _____
5. Dormitory _____
6. Medical inpatient _____
7. outpatient treatment services _____
8. commons/recreational _____
9. office _____
10. training/therapy _____
11. workshop _____
12. production _____
13. storage _____
14. garage _____
15. other (please specify) _____

VI. SOURCE OF FUNDING/CASH FLOW

Direct income for services rendered _____
(Please enclose a schedule of fees)

Third party reimbursement for services _____

Loans _____

Donations: individuals _____ groups _____

Proceeds from manufacturing _____ selling _____

Benefits or fund-raising affairs _____

Grants or contracts:

Federal _____

State _____

Municipal _____

Foundation_____

Private_____

Industrial/Union_____

Church_____

Other_____

What do you consider to be your primary source of funding?

Please provide a brief narrative description of your program.

What do you regard to be the major problems with your program?

What changes would you suggest to make your program more successful?

What methods do you use to evaluate the effectiveness of your program?

2/20/78

INDEPENDENT LIVING:

Six Model Programs

COPYRIGHT 1978

The Independent Living Research Utilization Project
The Institute for Rehabilitation and Research
Houston, Texas

Jean Cole
David Bailey

Lex Frieden
Laura Gerken

Independent Living: Six Model Programs is a 60 minute, color videotape describing six innovative programs which are designed to facilitate independent living by severely disabled individuals. Although each of these programs is substantially different from the others, they all benefit severely disabled individuals by providing the support required for them to live independently -- to participate actively in society, and to make decisions which affect their own lives. Each of these presentations was produced by the people who operate these programs and who are served by them. Funding for this project was provided by the Rehabilitation Services Administration, DHEW, Grant No. RSA-RD-22-P-59106/6-01.

CENTER FOR INDEPENDENT LIVING, INC.

2539 Telegraph Avenue
Berkeley, California 94704

Contact: Lynn Kidder

The Center for Independent Living was probably the first disabled consumer-operated service organization established in the United States. From the beginning it was geared toward making support services in the community available to disabled individuals. CIL is not a residential program, but a multi-faceted program of referral services, support services, and research and advocacy projects directed toward removing architectural and attitudinal barriers existing in the community. The goal of the organization is total integration of people with severe disabilities into community life by minimizing those aspects of a person's disability that become handicaps. To do this CIL provides various kinds of counseling programs, independent living skills training programs, and vocational rehabilitation services. Whenever possible, existing community services are used, so CIL also refers many people to agencies and organizations that provide such independent living services as vocational counseling, vocational rehabilitation and training, and financial support.

The central philosophy of CIL is that disabled people can be actively contributing members of society and that they themselves should be the ones who control their lives. To achieve the goals of an independent lifestyle with self-determination, CIL has worked to involve disabled people in all aspects of the program. CIL was founded and is operated by disabled individuals, the counseling and instruction of participants is conducted by disabled staff members, and through political and legal advocacy the Center is working to remove architectural and legislative barriers to the complete and active participation of disabled people in society.

CREATIVE LIVING

445 West 8th Avenue
Columbus, Ohio

Contact: Charles M. Frank

Creative Living was established in 1968 to assist young physically disabled individuals who wanted to pursue educational or vocational training. The Creative Living facilities are an apartment building specifically designed to be wheelchair accessible and to allow as independent a lifestyle as possible. The building is located next to the Ohio State University, where many of the program participants are students. Transportation to other parts of the city is available for those who are participating in vocational training programs or just beginning to work.

The program itself provides only the residential facilities and necessary physical assistance needed by an individual during his educational training program. The dominant focus of the program is self-help, and all the participants are motivated toward developing a self-sustaining lifestyle. The individual participant is expected to arrange and pursue his own training program. Once this training is complete, the participants are encouraged to locate and establish their own living arrangements in the community.

WORCESTER AREA TRANSITIONAL HOUSING, INC. (WATH)

507 Main Street
Worcester, Massachusetts 01608

Contact: Charles Croteau

Worcester Area Transitional Housing program was established in 1976 with the aid of the Handicapped Housing Division of the Massachusetts Department of Community Affairs to create a transitional housing program for disabled young adults. The initial intent of the program was to provide a setting for those who wanted to live independently but lacked the training and experience to do so.

WATH is a self-service, self-help transitional program that accepts individuals who have educational or vocational goals and who are motivated to actively pursue these goals. WATH is housed on one floor of a downtown apartment building and provides 20 dormitory style rooms for its participants. Medical and therapy are arranged outside the program, as are many of the training programs attended by the participants.

The staff of WATH have developed and conduct training modules designed to provide the participant with the skills and experience needed to live independently. A number of the residents are also enrolled in either the local college or local vocational training courses.

The WATH program is transitional in that once the participant has obtained the needed independent living skills and has attained his educational or vocational goals, he is encouraged to move out into the community. WATH maintains an apartment registry and an attendant registry and works actively in the community to ensure that physically disabled individuals can become functioning, contributing members of the community.

NEW OPTIONS TRANSITIONAL LIVING PROJECT

105 Drew Street
Houston, Texas 77006

Contact: Jean Cole, Ph.D.

New Options is transitional living program designed to foster independence among severely physically disabled individuals, enabling them to become a part of their community. Begun in 1976, the program consists of a six-week cycle of instructional modules that emphasize the skills needed to live and work with a minimum of assistance. New Options is a residential program that is planned and structured to provide information and first-hand experiences which enable participants to acquire necessary independent living skills in a short period of time. Being a dormitory-style setting with a non-professional attendant staff, living at New Options for six weeks is a new experience for many of the participants who have known only family or professional nursing staff.

The goals of the program include the establishment of an independent living skills situation which includes working with personal care assistants, involvement in educational and vocational opportunities, active participation in the community, and the enhancement of personal, physical, and functional skills. New Options also has an extensive independent living research program which is used to trace the influence of its program on ex-participants. This way modules can be created or modified to better train disabled individuals to participate actively in the community as contributing citizens.

GOVERNOR'S COUNCIL ON THE HANDICAPPED

State of Colorado
State Services Building, 5th Floor
1525 Sherman Street
Denver, Colorado 80203

Contact: Janet Anderson

There are three programs working with the Colorado Governor's Council on Handicapped to offer independent living opportunities in the Denver-Boulder Colorado area. While the goals of these three programs are the same -- helping disabled individuals establish independent lifestyles -- the manner in which they operate is different.

Atlantis Community, Inc. is a private, non-profit program that seeks to provide needed services to severely disabled people while respecting the individual's freedom and privacy. Atlantis began by leasing apartments from the Denver Housing Authority. Now, the program is broad enough to be able to help disabled individuals leave nursing homes and work toward an independent lifestyle. Their approach is to make available transitional living facilities with needed supportive services. With further development, the individual's apartment can be relocated in the community. Complete independence is achieved when the services of Atlantis are used only infrequently.

The Genesis House is a nursing home that a number of severely disabled people with ongoing medical support needs took over and incorporated.

Thus, Genesis House is a cluster living arrangement that is owned, controlled, and operated by the residents themselves.

The Governor's Council on the Handicapped has obtained a grant from VISTA-ACTION to establish independent living service support units throughout the state. Starting in the Denver area, the goal of the program is to gather the available resources within each community and coordinate and supplement them until they can operate on their own.

These three independent living programs are quite different, but they all have the common goal of independence for the severely disabled individual.

BOSTON CENTER FOR INDEPENDENT LIVING

50 New Edgerly Road
Boston, Massachusetts 02115

Contact: Robert Williams

BCIL was established in 1974 as a consumer-run self-help community where severely disabled individuals could develop independent living skills. Since then BCIL has developed into a non-profit corporation that coordinates three different phases of independent living that have evolved in the Boston area.

Since its inception BCIL has made transitional living facilities available to interested severely disabled individuals. The transitional program includes independent living skills training that enables the individual to participate in the community at large. For participants with more developed independent living skills and who desire a more personal lifestyle, BCIL has located an apartment building that makes cluster housing available in modified apartments with a pool of personal care assistants. BCIL has also been working to make available facilities and funding for individuals who wish to share an accessible apartment with a personal care assistant and live independently.

The goal of the program is to be a base of operations from which disabled individuals could bridge the gap between total dependence on an institution and living independently.

