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: Printed Materials
Subseries: Manuals

OA/ID Number: 52099
Folder ID Number: 52099-005

Folder Title:
"Independent Living: A Resource Manual" [1980] [2]

Stack: **Row:** **Section:** **Shelf:** **Position:**

DEVELOPMENT/IMPLEMENTATION OF INDEPENDENT LIVING PROGRAMS

OBJECTIVES

1. To present an analysis of model Independent Living programs.

2. To provide practical information in assisting those professionals who may develop or implement IL programs.

3. To identify housing alternatives and Federal programs which provide residential assistance to severely disabled individuals.

SUMMARY

(1) "The Environment as a Support System for Independent Living." Raymond Lifchez, Archives of Physical Medicine Rehabilitation, Vol. 60, October 1979. Reprint permission granted.

In extended interviews and visits with 150 physically disabled young adults living independently in Berkeley, California, the author studied the environment as they experienced it and evaluated its accomodation to their special needs. The environment in this study is considered in physical and psychosocial terms, that is, as a support system for the multifaceted needs of the whole person.

The framework for organizing the data was Mayer Spivak's construct of "archetypal place" in which he defines 13 fundamental places in terms of the behaviors they support: shelter, sleep, mate, groom, feed, excrete, store, territory, play, route, meet, compete, and work. For purposes of the present work, shelter and mate are discussed--shelter, because of the clarity of its relationship between existence and physical form, and mate because of its more abstract relevance to physical form.

(2) "Independent Living: Choosing From A Variety of Programs." Lex Frieden and Laurel Richards, Disabled USA, Vol. 2, No. 9, 1979. Reprint permission granted.

Discussed in this article are the three basic categories of Independent Living programs, each of which differs significantly from the others, both in breadth of services and in approach to service delivery.

Included is a presentation of specific characteristics by which each kind of program can be easily identified.

Drawing on data compiled by ILRU staff, the authors discuss the Center for Independent Living (CIL) in Berkeley, New Options in Houston, and Creative Living in Columbus, Ohio, as examples of independent living centers, transitional programs, and residential programs, respectively.

(3) "Independent Living: Houston Experience." Lex Frieden, American Rehabilitation, July-August 1979. Reprint permission granted.

For disabled individuals, Independent Living (IL) refers to living in their community, away from custodial institutions, and being responsible for their own affairs. The IL programs in Houston, Texas, identify closely with this philosophy, and the programs are implemented as community-based operations which offer a variety of services.

Cooperative Living, Independent Lifestyles, Free Lives, Creative Handicaps, and New Options are briefly described. Costs for services and funding sources for programs are identified.

Cited in the article, is evidence for program success. Out of the 80 participants in the New Options program, more than half are now attending school or have secured employment.

For IL programs to continue to be successful, housing, attendant care, and transportation services must be offered, and funding obtained for those services. Without these additional services, IL may well be "just a dream" for thousands of severely disabled persons who are capable of community living and/or employment.

(4) "Attendant Care as a Prototype Independent Living Service." Gerben De Jong, Archives of Physical Medicine Rehabilitation, Vol. 60, October 1979. Reprint permission granted.

Of all the services and programs associated with the movement for independent living, attendant care has particular symbolic significance for the movement's adherents. Because it is a self-directed service, attendant care can be contrasted with home health services which are directed by professionals and agencies. This article demonstrates how attendant care mirrors key independent living values and concepts, partially by evaluating the provisions of attendant care services under titles XIX and XX of the Social Security Act. An analysis is made of how selected states have used titles XIX and XX authority to make self-directed attendant care services available. Consideration is also given to how selected eligibility

criteria for titles XIX and XX create serious work disincentives that compromise the independent living goals implicit in self-directed attendant care services. Funding prospects and their effect are on the future of attendant care also are discussed.

(5) "A 'How To' Checklist." The BCIL Report, Regional Medical Rehabilitation Research and Training Center, No. 7, Boston, 1977. Reprint permission granted.

Dr. Frederick Fay, Tufts/New England Medical Center, Research and Training Director, presents a list of considerations for developing an Independent Living program. This checklist is derived from the BCIL experience, but offers information which may be adaptable to any situation.

Although this checklist pertains to initial program development, it may also be useful for those whose program has just newly begun. Decision-making on areas central to an IL program's success is emphasized, and may serve to encourage the maintenance of services already in action.

(6) "Integration Components, Training Components, Independent Living Rehabilitation Services." Elmer Bartels, Independent Living Rehabilitation Plan, Boston, 1979. Reprint permission granted.

Section II, III, and IV of this manual describe the organizational structure of the Massachusetts Rehabilitation Commission, and its intent to become more responsive to the needs of the disabled population in this state.

In compliance with the perceived intent of the legislation PL 95-602, these sections address the following areas:

-eligibility criteria

-funding mechanisms

-extended evaluation

-independent living goals

-follow-up services

-training methods

-descriptions of local IL centers and services

criteria for titles XIX and XX create serious work disincentives that compromise the independent living goals implicit in self-directed attendant care services. Funding prospects and their effect are on the future of attendant care also are discussed.

(5) "A 'How To' Checklist." The BCIL Report, Regional Medical Rehabilitation Research and Training Center, No. 7, Boston, 1977. Reprint permission granted.

Dr. Frederick Fay, Tufts/New England Medical Center, Research and Training Director, presents a list of considerations for developing an Independent Living program. This checklist is derived from the BCIL experience, but offers information which may be adaptable to any situation.

Although this checklist pertains to initial program development, it may also be useful for those whose program has just newly begun. Decision-making on areas central to an IL program's success is emphasized, and may serve to encourage the maintenance of services already in action.

(6) "Integration Components, Training Components, Independent Living Rehabilitation Services." Elmer Bartels, Independent Living Rehabilitation Plan, Boston, 1979. Reprint permission granted.

Section II, III, and IV of this manual describe the organizational structure of the Massachusetts Rehabilitation Commission, and its intent to become more responsive to the needs of the disabled population in this state.

In compliance with the perceived intent of the legislation PL 95-602, these sections address the following areas:

-eligibility criteria

-funding mechanisms

-extended evaluation

-independent living goals

-follow-up services

-training methods

-descriptions of local IL centers and services

This article provides practical information which details the account of an organization's efforts to develop cost-effective, high quality Independent Living services.

(7) "Introduction, Management, Summary." Fay et al., The BCIL Report. Regional Medical Rehabilitation Research and Training Center, No. 7, Tufts/ New England Medical Center. Boston, Massachusetts, 1977. Reprint permission granted.

In the years to come, the BCIL Report may well be regarded as a classic in Independent Living research. The report offers a definitive analysis of a center's first three years of operation. As a primary emphasis, it attempts to provide a guide and perspective to those who may wish to replicate its efforts.

For a nominal fee, the reader is referred to the "BCIL Report Appendix" for a lengthy examination of the various functions of the center. Important aspects of these functions include the following:

-center's by-laws

-articles of incorporation

-medical contracts

-rehabilitation commission contracts

-staff job descriptions

-goals and objectives

-program evaluation information and results

Selected selections from this report review the fiscal goals of the organization, management strategies, funding sources utilized, and staffing considerations. BCIL has succeeded in involving consumers in the day to day management of the organization. And it has provided a cost-effective alternative to long-term institutional care for the severely disabled.

(8) An Independent Living Program: Origins, Development, and Community Involvement. Unpublished paper, Melanie Tillmanns, February 1980.

Ms. Tillmanns provides an historical description of the Worcester Area Transitional Housing, Inc. (W.A.T.H.) program in Worcester, Massachusetts. Three facets of the program are analyzed for their philosophical and practical applications. These areas concern origins and development, priorities and methods for developing inter-agency relations

and community resources, and philosophical bases of the operation.

W.A.T.H. operates on the belief that Independent Living is a right and a responsibility of the community and its members as a whole, and not just from the support of one agency. With this in mind, the following areas have been highlighted in this paper:

- -funding sources available for staff, participants, and services
- -financial assistance for transitional and permanent housing
- -methods of cooperation with other community services and service agencies
- -assessment and training techniques used to identify potential employees to local employers

The W.A.T.H. program seeks to maintain and enhance the spectrum of IL services available to the participants, as their lifestyles, health, and/or community support systems change.

(9) Report, Vol. 5, No. 5, September/October 1979. Insert. Reprint permission granted.

This pamphlet deals with accessibility-related issues relevant for the disabled, and rehabilitation professionals who work with severely disabled individuals. Offered in this material is an overview of federal regulations, accessibility designs, and publications.

One outstanding feature concerns the description of "Barriers, the Access Game," an awareness tool which highlights the environmental difficulties that persons in wheelchairs encounter, such as narrow doorways and curbs without proper curb cuts. This game is available for use from Message Management Consultants in Indianapolis, Indiana.

(10) "Choosing An Independent Lifestyle: Housing Alternatives for Severely Handicapped Persons." Rehabilitation Brief, Vol. 1, No. 5, May 25, 1978. Insert.

Rehabilitation Brief taks a look at housing and how it is provided for at various colleges, residential centers, and Independent Living programs. It is advised that every community should offer opportunities for disabled persons to move from a nursing home into an IL situation.

Results of experiments in alternative housing projects are reviewed. Support was offered for the enhancement of vocational potential through Independent Living. Of the 40 residents in Houston's Cooperative Living Project, none had jobs before entering the project, but 20 members located full or part-time work after entering the project.

Another notable benefit was observed in the relative cost-effectiveness of housing programs. Monthly living costs were found to be significantly lower as compared with nursing home care or private residence with attendant care. It is recommended that community-based IL programs continue to be developed, and that various housing alternatives be offered to severely disabled individuals.

(11) HUD Programs That Can Be Used For The Disabled. Office of Independent Living for the Disabled, Washington, D.C., 1979. Insert.

The disabled, as a special user group, can benefit from many of HUD programs because these programs are targeted at low and moderate income people, of which the disabled make up a substantial component. It is well known that housing without supportive services is not sufficient to meet the needs of many disabled. Therefore, it becomes necessary to determine some mechanism(s) whereby an appropriate matching of housing and services may be assured.

All efforts must not be concentrated on one program such as Section 8 Rental Assistance. There are several programs listed which could, with some creative thinking, be utilized in the best interests of the disabled.

(12) "Developing Alternative Living Arrangements and The Residents Revisited." Chapter 8, Jean Cole and David Stock, Cooperative Living, Texas Institute for Rehabilitation and Research, Houston, Texas, 1977. Reprint permission granted.

The Cooperative Living Program was conducted as a three year Research and Demonstration Project which was funded by the Rehabilitation Services Administration and several other grants. The program provided for a residential facility for severely physically disabled, non-retarded, young adults. In Chapter 8, the authors outline strategies for developing and implementing housing alternatives for participants. The following factors are examined as they pertain to a housing situation:

-structure

-relationship to the larger community

-services

-management

-social system

-funding sources

Cooperative Living recognizes that the needs of the physically disabled individual varies greatly, depending upon such factors as degree of mobility, age, and traits of personality. A satisfactory housing situation for those persons must accomodate individual needs, so that he/she can function comfortably at his/her own level of independence and functioning.

(13) "A Small Group Independent Living Experiment for the Physically Handicapped," Don Rice, Human Factors, Vol. 20, No. 3, Baltimore, Maryland, June 1978. Reprint permission granted.

This article describes one attempt to provide low cost, wheelchair accessible housing, a project which shows promise for continuing economic and social success. The Independent Living residence, known as MiCasa SuCasa in San Diego, California, accomodates a variety of severe disabilities. Facility design, regulations, policies, and residential selection and considerations are outlined for the reader. Problem areas are defined, and alternatives and/or solutions are presented. It is stressed that for an individual to function successfully in the center, that he be knowledgeable about his disability, capable of directing daily activities, and motivated toward living as productive a life as possible.

(14) "Cooperative Living" Manual, Chapter 9. Jean Cole and David Stock.

The follow-up studies from the Cooperative Living program are summarized and analyzed in Chapter 9. Out of the 36 individuals reported in the study, 17 are now engaged in full or part-time employment. Of the 19 persons not presently employed, 13 are attending college or are involved in vocational training. Two individuals are receiving medical attention, and 4 persons are in the process of revising their goals.

Assistance from Vocational Rehabilitation in providing vocational services resulted in a decrease of their

support from fifteen persons to seven now sponsored at time of follow-up. Only 24 persons, out of an original 37, are receiving social service benefits.

These findings appear to present a convincing argument for continuing to meet the needs of the severely disabled through the provision of IL programs. Programs such as Cooperative Living offer hope, as well as vocational and personal opportunities, for those who have been denied access to participation in their community.

12

☆

The Environment as a Support System for Independent Living

Raymond Lifchez, MA

ABSTRACT. Lifchez R: Environment as support system for independent living. Arch Phys Med Rehabil 60: 467-476, 1979.

• In extended interviews and visits with 150 physically disabled young adults living independently in Berkeley, CA, the author studied the environment as they experienced it and evaluated its accommodation to their special needs. The environment in this study is considered in physical and psychosocial terms, that is, as a support system for the multifaceted needs of the whole person. The framework for organizing the data was Mayer Spivak's construct of "archetypal place" in which he defines 13 fundamental places in terms of the behaviors they support: shelter, sleep, mate, groom, feed, excrete, store, territory, play, route, meet, compete, and work. For purposes of the present work, shelter and mate are discussed--shelter, because of the clarity of its relationship between existence and physical form, and mate because of its more abstract relevance to physical form.

Until recently, accessibility of the physical environment to handicapped persons has been at most a peripheral matter in the practice and teaching of architecture. Environments have been designed primarily with able-bodied persons in mind and the consequences of this narrow point of view confront us today: the environment is largely inaccessible and few, if any, design methods recognize the needs of the handicapped user. Recently, however, federal legislation and the active role taken by handicapped persons have resulted in a growing awareness of these needs among architects and architectural educators. A climate of great concern and some confusion has resulted.

Generally, in their efforts to solve the problems of accessibility, architects and educators (as well as recent literature on barrier-free design) have placed undue emphasis on dimensions and abstract performance criteria. But such emphasis only transforms handicapped persons into objects, for example, into wheel-

From the Department of Architecture, University of California, Berkeley.

This article is adapted from the book *Design for Independent Living: Environment and Physically Disabled People* by Raymond Lifchez and Barbara Winslow, New York and London, The Whitney Library of Design and the Architectural Press Inc, 1979.

This work was supported by a grant from the Wallace Alexander Gerbode Foundation, San Francisco, and the Center for Independent Living, Inc, Berkeley.

Accepted for publication July 31, 1979.

chairs with specific measurable requirements. These are important criteria, but only as adjuncts to broader questions about life as a handicapped person in a world constructed for the able-bodied. Understanding these issues requires knowledge and empathy on the part of designers and handicapped clients, as well as a willingness to learn about the range of disabilities and their environmental consequences.

