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NEW LIFE OPTIONS

Independent Living and You

Inside:
Opportunities

Preface

Edward V. Roberts
Director, California State
Department of Rehabilitation
and Co-Founder of the Center
for Independent Living,
Berkeley, California



What an opportunity we have! Independent living was once a dream, and now it is becoming a reality. A better future for hundreds of thousands of people with disabilities is within our grasp. Independent living programs can provide opportunities, services and advocacy that we need in order to take charge of our own lives and build a better future for many.

The future depends on our ability to work together, to build self-help programs, to influence our social services system and to insure that each person with a disability has the opportunity to become a more independent and productive member of society.

Our greatest handicaps are outdated social attitudes, lack of opportunities and physically inaccessible environments. Together we can change all that and can create the new future. I urge you to take the challenge, to use the resources in this book to build an independent living program in your community.

Prepared By

The Institute for Information Studies
400 N. Washington Street
Suite 202
Falls Church, Virginia 22046

In Cooperation With
ILRU

Independent Living Research Utilization Project,
TIRR
1333 Moursund
Houston, Texas 77030

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Today People With The Most Severe Disabilities Can Live Independently

It used to be commonly assumed that people with severe disabilities could not lead "normal lives" as active, self-reliant members of their communities. This is simply not true; today, even people with the most severe disabilities are building lives of responsibility, value and joy. They are gaining jobs in private industry and the public sector; they are maintaining their own homes and raising families; and they are becoming actively involved in the development of community services that help themselves and others achieve greater independence.

This booklet is about options—new life options that are now available to people with severe disabilities. The new opportunities this booklet describes are the result of the passage of the Rehabilitation Act Amendments of 1978, and of the efforts of disabled people themselves and others who shared their concerns.

New Life Options provides information about special organizations—called independent living programs—where severely disabled people can get the services and goods that make independent living possible. Also outlined are some sources of technical assistance and financial support available to organizations interested in establishing independent living programs in their communities.

Quest For Independence

People with severe disabilities began organizing as early as 1959 in the quest for services they needed to live self-reliant lives. At the same time, rehabilitation professionals were becoming increasingly aware of helpful services that needed to be provided even to people who did not seem to have vocational potential.

Something had to be done.

People with disabilities began to develop self-help collectives for the purpose of providing and coordinating community services. As they gained experience, and also the assistance of rehabilitation professionals and others, the self-help organizations grew. It became apparent that the key to success in these programs was fostering self-reliance, with disabled consumers taking responsibility not just for their own lives, but for the operation of the service programs themselves.

These efforts were the beginning of what is now called the independent living movement. This movement encourages the growth of community-based service organizations—

independent living programs—which offer service or referral for service in many areas: housing, attendant care, readers, interpreters, and information about goods and services relevant to independent living for severely disabled people. Some of the programs are residential, others are not; some are intended to provide transitional living experiences for the disabled people who come to them, others are permanent hubs providing on-going services to disabled people. An example of each type of program is given here, along with other information those concerned with independent living services may find of value.

The Programs

Center for Independent Living, Inc.