DEFINITIONS RELATED TO THE CONCEPT
OF INDEPENDENT LIVING

Developed by the Independent Living Research Utilization Project
at the Texas Institute for Rehabilitation and Research
with grant support from the
Rehabilitation Services Administration
US DHEW

May, 1978

105 Drew Street
Houston, Texas 77006

PREFACE

A major goal of the Texas Institute for Rehabilitation and Research Independent Living Research Utilization Project is to categorize and define the different kinds of independent living programs existing in the United States. As a concept independent living is simple. When the effects of the local community, the structure of available monies, the goals of individual programs, and the needs of the client populations are considered, it can become difficult to differentiate between kinds of independent living programs.

The definitions presented in this paper are of terms relating to independent living and kinds of independent living programs. Obviously, they are neither exhaustive nor comprehensive, especially since new terms are created to describe new circumstances. However, there is a need to standardize the meanings of several key terms so that rehabilitation professionals, consumers, and others around the country will know that they are referring to the same thing when they use a particular term.

These definitions were developed after a review of the relevant literature by the Independent Living Research Utilization Project staff. The project's National Advisory Committee played a major role in this effort through group discussion of concepts and through written comments on early drafts of the definitions.

The definitions relating to independent living are structured so that the definition for each term builds upon those that precede it. Consequently, definitions of individual terms should not be taken from the text without appending the appropriate sections of the previous definitions. Likewise, the definitions of the terms of physical capability depend upon the prior terms to make the relationship between them clear.

INDEPENDENT LIVING

Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's own affairs; participating in day-to-day life in the community; fulfilling a range of social roles; and making decisions that lead to self-determination and the minimization of psychological or physical dependence upon others. Independence is a relative concept, which may be defined personally by each individual.

Discussion

The concept of independent living is very broad, but it focuses on the individual. This focus will necessarily include many levels of functional independence. Individuals may perceive these different levels as having varying degrees of importance. For instance, there are some behaviors and activities not central to personal control of one's destiny or the day-to-day management of one's life-style that are considered by some people to be earmarks of living independently. Whether or not individuals perform these particular activities themselves or rely on the assistance of others may have little to do with the control they exercise over their own lives. One example would be the ability to dress oneself without assistance. Some individuals perceive this activity to be an important example of their ability to live independently, whereas others view any extra time and energy spent dressing themselves as time and energy which could be spent more profitably at work. It should be noted that independent living is not dependent upon the existence of programs that foster functional independence. Instead, it is based upon the individual's ability to choose and achieve a desired lifestyle, and to function freely in society.

INDEPENDENT LIVING MOVEMENT

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

Discussion

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

Historically, the independent living movement has been characterized by a great amount of consumer involvement and consumer control. The most widely known, and perhaps the first effort to actualize independent living for severely disabled individuals on a broad scale began in Berkeley, California. In the early 1970's a group of disabled students established a self-help service program designed to meet their needs and expand their options. This university based program was the forerunner of a larger self-help program to serve people throughout the community. Similar programs have since been established elsewhere in the nation.

Also, the movement has been associated with expanding non-institutional residential alternatives for severely disabled individuals. This reflects

ties to earlier philosophical concepts of deinstitutionalization and normalization. Some independent living programs are direct descendants of former halfway house projects or group homes.

Finally, independent living programs have always been seen as sources of specific information and referral. This is partly due to the fact that many of these programs do not have the resources to provide direct services. It may also reflect a lack of coordination of services which already exist in the community. In some cases, programs have found it necessary to provide services as a means of filling gaps in the community level service delivery system.

INDEPENDENT LIVING PROGRAM

A community-based program that provides services, coordinates existing services and/or lists referral to assist severely disabled individuals to increase personal self-determination and to minimize unnecessary dependence on others.

Independent living programs have substantial consumer involvement, provide directly or coordinate through referral attendant care and housing, and provide information about goods and services relevant to independent living. Other services that are provided or coordinated by independent living programs include:

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

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

Discussion

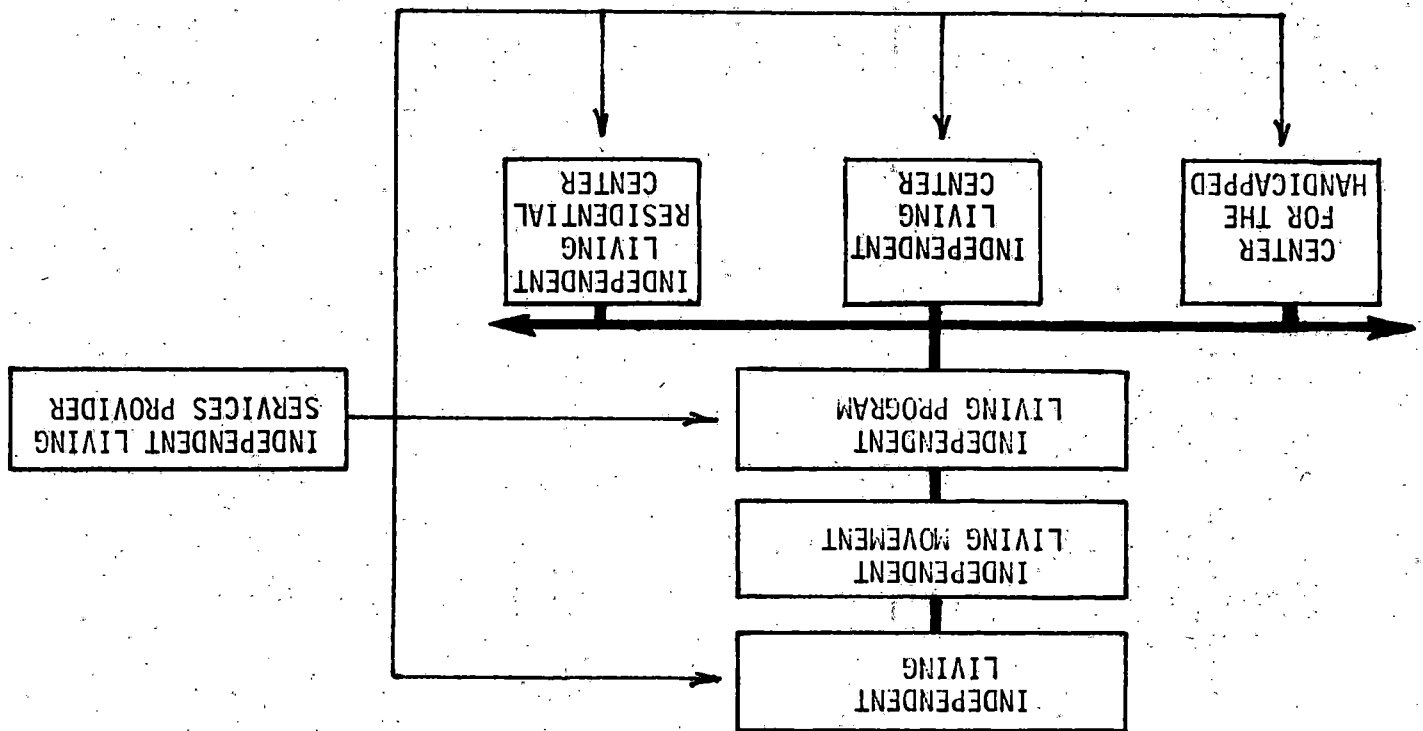
Independent living programs may be needed by individuals in order to develop personal and/or vocational skills. Whether these programs are conceived of as maintaining a certain standard of living or oriented toward achieving certain goals will depend upon the needs of the individuals using them. In addition to the needs of the individuals, the focus, degree of involvement, or level of commitment of an independent living program will depend upon the

availability of existing community services, the physical and social makeup of the community, and the goals of the program itself.

Under certain circumstances it may be advantageous to distinguish between different kinds of independent living programs. This should be done through the addition of an appropriate descriptor. For example, those programs which are designed to facilitate the movement of individuals from a level of relative dependence to relative independence after a specified length of time or after achieving specified goals may be regarded as transitional independent living programs.

Conceptually, independent living program is the most broadly defined term relating to organizations working with disabled individuals who wish to live independently. Several different kinds of independent living programs with specified purposes have been identified. Some of these are: Independent Living Center, Independent Living Residential Center, and the Center for the Handicapped. The accompanying chart illustrates the various level of abstractions and the relationships between these elements.

FLOW DIAGRAM OF INDEPENDENT LIVING CONCEPTS AND ORGANIZATIONS



INDEPENDENT LIVING SERVICES PROVIDER

An organization that does not have a program which meets the criteria necessary to be termed an independent living program, yet provides some services that contribute to opportunities for independent living by severely disabled individuals.

INDEPENDENT LIVING CENTER

An independent living program that is non-profit, is controlled by disabled consumers, is non-residential in nature, and provides a certain specific set of services.