For several years the author and his colleagues have been working to understand the needs of disabled individuals within the environment. Rather than focusing on the activities that are unique to people with severe disabilities, we have studied the wide range of everyday activities common to all people. Through extended interviews and visits with 150 disabled individuals living in Berkeley, we have sought to learn how they experience the physical environment and how they modify it in order to live in noninstitutional settings in the society at large.

From among the many disabled individuals interviewed, 7 were designated as key informants, and they are quoted by name in this article. They are a diverse group in terms of personality and lifestyle. This is not surprising since disabled people are more like a cross-section of our population than a homogeneous minority. The key informants are alike in at least 1 major respect, however, in that they are all actively pursuing and accomplishing personal goals.

Our study examined the environment at 3 levels: the intimate, the dwelling, and the community. This framework allowed us to draw some distinctions between the types of supports disabled people require at each level and to better understand the kinds of interactions that occur there. The intimate environment might include the disabled person and his bed or wheelchair or the disabled person in some of his interactions with his attendants. The dwelling environment might include the actual place of residence or places within the community that serve residential functions–the place of work, education, or ongoing contacts for social, or political, or recreation activities. The community environment includes both the physical environment of the community–the extent to which it is accessible, for example–and the services and supports it provides to the disabled population. This 3rd scale is especially noted as the environment in which the disabled person is least likely to effect permanent changes suitable to personal needs.

Commonly, people who are disabled, ill or poor exist in a restricted environment at all levels. The scope of their community may be limited due to lack of transportation and inaccessible buildings. Personal and intimate environments are likely to be affected as well, and the occupants often lack the money and power necessary to achieve desired changes.

Since behavior exists in an environmental context, the fullest kind of human existence is impossible in a severely restricted environment. Mayer Spivak[1] has given us an important and useful concept for evaluating the environment in these psychosocial terms. His concept of *archetypal place* links together the human experience with the environment of that experience:

> When. . . people live in environments restricted to a severely limited range of settings in which to carry out all the behavior that constitutes the human repertoire, their ability to function as individuals and family groups, and the integrity and quality of their society may be impaired. People fail to maintain deep lasting interpersonal relationships, they may suffer in their ability to work, provide or eat food, to sleep in deep renewing comfort, play, raise children, explore and protect territory, to meet with their peers, and make decisions which control the shape and quality of life. Each of the foregoing functions, and others, are associated with thirteen characteristic settings in the physical environment, with the rooms and furniture which focus and support behavior patterns in specific and appropriate ways. Such settings, taken together in their smallest irreducible group, are archetypal places.

In our study, we found Spivak's view useful in assuring that there would be breadth to our inquiry that was compatible with our search. Therefore we chose the concept of archetypal places as an organizing schema.

Spivak's system (fig) permits a great number of environmental needs to be organized under a relatively small number of basic human requirements, so that the former can be seen as nuances of the latter. Thus, for example, the need for security, in its many forms, can be discussed under the more general rubric of "shelter"; in this way the breadth of requirements the residential environment must meet in order to adequately satisfy this basic need can be indicated.

Of Spivak's 13 archetypal places *shelter* and *mate* present 2 very different sets of issues. Shelter is so commonplace a need that it is here we normally focus our attention in achieving an accessible environment and it is here that some of the most interesting innovations are made which tune personal space to meet personal needs. Mate, on the other hand, is a difficult concept because able-bodied people do not usually think of physically disabled people as sexual beings. This misunderstanding or stereotyping has had negative repercussions on the way physically disabled persons see themselves. Therefore, it was important to us to present to others the whole-bodied perspective of those who have physical disabilities.

SHELTER

Shelter can be broadly viewed as a place of retreat; a place to escape from aggression, stimulation, threat, social contact, and the elements; a place for nesting activities. The behavioral needs that are met by shelter are for physical comfort and for security. These needs exist on a continuum from the intimate to the community level and must be satisfied on each level.

The Developmental Implications

An important aspect of growing up and developing

a full set of environmental expectations is the evolution of a concept of personal shelter. From infancy children begin to seek a "shelter," first by crawling into and under things, hiding in small places, and selecting a small corner rather than a whole room as the setting for their play. As they grow older, this need is expressed by building forts and treehouses, digging caves, and fiercely protecting "my property." Adole-

THE TOTAL SET OF BEHAVIORALLY DEFINED ARCHETYPAL PLACES

TASKS	GENERALLY RELATED LIFE CYCLE STAGES						
	A	B	C	D	E	F	G
	INFANCY: Reflex control; orientation; communicate with siblings and parents.	CHILDHOOD: Gain motor, social, verbal, intellectual, emotional competence.	ADOLESCENCE: Forge identity; establish peer group regulations; social/sexual exploration.	COURTING-MATING: Group with peers; pair-bond; obtain sexual privacy.	REPRODUCTION, CHILD CARE: Nesting/nurturing: symbiosis; socialization.	MIDDLE LIFE: Care of aging parents; re-emphasis on worldly affairs; redefine indentity.	AGING MATURITY: Maintain identity, contact, health; accent care by others, mortality.
1 SHELTER	Elemental protection; protection for nesting activities; retreat from stimulation, aggression, threat, social contact; emotional recuperation.						
2 SLEEP	Neurophysiological processes; recuperation, rest; reduced stimulation; labor and birth, postnatal care of mother and child; death.						
3 MATE	Courting rituals; pair-bonding; copulation; affectionate behavior; communication.						
4 GROOM	Washing; mutual grooming.						
5 FEED	Eating, slaking thirst; communication; social gathering; feeding others.						
6 EXCRETE	Excreting; territorial marking.						
7 STORE	Hiding of food and other property; storage; hoarding.						
8 TERRITORY	Spying; contemplation; meditating; planning; waiting; territorial sentry; defending; observing.						
9 PLAY	Motor satisfactions; role testing; rule breaking; fantasy, exercise; creation; discovery; dominance testing; synthesis.						
10 ROUTE	Perimeter checking; territorial confirmation; motor satisfactions; social and community control.						
11 MEET	Communication; dominance testing; governing; education, worship socialization; meditation; cosmic awe; moral concerns.						
12 COMPETE	Agonistic ritual; dominance testing; ecological competition; inter-species defense; intra-species defense and aggression; mating; chauvinistic conflict.						
13 WORK	Hunting; gathering; earning; building; making.						

A 1 Protection from elemental extremes; explore dwelling. A:2 Recognize bed; learn daily rhythms. A:3 XX A:4 Lose fear of wet face, sudden temperature change; regular grooming as primary contact ritual. A:5 Regulate feeding satisfactions. A:6 Discover excretion as separate from self; associate with setting and time. A:7 Acquire confidence in food abundance. A:8 Identify bed as primary secure place. A:9 Explore close environment; develop manipulative, cognitive skills. A:10 Route connects parts of shelter structures, provides orientation & change; motor satisfaction. A:11 XX A:12 Master frustration in competition w/siblings for attention & toys. A:13 (See A:9).

B 1 Differentiate subsettings; retreat from overstimulation, threat; emotional recuperation. B:2 Associate bed w/fatigue; learn volitional control of sleep; illness and recuperation. B:3 XX B:4 Learn to bathe, dress oneself. B:5 Coordinate feeding tools; communication; differentiate food from symbiotic source in mother. B:6 Autonomously control excretion. B:7 Learn to prepare food. B:8 Establish play "turfs"; orient to neighborhood; play protect territory from lookout; plan, wait. B:9 Role modeling; interact w/peers; fantasy, exercise, exorcism, creation, discovery, dominance testing. B:10 Enlarge route maps; differentiate settings, provide social encounters; learn safe wandering limits. B:11 Regular play/meeting rituals & places; elaborate functions; dominance testing. B:12 Games; fight; agonistic ritual; dominance testing. B:13 Acquire intellectual, motor skills.

C 1 Find alternate private shelter: auto, attic, stairwell. C:2 XX C:3 Meet w/opposite sex in private, public settings; obtain sexual privacy anywhere: autos, barns, etc. C:4 Groom for mating encounters. C:5 Communicate w/peers over food & drink. C:6 Privacy in excretion. C:7 XX C:8 Expand territory into intellectual domains, job. C:9 Learn autonomous hobbies. C:10 Provides social contact w/opposite sex. C:11 Meet w/peers, both sexes; establish new rituals. C:12 Sexual display: cars, sports, clothes (see C:3). C:13 Refine work skills.

D 1 Find new shelter. D:2 Share bed w/mate. D:3 Select mate; achieve couple privacy. D:4 XX D:5 Share food w/mate; increase food abundance. D:6 XX D:7 Enlarge larder for family. D:8 Expand territory to include mate. D:9 (see D:12). D:10 Maintain community of contacts. D:11 Meet w/couples. D:12 Personal display; ecological, mating competition. D:13 Apply skills toward life support.

E 1, Expand shelter for offspring (see E:5). E:2 Maintain sexual privacy against invasion by new young family. E:3 XX E:4 XX E:5 Increase abundance; feed family; gather, communicate w/family. E:6 XX E:7 Increase capacity & variety of food. E:8 Expand territory to include young & check frequently. E:9 XX E:10 XX E:11 Expand functions, contacts; governing, educating, mystical awe. E:12 Display in common values; conspicuous consumption. E:13 Improve capacities, performance.

F 1 Shelter contracts as young leave. F:2 through F:7 XX F:8 Territorial needs contract as young leave shelter. F:9 through F:13 XX

G 1 Maintain location or adjust to imposed change; adapt surroundings to needs. G:2 More time in bed, sleep less; possible confinement, compression of world to bedside. G:3 Adjust sexuality to changing libido; possible illness or loss of mate (see G:2). G:4 Possible inability to care for self. G:5 Arrange special diet; reduction of taste, smell spectra. G:6 Possibly require aid and equipment; lowered mobility may reduce functional dependability. G:7 Possibly require assistance gathering & preparing food. G:8 Passive observation of archetypal activities performed by others. G:9 New leisure activities to fit changing capacities. G:10 Reduction in home range scale; fear of exposure to attack. G:11 Need for contact w/& support from peers. G:12 Probable withdrawal from competition/defeat by young; defensive, evasive postures. G:13 Less active roles w/in former context; fend off retirement.

Spivak's schema of architypal places. (From Spivak M: Architypal places. Architectural Forum, October, 1973. Reproduced with permission of The Whitney Library of Design.)

scents express their developing independence by seeking an alternative shelter; the car or van, the attic or basement room, the distant city to which one runs away in fantasy or reality are substitutes for the rejected shelter offered by and tied to the family. Ultimately, leaving the family home to live alone or with a mate is a cultural signal of independence; it is a sign of being "grown up" and assuming the rights and responsibilities of adulthood.

Each of these maturational experiences is laden with symbolism. Both in the mind of the maturing child and in the eyes of the world, the gradual development of independence is tied to the expression of a separate shelter. Confidence in the ability to "do it myself" is built by gradual successes in the effort to make a place of one's own; personal as well as geographic boundaries are developed by the possession of a space whose access can be controlled by the individual.

Those who are disabled from early childhood often miss or only partially experience these activities. They may be so "sheltered" by concerned parents that there is no need or opportunity for them to develop a concept of shelters of their own. Playing outdoors without attendance is almost impossible in a wheelchair. Those classic child-made environments, forts, are generally inaccessible, and treehouses are hopelessly out of reach. The severely disabled child, under the best of circumstances, may be excluded from the play with others which creates shelters. Alone, the effort required, the difficulty of handling materials, and the need for assistance are enough to overwhelm most efforts.

Shelter is often viewed by the disabled child as the protection and comfort that is provided by others. He is likely to view himself as having little influence on his surroundings; adaptations and changes are made by others. Because the spaces he occupies are rarely his own, the disabled child often lacks privacy. There are no places in which to hide, no retreats from everyone. Mary Ann recalls her childhood as a time of always being protected and sheltered, looked in on and cared for. Confined to a wheelchair that she could not move herself, Mary Ann could never retreat. The expressions of distress so common to the escaping child—slamming the door, hiding behind the furniture, locking youself in your room—were not available to Mary Ann.

Adolescence is usually a time of testing. Many small separations are undertaken in preparation for the larger separation to come. Among able-bodied people, resolution of the endless and inevitable conflicts of this age is often reached by separation. The adolescent finds alternate places with an identity that belongs to him and perhaps his peers. The room is only 1 alternative among many. Teenagers frequently choose to be absent from the home to find alternative environments. For some disabled teenagers their room may begin to serve this function. One young disabled woman describes her room as her "home base." She spends all her time there surrounded by her own things, maintaining her privacy by escaping into continuous schoolwork, an escape acceptable to both herself and her parents. However, there are inevitable difficulties in changing the image of a room that has functioned as a symbol of unity with the family into one that symbolizes independence. These problems are heightened if the room must also serve as the scene for family assistance in moving about, transferring, bathing, and so on.

As adults, most people have the experience of selecting, acquiring, modifying, and occupying a home or shelter of some form. This home is important not only for all the practical functions of shelter that it serves but also as a symbol of self in Clare Cooper's[2] terms, an image of its occupant that is constant in his own eyes and in those of the community. For the disabled individual there has been little opportunity historically to create this symbol. Houses or institutions were selected, built, and adapted to meet the needs of caretakers. With increasing numbers of independent disabled people, however, the situation is changing.

Numerous severely disabled Berkeley residents own or occupy homes alone or with others and find it rewarding. John takes an active role in planning and controlling his personal environment and relates this to good health, building self-confidence and discovering himself.

Conflicts sometimes arise from the necessity for environmental "appendages," which assure access to a home but also declare the disability of the occupant to the world. Carmen's house has 2 large and essential ramps to permit wheelchairs to travel from the house to the garden and from the garden to the street; both ramps are disguised as part of the garden itself, invisible from the street. The reasons are both practical: the police recommend locating ramps where they will not call attention to the increased vulnerability of the occupants; and psychological, Carmen wants the house to look as normal as other houses in the neighborhood. Ramps do not fit the image of normalcy.

The problem of selecting, adapting, and occupying a house of one's own is further complicated for the individual who has been disabled from birth or early childhood. Lack of experience in controlling the surroundings, either directly or by directing assistants, presents major difficulties for home seekers who are newly independent individuals armed only with a brief experience at a rehabilitation center or with no experience outside of the family home or convalescent hospital. They must deal with an unfamiliar and complex set of realities in their search for shelter. Housing must be found that is accessible. Too often a lack of understanding of all aspects of accessibility, such as room and door sizes, counter heights, or turning radiuses, prevents even essential needs from being met.

Finding and adapting acceptable housing that integrates with the network of community associations and services and that provides security and elemental protection can offer psychologically rewarding experiences on both the personal and interpersonal levels.

The Intimate Environment

The most intimate forms of shelter occur within the personal-space bubble. Clothing and protective devices, such as umbrellas or sunglasses, offer both elemental protection and some shelter from psychological invasion. For disabled people, these devices are supplemented by prosthetic devices and equipment. The wheelchair is so closely related to its occupant that it extends both the physical and psychological space occupied by the individual. While it provides a protective metal shell in the material sense, it also makes the occupant more visibly distinct and psychologically accessible to those who do not see disabled persons as people with the same rights to privacy as others.