2539 Telegraph Avenue
Berkeley, California
94704

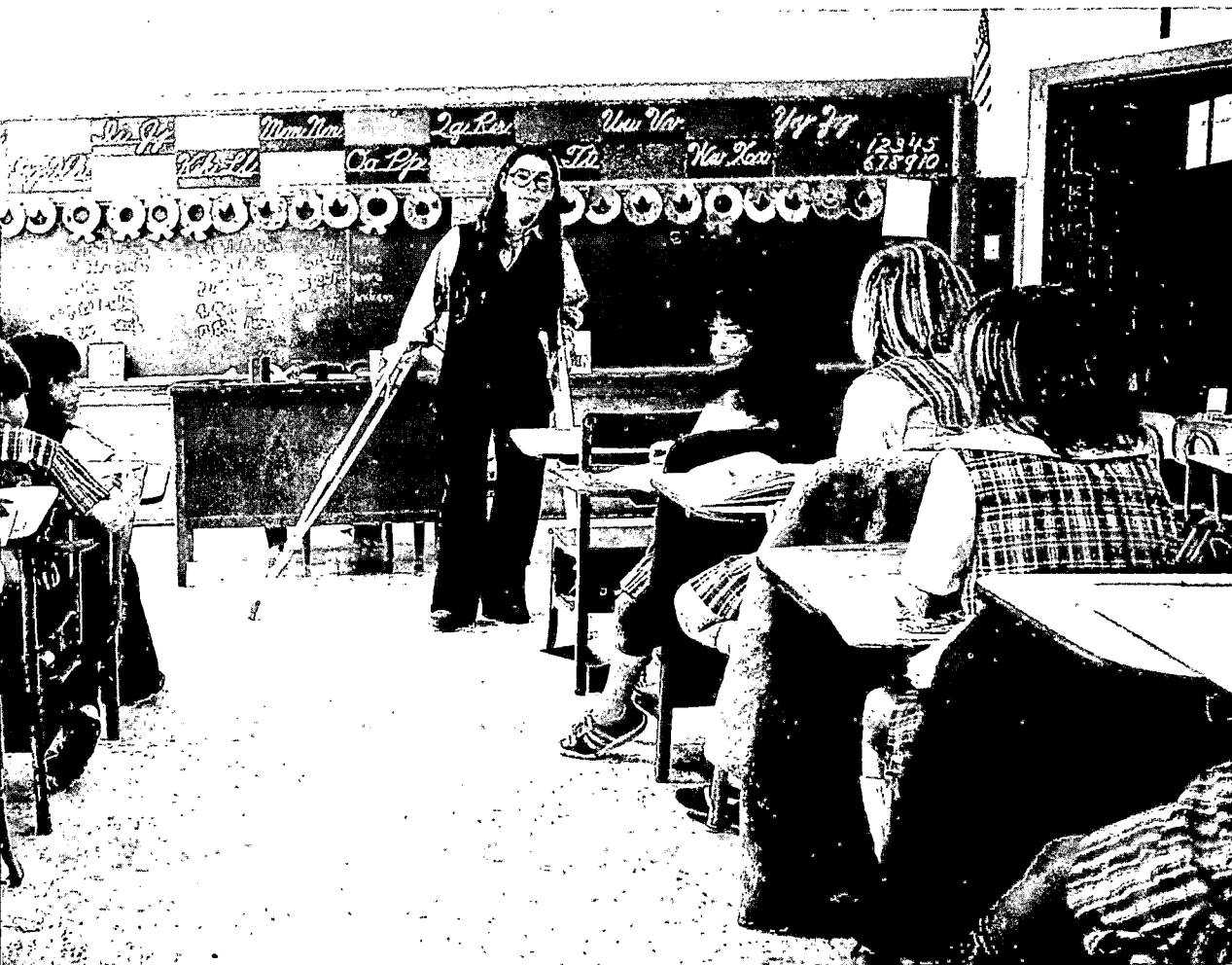
The Center for Independent Living (CIL) is a community-based center providing independent living services to more than 5,000 disabled residents throughout the San Francisco Bay Area. CIL is not a residential facility, but instead promotes the integration of disabled people throughout the community. The Center serves all disability groups—blind and deaf as well as mobility impaired individuals. Services available through the Center include:

- Help in obtaining information about social, medical and rehabilitation services available in the community-at-large.
- Financial and legal counseling to help make individuals aware of the funds available to them under Social Security Disability Insurance, Supplemental Security Income, Medicare/Medicaid, and other state and local programs.
- Peer counseling and guidance to determine which services meet the unique needs and aspirations of each individual consumer.
- Assistance in locating accessible housing or modifying existing units.
- Wheelchair repair and maintenance.
- Mobility training and reader referral services for blind persons.
- Interpreters for deaf and hearing-impaired individuals.
- Job development and placement services (including training programs in computer programming, paralegal services and a university program coordinated with Antioch College/West).

The Center was organized and is operated by disabled individuals. More than half of the 140 employees are disabled. All major administrative officers and a majority of board seats are held by people with severe disabilities.