At the minimum they are:

- attendant, reader, and/or interpreter referral;

- peer counseling;

- financial and legal advocacy; and

- housing assistance, community awareness, and barrier removal.

Other services can be provided, either as core, primary, or optional services.

INDEPENDENT LIVING RESIDENTIAL CENTER

An independent living program that provides housing, attendant care, and transportation provision or referral. Other services can be provided either as primary or secondary services.

CENTER FOR THE HANDICAPPED

Any single or multi-purpose facility which seeks to assist persons with physical, mental, developmental and/or emotional impairments to become more

functional members of the community by providing programs or services which may include, but are not limited to recreation, education, health care, social development, independent living, physical rehabilitation and vocational rehabilitation; but excluding any facility whose primary function is to provide residential care on a 24-hour a day basis (such as a group home or halfway house). For example, a sheltered workshop would be a single purpose center for the handicapped, and a facility providing several services for the handicapped would be a multi-purpose center for the handicapped.

(HUD definition, adapted from the Federal Register, Vol. 43, No. 41, March 1, 1978, p. 8441)

ABILITY DESCRIPTORS

The term handicap generally has been used to describe people who, for some reason, are physically or mentally unable to perform all of the personal or social functions, or fulfill the cultural roles in the manner expected of the general population. As a generic term, handicap implies a disadvantage, but when applied to disabled individuals it is very vague and often improperly used. Culyer (1974) argues that handicap is a subjective concept which depends upon society's view of the individual in question.

Unfortunately, this term is often used interchangeably with other, more definite terms that describe degrees of behavioral capability. Terms which more usefully describe behavioral capability are impairment, functional limitation, and disability.

IMPAIRMENT

The result of a disease, injury, or other condition (usually, but not necessarily pathological) which leads to a physiological anatomical, and/or mental deviation from normal biological functioning (Berkowitz, Rubin, & Worrall, n.d.; Nagi, 1975, 1977).

FUNCTIONAL LIMITATION

The inability to perform some physical or mental activity due to an impairment. A functional limitation may or may not result in a disability, depending upon the extensiveness of the impairment, the requirements of the activity to be performed, the frequency or intensity of the activity present in everyday living, and the length of time the limitation exists (Berkowitz, Rubin, & Worrall, n.d.) Thus, a person could have an impairment, but not be functionally limited if his/her normal activities are in no way restricted by the impairment.

DISABILITY

The end result of a series of circumstances leading to a long-term inability to perform any of the major-life functions, or an inability to perform in one's generally recognized social role (Nagi, 1977).

HANDICAP

The result of an accumulation of obstacles that are interposed by society between a disabled individual and his/her maximum functional level.

This usually comes about because society and the physical environment are not set up to allow disabled people to behave in the fashion in which they are capable. A handicap, therefore, is the consequence of the relationship between a disability and the social, cultural, and/or physical environment.

Discussion

A person has a disability if he/she is physically or mentally unable to perform in a generally expected manner. A person is handicapped if he/she is physically or mentally capable of fulfilling a social role, but society or the physical environment is unable to accomodate him/her or the methods he/she uses to fulfill that role. It is the presence of such situations in society that are the handicaps, not the people who have to experience them.

REFERENCES

- Berkowitz, M., Rubin, J., and Worrall, J. An evaluation of the structure and functions of disability programs. New Brunswick, N.J.: Rutgers University, Bureau of Economic Research, 1975.
- Berkowitz, M., Rubin, J., and Worrall, J. Economic concerns of handicapped persons. Awareness paper prepared for the White House Conference on Handicapped Individuals (no date).
- Culyer, A.J. Impairment, disability and handicap: A multidisciplinary view. London, England: Heinemann Educational Books, 1974.
- Nagi, S.D. Definitions of pathology, impairment, functional limitation, and disability. In E.B. Whitten (ed.), Pathology, impairment, functional limitation, and disability -- Implications for practice, research, program and policy development, and service delivery. Report of the First Mary E. Switzer Memorial Seminar. Washington, D.C.: National Rehabilitation Association, 1975.

SURVEY OF INDEPENDENT LIVING PROGRAMS

The Independent Living Research Utilization Project is in the process of conducting a survey of all known existing independent living programs in an effort to gather information about these programs in several different subject areas. The survey is being conducted for several purposes, primarily to determine the different kinds of programs that exist and to identify those aspects of an independent living program that are common to all programs and therefore relevant to the concept of independent living. Also, the survey would make it possible to collect the experiences and successful techniques of various kinds of independent living programs so that the information could be passed on to others in similar situations or with similar problems. This information could also be used by those who wish to establish independent living programs by showing them which techniques work and what kinds of planning must be done.

Another reason for the survey was to test the system of classifying independent living programs that was developed by the ILRUP with the assistance of its National Advisory Committee. Moreover, the survey would demonstrate how complete the list was, and show what other classifications were needed to properly describe the different kinds of independent living programs. Through the survey, the project would be able to locate programs that were not known to the several agencies and organizations who have compiled address lists of programs relevant to their particular interests. The survey would also determine if there were other definitions of the concept of independent living that were being used elsewhere in the country.

INSTRUMENT

The survey was designed as a demographic and descriptive instrument that would allow the project to analyze several different topic areas. The programs were asked to respond to questions about clientele, service mix, program focus, admission and discharge criteria, organizational structure and affiliations, funding sources, problems, and evaluation procedures.

The survey instrument was designed to solicit complete responses from the most comprehensive programs known to the project. Consequently, few programs were expected to complete all items on the survey. Respondents were instructed to answer only those items that were relevant to their particular program.

SAMPLE

The Independent Living program survey was distributed in essentially three mailings. Initially, the survey was sent out to programs already known to the ILRUP staff and to programs listed by HEW and HUD. A second mailing was sent to agency directors who were listed by CSAVR. The second mailing requested the directors to refer to the ILRUP any independent living programs they knew about in their state for inclusion in the survey. A copy of the survey form was included with the request to further explain the kinds of information the ILRUP was soliciting. There were 40 responses to the CSAVR mailing, about half of which appended addresses of programs

known to the agency. These addresses were then used in the third mailing along with programs listed by such sources as Gini Laurie (Housing and Home Services for the Disabled) and Susan S. Pflueger (Independent Living).

The initial intent was to survey independent living programs concerned with physically disabled clients. Through the survey and other work done by the ILRUP, however, interest in the survey was expressed by organizations whose primary function was not directed primarily toward physically disabled people. As a result, the surveyed sample includes programs from all categories of the field of independent living for severely disabled individuals, but does not attempt to be an exhaustive list of programs serving such clients as persons with mental disabilities.

RESULTS

Approximately 450 survey forms were sent out to programs appearing to be concerned with independent living for severely disabled people. This number includes the forms sent to approximately 125 agencies listed in the CSAVR directory.

To date 63 useable responses to the survey have been received. Several programs which are in the planning stages responded, and these were not included in the sample to be analyzed.

CLASSIFICATION

Using the program classifications and criteria developed by ILRUP and its National Advisory Committee, it was found that 11 of the 63 respondents could be termed Independent Living Centers (an independent living program which is controlled by disabled consumers and provides the minimum core of services of: attendant, reader, and/or interpreter provision or referral; peer counseling; financial and legal advocacy; housing provision or referral; and community awareness and barrier removal programs). Of these, all but three were residential programs or had residential provision as a major service. Two of the programs could be considered extended residential programs in that they actively sought housing for their clients rather than providing it as a core service at a central facility or campus.

Eight of the remaining programs met the criteria for an Independent Living Program (a community-based program which has substantial consumer involvement, provides directly or coordinates through referral attendant care and housing, and provides information about goods and services relevant to independent living); all but two of which included residential provision as a primary service. Two of these programs could be termed Independent Living Centers except that they did not meet the non-profit restriction in the definition. There were nine other programs which could be termed Residential Service Providers since, in almost all cases, the only criterion for Independent Living Program they did not meet was that of communication and information exchange.

Another feature which distinguishes the Residential Service Providers from the Independent Living Programs and Independent Living Centers is the provision of personal care assistance. All of the programs classified as Residential Service Providers and most of those classified as Independent Living Programs or Independent Living Centers provide personal

care assistance as a major client service. None of the Residential Service Providers, however, maintain an attendant registry that their clients could use in place of PCA staff. Seven of the eleven Independent Living Centers and two of the Independent Living Programs, on the other hand, maintain attendant registries that compliment a residential PCA staff. Similarly, only three of the Residential Service Providers have housing registries, while three of the seven Independent Living Programs and nine of the eleven Independent Living Centers provide housing registries (three of which are non-residential programs).