The basic needs at a personal scale are related to physical and emotional security. The immediate surroundings of most disabled individuals include a variety of devices—manual, mechanical, and electrical—that enable them to meet their basic needs. Varying in nature from catheters and legbags through wheelchairs and mechanical beds to electric door openers and voice-responsive phones, these devices cooperate with the person's existing abilities and furnish the assistance he requires to make possible an independent life. If these devices fail, many disabled people are literally helpless. Late-night wheelchair breakdowns have left many stranded on the street, immobile and vulnerable.

Electrical failures can both immobilize electric wheelchairs and deactivate voice-responsive telephones. The most minor accident, such as dropping the slide-board used for transferring, can isolate a disabled person in a situation that he is unable to leave. Physical security at the personal scale implies the need for back-up systems for any electric or mechanical device that can fail. This need is frequently met by the presence of other people who can assist in emergencies. The preference for living in close proximity to others, particularly able-bodied individuals, is 1 response to this need. Being dependent on attendants or machinery and being helpless for those hours of the night when there is no one around to help decreases feelings of security. A fear of Mary Ann, who has a disabled roommate, is "You think about being alone at night, thinking that if something happens at night, you can't get yourself out of bed, like in a fire or something."

Physical security for the disabled person can mean more dependence on elemental control than it does for the able-bodied person. Spinal-cord injury frequently affects the metabolsim; the body is less able to adjust to temperature change and may be unable to sweat. The usual responses of exercising to warm up and of sweating to cool down are not available, so comfort is possible only when the temperature is within a restricted range. Tom's room is always kept in the upper seventies (20-30C); his windows are not open on even the hottest days, due partially to the great difficulty of opening the windows without assistance. Lennis can frequently be found sitting in the full sun, often wearing a sweater and a slight sunburn. For him, a concern in choosing a place to live is that the windows should face south or west so that he can sit in the sunshine. For individuals with metabolic dysfunction, it is essential to provide a heating system that permits each individual to control the temperature and ventilation of the space he occupies.

Other disorders, such as multiple sclerosis, tend to reduce the body tolerance for heat; comfort may be possible only in spaces that are cool and breezy. Two male informants, both afflicted with multiple sclerosis, have chosen apartments with large windows that can be fully opened. They prefer natural air currents to the chill of air conditioning.

For individuals with temperature sensitivity, a major requirement is flexibility and the opportunity to personally control comfort. Responses to this need vary from being prepared with extra sweaters and jackets kept within easy reach and carried on all excursions, to keeping the body constantly supplied with liquids (a water bottle or glass and straw are permanently affixed to many wheelchairs), to restricting the selection of sapces in which to live and work to those with accessible and flexible temperature-control systems.

The need for elemental protection is often increased by various factors related to disability. Asked about how she deals with the elements, Mary Ann responded, "I hate them all. Rain makes your wheels and brakes slip, and it's hard for cars to see you. Cold makes your circulation poor." In Berkeley, the weather is usually mild, there is never snow, temperatures are moderate, and rains are confined to a few months of the year. A common approach to elemental protection here tends to be passivity. When the weather is inclement, activities that necessitate going outdoors are simply postponed.

Lennis, who describes himself as a "flexible survivalist," says, "I deal with the problem by 'contingency planning.' For instance, if I need to miss a class, I make sure I have all the books and there is someone there who will take notes for me. I just have to switch gears, not let the situation bring me to a grinding halt."

Other souls can be seen in the midst of rainstorms in a wide assortment of protective coverings. Hoods, capes that cover the back of the chair and keep the seat as well as the driver dry, and umbrellas that are fitted into special slots on the back of the chair are common. During the rainy seasons, two of our informants described "devices I would most like to see invented" as a hood similar to that on a baby carriage, which would fold away but was always there when needed, and a "golf cart-type cover, a canopy which would keep the whole chair dry."

John finds the elements a pleasing aspect of the environment. "Berkeley is an accepting place. It has places of power. The bay is like open arms to fog, ocean, the elements. I see more people enjoying the rain here than in other places."

Security from the threat of physical harm by others is a constant concern for many wheelchair occupants. They feel that the chair itself is an advertisement of their vulnerability and inability to resist attack, and many regard themselves as "moving targets" for purse snatchers and muggers. A less obvious threat is posed by the unconscious fears and hostilities many people have toward disabled people. While typical street violence may be avoided by careful selection of times and routes, the danger of unpredictable violent assault by an individual who feels threatened by disabled people can inhibit making potentially rewarding contact.

Peter stresses that while security is an important consideration, and one that he is constantly aware of:

> Danger is just a part of it all; part of being disabled is accepting that a lot of things are going to be harder, more time consuming, less safe. Most of us are very accustomed to being in some form of danger. We are susceptible to infections, injury, and so on; but you can't let that get in the way of leading your life. So, you just accept the danger, and if you want to do something enough, you do it.

One can never be certain about security from attack. Most disabled people are extremely careful in their planning to avoid areas that have a dangerous reputation, time periods during which streets are likely to be deserted, situations in which they are likely to be isolated with an unknown individual. The desire to avoid difficult situations, however, may result in spending more time at home than is actually desired.

The Dwelling Environment

The dwelling provides the primary shelter; it offers a retreat from all hostile forces and provides comfort. For most disabled individuals the dwelling is the only environment in which a real sense of both physical and emotional security is possible. The importance of direct control of the surroundings is a critical element in this feeling. The home of the disabled person is generally more specifically adapted to the needs of the individual than that of an able-bodied person.

The dwelling must serve as a sure "escape route" from threatening situations. This implies ramps to entries that are easily maneuvered, no barriers like curbs at streetside, and door hardware that is workable. Handles with lever-type action, keys on extenders, adequate space for wheelchair manipulation to open and close door, good lighting, and accessible doorbells are some common adaptations. Special devices such as intercom locking devices controlled from the bed are also in use.

Once indoors, the dwelling must offer security from invasion. Locks must be effective and easily operated. Many of the best locks in terms of security are dependent upon small-muscle control for their operation; large-scale versions which are more manageable or different designs are preferable. One informant noted:

> When I go out, I lock everything—every window. When I come back it's really hot, but it's better than being ripped off. I'm not as worried about being ripped off in this place, 'cause while this place is accessible, I really go to great pains to see that it doesn't happen; and after I've done all I can, if it happens, it happens, and well, I am insured and I do have my stuff marked with my name. I am usually out with someone, but if I'm around at home, I will keep my doors locked if I'm not expecting anybody. And the whole thing behind that is that I have taken a self-defense course, and I would give somebody a pretty good battle. I'm most vulnerable when I am lying down, it's sort of like someone pulled the plug on me. But it's not one of those things that I can just sit around and worry about all the time.

Windows that permit the occupant to see the visitor before admitting him are important. They must be low enough to be used from a wheelchair and located so that the chair can be moved into an effective viewing position. For those who are restricted to a single room, a voice-activated entry communications and access system may be desirable.

To find an effective balance between security and social isolation is a problem for those who need to spend long periods of time in bed and cannot leave the bed without assistance. Admitting visitors personally is impossible. Various approaches are taken. Peter often leaves his door open; visitors and attendants come and go freely, and he counts on the constant flow of a number of people through his home to provide security. His apartment is located in a building in which neighbors can hear any disturbance, which supports this approach, as does his decision to share his apartment with another active disabled man, who also brings in a steady stream of visitors into the space.

Carmen handles this issue by sharing the space with a number of able-bodied people who can respond to visitors. Regular callers are given keys and the doors are open during active hours. Mary Ann and her roommate solve the problem by giving keys to attendants and other frequent visitors. They schedule all other visits in advance so they are prepared to greet the guest. Due to the high attendant turnover and the dangers inherent in having distributed many keys, this approach requires periodic lock changes.

The security problems posed by the necessity of hiring attendants and providing them with access before their reliability has been proven is a constant worry for disabled people. Attendants are often hired from among the "street people." Most are conscientious, reliable, concerned, and value working with people. However, others are untrained, irresponsible, or simply out to take advantage of an easy victim. Stories are told about homes robbed after attendants were hired, given keys, and then never seen again. Screening programs and referral systems attempt to control this problem, but the undeniable vulnerability of those who are dependent on assistance is a continuing problem that even the security of the dwelling cannot overcome.

A sense of security is sometimes enhanced by the presence of a telephone, another means of communicating with people. This link with help, however, is not always reliable, particularly when it cannot be easily or quietly employed. Lennis described an uncomfortable situation in which he heard someone in the next room at about 3 o'clock in the morning. It turned out to be his attendant, but Lennis had some uneasy moments; he hesitated to use his phone line to call for help because when it is activated, anyone in the next room can hear the operator come on the line. When asked if he would feel more secure if there were a lock on the door between the bedroom and living room and on the door between the bedroom and bath, he answered that if he started putting so much hardware on the doors, there was the danger of being locked in. He felt security was, to a large extent, within his own head.

Too often such concerns as effective security or adequate protection from the elements while entering or departing a dwelling must be relegated to the status of "luxury items." Merely finding a building with an accessible entrance and adequate space in the interior poses monumental problems. Gary has experienced many difficulties simply finding minimally acceptable housing.

> Most apartments, particularly in the newer buildings, are cramped. There's just not enough room to move around. The biggest hassle has been hallways and making turns in hallways. This place that I'm living in now, the hallways are relatively wide in comparison to the other 2 places that I lived in. I guess that's the first thing; basically, if you can find an apartment that is in an older building, like this, you've got half a chance. If you're going to be moving in with another crip, you'd best get 2 bedrooms, particularly if there are 2 electrics; otherwise it's just too cramped. As far as closet space and stuff like that, this is the 1st apartment where I could even get near the closets. . . .
>
> We'd looked at 3 or 4 places, and we said, well, okay, this place is still cramped, but we can do it. For almost a year we did it. And for me, I guess, I'm in a better position to try out things like that, because I'm not, say, a quad or someone who has limited use of their hands. I have good use of my hands and arms, and considering that you develop all kinds of weird-ass ways to get in and out of doorways. I mean, I can remember times when I would use my head to help myself get out of a doorway if I had to put some extra push on the chair. I would get myself up against the chair and try to push myself out of the door, and maybe one end would go and the other end would get stuck, so maybe I would have to use another portion of my body to either open the door or something like that. When you're in a cramped environment, you learn to use everything you've got, and that can be anything from 1 extra finger that you didn't think you'd have to use to using your leg to kick something.

Shelter has strong psychological overtones. As well as offering security and access, it must provide the symbols of comfort. Returning to the hearth is more than a literary cliche', the presence of a visible heat source like a fireplace or a sunny, protected patio is an important element in the concept of dwelling. Heatihg systems that offer even and controlled temperatures are important for the maintenance of physical comfort. Heat sources that offer varying degrees of warmth and the opportunity to adjust to the source are emotionally important. Any heating system to be used in the homes of the disabled person should be designed to be easily operated with minimal muscle control. In addition, surfaces that can become hot and cause burns must carry visual warnings as some disabilities destroy those sensations that warn of burns or other injury.

In extreme climates, metabolic problems may tend to confine some people to the home unless temperature-controlled access to transportation is available. Sheltered access to the garage or a heated garage may be a necessity rather than a luxury. A sheltered front entry is important for those who require time to operate locks and opening devices, and nonskid surfaces on outdoor paving may be necessary for those who do go out in rainstorms.

The Community Environment

At the community level, one of the most important aspects of shelter is its environmental messages. A town like Berkeley, which has demonstrated its concern for the welfare of the disabled population with visible acts such as curb cuts, timed stop lights, and ramps, sends a message to disabled inhabitants and visitors that clearly says, "You are welcome here; this place offers shelter and concern." The physical environment was frequently the 1st subject mentioned by the informants in discussing Berkeley. It induced an immediate sense of security for many upon their arrival. "If they care enough to make things physically accessible, which was never true anywhere else I lived, then probably they will also be more accepting of me personally."

Berkeley also offers shelter for a wide range of public and semipublic activities. Most restaurants are accessible and have come to function as common gathering places in which one can find shelter from the elements and social companionship. While the private homes of the vast majority of the population cannot be entered, such public facilities play a particularly important role in social interactions among able-bodied and disabled people. They provide both an arena in which to meet and a ground upon which the 2 populations can participate equally.

MATE

The rituals of mating include courting, pair bonding, expressions of affection, communication, sexual expression, and child care. The formation of intimate relationships and the expression of the feelings generated in these relationships are an important dimension in the lives of disabled people.

Perhaps the most important aspect of mating or courtship is the validation it offers of a person's worth and the meaning it often appears to impart to life. A paraplegic man says, "Being disabled, I feel alienated.

I want to be–I like to feel I'm still sexually attractive, seductive. How can I be appealing if I'm still in a chair? I've come to realize life has to offer something more than sex. I'm now searching for that meaning. I want to feel alive."

The Developmental Implications

Children pattern their play and their plans for the future after the behavior of the adults around them. One of the most important aspects of this patterning is the concept of family, of ultimate marriage and possibly having children, as an expression of adulthood. This process is as important in the development of most disabled children as it is in the lives of their able-bodied peers. They grow up as part of a family, and their expectations for the future may include the development of their own family. While this may be accepted within the families of disabled people, who see them as whole persons, it is frequently a difficult idea for outsiders to grasp. For some disabled children, there is a false expectation that they will remain a "child," cared for by the same family group through adulthood. A few anticipate institutionalization.

Major problems for many disabled people occur as a result of society's unwillingness to view them as sexual beings and potential mates. Institutions traditionally treat them as children, separating the sexes and regarding expressions of affection as a perversion or inappropriate behavior that must be discouraged. Troubled by this negative image, the disabled person must also deal with the cultural images that associate sexuality with physical perfection and beauty. As Tom says: "I see myself as having sexual potential, as having marriage potential, but if you took 12 women off the street and lined them up to look at me, I wonder what they would see?"

One effect of this prejudice can be seen in the continuing efforts of the informants to change attitudes. As Peter says, "If there's a little kid on the street and he asks, 'What's wrong with you?' there is a certain responsibility to educate him in disability. The answer must be calm and direct and honest. You are always sort of a representative, and you can influence his attitudes in later life."

In Berkeley, some change in attitudes can already be seen. John says:

> Before I came to Berkeley I had career potential and I've realized it. Berkeley told me I had sexual potential as well, which means that in some way the community must recognize it. Career potential is always there, but before coming here I was confronted by an attitude toward me of my being asexual. It goes along with the stereotype. The best sex comes from the best looking people! Righteous turn-on! Rehabilitation center turn-on! People see a disabled person least of all as an ideal society member. It is only since coming to Berkeley that I can see myself as a person important to society.

Developing reasonable expectations of the self and finding potential lovers are difficult tasks for all adolescents. The teenager who has been disabled from birth must throw off a lifetime of societal assumptions as well as battle the physical difficulties of making contact. Newly disabled people must reassess their own value system, which had awarded points for beauty and athletic prowess. Peter uses the term physicalism to describe the value structure that must be overcome; like racism and sexism, it is often particularly important in relationships between the sexes.