As a private, non-profit organization, CIL is supported by a variety of financial sources, including grants and contracts from federal, state, and local governments. Other funding comes from fees for services, donations and gifts.





An example of an INDEPENDENT LIVING CENTER, CIL is a community-based, non-profit, nonresidential program controlled by disabled consumers and providing services directly or through referral. The services include housing assistance, attendant care, readers, and/or interpreters, peer counseling, financial and legal advocacy and community awareness and barrier removal programs.



Creative Living, Inc.
445 West 8th Avenue
Columbus, Ohio
43201

Creative Living is a residential program providing single and family living free of architectural barriers and with 24 hour, on-call, attendant care services to paraplegic and quadriplegic individuals.

The program is housed in an 18-unit apartment complex located five minutes from the Ohio State University campus. The building was designed specifically to meet the needs of severely physically disabled tenants. All doors operate by pressure-sensitive switches. Halls and doorways are extra-wide and the location of phones, electrical outlets and other such accessories are adapted to the needs of wheelchair users. There are no stairs or curbs in or around the building. All sinks, cabinets, closets, and clothes racks are accessible to residents.

Twenty-four hour, on call, attendant care services are provided by trained university students. Four attendants reside in the apartment complex, and a pool of 20 additional attendants is available for "one-to-one" service, as required.

Creative Living is a non-profit corporation organized by church, medical and community leaders. Financing for the apartment complex was obtained through the *FHA* 236 loan program. The corporation has established an endowment fund to insure continued financial stability for the project.





As an example of an
**INDEPENDENT LIVING
RESIDENTIAL PROGRAM,**
Creative Living provides live-in
arrangements, shared
attendant services, and
transportation directly and
through referral. Other services
like health care maintenance
are also provided.

**New Options
Transitional
Living Project**
105 Drew Street
Houston, Texas
77006

New Options is a transitional living program sponsored by The Institute for Rehabilitation and Research (TIIR) in Houston, Texas. TIIR began this hospital-affiliated training program in 1976 with support from a DHEW grant.

Program participants reside in dormitory-style housing for six weeks. Each participant is provided a private room, semi-private bath, and recreation space in addition to all meals, transportation and attendant services.

The participants undergo intensive training designed to show them options available in:

- Exploration of vocational and educational programs; range of employment opportunities available to persons with various disabilities
- Methods of locating, training, and working with personal care attendants
- Rearranging environmental elements to improve personal capabilities; self analysis of personal skills; assistive equipment needs
- Exploration of various modes of transportation, both public and private
- Financial assistance programs; money management
- Comparison of diverse living situations and support services
- Learning skills to enhance communication and assertiveness; self-concept vs. public image; personal feelings about common concerns
- Self-directed care; routine medical maintenance; emergency care plans; medical resources in the community
- Issues of public concern affecting handicapped persons
- Sexuality and disabilities; close personal relationships
- Utilization of time and energy; leisure activities

Participants learn how a residential system operates. They learn to schedule and utilize shared attendant services, arrange personal transportation, and effectively utilize time and resources. They are guided and encouraged to take on new responsibilities with the help of program staff.





An INDEPENDENT LIVING TRANSITIONAL PROGRAM, New Options is a short-term skills training program. The training has the goal of assisting disabled individuals to move from comparatively dependent living situations to comparatively independent living situations.



**Boston Center for
Independent Living**
50 New Edgerly Road
Boston, Massachusetts
02115

Established in 1974, the Boston Center for Independent Living (BCIL) is a multifaceted program. It manages and coordinates the operation of three independent living situations serving quadriplegic individuals in the greater Boston area.