Of the eleven programs classed as Independent Living Centers, four were known to be developed under the Center for Independent Living model, which was used to generate the definition of an Independent Living Center. Two others were developed under the Transitional Training model, which was also known beforehand to be sufficiently comprehensive to be termed an Independent Living Center. None of the responding programs that were developed under either of these two models failed to meet the criteria for an Independent Living Center.

In summary, the classification system developed by the ILRUP with the National Advisory Committee is detailed enough to discriminate different kinds of programs on an organizational/service provision level. The classified programs were not limited to those serving physically disabled persons, as several programs under the auspices of national organizations concerned with other kinds of disability were classed as Independent Living Centers.

OVERALL RESULTS

The remaining 35 programs can be classified according to the definitions as Independent Living Service Providers -- programs which provide services useful for living independently, but fail to meet the criteria for an independent living program. (The nine Residential Service Providers have already been mentioned, as they meet all the criteria with the exception of information provision).

The other programs range in provided services from strictly one or two services (e.g. housing and attendant care, transportation and/or independent living skills training) to a more complete list of services. More than fifty percent of all respondents provided the following services:

Independent Living Skills Training	71%
Transportation	67%
Residential provision/registry	62%
Social/recreational services	57%
Financial and counseling	52%
Community counseling services	52%
Peer counseling	52%
Client advocacy services	51%
Attendant services/registry	60%

There was no discernable pattern in the provision of these services, so a program that provided advocacy and peer counseling services need not also provide independent living skills training or social/recreational services. Interestingly enough, while 37 programs offered residential provisions, only half of them (17) maintained a housing registry, and

only 6 responding programs maintained a registry without providing housing for their clientele. Similarly, while 38 programs made some provision for personal care assistant services, only 13 maintained a PCA registry, and only 6 maintained a registry without providing attendant services.

In general, the lack of a discernable pattern in the services offered by the responding programs suggests that the needs of program clientele are diverse and heavily influenced by existing community services and support. The rank ordering of the provided services shows some indication of those services that are deemed important by the programs and the program participants. Independent Living Skills Training, Transportation, and Residential provision or registry are the three services most frequently offered by the responding programs. It is interesting to note, however, that transportation is not considered one of the three most important services by the responding Independent Living Programs or Independent Living Centers (those were Independent Living Skills Training, Residential provision/registry, and Attendant Services provision/registry). S

The responses on the financial and organizational sections of the survey were so sparse no general statements can be made at this time. However, a number of survey forms are still being returned and further analysis of the data should be possible for inclusion in the Final Report. Of the classified programs, for instance, only a few provided any financial information. Those who did respond to the particular items complained of a lack of available funds and insufficient community support.

The survey solicits enough information that with a larger response sample it will be possible to analyze the data more completely. Several of these topic areas include: level of consumer involvement in the various kinds of independent living programs, relationship between organizational structure, size of program and kind of program, the pattern of affiliation with other organizations, the frequency of independent living programs that serve single or multiple kinds of disabilities and the problems or experiences associated with the different program focuses, interaction with funding or assistance agencies, and whether there are unique cooperative relationships that are not generally known. There is evidence, however, that some of the sections on the survey may have been confusing to many of the respondents, so a larger sample will be needed for further analysis.

CONCLUSIONS

The response rate to the survey was comparatively low (approximately 14% have responded to date). This may be due to the fact that there are relatively few programs operating in the field of independent living that have begun to keep the kinds of information solicited by the survey. In spite of the small sample size, however, several objectives were accomplished by the survey which augur well for future efforts.

First, the effort of conducting the survey generated a more complete listing of programs fostering independent living than was previously available. A number of agencies and organizations have been maintaining lists, but the scope of these lists were limited to the objectives of each agency.

Furthermore, a large proportion of the programs are recent efforts, or had changed locations, which meant that the lists had to be brought up to date.

Second, a lot of interest was generated by the survey. Most of the CSAVR respondents, for instance, have requested copies of the final results of the survey, even when they indicated that there were no independent living programs in their state. A number of other respondents provided addresses of programs that were unknown to the other list compilers. Also, interest was expressed by organizations not initially considered in the survey sample. Both the national office of UCPA and a number of organizations affiliated with the National Association of Private Residential Facilities for the Mentally Retarded have expressed an interest in participating in the survey.

Third, the different kinds of programs that are in existence are more diverse than previously expected. The program classification system developed at the National Advisory Committee Meeting is not broad enough to completely reflect the diversity shown in the survey results. Several other concepts have been suggested, such as "semi-independent living," "cluster living program" and "group housing."

Fourth, the diversity of the programs and their service mix implies that more thought has to go into determining what constitutes a successful independent living program than had previously been expected. Two areas that were not explored in sufficient detail were client needs and existing community support networks. Quite obviously, a program need not be comprehensive if the environment of the community in which it operates is sufficiently rich to provide many of the services needed by its clientele.

The survey does show that there are several elements to living independently that must be addressed if a program is to be successful in helping people with severe disabilities to live independently. How these elements are arranged for, or provided, however, depends upon a number of other elements. Apparently, the presence or absence of these other elements in the community has a lot to do with the particular structure of the organization working with severely disabled individuals.

SUMMARY OF PILOT TRAINING CONFERENCE

In order to pilot test the information and materials generated by the Independent Living Research Utilization Project, an independent living conference was held in Lubbock, Texas on August 21-23, 1978. The initial intent of the conference was to provide an impetus and the organizational tools to establish an independent living program in the Lubbock community.

Lubbock was chosen for several reasons. It was known to have a relatively sizeable number of severely physically disabled individuals. Since it is located in a largely rural area, a Lubbock program would also draw people from the surrounding communities. Texas Tech University and Texas Tech Medical School are both in Lubbock which would provide expert resources in education, medical assistance and research. An R&T Center concerned with mental retardation and with training people to work with mentally retarded individuals is also located at Texas Tech.

Further, there are a number of people living and working in the Lubbock area who are known to the project staff, both as rehabilitation professionals and disabled consumers. Thus, entrance into the community would be easier than into one where the project staff and its goals were unknown.

Arrangements to sponsor the workshop were made with the R&T Center at Texas Tech and with a local organization called Lubbock Area Extended Rehabilitation Services, Inc. Fortunately, a training program sponsored by East Central Oklahoma University on programs for developmentally disabled individuals was to be scheduled for the same week, so the two programs were combined into one 2½ day seminar.

The attendees were primarily agency personnel, many of whom were from a number of different communities in West Texas with only a few consumers or consumer representatives. The importance of consumer representation had been emphasized with local conference organizers prior to the meeting, but they reportedly were unable to generate substantial interest among consumers in the community.

The conference began with an analysis of the concept of independent living. Next, the videotape portraying six alternative approaches to independent living programs developed by the Independent Living Research Utilization Project was presented. Afterwards, there was an analysis of those elements that a successful independent living program should contain.

The second day of the conference was spent presenting information on resources available to persons interested in developing an independent living program. These resources included programs for financial support, direct service delivery, and environmental alteration. The presentations concerned with financial resources dealt with outlining the various support programs available both to individuals and how they could best be tailored to individual needs and community circumstances. The presentations dealing with environmental alteration ranged from outlining the needs and requirements for properly modified vehicles through the use of federal guidelines to ensure building accessibility. The use of legal advocacy was discussed,

and several actual programs were described, detailing the problems faced in trying to apply service goals to a real world situation.

The conference closed with a presentation on the effects of consumer involvement and courses of action that are helpful in ensuring successful consumer organization. An open discussion was then held to describe the various community situations existing in West Texas and to share experiences with overcoming local problems.

In overview, the conference was reported as valuable by those who attended. The inclusion of the ECOU program as a co-sponsor broadened and strengthened the content, and the collaboration with Texas Tech added a perspective toward mental retardation that was very worthwhile.

These factors led to some alteration in the original goals of the meeting as they had initially been conceived by the Independent Living Research Utilization Project. Instead of focusing on the actual planning of a new independent living program in the Lubbock community, the conference served a more general purpose of increasing awareness about initial issues in independent living and providing information on support mechanisms available in many communities. The conference also increased the awareness of attendees about efforts being made elsewhere to achieve goals similar to their own. The lack of disabled consumers attending the conference and the large number of out-of-town attendees meant that it was not feasible to focus specifically on how to start a program in Lubbock itself or how to research possible community support networks in this local area. The emphasis on mental retardation and developmental disabilities meant that the major concern of the discussions was either with enriching the lives of institutionalized individuals, or with the problems of helping institutionalized persons move into sheltered living arrangements.