The Intimate Environment

Privacy is essential for the development of close open relationships and for sexual expression. The problems of working things out so that it is possible for a relationship to begin, develop, and possibly become intimate are particularly difficult when environmental barriers close other doors to you. Tom describes his frustration in pursuing relationships that seem to show promise:

> I used to live in a 1st-floor apartment with David. The woman upstairs and I were very close. We spent a lot of time together, but there was no elevator so I never saw her apartment, and I had a roommate so we were never alone. There was just nowhere to go. Maybe it wouldn't have worked out anyway, but it never had a chance.

The adolescent years for disabled people can be particularly difficult in this respect. Most teenagers are in pushchairs and are dependent upon the aid of parents or friends to move around. Making acquaintances under these conditions is difficult, pursuing them impossible. The acquisition of an electric wheelchair can radically change the life of a person who has rarely had any real privacy; it offers the opportunity to go somewhere alone, to make one's own choices, to control one's mobility. Once involved in a relationship, it can permit a relatively equal status among partners for even the severely disabled. When both partners can move about independently "taking care of themselves," there is less necessity for the more able-bodied partner to assume a caretaker role. One Berkeley woman who is slightly disabled herself recently returned from a vacation with a more severely disabled friend. From her unique viewpoint on "both sides of the fence," she expressed her understanding of the difficulties of sustaining a relationship complicated by disability: "If you're the person causing the problem, you feel responsible. It can complicate relationships. In some ways, our vacation was a hassle just keeping from becoming upset or making him feel like a burden; yet I had one of the better times of my life just because of who I was with."

The issue of dependency in a marital or romantic involvement is a serious problem for many disabled people; even in situations in which the disabled partner has led a fairly independent life prior to involvement there is a constant danger of falling into patterns that lead to dependency. Tom, divorced after 8 years of marriage, is now amazed by the extent to which he had become dependent with no understanding of the destructive effects it was having on his relationship

with his wife. A "strong quad," Tom now does everything for himself; he cleans, cooks, drives, works, bathes, and writes without assistance. When he needs help with tasks requiring special dexterity, he hires someone to perform them. Yet, during his marriage, his ability to "take care of himself" was so eroded that his wife's most serious concern when she left was that he would be completely incapable of managing the simplest tasks alone.

The major factor in the development of this dependence was a failure to adapt the environment to his needs.

> It just didn't seem necessary. She drove the car, and as long as I was a passenger and had some help we managed. She did most of the cooking and so forth. It was easier for her and we couldn't change things easily. If she helped me get dressed and pushed me to the bus stop, we could both sleep longer.

The importance of organizing the environment so that each disabled person can meet his needs without burdening a relationship cannot be stressed enough. Attendants who have become emotionally involved with their employers universally emphasize the importance of terminating the professional relationship if they wish to maintain the emotional one. The intensity of physically caring for someone has a dual character; it leads to the development of attractions and closeness and then destroys the same closeness when the caretaking is a necessity, neither a free choice made from love, nor a job which can be completed and left, both physically and emotionally.

Carmen says, "You should never make a lover out of an attendant. It's true about the mystery–familiarity does breed contempt. On the other hand, it is good to have as a lover someone who has been an attendant to someone else. They understand." When an attendant does become a lover, however, the role must be redefined.

The Dwelling Environment

The homes of disabled people are often the homes of a family–houses containing children, friends, pets, and mates, in addition to the disabled individual. There has been a prevailing tendency for designers to view disabled people as isolated from social contacts and associations. When disabled people are regarded as members of a family, a tendency remains to treat them as a special case, providing them with a specially equipped sick room. A space is provided near the kitchen so the homemaker can also function as a caretaker. The rest of the family lives upstairs and lives apart.

While this pattern is not appropriate for anyone who is truly regarded as a family member, it is still a spatial necessity in many homes. Two-story houses make up a large part of the residential stock of this country, and the upper half is usually inaccessible to the disabled person. When a family member becomes disabled, and the existing home has no accessible private space, arrangements are often made that are difficult for everyone. In 1 case, the dining room is the only possible place for a disabled young man. His room functions, however, as a corridor to the kitchen, denying him any real privacy. Furthermore, it cannot be closed off completely from the living room and lacks a full bathroom. He is in the unfortunate position of both feeling guilty for the inconvenience of his presence and resenting the lack of any real comfort. The likelihood of a member of any family suffering a temporary or permanent disability is high, and should be considered in planning any home.

For the many disabled individuals who do lead active sex lives, both the environment and the personal support system must be arranged to make lovemaking comfortable and convenient. Often, there are complications of prosthetic devices and transferring, which require the aid of a skilled attendant. Carmen, describing the problems she finds in lovemaking, says:

> Most men don't know how to get past the wheelchair, and I don't know how to get past the iron maiden myself. Making love with me is a real trapeze act–the first time is uncomfortable, a little frightening. A lot has to do with bladder problems and my catheter. And there's the time thing: you can't just jump up, take a shower, and douche, and be done. You need all those other hands. By the time you've taken care of 1 night, you're into the next.

Mary Ann commented on the added complications when the relationship involves 2 disabled people in wheelchairs. Like many other facts of life for the disabled, lovemaking cannot be totally spontaneous. "You have your plan when you want to go to bed; it can be worked out. It can be any kind of situation when 2 people become interested in each other. It might be 2 disabled people with an attendant." Arranging a bedroom space so that it permits sexual relationships to take place with whatever assistance is required, and with privacy as well, is essential.

The Community Environment

The tendency to view disabled people as leading rather isolated existences, or at least relating primarily to other disabled individuals, is reflected at the community level in seating arrangements for disabled people that ignore the presence of a partner. One young woman, frustrated by attending numerous movies and concerts separated from her date, proposed a folding seat for the side of her wheelchair which would permit her date to sit close at hand. "As it is," she says, "when I go out with someone, we are so separated by the chair that he never even gets to put his arm around me. There is no easy sort of progression."

When a couple who are both in wheelchairs are on the sidewalks, a different spatial problem occurs. Two chairs are frequently too wide to travel side by side and when they follow each other, communication is impossible. The most comfortable position for talking

appears to be side by side, but facing in opposite directions—an arrangement that also tends to block sidewalks unless a widened area is provided.

The community also tends to express its reluctance to accept disabled people as sexual individuals in the design and operation of hospitals and care facilities. Rooms are rarely provided that have space for a mate to visit for even temporary stays. Beds tend to be single, and privacy is often limited. "For the patients' protection," bedrooms can rarely be locked from within. Such "don't touch" messages sent by the environment are reinforced by policy.

CONCLUSION

In reading about archetypal places from the point of view of those with physical disabilities, one must not only focus on information, one must also read between the lines. For the individual environment to work well—that is, the dwelling, work place, communal space and so on—there must be a much broader context to support these settings. For the dwelling or workplace to be truly accessible the town or community must have a critical mass of physically disabled residents, a cohort, who recognize and support their connectedness. Out of this connectedness comes, at the 1 extreme, the small, discrete acts between people who understand one another—neighboring, sharing, even friendship—because they share experiences in life and the goal of independent living. On the other extreme, there is the awesome potential for political activism, which if need be can ensure the rights and privileges of those with physical disabilities.

Out of this critical mass, networks are formed in response to the individual's and the collective needs. Legal assistance, medical and attendant care referrals, equipment service, transportation, housing, jobs, recreation and other social services are tailor-made to work within the town and to be highly responsive to the special needs of those with physical disabilities. Like pioneers in a new territory, the physically disabled often discover their connectedness and collective vitality in building these critical networks which will be major supports in each person's effort to live independently.

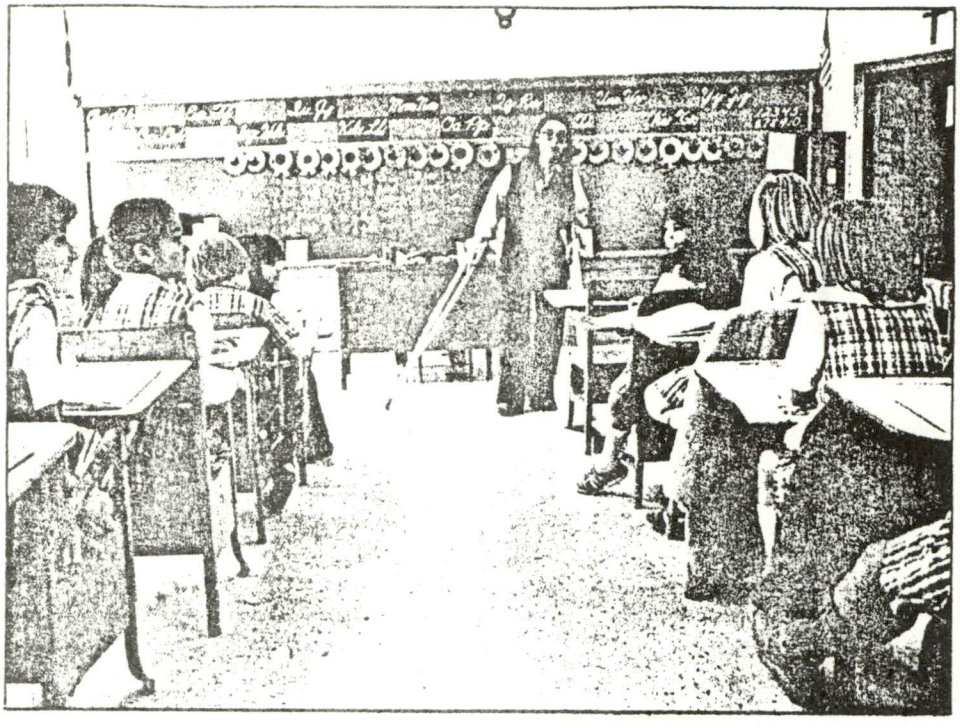
It is, therefore, only within a broad context of social supports and life opportunities that the physical environment per se is truly a setting for independent living.

ADDRESS REPRINT REQUESTS TO:
Raymond Lifchez, MA
Room 332, Wurster Hall
University of California
Department of Architecture
Berkeley, CA 94720

References

1. Spivak M: Archetypal places. Architectural Forum, October, 1973, pp 43-48
2. Cooper C: House as symbol of self. *In* Lang J, et al (ed): Design for Human Behavior: Architecture and the Behavioral Sciences. Stroudsburg, PA, Dowden, Hutchinson, and Ross, 1974, p 144

Independent Living: Choosing From A Variety of Programs



FOR PEOPLE WHO ARE not familiar with the concept of independent living programs for severely disabled people, the imprecise vocabulary that surrounds these programs and services can be confusing. As is usual with new concepts, widespread acceptance of new terminology develops slowly.

The problem does not lie with the general concept of independent living. That is fairly easy to explain: Given appropriate support services, information and skills, and accessible environments, severely disabled people can participate in all aspects of life. The problem comes when we try to distinguish between different kinds of programs which provide independent living services.

Programs frequently referred to as independent living centers can vary tremendously in the breadth of services, and have little in common except services to severely disabled clients. Three well-known programs come to mind: The Center for Independent Living (CIL) in Berkeley; New Options in Houston; and Creative Living in Columbus, Ohio. Although each of these are referred to as centers, they could scarcely be more different.

For instance, CIL does not provide housing or attendant care to its clients, but instead concentrates on coordinating community resources.

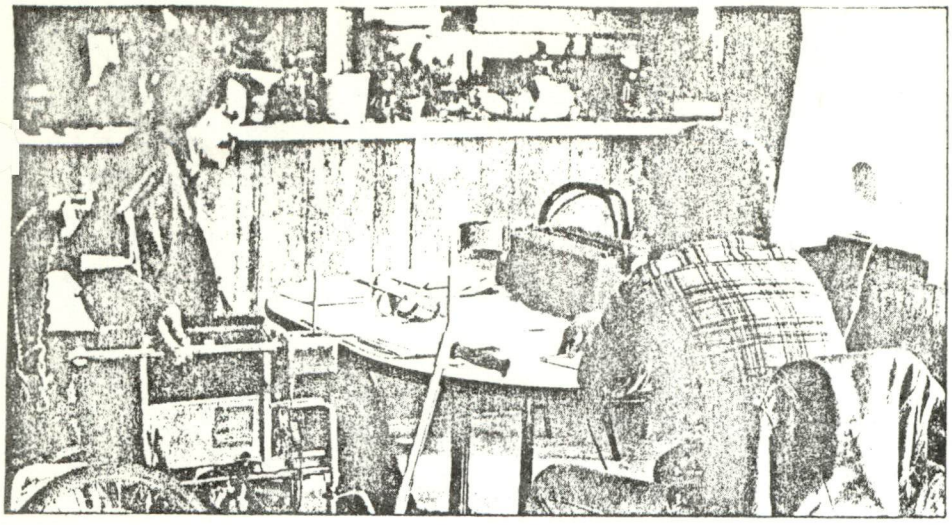
New Options is transitional, which means that it focuses on providing its clients with opportunities to learn and practice skills which facilitate their ability to live independently.

Creative Living is a residential program, set in a specially designed apartment complex, in which clients share attendant services and transportation.

Moreover, CIL is not a live-in program; the other two are. New Options does not provide services to individual participants for more than six weeks; the other two do. Creative Living does not provide formalized peer counseling; the other two do.

The question arises, then, what *is* an independent living center, or more tellingly, what *is not* an independent living center? Are there any bases on which to compare and categorize all the programs providing independent living services?

To answer these questions, the Rehabilitation Services Administration of



HEW has sponsored the Independent Living Research Utilization (ILRU) project at The Institute for Rehabilitation and Research (TIRR) in Houston, to undertake the major task of developing a glossary of terms for independent living.

Six features, by which programs providing independent living services can be compared and categorized, were identified. They are: Service setting, service delivery method, service delivery style, vocational emphasis, goal orientation, and disability type served.

Each of these features denotes a continuum or dimension within which programs may vary. The *service setting* may range from residential to non-residential; the *service delivery method* may range from direct to indirect, or a combination of both; the *service delivery style* may range from non-handicapped to consumer; the *vocational emphasis* may range from primary to incidental; the *goal orientation* may range from transitional to ongoing; and the *disability type served* may range from single to many.

By comparing programs along these dimensions, one can distinguish the differences between many programs designed to facilitate independent living. Also, it is possible to reliably identify several basic *types* of programs.

Conceptually, *independent living program* is the most broadly defined term relating to organizations working with disabled individuals who wish to live independently. What kinds of features an independent living program has will depend on the needs of the clients served, the availability of existing community resources, the physical and social make-up of the community, and the goals of the program itself.

To be exact, an independent living program is a community-based program which has substantial consumer involvement and provides directly, or coordinates indirectly through referral, those services necessary to assist severely disabled people to increase self-determination and to minimize unnecessary dependence on others.

Services that must be provided or coordinated by an independent living program are housing, attendant care, readers and/or interpreters, and information about goods and services relevant to independent living.

Other services that are provided or coordinated by independent living programs include transportation, peer counseling, advocacy or political action, independent living skills training, equipment maintenance and repair, and social-recreational services.