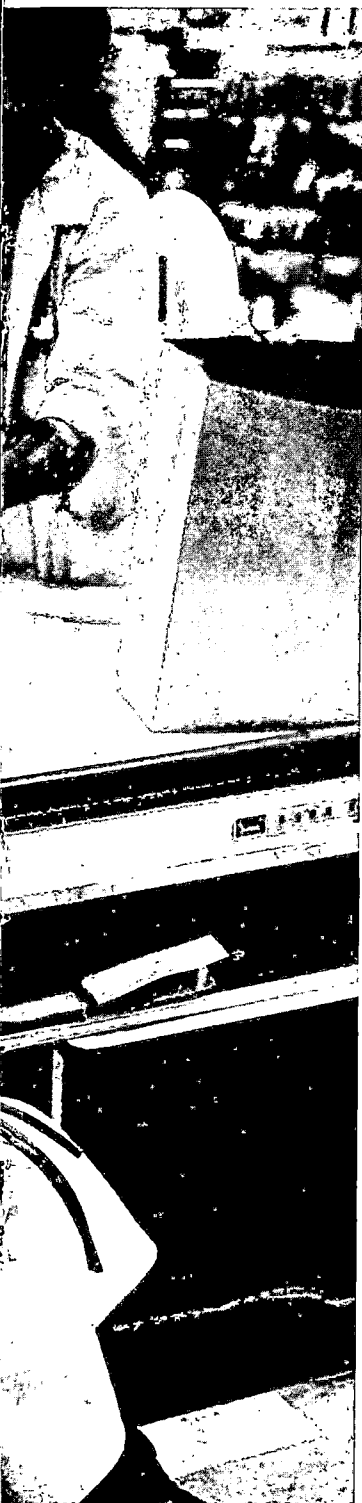
BCIL's *transitional living program* provides training in survival skills for independent community living. Program participants are newly disabled individuals, or those individuals who desire to live outside of nursing homes or institutions. The training program teaches participants to hire, train, and manage their own attendants; manage personal finances and health care maintenance costs; and provide for individual transportation needs. The training program lasts from six to nine months.

The second type of program which the Center operates is a *residential project* located in East Boston. The Center leases six apartment units in a subsidized housing complex. Transportation and shared attendant care services are provided by BCIL. This environment provides residents with the opportunity for community living while still allowing them the financial advantage of shared attendant care services.

BCIL also operates as an *independent living center* providing information and referral services for disabled individuals seeking to secure modified housing and individual personal attendants. The Center maintains a register of accessible housing and trained personal care attendants. Disabled people using this service live in their own apartments and homes throughout the Boston area.

BCIL is a nonprofit corporation. Financing is obtained through grants and contracts with state agencies and the federal government to develop training programs and demonstrate innovative living arrangements. The Center also acts as a conduit for the distribution of Medicare/Medicaid allotments for attendant care.





BCIL operates three service components, a TRANSITIONAL PROGRAM, a RESIDENTIAL PROJECT and an INDEPENDENT LIVING CENTER.



Independent Living Service Providers

Hospitals and rehabilitation facilities may be another source of independent living services. For example, out-patient care received at a rehabilitation facility can help an individual enhance or maintain an independent lifestyle. In this case, the hospital or rehabilitation facility is considered an *independent living service provider*. An independent living

service provider offers several discrete services, but does not provide or coordinate through referral a full set of such services.

The Services

If you are a disabled person, the Rehabilitation Act Amendments of 1978 (PL95-602) may aid you in obtaining services that you need to live more independently. A newly enacted Title VII makes it possible for states to provide "comprehensive services for independent living." These services can enhance your ability to live independently. Eligibility for independent living services under Title VII is not restricted by vocational potential or employment status. Some of the services that are allowable under Title VII include:

- Housing Arrangements and Modifications
- Transportation
- Attendant Care
- Physical Rehabilitation
- Therapeutic Treatment
- Prostheses, Appliances, and Devices
- Development of Language and Communication Skills
- Preventive Services
- Recreational Services
- Job Placement Services
- Child Development Services
- Services to Preschool Children (Including Physical Therapy)

Ask your state vocational rehabilitation agency office to find out whether or not your state participates in the "comprehensive services for independent living" program.