The Lubbock experience, with changing conference goals that emerged as the meeting progressed, has emphasized to the ILRU Project staff the importance of flexibility in planning such community meetings and the need to tailor program content to the interests of the groups of persons attending. The collaborative effort with conference co-sponsors who work with DD and MR programs made the ILRU Project staff aware of concerns of these populations and pointed out similarities of their needs with those of other disability groups.

TEXAS INSTITUTE FOR REHABILITATION AND RESEARCH
IN THE
TEXAS MEDICAL CENTER
1333 MOURSUND AVENUE
HOUSTON, TEXAS 77030

P. O. Box 20095
Houston, Texas 77025

Telephone
Area Code 713, 797-1440

FACILITATING INDEPENDENT LIVING: COMMUNITY OPTIONS
SMALL GROUP PROCEDURES

THE TASK

In this seminar we have spent the past two days exploring the general concept of independent living, examining several alternative types of programs, and gaining information on potential resources available in most local communities. Your task in this small group is to develop plans for an independent living program in your home community.

In developing any type of program, things often fail to get off the ground because people stop at the conceptualization stage instead of developing on-going plans of action. You obviously will not be able to do all of the required planning for an independent living project in one afternoon. However, each group should leave the seminar with

- a) an overview of an independent living project that is needed and could be implemented in your local community;
- b) a written set of goals that specify what must be accomplished in order to develop the project you identified; and
- c) an on-going committee or working task force that will take responsibility for future planning and implementation of the independent living project.

GETTING STARTED

As a group you should designate a coordinator to lead your discussion and a recorder to record group decisions and report on the work of this group when we reconvene at 3:15 for a large-group summary session. Seminar faculty members will sit in on your group as resource persons, but they should not assume leadership roles.

One way to get started is to introduce yourselves, including where you work and what your duties are. Do your introductions and selection of a coordinator and recorder now. This should take 5 to 10 minutes.

BRAINSTORMING

Use the "imaging" process described below (Schindler-Rainman, 1977) to come up with an overview of the kind of independent living project that could operate successfully in your local community. This approach will stimulate your creativity and encourage you to think ahead in outcome-oriented terms.

Take an imaginary leap one year ahead. Imagine that you are looking at a working independent living project in your community, and you are pleased with services it is providing and the way it operates. Talk as a group about what you see. Be specific. For example...

"I see handicapped individuals who have developed friendships with able-bodied neighbors."

"I see a van that takes people on necessary trips to school or work and that is also available when individuals want to go shopping or out for the evening."

"I see a way for people to get help with financial planning."

"I see handicapped people who usually get along well with attendants and who are able to work out conflicts and disagreements when they come up."

As a group, brainstorm what you would like to see in your community a year from now. Think and talk in the present tense as you list your images. Remember that in brainstorming you list all ideas. Anything goes. Do not discuss. Do not judge. The group recorder should write down all the ideas that are voiced. Take about 10 minutes for this task.

AN INDEPENDENT LIVING PROJECT FOR THE COMMUNITY

It is now important for the group to begin thinking systematically about an actual project for your community. Look at each of the "pieces of the puzzle" that were discussed at the beginning of the seminar, and write down your group's ideas about each piece.

The pieces are listed below.

- 1) client needs
- 2) community resources and financial resources
- 3) program objectives
- 4) program structure
 - organizational structure
 - operational structure

In thinking about some of the pieces you will probably have more questions than answers. That's okay. It is important to record the questions so that you know what issues must be addressed in future planning meetings. (For example, the group may not know at this point what all of the client needs are in your community. Go ahead and list the needs you know about for sure, and put question marks by things you think may be needed.)

It is also important that you not try to resolve all differences of opinion about various options at this session. List all alternatives that seem reasonable and should be investigated more thoroughly in the future. Later planning meetings can be used to decide what is actually feasible. In many areas, more information will have to be gathered before decisions can be made.

Spend about 10 minutes working on each of the "puzzle pieces" listed below. Remember that it is important not to bog down in detailed planning during this session. The purpose is to gain an overview of what a good independent living project for your community would look like.

1) Client Needs.

What types of handicapped individuals may need independent living services? Students? Workshop clients? How old are they? Have they ever lived independently in the past before becoming disabled? Where do they now live?

What services do these people need?

2) Community Resources and Financial Resources

What programs currently serve the individuals identified above?

What other programs that were discussed in the seminar might serve them?

What sources of funds might be available through grants, agency programs, foundations, clubs, etc?

PROGRAM OBJECTIVES

- 1) In what ways might this project complement existing programs in the community, and in what ways might it conflict with established programs?

- 2) How could potential consumers be involved in the planning and management of this project?

PROGRAM STRUCTURE

Organizational Structure

Based on models you have learned about and others you could imagine, what sort of management structure might work effectively (board of directors, resident council, executive director, etc.)?

.....

Operational Structure

What services should this project provide? Be as specific as possible in listing services (for example instead of "transportation" you should list "pick-me-up van service," or "referral to existing community transportation provided by Goodwill").

SUMMARY OF PROJECT OVERVIEW

The group should now be able to summarize very briefly the general type of project that might be developed. Some questions will obviously remain to be answered, but the group should have some shared notion of the shape the project might take.

The recorder should take about 5 minutes to practice summarizing the group's work so far. This summary will be given to the larger group when it reconvenes at 3:15.

After this summary, the group may want to take 30 seconds to stand up and stretch.

GOALS

During this session the group will develop a list of goals that specify what must be accomplished in order to develop the independent living project. The purpose of this list is to outline general directions for future work. There will not be time today to develop a polished set of formal goals, objectives, and strategies, although this is an important part of the planning process that should be continued at later meetings. Please record these goals on the last page of this handout.

Sample goal statements the group might develop today are listed below.

- 1) Establish a task force with elected leaders and appropriate community representation to continue planning the independent living project outlined today.
- 2) Develop a list of goals, objectives, and strategies for the task force.
- 3) Investigate the needs of handicapped university students in the Lubbock area.
- 4) Meet with DHR representatives to learn about the _____ program in the Lubbock area.

ESTABLISHING A COMMITTEE FOR FUTURE PLANNING AND IMPLEMENTATION

The group should now establish an on-going committee or task force with responsibility for carrying on the work begun today in planning an independent living project for your community. Decide who should be represented on this committee. Assign responsibility to some individual or individuals for convening the committee and for acting as leaders until regular leaders can be elected. It is important that members of your group make a commitment to see that further efforts are made on this project. The session today should serve as a beginning for an organized process that can culminate in the establishment of a successful independent living program.

(Material adapted by TIRR Independent Living Research Utilization Project from Small Group Procedures developed by Texas Tech University Research and Training Center in Mental Retardation.)

Hubbock Conference Materials

TEXAS INSTITUTE FOR REHABILITATION AND RESEARCH
IN THE
TEXAS MEDICAL CENTER
1333 MOORSUND AVENUE
HOUSTON, TEXAS 77030

P. O. Box 20095
Houston, Texas 77025

Telephone
Area Code 713, 797-1440

FACILITATING INDEPENDENT LIVING: COMMUNITY OPTIONS
SMALL GROUP PROCEDURES

THE TASK

In this seminar we have spent the past two days exploring the general concept of independent living, examining several alternative types of programs, and gaining information on potential resources available in most local communities. Your task in this small group is to develop plans for an independent living program in your home community.

In developing any type of program, things often fail to get off the ground because people stop at the conceptualization stage instead of developing on-going plans of action. You obviously will not be able to do all of the required planning for an independent living project in one afternoon. However, each group should leave the seminar with

- a) an overview of an independent living project that is needed and could be implemented in your local community;
- b) a written set of goals that specify what must be accomplished in order to develop the project you identified; and
- c) an on-going committee or working task force that will take responsibility for future planning and implementation of the independent living project.

GETTING STARTED

As a group you should designate a coordinator to lead your discussion and a recorder to record group decisions and report on the work of this group when we reconvene at 3:15 for a large-group summary session. Seminar faculty members will sit in on your group as resource persons, but they should not assume leadership roles.

One way to get started is to introduce yourselves, including where you work and what your duties are. Do your introductions and selection of a coordinator and recorder now. This should take 5 to 10 minutes.