It should be noted that custodial care facilities and primary medical care facilities are specifically excluded from the definition of an independent living program.

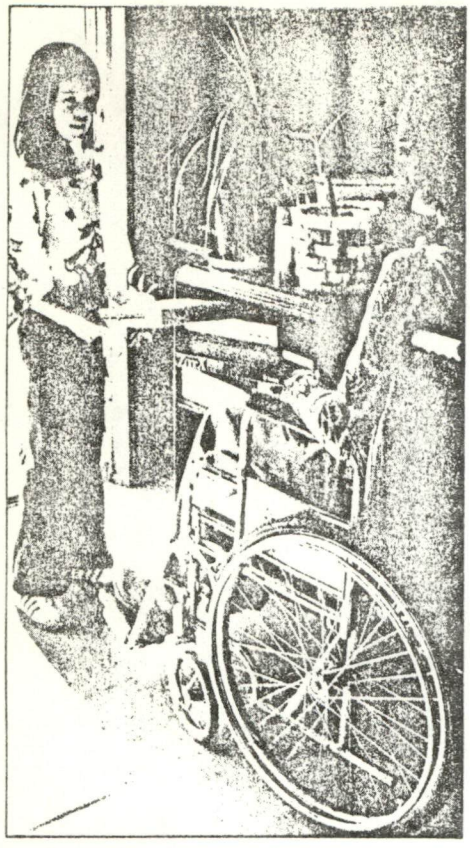
If one cares to discriminate further, three different types of *programs* with specific purposes have been identified. They are independent living centers, independent living transitional programs, and independent living residential programs.

An *independent living center* is a community-based, nonprofit, non-residential program which is controlled by the disabled consumers it serves. In addition to services already noted as part of an independent living program, an independent living center also promotes community awareness and barrier removal programs.

The CIL in Berkeley is perhaps the foremost example of an independent living center. The CIL 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 multifaceted 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 CIL 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, and CIL 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 people, and the counseling and instruction of participants is conducted by disabled staff members. Through political and legal advocacy, the Center also works to remove architectural and legislative barriers to the complete and active participation of disabled people in society.

Unlike an independent living center in some ways and very much the same in others is an *independent living transitional program*, which facilitates the movement of severely disabled people from comparatively dependent living situations to comparatively independent living situations.

The primary service provided by these programs is skills training in such areas as attendant management, financial management, consumer affairs, mobility, educational-vocational opportunities, medical needs, living arrangements, social skills, time management, sexuality, and other areas. Transitional programs are usually goal-oriented and time-linked.

The New Options program at TIRR in Houston is an example of an independent living transitional project. It is designed to foster independence among severely physically disabled persons, 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 structured to provide information and first-hand experiences which enable participants to acquire necessary independent living skills in a short period of time.

Because it is 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 help or a professional nursing staff.

The goals of the program include the establishment of an independent living situation which includes working with personal care assistants, involvement in educational 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 traces the influence of the program on ex-participants. This way, modules can be created or modified to better train disabled individuals to participate in the community as contributing citizens.

Independent Living: HOUSTON EXPERIENCE

Lex Frieden

Independent living means participating in day-to-day life and making decisions that lead to self determination. For disabled people, this implies living in the community, away from custodial institutions, and being responsible for one's own affairs.

This style of independent living may be facilitated by community based programs which provide services like attendant care, transportation, peer counseling, equipment maintenance, and information about other services.

In Houston, a variety of independent living programs have evolved to assist severely physically disabled people. The first of these was the Cooperative Living Residential Project, which operated from 1972 through 1975.

Cooperative Living

Organized by a group of severely physically disabled people who were former patients of the Texas Institute for Rehabilitation and Research, (TIRR), Cooperative Living demonstrated the benefits of sharing services required to support independent living. Housed in a barrier-free dormitory-style building near downtown Houston, the Cooperative Living residents hired and managed their own attendants, arranged for their own transportation on a shared basis, and generally practiced the skills required in order to live independently. Most of the 40 people who lived in the project in its 3 years of operation as an RSA-funded research and demonstration project began working or going to school while they lived there. The average number of residents at any time was 12.

Most people graduated from the Cooperative Living program in about 15 months and moved to more independent living arrangements in the community. Many of them chose to continue sharing support services and formed their own corporations to provide independent living services. These organizations, like Independent Lifestyles, Free Lives, and CLASP (Cluster Living and Shared Providers), exist in Houston today as independent entities.

Independent Lifestyles

Independent Lifestyles, Inc. provides supportive services for 23 severely physically disabled persons who live at Banyan Townhomes, a group of condominiums developed and financed by the residents themselves. Attendant care is available on a 24-hour basis. Each resident pays for his or her own attendant care according to the number of hours of service subscribed to each month. The average monthly charge for attendant care ranges from $175 to $230.

Independent Lifestyles has an office where attendants activities are coordinated through the use of an activity board. The activity board has the residents listed with their apartment number and a code by which the attendants know what is needed each day for each resident, such as dressing, preparing a meal, turning and transferring, personal hygiene, and so on. Each resident is responsible for making sure that each service he or she requires is recorded on the activity board.

Transportation to and from necessary activities is provided by the project from 7 a.m. to 6 p.m., Monday through Friday, in a specially equipped van. Transportation charges average $85 per month.

Independent Lifestyles is recognized by the Texas Rehabilitation Commission as an approved vendor of services. The project is directed by a board elected from the residents themselves. Financial support for the program comes from charges to residents, which are below the actual cost of providing the service, and from contributions.

Free Lives

Free Lives is a cluster of 11 severely disabled persons who live in the same wing of the 292-unit Independence Hall, an FHA 236 project for handicapped and elderly people. Each resident has his or her own barrier free apartment and subscribes to a cooperative attendant service. Routine

physical care activities are scheduled by the residents, and the 12 person staff is managed by a chief attendant. Cafeteria service is available in the complex, although some residents prefer to use their own kitchens for preparing meals.

Transportation is provided on a prescheduled basis by the apartment sponsors, Houston Goodwill. Service charges are based on mileage. The City of Houston also operates an accessible dial-a-ride service which serves Independence Hall. Apartment rent ranges for $97.50 to $172 per month, depending on the resident's ability to pay. Attendant services are $260 per month. Some resident's services are subsidized by the Texas Rehabilitation Commission and Goodwill. Free Lives has an elected grievance council and a resident administrator who interact with the attendant manager and the project management.

Creative Handicaps

Creative Handicaps is a voluntary organization of disabled and nondisabled people which sponsors an independent living service program. The project is located at Willow Woods Apartments in Southwest Houston. In contrast to Banyan Townhomes and Independence Hall, Willow Woods is an ordinary apartment complex where most tenants are able bodied. Twenty units in the complex have been adapted to be relatively barrier-free.

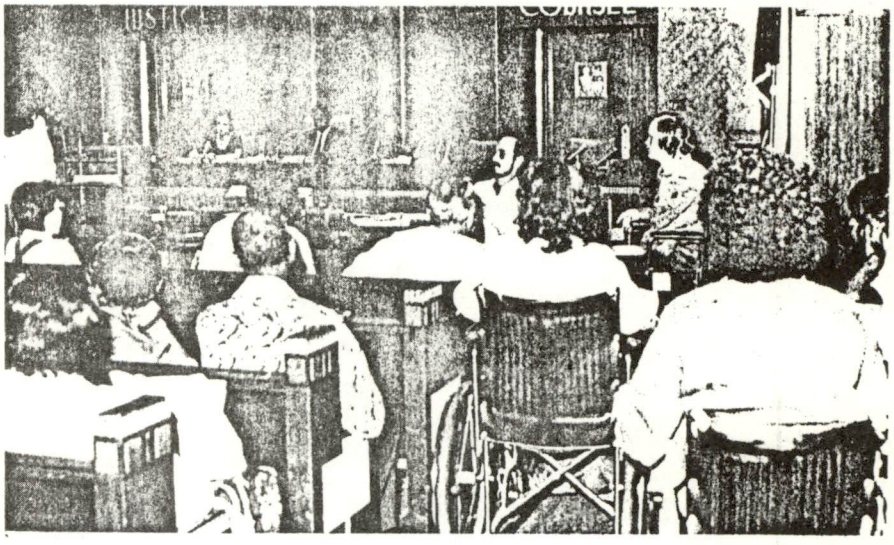
Creative Handicaps coordinates attendant care and transportation for 29 severely disabled persons. Residents pay $220 per month for attendant care. Some residents receive Medicaid benefits which help pay their attendant care expenses.

Although some residents are eligible for Section 8 rent subsidy from the Houston Housing Authority, the apartment owners have discontinued Section 8 agreements. Monthly rent at Willow Woods is $325 for a two bedroom apartment.

Transportation is available via Houston's Pick Me Up service for disabled people on an advance reservation basis at $1 per trip, or on a limited, no cost basis from Creative Handicaps.

New Options

The original Cooperative Living project actually evolved into an independent living skills training program called New Options. New Options is a 6-week, live-in program supported by the Rehabilitation Services Administration, the Rehabilitation and Training Center 4 at TIRR, and the Texas Rehabilitation Commission. The program presents certain information, skill training, and experiences in an effort to facilitate the behavioral adaptation and personal adjustment of people to severe physical disabilities. It is composed of three primary elements: a residential support system; individual counseling and consultation; and training, practice, and information modules. The residential



support system includes attendant, food, and transportation services. Individual counseling and consultation at New Options is provided primarily by full time professional staff. Counseling is directed toward solving specific, individual problems, identifying needs, and developing future plans.

The key element of New Options is the training module. Presently there are 11 such modules that focus on such subjects as financial management, consumer affairs, living arrangements, functional skills, mobility, sexuality, homemaking skills, vocational-educational opportunities, medical needs, and social skills.

Active disabled people who serve as role models are employed to lead the modules. Each module generally meets once a week for 2 to 4 hours. A number of educational techniques, mostly of an experiential nature, are used in the modules to transmit information. Field trips are used extensively to provide opportunities for participants to observe various situations first hand. Considerable free time is programed into the schedule so that participants may explore the community on their own, practice activities individually, or complete personal agendas.

Eighty people have participated in the New Options program thus far. Most of them were living in nursing homes or with their parents before they entered the program. Only a few had tried to work or go to school. Now, almost half of the former participants are living more independently than they were before, and more than half are working or going to school.

New Initiatives

In spite of these progressive programs, the greatest barriers to independent living by severely disabled people in the Houston area are the lack of comprehensive community-based service programs and the absence of sufficient numbers of barrier-free living units. The Coalition for Barrier Free Living (CBFL), a local diabled rights advocacy organization, is presently attempting to alleviate these problems by encouraging and assisting in the development of new programs in the areas of transportation, attendant care, job placement, housing, barrier removal, and information sharing.

Products of the Coalition for Barrier Free Living are not limited to printed materials but include projects like the planned Independent Living Center.

CBFL recently proposed that the City of Houston Community Development Division build a center for the handicapped. The project was awarded a $3 million grant from the U.S. Department of Housing and Urban Development. Plans call for this center to be managed by a board composed primarily of disabled people appointed by the CBFL. The facility will house a completely accessible gymnasium and swimming pool, a specially adapted auditorium, equipment repair areas, meeting rooms, classrooms, and office space.

Services offered through the center will include attendant referral and training, financial and legal advocacy, peer counseling, housing locating and modification, transportation information and referral, public education programs, and others. All of these services should enhance the feasibility of independent living by severely disabled people in Houston.

Conclusions

Several interesting conclusions may be drawn from the Houston experience. First, there is no doubt that well conceived and well managed service programs can provide the support required for most severely disabled people to live independently. Also, it appears as if a broad range of independent living services must be provided in order for a program to be really effective and to meet the needs of people with varying degrees of severe disability. In addition, programs must be flexible enough to evolve over time as the environment and the needs of the disabled community change. Furthermore, programs should be planned and managed with substantial involvement of disabled people throughout the process in order to maintain self-determination. Finally, programs need to be community based and comparatively noninstitutional to avoid paternalism and to encourage integration.

Today, as a result of independent living programs, many severely disabled people are living independent and productive lives. However, the need for more programs providing attendant care, transportation, and housing in a coordinated fashion is critical. Without these additional programs and the funding needed to support them, independent living will remain only a dream for thousands of people confined to nursing homes or living with their parents because there are no suitable alternatives.

Mr. Frieden is New Options Research Director, Research Director, The Institute for Rehabilitation and Research (TIRR) Houston.

Attendant Care as a Prototype Independent Living Service

Gerben DeJong, MPA, MSW, Teg Wenker, MEd

ABSTRACT. DeJong G, Wenker T: Attendant care as prototype independent living service. Arch Phys Med Rehabil 60: 477-482, 1979.

• Of all the services and programs associated with the movement for independent living, attendant care has particular symbolic significance for the movement's adherents. Because it is a self-directed service, attendant care can be contrasted with home health services which are directed by professionals and agencies. This article demonstrates how attendant care mirrors key independent living values and concepts, partially by evaluating the provisions of attendant care services under titles XIX and XX of the Social Security Act. An analysis is made of how selected states have used titles XIX and XX authority to make self-directed attendant care services available. Consideration is also given to how selected eligibility criteria for titles XIX and XX create serious work disincentives that compromise the independent living goals implicit in self-directed attendant care services. Funding prospects and their effect are on the future of attendant care also are discussed.

Attendant care is one of the services most closely associated with the movement for independent living, especially for severely physically disabled persons, for whom it is most essential. The self-directed nature of attendant care services has made attendant care a model independent living service.

Simple as it is, attendant care is not a well understood service. The provision of attendant care services cuts across at least 3 major sectors of the human services system—health care, income assistance, and social services. To understand how a relatively straightforward service such as attendant care is now (or should be) provided sometimes requires the perspective of a human services renaissance person. Such a global perspective is rare these days when proliferating categorical grant programs and the like confine most of us to our own niche in the system.

One purpose of this article is to cut through the bewildering complexity surrounding the public funding of the attendant care services. The article does so by first considering the simple elements that make up the attendant care model, which is contrasted with the home health model. Home health services are an alternative source of in-home services for persons with severe physical disabilities. Our intent in contrasting attendant care and home health services is to demonstrate how the attendant care model reflects key values and concepts espoused by the movement for independent living. However, the attendant care model seldom exists in its purest form. The public provision of attendant care services makes it necessary to accommodate the model to the requirements of major funding sources such as title XIX (Medicaid) and title XX (Social Services) of the Social Security Act.

This article also examines how states have used titles XIX and XX to provide attendant care. Compromises in the independent living goals of the attendant care model, caused by the employment disincentives arising from the criteria used to determine eligibility for income and medical assistance benefits, are analyzed. We conclude by observing some of the trends that are likely to shape the future of attendant care.

DEFINITION

Attendant care services are those tasks performed by an attendant when assisting a severely disabled person in bathing, dressing, grooming, toilet care, and other activities of daily living. If needed, an attendant also helps with meal preparation, food shopping, and household chores. The cost of attendant care varies from minimum wage to $5 to $6/hour. The need for an attendant varies from about 2 to 6 or more hours/day depending on the severity of the person's disability. An attendant is recruited, hired, trained, supervised, and if necessary, fired by the disabled consumer. The provision of care is directed by the consumer, not the provider. This is the distinguishing feature of the attendant care model.