If your state does participate, the state must submit a plan to the Commissioner of the Rehabilitation Services Administration (RSA) in DHEW. The plan must describe the quality, scope, and extent of services to be provided under the program in your state. It must also designate the state office responsible for administering funds. This law requires that the state plan be developed with the substantial involvement of persons with disabilities. *As a handicapped individual, the Law insures your right to play a substantial role in developing your state's plan.*

DHEW regulations implementing Title VII will appear in the *Federal Register* during 1979. These regulations will spell out in greater detail the requirements for state provision of comprehensive services for independent living. For more information about Title VII programs or to obtain copies of the DHEW regulations implementing Title VII, ask your state vocational rehabilitation agency office or write Special Assistant, Independent Living Project, Office of Program Development, Rehabilitation Services Administration, Mary Switzer Building, Washington, D.C. 20201.

You Can Do It Too

Title VII can also help if you want to establish an independent living program in your community. It authorizes states to administer grant programs to assist local public and private nonprofit organizations in establishing and operating independent living programs. Individuals are not eligible for grants.

Title VII requires that any organization applying for grant monies to establish independent living programs must demonstrate that handicapped individuals will be substantially involved in the policy direction, management and operation of the proposed program.

If you feel your state is not following Title VII regulations on providing services or substantial disabled consumer involvement in developing the State Plan for services you may contact the National Center for Law and Handicapped, 1235-North Eddy Street, South Bend, Indiana 45517 for possible referrals.

It is possible that your organization may receive grant monies to establish independent living programs by applying directly to the Commissioner of RSA.

If your state does not participate in the independent living program of Title VII, consult the regulations published in the Federal Register for the correct procedure.

Other programs authorized by the Rehabilitation Act Amendments which may prove helpful include the Community Services Employment Opportunities Program, Projects With Industry, and Business Opportunities for Handicapped Individuals. These programs are authorized under Title VI of the Rehabilitation Act. Most of these programs are administered through your state vocational rehabilitation agency office. Ask your state office about programs authorized under Titles VI and VII of the Rehabilitation Act of 1973 or write to the Rehabilitation Services Administration, Department of Health, Education, and Welfare, Washington, D.C. 20201.

Who Else Can Help You

Other federal programs may assist you by providing start-up financing for independent living programs. Some can help you plan and organize your program and advise you on management and legal aspects of setting up a nonprofit organization. An important free book you will want is *Federal Assistance for Programs Serving the Handicapped*; to get a copy, write:

Department of Health, Education and Welfare
O.H.D.S.

Office for Handicapped Individuals
Washington, D.C. 20201

Ask for Department of Health, Education and Welfare
Publication No. (O.H.D.S.) 78-22001.

Other sources of information on specific programs which may assist you include:

Office of Independent Living
Department of Housing and Urban Development
Washington, D.C. 20410
(202) 755-7366

Independent living programs which provide assistance to disabled individuals seeking low cost accessible housing may be eligible to receive financial assistance from HUD in the form of grants, loans, or mortgage assistance. *HUD Programs That Can Help the Handicapped* is a brochure which provides information about HUD programs and eligibility requirements; it is available by writing to the above address.

Health Care Financing Administration
Department of Health, Education and Welfare
Washington, D.C. 20201
(202) 245-0128

Administers Medicare/Medicaid programs which can provide financial assistance to disabled individuals in need of personal attendant care and/or home health maintenance services. Funds may be funneled through independent living programs which provide attendant referral and training services.

Cooperative Bank Work Group
ACTION
806 Conn. Avenue, N.W., Room M507B
Washington, D.C. 20525
(202) 254-3513

Independent living programs operating as consumer cooperatives may be eligible to apply for loans from the newly established National Consumer Cooperative Bank. The Bank also provides technical assistance to cooperatives to help them organize, plan and finance their operations.

National Congress for Economic
Community Development
1828 L Street, N.W., Suite 401
Washington, D.C. 20036
(202) 659-8411

Provides information on economic community development grants and community action programs administered under the Community Services Act of 1975. Grants are awarded to community-based organizations for projects which promote the social, economic and/or physical rehabilitation of communities. Organizations receiving grants must be private nonprofit corporations working in the interest of low-income individuals, including disabled people.

Office of Comprehensive Employment
Department of Labor
Washington, D.C. 20213
(202) 376-6366

Independent living programs providing job training and placement services designed to promote employment of handicapped individuals in competitive (nonsubsidized) employment are eligible to apply for grants under the Comprehensive Employment and Training Act (CETA) programs.