BRAINSTORMING

Use the "imaging" process described below (Schindler-Rainman, 1977) to come up with an overview of the kind of independent living project that could operate successfully in your local community. This approach will stimulate your creativity and encourage you to think ahead in outcome-oriented terms.

Take an imaginary leap one year ahead. Imagine that you are looking at a working independent living project in your community, and you are pleased with services it is providing and the way it operates. Talk as a group about what you see. Be specific. For example...

"I see handicapped individuals who have developed friendships with able-bodied neighbors."

"I see a van that takes people on necessary trips to school or work and that is also available when individuals want to go shopping or out for the evening."

"I see a way for people to get help with financial planning."

"I see handicapped people who usually get along well with attendants and who are able to work out conflicts and disagreements when they come up."

As a group, brainstorm what you would like to see in your community a year from now. Think and talk in the present tense as you list your images. Remember that in brainstorming you list all ideas. Anything goes. Do not discuss. Do not judge. The group recorder should write down all the ideas that are voiced. Take about 10 minutes for this task.

AN INDEPENDENT LIVING PROJECT FOR THE COMMUNITY

It is now important for the group to begin thinking systematically about an actual project for your community. Look at each of the "pieces of the puzzle" that were discussed at the beginning of the seminar, and write down your group's ideas about each piece.

The pieces are listed below.

- 1) client needs
- 2) community resources and financial resources
- 3) program objectives
- 4) program structure
 - organizational structure
 - operational structure

In thinking about some of the pieces you will probably have more questions than answers. That's okay. It is important to record the questions so that you know what issues must be addressed in future planning meetings. (For example, the group may not know at this point what all of the client needs are in your community. Go ahead and list the needs you know about for sure, and put question marks by things you think may be needed.)

It is also important that you not try to resolve all differences of opinion about various options at this session. List all alternatives that seem reasonable and should be investigated more thoroughly in the future. Later planning meetings can be used to decide what is actually feasible. In many areas, more information will have to be gathered before decisions can be made.

Spend about 10 minutes working on each of the "puzzle pieces" listed below. Remember that it is important not to bog down in detailed planning during this session. The purpose is to gain an overview of what a good independent living project for your community would look like.

1) Client Needs.

What types of handicapped individuals may need independent living services? Students? Workshop clients? How old are they? Have they ever lived independently in the past before becoming disabled? Where do they now live?

What services do these people need?

2) Community Resources and Financial Resources

What programs currently serve the individuals identified above?

What other programs that were discussed in the seminar might serve them?

What sources of funds might be available through grants, agency programs, foundations, clubs, etc?

PROGRAM OBJECTIVES

1) In what ways might this project complement existing programs in the community, and in what ways might it conflict with established programs?

2) How could potential consumers be involved in the planning and management of this project?

PROGRAM STRUCTURE

Organizational Structure

Based on models you have learned about and others you could imagine, what sort of management structure might work effectively (board of directors, resident council, executive director, etc.)?

.....

Operational Structure

What services should this project provide? Be as specific as possible in listing services (for example instead of "transportation" you should list "pick-me-up van service," or "referral to existing community transportation provided by Goodwill").

SUMMARY OF PROJECT OVERVIEW

The group should now be able to summarize very briefly the general type of project that might be developed. Some questions will obviously remain to be answered, but the group should have some shared notion of the shape the project might take.

The recorder should take about 5 minutes to practice summarizing the group's work so far. This summary will be given to the larger group when it reconvenes at 3:15.

After this summary, the group may want to take 30 seconds to stand up and stretch.

GOALS

During this session the group will develop a list of goals that specify what must be accomplished in order to develop the independent living project. The purpose of this list is to outline general directions for future work. There will not be time today to develop a polished set of formal goals, objectives, and strategies, although this is an important part of the planning process that should be continued at later meetings. Please record these goals on the last page of this handout.

Sample goal statements the group might develop today are listed below.

- 1) Establish a task force with elected leaders and appropriate community representation to continue planning the independent living project outlined today.
- 2) Develop a list of goals, objectives, and strategies for the task force.
- 3) Investigate the needs of handicapped university students in the Lubbock area.
- 4) Meet with DHR representatives to learn about the _____ program in the Lubbock area.

ESTABLISHING A COMMITTEE FOR FUTURE PLANNING AND IMPLEMENTATION

The group should now establish an on-going committee or task force with responsibility for carrying on the work begun today in planning an independent living project for your community. Decide who should be represented on this committee. Assign responsibility to some individual or individuals for convening the committee and for acting as leaders until regular leaders can be elected. It is important that members of your group make a commitment to see that further efforts are made on this project. The session today should serve as a beginning for an organized process that can culminate in the establishment of a successful independent living program.

(Material adapted by TIRR Independent Living Research Utilization Project from Small Group Procedures developed by Texas Tech University Research and Training Center in Mental Retardation.)

NATIONAL CONFERENCE ON INDEPENDENT LIVING
Conference Participants

Thomas E. Backer, Ph.D.
Human Interaction Research Institute
Kirkeby Center, Suite 1120
10889 Wilshire Blvd.
Los Angeles, California 90024

Bill Bean, Ph.D.
Rehabilitation Services Administration
Department of HEW
Switzer Bldg.
Washington, D.C. 20201

Michael Bjerkesett
National Handicap Housing Institute
Suite 1216
12 South 6th Street
Minneapolis, Minnesota 55402

Doris Buckholtz
Texas Department of Human Resources
John H. Reagan Bldg.
Mail Code 421-0
Austin, Texas 78701

Charles Carr
Boston Center for Independent Living
3610 Mystic Valley Parkway #N-807
Medford, Massachusetts 02155

Al Condolucci
Residential Services
UCP of Pittsburgh
4 Smithfield Street
Pittsburgh, Pennsylvania 15222

Gerben DeJong
Tufts-Rehabilitation Institute
185 Harrison Ave.
Boston, Massachusetts 02111

Fred Fay, Ph.D.
RT 7, Tufts
New England Medical Center
185 Harrison Ave.
Boston, Massachusetts 02111

John Fenoglio
Assistant Commissioner General
Programs
Texas Rehabilitation Commission
118 E. Riverside Dr.
Austin, Texas 78704

Pat Figueroa
Center for Independence
432 Park Ave. South
Room 1202
New York, New York 10016

Charles Frank
Creative Living
1707 Roxbury Road
Columbus, Ohio 43212

Joni Fritz
National Association of Private
Residential Facilities for the
Mentally Retarded
6269 Leesburg Pike, Suite B-J
Falls Church, Virginia 22044

Don Galvin, Ph.D.
Rehabilitation Counseling Program
Michigan State University
Lansing, Michigan

Gail Gibran
Office of Independent Living
Room 9108
Department of HUD
Washington, D.C. 20410

Helen Goodkin
Rehabilitation Institute of Chicago
345 E. Superior Street
Chicago, Illinois 60611

Judy Heumann
Center for Independent Living
2539 Telegraph Ave.
Berkeley, California 94704

Raymond Hill
Independent Living Program
261 Mark Ave.
Detroit, Michigan 48201

Tom Hill
Goodwill Industries
5200 Jensen Drive
Houston, Texas 77026

Terry Hirsch
Independent Living Rehabilitation
Program
Criss Cole Rehabilitation Center
4800 North Lamar
Austin, Texas 78756

Joe La Rocca
The Urban Institute
2100 M Street, NW
Washington, D.C. 20037

Gini Laurie
Rehabilitation Gazette
4502 Maryland Ave.
St. Louis, Missouri 63108

Peter Leech
Community Resources for Independence
899 Second Street
Santa Rosa, California 95404

Herbert Leibowitz
Office of Rehabilitation Services
Dept. of HEW
50 Fulton Street
San Francisco, California

Joan Leon
Department of Rehabilitation
830 K Street Mall
Room 322
Sacramento, California 95814

Douglas Martin
Westside Community for Independent
Living
11687 National Blvd.
Los Angeles, California 90064

Euline McCorkle
Ann Arbor Center for Independent
Living 2462 East Stadium Blvd.
Ann Arbor, Michigan 48104

Bob McHugh
National Paraplegia Foundation
369 Elliot Street
Newton Upper Falls, Mass. 02164

Mary O'Hara
Handicap Housing Service, Inc.
230 Metro Square Bldg.
7th and Robert Streets
St. Paul, Minnesota 55101

Nick Pagano
Bronx Developmental Services
3036 East Tremont
Bronx, New York 10461

Owen Pollard
Bureau of Rehabilitation
32 Winthrop
Augusta, Maine 04330

Don Riel
Worcester Area Transitional Housing
507 Main Street
Worcester, Massachusetts 01608