NEED

From time to time, the Social Security Administration, the National Center for Health Statistics and various university-based research organizations have conducted surveys on the incidence and prevalence of disability. These surveys[1-4] indicate that about 1.1% of all working-age adults and about 6.5% percent of all elderly need some assistance from another person with personal care. Given the age distribution of the population in 1977, we estimate that about 2.9 million adult Americans need such assistance.

From the Medical Rehabilitation Institute, Tufts-New England Medical Center, Boston (Mr. DeJong), and the Follow-Up and Demonstration Project, Division of Vocational Rehabilitation, Everett, WA (Ms. Wenker).

This article was supported in part by grant 16-P-57856/1-05 from the Rehabilitation Services Administration, Department of HEW to Medical Rehabilitation Research and Training Center 7 of Tufts-New England Medical Center.

Submitted for publication June 1, 1979, and accepted July 31, 1979.

According to a study conducted by Brandeis University,[5] the need for attendant care is considerably more limited than that suggested by these national data. The attendant care model assumes a greater amount of daily assistance than that reported in national surveys. Extrapolating from state and national data presented in the Brandeis study, we estimate that about 160,000 working-age adults and about 250,000 elderly are functionally dependent enough to require the scope of assistance rendered by a paid attendant.

CONTRAST WITH HOME HEALTH SERVICES

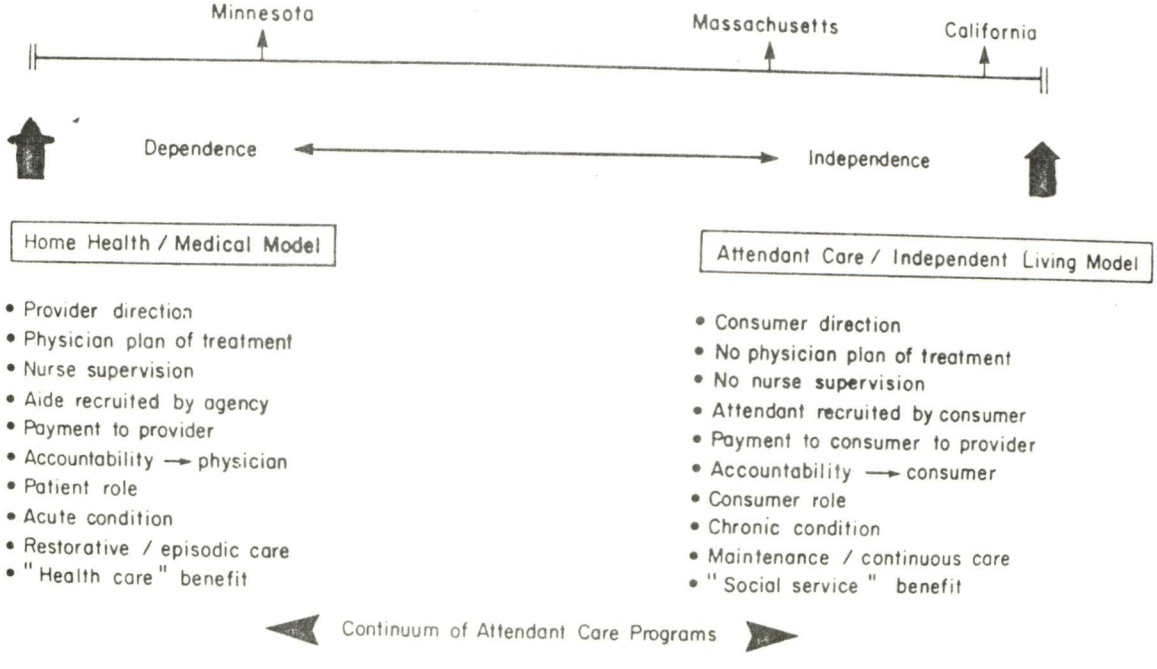
The attendant care model assumes that disabled individuals who are well versed in their own health care needs have the necessary ability and skill to direct and monitor their own personal care. The concept of self-direction is not widely accepted or supported by health professionals. Presently, opportunities are rare within the health services system for severely disabled individuals to assume a leadership role with regard to their own health care. The conventional approach is just the opposite, as illustrated in the delivery of home health services.

In the home health system, a disabled person does not direct his own care. Instead, care is provided by an agency-supervised home health aide. The home health agency functions as the manager in the provision of personal care services and carefully specifies the duties to be performed by the home health aide. Furthermore, the aide's duties are supervised by an agency-employed registered nurse. The disabled person is a passive recipient of services—in essence, a patient.

Since Medicare is the main source of reimbursement for home health services, most such agencies shape their operating policies after those of the Medicare program. Unfortunately, the disabled individual's ability to direct his own care is very much restricted by Medicare requirements. For example, the Medicare program requires that home health services be rendered in keeping with a physician plan of treatment, be supervised by a skilled nurse, and be reviewed every 60 days.[6]

Professional intervention and supervision are at the core of the home health model. However, ongoing reassessment by health care professionals tends to undermine an individual's confidence and independence. Such professional control can unintentionally reinforce dependent behavior. The attendant care model rejects the submissive, compliant patient role inherent in the home health model of in-home support services. In the attendant care model, independence is fostered by holding the disabled individual responsible for managing and reimbursing his attendant.

The comparison between the home health and attendant care models also illustrates significant differences in role behavior. In the former, the disabled person is a patient; in the latter he is a consumer. Yet, both models are needed. The home health model is intended to provide acute, restorative care during a period of illness or recuperation immediately following hospitalization. The attendant care model is intended to provide ongoing routine care as an alternative to long term institutionalization (figure). Considering the polarity of their respective goals, these 2 service delivery models should also be expected to have equally disparate methods to be responsive to the needs of the persons they serve.



SYMBOLIC SIGNIFICANCE

Of all the services and programs associated with the ovement for independent living, attendant care has quired unusual symbolic significance. It has become premier issue for independent living advocates be- use this model incorporates many of the values and ncepts cherished by the movement. Elsewhere in this ue, we have noted how the movement for indepen- nt living has been indebted to the contributions of her social movements—the civil rights, the consumer, e self-help, the demedicalization, and the deinstitu- nalization movements. The attendant care model, corporates the values and assumptions that character- each of these movements.

In our society survival needs such as food, shelter, d health care are often elevated to benefit rights or titlements. Attendant care is viewed as a survival ht, a benefit necessary to the physical survival of e individual, since a severely physically disabled rson cannot participate in school, work, recreation, the political life of the community without it. Be- use of its indispensable nature, attendant care takes the character of an inalienable right with status mparable to a civil right.

According to the consumer movement, the con- mer, not the provider is best able to judge the lequacy of services and products. Thus, as a consumer attendant care, the disabled individual is best able monitor the adequacy and quality of the care receives. Having several years or more of experience th the idiosyncrasies of his own disability, the dis- led individual is often better qualified to evaluate e care he receives.

The self-help movement goes beyond the assump- ns of the consumer movement in that the former sumes that the individual is not only capable of aluating service quality, but that he is also able to anage and direct the services he needs. Likewise, e attendant care model assumes that the disabled dividual is best able to manage and direct his own re provider.

The demedicalization debate centers around the ncern that there is too much unnecessary medical tervention into various problems and life conditions ose etiologies are social and economic rather than edical. In the case of physical disability, the move- nt for independent living asserts that a continuous edical presence is unnecessary once an individual medically stable. The role expectations of the endant care model are in marked contrast to the havioral assumptions of the medical model and e sick role that come with medical intervention. the attendant care model, accountability is centered the consumer, not the physician. The attendant care del assumes that he does not require the acute/ storative care assumed in the medical model or in me health services. Disabled persons are assumed to sufficiently experienced to monitor their own physical condition and to seek additional care when needed. Disabled persons are not "sick," do not wish to be exempted from various social and civic responsibilities and do not wish to be deprived of their personhood.

The features of the medical model that induce dependence are sometimes most evident in large-scale institutional programs managed by medical personnel. Attendant care is viewed as an alternative to institutionalization. It allows relatively low skilled individuals to provide personal care services in a community setting that would otherwise be provided in an institutional setting. Often a person is institutionalized because there are no attendant care services available in the community.

The attendant care concept touches nearly all the themes considered dear to the independent living movement, and the convergence of all these themes and values have helped to elevate attendant care to symbolic prominence. Attendant care is viewed in some quarters as a bellwether service to determine whether public officials and others truly understand the needs and aspirations of persons with severe physical disabilities. In short, attendant care is considered a litmus test service by independent living advocates.

SERVICES UNDER TITLE XIX

The Medicaid program has become one of the main sources of funding for participant-directed attendant care services. This has been made possible by a relatively obscure federal regulation (42 CFR 440.170(f)) that permits personal care services to be provided in a person's home "by an individual, not a member of the family who is qualified to provide such services, where the services are prescribed by a physician in accordance with a plan of treatment and are supervised by a nurse." Although this regulation contains many of the trappings characteristic of the medical model in home health services, the regulation does not specify the amount of nurse supervison required, allowing a great amount of consumer discretion and direction. A person who is medically stable and has acquired the necessary health maintenance skills would require only distant and minimal nurse supervison under the Medicaid regulations.

At least 8 states have used the Medicaid program to finance attendant care services. These include Massachusetts, Minnesota, Montana, Nebraska, Nevada, New York, Oklahoma, Wisconsin and the District of Columbia. Massachusetts and Minnesota have had contrasting experiences with this program.

Massachusetts

The Massachusetts attendant care program began in 1975 when the state Medicaid program contracted with the Boston Center for Independent Living to arrange for the provision of attendant care services. Since then,

3 other independent living centers have contracted with the Medicaid program–Worcester Area Transitional Housing, the Southeastern Massachusetts Independent Living Program, and the Franklin County Home Care Corp. The basic premise underlying the Massachusetts attendant care program is that many severely disabled individuals are well aware of their own health care needs and do not need the degree of medical intervention common to other home health service programs.

To be eligible for attendant care services in Massachusetts, a person must be 18 years or older, limited in his upper extremities, psychologically and medically stable, and eligible for Medicaid. Medicaid eligibility is determined by the public welfare department; attendant care needs are determined by the independent living program. A registered nurse and an occupational therapist from the independent living programs complete an on-site assessment of attendant care needs with the prospective consumer. Reassessments are made at least once per year and sometimes more often depending on the medical condition of the consumer. The Medicaid program reimburses need assessment services on a fee-for-service basis.

Should an applicant be lacking in any skills related to the utilization of attendant care services, the independent living program provides training to enhance the applicant's ability to manage his own personal affairs. This service is also reimbursed by the Medicaid program.

The responsibility for recruiting attendants falls mainly on the consumer. After the initial assessment, the independent living program acts mainly as an intermediary in the payment process. Time sheets, signed by both the attendant and the consumer, are submitted by the consumer to the independent living program, which in turn sends the bill to Medicaid for payment. The independent living program issues a check to the consumer who in turn pays the attendant.

The hourly wage for an attendant in Massachusetts is set by the state Rate Setting Commission and is presently set at $3.50. The typical consumer needs about 4 hours of attendant care/day divided between the morning and evening hours. If needed, a night-time attendant is available to turn an individual in bed to avoid pressure sores. A night-time attendant (who frequently lives with the consumer) receives $5.00/night. The Massachusetts Medicaid program does not provide 24-hour, live-in attendant care services.

About 175 individuals participate in the Massachusetts Medicaid supported attendant care program. In addition, about another 25 individuals participate in an attendant care program supported by the Massachusetts Rehabilitation Commission. This second program is available to individuals who are employed and not eligible for Medicaid. It is supported entirely with state funds and administered through the various independent living programs in a manner similar to the attendant care program funded by Medicaid.

Minnesota

The Minnesota program is centrally administered through the state Medicaid program, not through local independent living programs as in Massachusetts. Current enrollment is 100 participants and 130 attendants. The Minnesota program pays for both live-in and part-time attendants. Medicaid pays up to a maximum of $800/month/eligible participant. Many severely disabled individuals choose to split this sum between several attendants to assure regular care.

The participant is responsible for recruiting an attendant and a registered nurse to supervise his care. But for the most part, the Minnesota program is a provider-based as opposed to a consumer-based system. The attendant and not the consumer bills the Medicaid program and provides the necessary documentation (eg, ensuring that the treatment plan is on record and certified by the physician every 90 days). The physician determines the services to be provided, the expected duration of service, the frequency of nurse visits, and the qualifications of the attendant.[7]

Thus, the Minnesota attendant care program leans more to the home health or medical model, making the physician rather than the consumer the principal decision-maker. Moreover, the duties of the attendant compromise the self-direction goals of the attendant care model in the Massachusetts program.

In Massachusetts, both personal care and housekeeping services are funded by Medicaid. In Minnesota, there is a delineation between personal care services considered to be medical and housekeeping services considered to be nonmedical. The attendant must thus submit a separate bill for housekeeping tasks to the state's title XX Social Services program.

SERVICES UNDER TITLE XX

A second major source of funding for attendant care services is the social services authority under title XX of the Social Security Act, which allows states to fund various in-home services without the medical supervision required in the Medicaid program. California offers an example of how title XX is utilized to fund attendant care services.

California

The California program began in the late 1950s[8] when disabled persons were given a "special needs" allowance to supplement their public assistance grant. When the Supplemental Security Income (SSI) program came into being in 1974, the attendant care program was combined with California's new In-Home Support Services (IHSS) program, supported in part with federal funds under title IVA, the precursor to title XX.

Unlike the Massachusetts and Minnesota programs, California's program is administered through county departments of public welfare. The hours of attendant

care needed by a disabled person are determined mainly by the county social service worker based on a personal interview. The social service worker may call upon the expertise of an occupational therapist. The consumer may solicit the statement of a physician in documenting his need for attendant care. The final number of attendant care hours agreed upon is to some degree negotiable. The attendant care needs of an individual are re-evaluated every 6 months or sooner depending on the nature of the disability.

Hourly compensation for attendant care is set at the minimum wage in California. At present, the total cost of attendant care for any one individual may not exceed $621/month. Thus, the maximum number of attendant care hours that an individual can receive is to some extent determined by this monthly ceiling. Moreover, the disabled individual must take into account outlays for social security payroll taxes and other fringes when computing the cost of attendant care.

The consumer is very much in the driver's seat. He recruits, manages, and pays his own attendant(s). Neither a physician's plan for treatment nor a nurses's supervision is required. Because of the absence of medical intervention, the California program incorporates the attendant care model in its almost purest form.

It is difficult to determine how many individuals are participating in California's attendant care program. Because it is administratively blended into the state's larger IHSS program, to distinguish between individuals receiving attendant care and those receiving other forms of in-home care such as chore and homemaker services is difficult. Current estimates suggest that several thousand or more disabled individuals receive attendant care services in California.