Office of Minority Business Enterprise (OMBE)
Department of Commerce
Washington, D.C. 20230
(202) 377-3024

OMBE can assist independent living programs operating on a for-profit basis by providing business information, counseling, and financial packaging assistance.

Technical assistance services are provided locally by OMBE funded Business Development Centers in communities throughout each of six (6) regions. For more information about local OMBE programs, contact your nearest regional office in Atlanta, Chicago, Dallas, New York, San Francisco, or Washington, D.C.

Office of Financing
U.S. Small Business Administration
Washington, D.C. 20416
(202) 653-6977

SBA can provide start-up financing and technical assistance to organizations establishing independent living programs through the 7(h) and 8(a) loan programs. Under Section 7(h) of the Small Business Act, SBA makes loans to handicapped individuals or nonprofit organizations employing handicapped individuals. To be eligible for assistance under the 8(a) program, an organization must operate on a for-profit basis and be owned and controlled by one or more persons who have been deprived of opportunity to develop and maintain a competitive position in the economy because of social or economic disadvantages.

A further source of revenue is private foundation grants. For information on private grant-making organizations and their activities, consult the *Foundation Directory* published by the Columbia University Press or write to the **Foundation Center**, 888 Seventh Ave., New York, N.Y. 10019.

You may want technical assistance in putting together a qualified organization. You can contact the

programs given as examples in this pamphlet for assistance or contact the *Independent Living Research Utilization (ILRU) Project* at the Institute for Rehabilitation and Research (TIIR), 1333 Moursund, Houston, Texas 77030, Phone (713) 797-1440, for information about other programs.

The Bottom Line

Passage of Title VII of the Rehabilitation Act opens the door to new opportunities in independent living for disabled citizens in this country. Keeping the door open will require vigilance on the part of disabled people.

The community programs described in this booklet can help you to plan, organize and finance a local independent living program. But the bottom line is the word "local".

Each locality is different, so your initial planning should include an assessment of community resources. Find out how your local government operates and learn to use it to your best advantage. Know who's important in your community, who can help you, and how. And, finally, you must be able to communicate your needs to community leaders. You must be able to tell them what you want to do, how you plan to do it, and how it will benefit the community-at-large.

Effective community advocacy will make people aware of your needs and start changing the attitudes and environment in your community.

Organizing and operating an independent living program has been achieved by other people with severe disabilities. It was accomplished through hard work and struggle. Most importantly, success came from disabled people demanding their rights to full independence and dignity.

Afterword

Lex Frieden
Director, Independent Living
Research Utilization Project,
Houston, Texas



The efficacy of the independent living concept is being proven each day by more and more severely disabled individuals as they choose to assume the responsibilities of directing their own lives and as they become active participants in the mainstream of life in their communities. This movement toward independent living by severely disabled people is being aided by the development of a variety of new consumer-directed service delivery programs called independent living programs. Although there are many disincentives to independent living at the present time, and although government funding for independent living programs is less than adequate, the movement will continue to grow as severely disabled people realize the benefits of freedom from institutions, from restrictive statutes and rules, and from pejorative attitudes. As the movement gains momentum, the general public will become more aware of the abilities of disabled people and more supportive of the programs and changes needed to maximize those abilities. Independent living is a challenge for us all. For severely disabled people who want to meet the challenge, it can be met.

"Photographs are courtesy of Medical Illustrations and Audio Visual Education, Baylor College of Medicine and New Options, The Institute for Rehabilitation and Research, Houston, Texas".

"The photographs are not intended to represent any single program but are meant to depict the wide range of activities characteristic of severely disabled people living independently".

Reader Response Form

WOULD YOU LIKE TO BE ON OUR MAILING LIST TO RECEIVE OUR PUBLICATIONS? If the answer is yes, please take a few minutes to answer the following questions and return this card to us.