Ed Roberts
Department of Rehabilitation
830 K Street Mall
Room 322
Sacramento, California 95814

Ralph Rouse
Office of Rehabilitation Services
Dept. of HEW
1200 Main Tower
Dallas, Texas 77202

Vickie Ruttko
Department of Human Resources
Project CLASP
Unit 26
1300 East 40th Street
Houston, Texas 77022

Len Sawisch
Center for Handicapped Affairs
1026 Michigan 48912
Lansing, Michigan 48912

Rodney Shaw
Independent Lifestyles
1917 Augusta Drive
Houston, Texas

Mike Smith
CP Research Foundation of Kansas
4320 E. Kellogg
Wichita, Kansas 67218

Terry Smith
Texas Rehabilitation Commission
1964 West Gray
Houston, Texas 77019

Sue Suter
Department of Vocational Rehabilitation
623 East Adams Street
Springfield, Illinois 62706

Max Starkloff
Paraquad
14 N. Newstead
St. Louis, Missouri 63108

Susan Stoddard
Berkeley Planning Associates
2320 Channing Way
Berkeley, California 94704

Leon Thornton
Center for Continuing Education
in Rehabilitation
University of Arkansas
Hot Springs Rehabilitation Center
Hot Springs, Arkansas 71901

Dave Williamson
Office of Independent Living
Room 9108
Department of HUD
Washington, D.C. 20410

Mike Clowers, Ph.D.
University of Washington
Department of Rehabilitation Medicine
Seattle, Washington 98195

Bruce Curtiss
Center for Living Independently
in Pasadena
453 East Green Street
Pasadena, California 91101

John Sullivan
Southwest Center for the Hearing
Impaired
San Antonio, Texas

Ted Thayer
Texas Rehabilitation Commission
118 E. Riverside Dr.
Austin, Texas 78704

PROJECT STAFF

Independent Living Research Utilization Project
Texas Institute for Rehabilitation and Research
1333 Moursund Avenue
Houston, Texas 77030

Jean Cole, Ph.D.
Co-principal Investigator

Lex Frieden
Co-principal Investigator

David Bailey
Project Coordinator

Laura Gerken
Administrative Assistant

PROGRAMS PROVIDING INDEPENDENT LIVING SERVICES
FOR SEVERELY DISABLED INDIVIDUALS
September, 1978

The following programs provide services which are designed to facilitate independent living by severely disabled persons. Some of these programs may be characterized as multipurpose independent living centers while others provide only a few services necessary to support independent living.

This listing is based on survey research done by the Independent Living Research Utilization Project at TIRR in Houston, Texas, and on updated versions of earlier lists compiled by the Clearinghouse on the Handicapped at HEW and the Office of Independent Living for the Disabled at HUD.

This listing is neither exhaustive nor entirely accurate. New independent living programs are started frequently, existing programs occasionally relocate or change administrators, and some programs are discontinued. New and updated information for this listing may be reported to the

Independent Living Research Utilization Project
Texas Institute for Rehabilitation and Research
1333 Moursund Avenue
Houston, Texas 77030

An asterisk (*) by any program on the list indicates that the program responded to the ILRUP survey. A double asterisk (**) indicates that the program meets the criteria for the comprehensive definition of an Independent Living Program or Independent Living Center as specified by the ILRUP. The definitions of these terms are available upon request from the ILRUP.

Work on this project was supported in part by Grant No. RSA-RD-22-P-59106/6-01 from the Rehabilitation Services Administration, DHEW.

Alabama

Homebound Program for the Severely Handicapped*
2129 E. South Blvd.
Montgomery, Alabama 36111
Contact: N. Elane Wilcox, Ph.D.

Alaska

none

Arizona

Tuscon Center for Independent Living
P. O. Box 26594
Tuscon, Arizona 85726
Contact: Cecilia V. Oakes

Community Outreach Program for the Deaf*
3200 N. Los Altos
Tuscon, Arizona 85705
Contact: Marguerite Harmon

Casa Grande Rehabilitation Center*
208 West Main Street
Casa Grande, Arizona 85222

Arkansas

Our Way Inc.
P.O. Box 2580
Little Rock, Arkansas 72203

Hot Springs Rehabilitation Center*
P.O. Box 1358
Hot Springs, Arkansas 71901
Contact: Peter Wiseman

California

Center for Independence for the Disabled
8100 Garden Grove Blvd.
Garden Grove, California 92644
Contact: Dale Mackintosh

Center for Independent Living
2539 Telegraph Road
Berkeley, California 94704
Contact: Phil Draper

California Association of the
Physically Handicapped, Inc.*
2031 Kern
Fresno, California 93721
Contact: Douglas Broten

Self Dependence for the
Handicapped Resource Center
24800 Mission Blvd.
Hayward, California

Community Service Center
for the Disabled, Inc.**
4607 Park Blvd.
San Diego, California 92116
Contact: William Tainter

Disabled Resources Center, Inc.
1962 Pine Avenue
Long Beach, California 90806
Contact: Jerry Stein

Good Shepherd Center for Independent Living
4323 South Leinert Blvd.
Los Angeles, California 90003
Contact: Vivian Purnell

Westside Community for Independent
Living, Inc.**
11687 National Blvd.
Los Angeles, California 90064
Contact: Douglas Martin

Center for Living Independently
in Pasadena
453 East Green Street
Pasadena, California 91101
Contact: Bruce Curtiss

Mr. Diablo Rehabilitation Center
Independent Living Project**
490 Golf Club Road
Pleasant Hill, California 94523
Contact: Annis Arthur

Resources for Independent Living
7767 La Rivera Drive, #61
Sacramento, California 95826
Contact: Steve Hoffmann

San Francisco Independent
Living Program*
814 Mission Street
San Francisco, California 94103
Contact: Ray Uzeta

Adult Independence Development Center*
6350 Rainbow Drive
San Jose, California- 95129

Community Resources for Independence
899 Second Street
Santa Rosa, California 95404
Contact: Peter Leech

Center for Independent Living
14550 Archwood Street-
Van Nuys, California 91405
Contact: Norma Vescovo

Otherwise Abled Project
522 North Salsipuedes St.
Santa Barbara, California 93103
Contact: Annette Rubins

Colorado

Atlantis Community, Inc.
2965 West 11 Avenue
Denver, Colorado 80204
Contact: Cecil Gamble

Connecticut

New Horizons
2150 Corbin Ave.
New Britain, Connecticut 06050

Jewish Community Council
Housing Corporation
Tower One
New Haven, Connecticut

Southern Connecticut Quadriplegia, Inc.*
P.O. Box 441
Southport, Connecticut 06490

Delaware

Independent Living, Inc.*
4 Golden Acre
Wilmington, Delaware 19809
Contact: Ann Ressler

District of Columbia

none

Florida

Park Villa Assoc. for Retarded Citizens
3100 75th Street North
St. Petersburg, Florida 33710
Contact: Bert Mueller

Palm Beach Habilitation Center
P.O. Box 631
Lakeworth, Florida 33460
Contact: Bob Benedict

McDonald Rehabilitation Training Center
4304 Boy Scout Blvd.
Tampa, Florida 33607
Contact: Leonard H. Greco

Georgia

Easter Seal Rehabilitation Center*
3254 Northside Parkway, NW
Atlanta, Georgia 30327
Contact: Betty Nichols

Georgia Rehabilitation Center*
Roosevelt-Warm Springs Rehabilitation Center
Warm Springs, Georgia
Contact: Robert Long

Shepherd Spinal Center**
3200 Howell Mill Road, NW
Atlanta, Georgia 30327
Contact: Leslie Hodson

Hawaii, Idaho

none

Illinois

Winning Wheels, Inc.*
Box 121
Prophetstown, Illinois 61277

Indiana

The Center for Independent Living*
324 East New York Street
Indianapolis, Indiana 46204

Indiana Rehabilitation Center*
for the Blind*
506 West 30th Street
Indianapolis, Indiana
Contact: Sheron Cochran

Iowa

none

Kansas

Cerebral Palsy Research Foundation
4320 East Kellogg
Wichita, Kansas 67218
Contact: Joe Kelly

CP Research Foundation*
Urban Residential Center
1515 S. Bleckly
Wichita, Kansas
Contact: Michael Smith

Kansas Rehabilitation Center for the Blind*
2516 West Sixth Street
Topeka, Kansas 66606
Contact: Lowell Holland

Maine

Middle Street House
45 Middle Street
Augusta, Maine 04330
Contact: Karen Davis

Independent Living Center*
Husson College - Bell Dorm
One College Circle
Bangor, Maine 04401
Contact: Brenda Harvey

Shalom House*
90 High Street
Portland, Maine 04101
Contact: Joseph Brannigan

Maryland

Disabled Students' Services
University Counseling Center
University of Maryland
Shoemaker Blvd.
College Park, Maryland 20742
Contact: Michael Borg

Baltimore Citizen's Housing for the
Disabled, Inc.**
2301 Argonne Dr.
Baltimore, Maryland 20742
Contact: Jim Fitzpatrick

Massachusetts

Boston Center for Independent Living, Inc.**
50 New Edgerly Road
Boston, Mass. 02115
Contact: Robert Williams

Tufts Research and Training Center
Box 1014
171 Harrison Ave.
Boston, Mass. 02111
Contact: Fred Eay, Ph.D.