WORK DISINCENTIVES

One of the most vexing issues accompanying the provision of attendant care services is the work disincentive problem. Simply stated, under current eligibility rules for publicly financed attendant care services, a person loses several thousand dollars worth of attendant care benefits when accepting gainful employment. Most jobs, especially entry level positions, do not pay enough to allow a disabled person to pay for his own care. Thus, when accepting employment, an attendant care consumer works to his economic disadvantage. The irony is that the eligibility criteria to receive aid for independent living contain the very elements that undermine the independent living goal. Why?

The source of the problem is that a person's eligibility for Medicaid and social services is closely linked to a person's income maintenance status. To be eligible for Medicaid or social service benefits such as attendant care, a person must be eligible for the SSI program, or at least meet the categorical requirements for it. To meet these requirements, a person must (1) have a medical impairment and (2) be unable to participate in a "substantial gainful activity" (SGA), ie, be unable to work. However, as soon as a disabled person earns $280/month ($3,360/year), he is no longer considered unable to perform gainful work and therefore is no longer considered disabled for purposes of the SSI program. Once working, disabled persons not only lose their SSI benefits but also their Medicaid and social service benefits, including attendant care. The combination of all these benefits—with medical and attendant care being the most important—adds up to a significant dollar amount which a disabled person, even with an above average income, cannot afford to replace from his own earnings. The disincentives involved in the Social Security Disability Insurance (SSDI) and Medicare programs are slightly different, but the dynamics are similar.

The loss of medical and attendant care benefits can be delayed if a person is participating in a 9-month "trial work period" (and an additional 3-month grace period) or if a person has a time-limited "self-support plan." The purpose of the trial work period is to encourage and allow a disabled person to test his work ability without loss of benefits. This delay is a once-in-a-lifetime allowance, however, and after it has been used, the disincentives still operate forcefully. Both California and Massachusetts have passed legislation allowing disabled persons to accept gainful work and retain attendant care benefits. Financing is borne entirely by the states and there is not federal participation.

Though the disincentive problem has been known for some time, it has not captured the attention of Congress and the Administration until recently. As of this writing, several bills have been introduced in the 96th Congress to remedy the problem. Most bills, including the administration's proposal, make special provisions for the disincentives arising from the financing of attendant care. Specifically, these bills propose to exclude attendant care costs and other work-related expenses from "countable income" when determining whether a person's income exceeds the SGA limit. Moreover, some of these bills propose to raise the SGA income limits to more realistic levels.

THE FUTURE OF ATTENDANT CARE

One important solution to the problems of attendant care delivery and disincentives is to divorce eligibility for attendant care from eligibility for income assistance. A persistent feature in the American system of delivering publicly subsidized health and social service benefits is the manner in which these benefits are linked to the receipt, or potential receipt, of income assistance benefits. The receipt of attendant care services should not be related to a person's income maintenance or vocational status. Instead, attendant care should be an entitlement service that is related to a person's functional status or capacity.

The new independent living authority under PL 95-602 offers a modest opportunity for states to provide attendant care services without regard to income maintenance or vocational status. However, funds to implement the new independent living provisions are likely to be so limited in the foreseeable future that pressures will mount—as they already have—to have states continue their attendant care efforts under their respective title XIX and title XX programs. The fear is that relatively costly attendant care services would leave few independent living dollars left for innovative programs geared for a broader segment of the disabled population.

If anything, pressures will continue to grow to finance more attendant care services under the Medicaid program. Federal appropriations for Medicaid are open-ended; appropriations for title XX and other programs are closed-ended. Most states have already exhausted their federally established title XX allotments, which encourages them to refinance services under the Medicaid program whenever possible. Attendant care is one of those services that can be financed under either Medicaid or title XX.

In the near future we can also expect attendant care services to be pushed in the direction of the home health or medical model, in part, as a byproduct of Medicaid funding. But more important, the demands for "quality assurance" are likely to impose new requirements for training and supervision that are more in keeping with the home health model.

This direction is most evident in the "HR 3 Report" prepared by HEW[9] in response to Congressional concern over the lack of accountability and coordination in federally subsidized home care services such as home health and attendant care. Because the attendant care model is in conflict with traditional quality assurance standards which emphasize the training and supervision of care providers, the authors of the HR 3 Report recommended that the current Medicaid regulation allowing federal funding for attending care be rescinded. Instead, the report recommends that attendant care be financed under the title XX program, ignoring the restrictive income limits imposed by most states to contain costs within federally established state expenditure ceilings. The report does not adequately reflect the self-determination goals of disabled persons.

The HR 3 Report demonstrates the widespread assumption, held by agency professionals and policymakers, that disabled persons are not self-directed. The efforts of the home health industry to eliminate attendant care services constitute a trend to be avoided. Yet such a trend becomes difficult to resist when heralded under the politically popular banner of "quality assurance." Given the pressures of provider interests, only consumer vigilance will enable the attendant care model to remain intact.

Personal care is one of the first areas of human activity through which an individual learns to become independent. Yet, it is still one of the last areas in which a severely physically disabled individual learns to become truly independent. To be dependent in the care of one's own body is to renounce much of one's personal autonomy. The management of one's personal care is critical to one's sense of self-worth and independence.

ADDRESS REPRINT REQUESTS TO:
Gerben DeJong, MPA, MSW
Box 190
Tufts-New England Medical Center
171 Harrison Ave.
Boston, MA 02111

References

1. Posner I: Functional capacity limitations and disability. Social Security Disability Survey, Report No. 2, HEW Publication (SSA) 77-11717, Washington, DC, U.S. Department of Health, Education and Welfare, 1972
2. Nagi SZ: R&D in Disability Policies and Programs, An Analysis of Organizations, Clinics, and Decision-making. Columbus, OH, Mershon Center of Ohio State University, 1973
3. Nagi SZ: An Epidemology of Disability Among Adults in the United States. Columbus, OH, Mershon Center of Ohio State University, 1975.
4. National Center for Health Statistics: Home Care for Persons 55 and Over, United States, July 1966-June 1968. Vital and Health Statistics, Series 10, No. 73, DHEW Publication (HSM) 72-1062. Washington, DC, Government Printing Office, 1972
5. DeJong G: Need for Personal Care Services by Severely Physically Disabled Citizens of Massachusetts. Personal Care and Disability Study, Report No. 1. Waltham, MA, Levinson Policy Institute of Brandeis University, 1977
6. DeJong G.: Meeting the Personal Care Needs of Severely Physically Disabled Citizens in Massachusetts. Personal Care and Disability Study, Report No. 2. Waltham, MA, Levinson Policy Institute of Brandeis University, 1977
7. Minnesota Department of Public Welfare: Personal Care Services. St. Paul, 1978
8. California State Benefits and Advisory Board: In-Home Supportive Services. Sacramento, CA, Health and Welfare Agency, 1977
9. Department of Health, Education and Welfare: From Simple Idea to Complex Execution, Home Health Services Under Titles XVIII, XIX, and XX. Washington, DC, Health Care Financing Administration, Government Printing Office, 1978

13

A "HOW TO" CHECKLIST

Two lessons stand out as important from the BCIL experience. First, BCIL has shown that is is possible to develop a quality independent living rehabilitation program in a short period of time. Second, it is important to think through every step of the CILs development. The following checklist should help trigger productive thinking on many key decisions.

Nothing in the checklist is meant to suggest that there is only one way to develop a CIL. No two CIL's are alike. Differing funding sources, philosophies, organizational structures, goals and residents influence the particular character of any organization. However, at least two philosophic tenets appear to provide common links between BCIL and other CILs:

1. People with disabilities plan and implement the decisions that affect their lives.

2. The programs are aimed at enabling persons with disabilities to live independently in the community rather than be dependent on institutional living.

CHECKLIST

I. Review literature on other centers for independent living

II. Develop nucleus of committed people who are willing to work.

A. Develop selection criteria for board, officers, and advisory committee (consumer majority? provider support? abilities? disability representation? interest? committment? fiscal management skills?)

B. Determine initial officers (President, Clerk, Treasurer...)

C. Identify and involve potential members for Board of Directors and Advisory Committees.

1. Representatives of Key consumers constituencies (National Paraplegia Foundation, National Association of the Physically Handicapped, National Association of the Deaf, Paralyzed Veterans of America, American Counsil of the Blind, Disabled in Action, and/or other consumer organizations).

2. Representatives of provider organizations (State Departments of Vocational Rehabilitation, Medicaid, Social Services, Regional Rehabilitation Research and Training Center, State or local housing authorities, area rehabilitation facilities, Easter Seal Society, and/or other service providers).

III. Discuss and agree on the CIL's program philosophy, purposes and target population.

A. Develop written preliminary program description

B. Interest and involve broad base of support

IV. Select and develop an appropriate organizational structure for carrying out the CIL's purposes.

A. Review state and federal laws on incorporation and tax status of organizations (e.g., 501 (c) 3 vs. 501 (c) 4)

B. Prepare CILs articles of incorporation and by-laws. Some of the areas By-laws should cover are:

1. name of the organization
2. principal office location
3. applicable definitions
4. fiscal issues
5. purposes of the organization
6. leadership responsibilities
7. membership responsibilities
8. process for calling meetings
9. process for board and/or membership nominations, elections, voting, resignations, suspension and removal
10. authority to enter into financial agreements
11. personal liability
12. process for amending by-laws

C. Submit organizational papers to appropriate authorities for incorporation, tax status, and employee identification number

D. Affiliate with state coalition or national organization

V. Establish short and long term goals and objectives for the CIL (one, three and five year plans)

A. Determine what other service organizations in the area provide adequately.

B. Determine which services the CIL will advocate for and which it will provide itself:

Activities of Daily Living, Architectural barriers/barrier free design, Attendant services, Chore Services, Coalition development communications, Community Organization, Consumer Affairs Information, Economic Support Services, Educational liaison, Employment services, Equipment repair, Home Health Aide (Fiscal conduit services), Homemaker, Housing Development and Adaptation, Independent Living Training, Information Services, Legal services, Lobbying, Life Support Services, Medical Services, Mobility Skills, Outreach and Recruitment, Personal Care Assistants (recruitment, selection, training), Public Relations/Education, Recreation, Rehabilitation Services, Sex Education, Social Services/State Agency Liaison, Transportation, Vocational Liaison.

C. Determine funding sources for each CIL high priority service objective. To pay for program services, develop fundable proposals and contracts with private foundations and public agencies. Some of the many options to consider include:

   a. individuals
   b. private sector (foundations, civic groups)
   c. State Vocational Rehabilitation Agency
   d. State Housing Finance Agency
   e. City Housing Authority
   f. Department of Community Affairs
   g. Department of Housing and Urban Development
   h. Rehabilitation Services Administration
   i. Veteran's Administration
   j. Department of Public Health
   k. Bureau of Developmental Disabilities
   l. Department of Labor - Comprehensive Employment Training Act
   m. CETA (10)
   n. Department of Public Welfare
      1. Medicaid (Title XIX)
      2. Social Services (Title XX)
   o. Rehabilitation Research and Training Centers
   p. Department of Health, Education and Welfare

D. Secure adequate start-up funds

VI. Develop a comprehensive written program plan to meet the CIL's advocacy and service objectives. This plan should include a description for proposed implementation describing:

A. Prioritized activities to be undertaken.

B. Persons responsible for carrying out activities. (Board, committees, executive directors, staff volunteers).

C. Methods used in carrying out activities.

D. Location of implementation of activities.

E. Anticipated time duration of activities.

VII. Draw up a budget for the CIL's comprehensive program plan and organizational operating costs. Make cost projections for the long term plans (three and five year plans).

VIII. Develop and implement a management system to administer the CIL's plan. Systems to provide accountability should be in writing and should include:

A. CIL Program Content

1. internal record keeping system (data collection) on program utilization
2. a process to prepare external program reports at appropriate times
3. calculations of specific program costs
4. evaluation processes to measure program effectiveness and growth
5. standards for quality service
6. written program descriptions
7. an operational planning process
8. geographical scope of program

B. CIL Resident (Program Participant)

1. confidentiality protection
2. standard means to periodically review client policies
3. program eligibility criteria
4. standardized forms
5. efficient application admission and graduation procedures
6. measures of resident performance
7. objectives of resident participation

C. CIL Fiscal Controls

1. accounting procedures with back-up information on cash receipts, cash disbursements, payroll, closing procedures, budgets, etc.
2. use of standard report forms
3. annual audit by certified persons
4. a control system for making and receiving payments
5. a plan to correct deficiencies
6. a plan to seek continuing financial support (grant, fee for services, etc.)

D. CIL Facility Operations

1. appropriate site location
2. costs to occupy
3. signed lease
4. office procedures regarding correspondence, hours, absences
5. inventory of all equipment
6. building saefty and appropriate insurance

E. CIL Personnel Policies

1. hiring practices
2. benefits plan
3. assurance of compliance with federal and state laws
4. job descriptions
5. job evaluations
6. appropriate supportive equipment
7. staff training
8. system to measure job performance
9. staff reporting
10. salary and pension plans

IX. Develop an assessment system to measure progress towards CIL objectives

A. Review at least annually

B. Prepare an annual report

X. Select effective staff

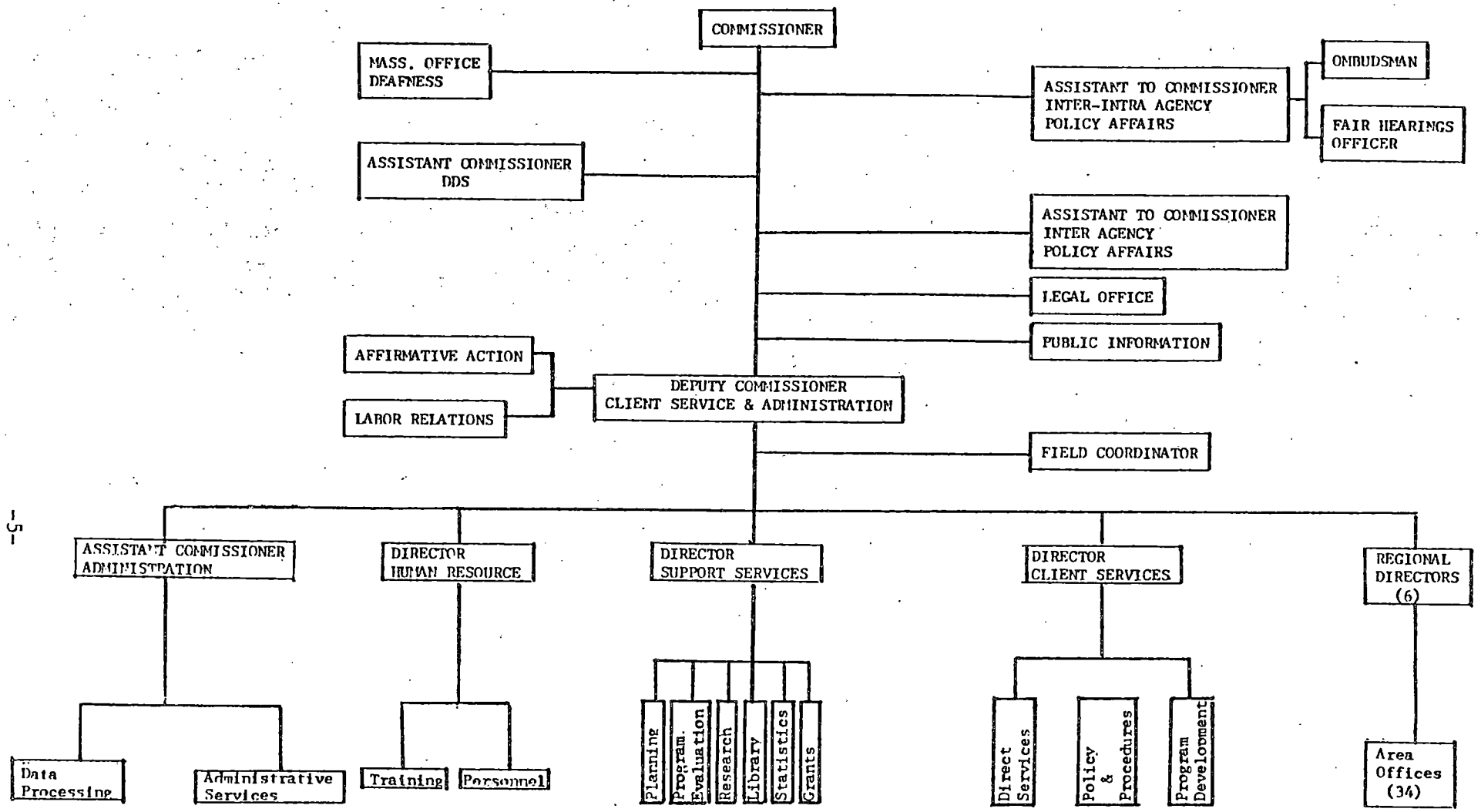
Independent Living Rehabilitation Plan, 1979: Sections II, III, and IV.