1. I am a disabled individual or family of one.

☐ yes ☐ no

2. I am visually impaired.

☐ yes ☐ no

3. I work in:

- ☐ 01—state agency (general)
☐ 02—state agency (blind)
☐ 03—private facility/workshop
☐ 04—federal/regional office
☐ 05—legislative
☐ 06—professional organization
☐ 07—consumer organization
☐ 08—insurance company
☐ 09—medical organization
☐ 10—academic
☐ 99—other (describe) _____

4. I work as a:

- ☐ 01—counselor
☐ 02—placement specialist
☐ 03—educator/researcher
☐ 04—staff development specialist
☐ 05—administrator
☐ 06—information provider
☐ 07—medical, including nurses and physical therapist
☐ 99—other (describe) _____

Your response to the following questions will help us develop better publications in the future.

5. I found this publication to be (check all that apply):

- ☐ useful and informative
☐ informative but not practical
☐ irrelevant to my needs
☐ too short
☐ too long
☐ not clear

6. I found out about this publication through:

- ☐ automatic distribution
☐ notice in a newsletter or magazine
☐ a friend or colleague
☐ don't remember/not sure
☐ other _____

7. My interest in seeing publications on the following subjects are as follows:

Community Advocacy

Job Opportunities in Science and Technology

Small Business Enterprises for Handicapped Individuals

Understanding Your Rights as a VR Client

Sheltered Industrial Employment and the Minimum Wage

Other _____

High
Interest

Medium
Interest

Low
Interest

8. For future publications, I would like to suggest the following improvement in format, distribution or content:

9. I would attend a workshop on:

Media Relations

Independent Living Program Management

Community Advocacy

Lobbying and the Legislative Process

Highly
Likely

Maybe

No

Thanks For Your
Cooperation!

Place
Stamp
Here

Post Office
Will Not Deliver
Without Postage

Institute for Information Studies
400 N. Washington Street, Suite 202
Falls Church, Virginia
22046

Fold



The Institute for Information Studies, under a grant from the National Institute of Handicapped Research developed four documents on topics of priority concern to the rehabilitation community:

New Life Options: Independent Living and You
(Co-produced with ILRU Project of The Institute for Rehabilitation and Research (TIIR)).

This 16-page booklet explores the new options that are now available to disabled individuals seeking an independent lifestyle of their own making. It traces the history of the movement, describes selected independent living programs and their services and discusses the new opportunities for consumers provided by the 1978 Amendments to the Rehabilitation Act. The booklet includes a section on sources of technical assistance and financial support for independent living programs.

Making Friends and Influencing the Media

Consumer organizations and advocacy groups will be assisted by this manual on developing public relations programs. Unlike most PR manuals, this one focuses on how to influence the image of disabled people as they are portrayed in the mass media. The manual takes a practical "how-to-do-it" approach and provides examples of press releases, tip sheets and other tools of the trade. Included in the manual is a section on media regulations and how they can be used by consumer groups to access the media.

Rehabilitation Engineering Sourcebook

The first of an on-going series, it presents 150 case examples in which the application of technology has solved specific work-related or other functional problems of people with vision, hearing, or physical-motor disabilities. Designed as a reference work primarily for vocational rehabilitation counselors and work supervisors, it contains useful information for other rehabilitation professionals and rehabilitation engineers as well. Special features include: Guidelines for Formulating Problem Statements and Sources of Further Information for readers wishing to consult with contributors on technological solutions for their own clients' and subordinates' functional problems; and a loose-leaf format to which subsequently published materials can be added.

Work Disincentives

Written primarily for the policy maker and others with a vested interest in the issue, this document synthesizes the available research-based knowledge on disincentives to work. Policy options are offered and pros and cons are delineated. This document is prepared by Dr. Monroe Berkowitz, well-known authority on the subject.

The above documents are available while supplies last from the Institute for Information Studies. (Order form enclosed) Copies are also deposited in:

National Rehabilitation Information-Center
8th and Varnum Streets, NE
The Catholic University of America
Washington, DC 20064
(202) 635-5826

U.S. Department of Commerce
National Technical Information Service
5285 Port Royal Road
Springfield, VA 22161
(703) 557-4650

ERIC Document Reproduction Service
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Arlington, VA 22210
(703) 841-1212

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