Stavros Foundation
691 South East Street
Amherst, Mass. 01002
Contact: Chris Palamis

Highland Heights*
Fall River Housing Authority
P.O. Box 989
Fall River, Mass. 02722

New England Spinal Cord Injury
369 Elliott Street
Newton Upper Falls, Mass. 02164
Contact: Bruce Marquis

Worcester Area Transitional Housing**
507 Main Street
Worcester, Mass. 01608
Contact: Executive Director

Southeastern Massachusetts Independent Living
Program* (planned)
Lakeville Hospital
Lakeville, Mass. 02346
Contact: Anne Chace

Northeastern Massachusetts Independent Living
Program (planned)
c/o New England Spinal Cord Injury Foundation
369 Elliott Street
Newton Upper Falls, Mass.
Contact: Susan Halloran

Michigan

Ann Arbor Center for Independent Living**
2462 East Stadium Blvd.
Ann Arbor, Michigan 48104
Contact: Euline McCorkle

Rehabilitation Institute Center for Independent Living**
261 Mack Ave.
Detroit, Michigan 48201
Contact: Dave Harding

Center for Handicapper Affairs
1026 East Michigan
Lansing, Michigan 48912
Contact: Len Sawisch

Michigan Rehabilitation Center for
the Blind*
1541 Oakland Dr.
Kalamazoo, Michigan 49008
Contact: Paul Glatz

Minnesota

St. Anthony Rehabilitation Inn
Minneapolis, Minnesota

Physically Handicapped Office
State Dept. of Public Welfare
St. Paul, Minnesota

Project Independence
Independence for Impaired Individuals
1528 Inglehart
St. Paul, Minnesota 55104

Handicapped Housing Service, Inc.
230 Metro Square Bldg.
7th and Robert Streets
St. Paul, Minnesota 55101
Contact: Mary O'Hara

Mississippi

none

Missouri

UCP Association of Greater St. Louis*
8645 Old Bonhomme Rd.
St. Louis, Missouri 63132

Missouri State Bureau for the Blind*
916 East Capitol Ave.
Jefferson, Missouri 65101

Montana, Nebraska, Nevada

none

New Hampshire

Independent Living Program (planned)
c/o Division of Vocational Rehabilitation
105 Loudon Road, Bldg. 3
Concord, New Hampshire 03301
Contact: Peter Myette

New Jersey

Independent Living for Adults
P.O. Box 563
Hackensack, N.J. 07601
Contact: Jan Blehl

New Jersey Division of Vocational Rehabilitation
Services*
Independent Living Facilities Survey
54 Broad Street
Red Bank, New Jersey 07701
Contact: Katryne A. Cronin

New Mexico

none

New York

Institute of Rehabilitation Medicine*
New York State Office of Vocational
Rehabilitation
400 East 34th Street
New York, New York 10016

Center for Independence of the Disabled*
432 Park Avenue South
New York, New York
Contact: Pat Figueroa

Human Resources Center*
Albertson
Long Island, New York 11507

Handicapped Adults Association*
177 Dreiser Coop
Bronx, New York 10475

Independent Living for the Handicapped, Inc.**
The Reichard S. Weinberger Fund
9 Winthrop Street
Brooklyn, New York 11225

Institute of Rehabilitation Medicine*
400 East 34th Street
New York, New York 10016

UCP of New York State**
815 2nd Avenue
New York City, New York

North Carolina

Cara-More Community*
625 West Cammeron Ave.
Chapel Hill, N.C. 27514
Contact: Serge Adihoff

Bell House*
c/o Mrs. G. Edward Bell
Rt. 1, Box 335
Pleasant Garden, N.C. 27313

North Dakota

New Horizons Manor**
2525 North Broadway
Fargo, ND 58102

Fraser Hall*
711 S. University Dr.
Fargo, N.D.
Contact: Douglas Seiler

Ohio

Creative Living*
445 West 8th Avenue
Columbus, Ohio 43210

Help for Retarded Children*
13032 Euclid Ave.
East Cleveland, OH

Vistula Manor
Toledo Metropolitan
Housing Authority
Toledo, Ohio

Residential Care Independent Living Program**
2144 Agler Road
Columbus, Ohio
Contact: Sharon Cowen

Oklahoma, Oregon

none

Pennsylvania

Goodwill Industries of
North-Central Pennsylvania
DuBois, Pennsylvania 15801

Erie Independence House**
956 West 2nd Street
Erie, Pennsylvania 16507
Contact: Bob Kerner

Inglis House
Esther M. Klein Apartments
200 Belmont Ave.
Philadelphia, Penn. 19131

UCP of Pittsburgh**
4 Smithfield Street
Pittsburgh, Penn. 15222
Contact: Doug Williams

Rhode Island

Independent Living Program (planned)
c/o Division of Vocational Rehabilitation
40 Fountain Street
Providence, Rhode Island 02903
Contact: Jill Sharpe

South Carolina

none

South Dakota

Harmony Homes, Inc.**
P.O. Box 882
Aberdeen, South Dakota 57401
Contact: Terry Johnson

Tennessee

Home II, Inc.*
1514 Demonbrun St...
Nashville, Tenn. 37203
Contact: Mr. Brewer

Texas

Coalition for Barrier Free Living
P.O. Box 20803
Houston, Texas 77025

Independent Lifestyles*
Banyan Condominiums
1917 Augusta Drive
Houston, Texas 77057
Contact: Rodney Shaw

Goodwill Industries of Houston*
Independence Hall
6 Burress Street
Houston, Texas 77022

CLASP*
Willowood Apartments
5151 South Willow Drive
Houston, Texas 77035
Contact: Irene Sarver

San Antonio Blind Project*
Cypress Tower
Suite 711
10002 North Main Ave.
San Antonio, Texas 78212
Contact: Chris Opdahl

New Options Transitional Living Project**
Texas Institute for Rehabilitation and Research
1333 Moursund Ave.
Houston, Texas 77030
Contact: Jean Cole, Ph.D.
Lex Frieden

UCP Assoc. of Alamo Area**
2336 Jackson Keller
San Antonio, Texas 78230
Contact: Robert Mazer

Independent Living Project*
DeVille Apartments
4039 Bellefontain
Houston, Texas

Independent Living Program*
Criss Cole Rehabilitation Center
4800 N. Lamar
Austin, Texas 78756

Handicap Services**
UT Arlington
201 Davis Hall
Box 19088
Arlington, Texas 76019

Utah

Community Services Council*
Salt Lake City Center for Independent Living
1864 South State Street
Salt Lake City, Utah 84115
Contact: Lowell Bennion

Utah State Vocational Rehabilitation Agency*
250 East 500 South St.
Salt Lake City, Utah 84111
Contact: Jack Landro

Vermont

DeGreousbriand Unit
Medical Center Hospital of Vermont
Burlington, Vermont
Contact: John Nelson

Independent Living Program (planned)
c/o Division of Rehabilitation
81 River St.
Montpelier, Vermont 05602
Contact: Philip Grzewinski

Virginia

The Virginia House*
1101 Hampton Street
Richmond Virginia 23220

Washington

University of Washington
Department of Rehabilitation Medicine
Seattle, Washington 98195
Contact: Michael Clowers, Ph.D.

Wisconsin

Christian League for the Handicapped*
Box 98
Walworth, Wisconsin 53184
Contact: Clark Dempsey

Ontario, Canada

Clarendon Foundation*
Cheshire Homes
21A Vaughn Road
Toronto, Ontario
M6G 2N2
Contact: Mrs. J. Rodger