II Integration Components

a. Present Structure

The Massachusetts Rehabilitation Commission has recently completed an administrative organizational change which was intended to make the organization more responsive to the needs of the disabled population in Massachusetts. Presently, this structure consists of the Commissioner, Deputy Commissioner of Client Services and Administration, Assistant Commissioner of Disability Determination Services, Assistant Commissioner of Administration, Director of Human Resources, Director of Support Services, Director of Client Services, Regional Directors and Area Supervisors. The following organizational chart is provided for a pictorial representation of the organization of the Massachusetts Rehabilitation Commission.

Within this structure, services are provided to eligible handicapped



MASSACHUSETTS REHABILITATION COMMISSION

Organizational Chart

individuals by vocational rehabilitation counselors from thirty-four local area offices. The process consists of referral, application, acceptance, IWRP development, provision of services, closure. This same system will be utilized for implementation of the Independent Living Program within the MRC.

In order that this same system can be utilized, a number of changes/ additions to MRC reporting forms are necessary. These would consist of identification of the client receiving independent living services and placing an "I" on the master list in the special program box. Also, the MIS-2 should have a new box added to section G8 which indicates the # of successful closures from an independent living standpoint.

i.e. G8

Closed 26 Rehabilitated	110	SSDI	SSI	ILP

This would allow the Agency instant access to the numbers of clients who have successfully achieved an Independent Living goal. Furthermore, it is recommended that the MIS-5 be modified to include a section on Independent Living Clients. The R-300 must be modified to include a check box for Independent Living. Lastly, appropriate changes must be made in the EDP system to reflect Independent Living Clients and identification of services rendered.

b. Eligibility:

Title VII, Part A, Section 702 (a) defines eligibility as "any individual whose ability to engage in or continue in employment or whose ability to function independently in his family or community, is so limited by the severity of his disability that vocational or comprehensive rehabilitation services appreciably more costly and of appreciably greater duration than those vocational or comprehensive rehabilitation services required for the rehabilitation of a handicapped individual are required to improve significantly either his ability to engage in employment or his ability to function independently

in his family or community". Priority of services....shall be given to individuals not served by other provisions of this Act." This definition of eligibility is clarified further in § 1363.31 - Eligibility contained in the Draft Regulations dated 4/16/79. It is stated that "in determining eligibility for independent living services there will be a determination that services can feasibly be expected to assist an individual to function more independently in family or community or engage or continue in employment. Furthermore, § 1363.31 states that "eligibility will be based to the greatest extent possible on existing case record information". "Special diagnostic studies will be conducted only where absolutely essential". "The purpose of the evaluation will be both to determine eligibility and to identify the services needed to be provided. "Moreover, the Certification of Eligibility/Ineligibility will be completed and reviewed in a manner similar to that carried out under the vocational rehabilitation program. Attached, as Exhibit I, is a pre-print form which may be used for the Certification of Eligibility/Ineligibility/Extended Evaluation. For the purposes of internal operations, any client or potential client having an identified vocational goal will be served under the basic program (Title I). Clients or potential clients not having a vocational goal will be rendered services under the Independent Living Program (Title VII).

c. 1. Funding Mechanisms:

Funding for the Independent Living Program will be separate from 110, SSDI, and SSI. Section 110 dollars will be used to determine an individual's eligibility for the vocational rehabilitation or independent living rehabilitation programs. Furthermore, it can be expected that some individuals will be eligible for both programs, but priority of service will be given to those clients who are not covered by other provisions of P.L. 95-602. Upon accepting a client for services of

independent living, and having completed an IWRP, services provided will be paid for through the use of Independent Living Funds. In addition, administration and staffing costs will be absorbed by Title VII funds on a prorated formula based on the number of clients served in this program versus the basic program (Title I).

2. Alternative Resources:

Whenever possible, alternative resources will be used in providing services to individuals under an IWRP for the achievement of an independent living goal. The expectation of using alternative resources to a maximum will broaden the financial base of the independent living service program to the maximum extent.

When an individual who is eligible for vocational rehabilitation is being provided services solely for the purpose of continuing or engaging in employment, it is expected the individual will be served under the basic 110 program unless the individual is also eligible for the Trust Fund Programs. In these cases, use of the Trust Fund monies will, as well, be a priority.

d. Extended Evaluation:

If upon the completion of the preliminary diagnostic study, a determination cannot be made as to the applicant's eligibility for the Independent Living Service Program; it is appropriate to use the extended evaluation (06) status in order to determine eligibility. Funding will be similar to the basic V.R. program, e.g. use of 110, SSDI, SSI funds.

It should be mentioned that although a client may remain in this status a maximum of 18 months, it should not be necessary for the most part in making a determination as to the eligibility/ineligibility of the client for the program. Pre-existing evaluation and diagnostic information will be utilized to the fullest degree possible.

e. Independent Living Rehabilitation Goals

Upon acceptance of a client into the Independent Living Rehabilitation Program, a thorough diagnostic study should be carried out by a complete analysis and synthesis of the information contained in the case record. Specialty examinations should only be conducted where absolutely essential.

In the development of the IWRP for an ILRP client the procedures shall be similar to those in effect under the basic V.R. program. Among other factors, the Individualized Written Rehabilitation Plan will indicate the specific services and their expected duration for each individual.

In establishing goals with the client in this independent living rehabilitation service program, it is important that they (goals) be stated in behavioral terms. For example: successful completion of a driver training program should indicate what the client can now do after the training as compared to before the training program. This may include but need not be limited to: 1) able to get to and from social/recreational activities/or functions, 2) able to drive to and from the grocery store, 3) more independent in terms of mobility, 4) etc.

f. Follow-Up Services

These are services which are provided to a closed (08,26,28,30) client in order to:

1) assess whether the client can benefit from services (08)
2) assess the adequacy of the case closure (26,28,30)
3) provide a benefit to the individual client in order that they are able to continue to live and function independently (26)

4) assess the potential of the client to enter the basic VR program.

Follow-up services should be provided to all clients on a yearly basis, the cost of which are assumed by the Independent Living Fund (Title VII).

g. Post-Independent Living Rehabilitation Services

These are services that are provided to successfully closed clients in order that they maintain their independent functioning in their family or community.

If upon the provision of post-I.L.R.S. it becomes apparent that the client may be eligible for the V.R. program, a case will be opened and a preliminary diagnostic study completed.

III Training Component

a. Overview

In order that all staff be trained appropriately regarding Independent Living Rehabilitation, a common conceptualization must first be realized. This is that vocational rehabilitation is a part of independent living. Albeit V.R. has been the major core of all state V.R. agencies, this focus is rapidly changing. With PL 95-602, it is no longer necessary to have a vocational goal in order to be eligible for services. With this broader philosophy, providers of services will need new skills and talents to successfully assist in meeting the goals of this program.

Before any training program can be implemented or developed, a training needs assessment must be conducted at all levels of the Commission. After having carried out this training needs assessment, only then can a viable training program be developed. Moreover, the training needs at different levels will differ markedly which will mean that it will be most difficult to develop a comprehensive training package. With this as an introduction

to the training component of the plan, the following outline is offered.

b. Information:

It is imperative that information be given to all staff who will be participating in the Independent Living Rehabilitation Program. Information is critical to the performance of the job by counselors, supervisors, and administrators. Therefore, it is recommended that the most current data regarding Title VII be available to all staff. This will consist of the law (95-602), the regulations (Part 1363), and the guidelines (not available) as a minimum. It will also entail a review of relevant literature regarding independent living. Therefore, the first major training component is to ensure that all the appropriate information is available and understood by those using it.

c. Skill Building

Another major focus of any training program will be concerned with the building of skills and increasing the skill level of staff providing services to this severely handicapped group. New skills will be necessary in the areas of:

1) developing an IWRP without a vocational goal;
2) counseling with this population;
3) assessing the needs of the ILP clients;
4) educating the community in understanding and providing certain needs of this population;
5) developing behavioral goals and assessing the client's growth in achieving these goals;
6) knowing where and if there are resources in the community;
7) learning how to deal with their feelings towards this severely handicapped group.

Training is a vital part of the Independent Living Program. Training of the counselor staff is often the first thought that comes to mind. Yet, training is needed for the management staff of the Commission. To avoid training the management staff would be irresponsible since the managers will need to be supportive of their staff and the program in general. Managers will need to comprehend the philosophy of this program; they will need to deal with their attitudes regarding the program and the clients who will be entering into this program.

In addition, the consultants to the area offices, as well as to the Administration Office, will need to understand the Independent Living Rehabilitation Program in order to help counselors make appropriate decisions.

IV Independent Living Rehabilitation Services:

A. Scope & Nature:

Independent Living Rehabilitation Services (ILRS) are any goods and services necessary to enable a severely handicapped individual to live independently within his family or community which are provided in accordance with 45 CFR 1361. These include but are not limited to the following:

1) evaluation of rehabilitation potential;
2) counseling, guidance, and referral;
3) physical and mental restoration;
4) maintenance;
5) transportation;
6) service to members of a handicapped client's family necessary to the adjustment or rehabilitation of the handicapped client which may include but are not limited to respite care, day care services, homemaker services, and counseling;

7) interpreter services for the deaf;

8) reader services, rehabilitation teaching services, and orientation and mobility services for the blind;

9) telecommunications, sensory, and other technological aids and devices;

10) independent living services; post independent living services

11) other goods and services;

12) comprehensive assessment for independent living;

13) family planning, genetic counseling, and referral for further services as appropriate;

14) referral and counseling services with respect to attendant care;

15) attendant care and training of personnel to provide such care;

16) health management training;

17) health maintenance programs;

18) independent living skills counseling and training;

19) peer counseling;

20) community and transitional housing referral and assistance;

21) client advocacy services;

22) individual or group social or recreational activities;

23) education and training necessary for living in the community and participating in community activities;

24) any other services or programs which will assist the

handicapped individual to live and function independently in his family or community.

12

B. Advocacy:

"Advocacy" means the processes used by the individuals representing, supporting, or pleading for the rights and interests of a severely handicapped individual receiving independent living rehabilitation services or applying for such services, in order to ensure that all available legal and administrative remedies are being pursued to safeguard the rights and interests of the individual and to bring about desired improvements or changes in administrative entities and programs affecting these individuals. Advocacy for this program has two dimensions: Individual and Program Advocacy. Individual advocacy is the responsibility of the counselors and/or supervisory staff who work directly with the client towards meeting an independent living goal. This may include, but is not limited to, advocacy with public and private providers of services including state and federal governmental programs. Additionally, individual client advocacy will be provided by the service providers with whom we contract for a group of clients or under an individual purchase of service agreement.

Program Advocacy will be provided by area, regional and central office management and program staff. This will be directed towards the expansion of services available to maximally impact the needs of the eligible severely handicapped citizens of this Commonwealth.

C. Comprehensive Service Centers:

Once vocational and social services became more readily available in Massachusetts communities, it became clear that the options of the sixties were inadequate both in quantity and nature to meet the needs of the disabled.

13

The Massachusetts Rehabilitation Commission has undertaken a number of pilot projects and new initiatives to respond to the many unmet needs. The following are some examples:

1. South Shore Alcoholism Rehabilitation Program is an intensive residential alcoholism rehabilitation program based on the Alcoholics Anonymous model. It's goal is to help chronically and severely disabled alcoholics who have not achieved success in any other program to: a) maintain sobriety; b) develop new coping skills; c) develop transitional living and working plans. (One center serves Eastern and one Western Massachusetts.)

2. Centers for Independent Living -- in this area, MRC has worked closely with the Boston Center for Independent Living, Worcester Area Transitional Housing, and the Stavros Foundation's Independent Living Services of Western Massachusetts which are currently in operation. Moreover, MRC has recently funded two (2) additional independent living rehabilitation programs through the Innovation and Expansion (I & E) Grant process. These are: 1) Southeastern Massachusetts Independent Living Rehabilitation Program, and 2) Northeastern Massachusetts Independent Living Rehabilitation Program. Presently, the focus of these experiments is on developing a clear, structured program format with the purpose of establishing an ongoing fee for service. To this end, the MRC is working with Medicaid and the Rate Setting Commission.

   a. Boston Center for Independent Living -- services

14

are provided to severely physically disabled clients to increase their personal independence so that they may successfully make the transition to independent community living. This program is consumer oriented.

b. Worcester Area Transitional Housing -- the purpose of this program is to provide opportunities for the residents to increase their growth, independence, and functional development in a non-institutionalized setting in order that they may live independently in the community.

c. STAVROS Foundation, Inc. -- this consumer-controlled, community based program offers independent living services to the severely handicapped population of Western Massachusetts. These I.L. services include: 1) a program of outreach/peer counseling, 2) the development of a mechanism for Personal Care Assistance in the Amherst area, and 3) planning for the development of a mechanism for Personal Care Assistance throughout the state.

d. Southeastern Massachusetts Independent Living Rehabilitation Program -- this program currently in the developmental stages provides outreach services, peer counseling, and training in independent living skills to clients of the MRC so that they may successfully live independently in the community.

e. Northeastern Massachusetts Independent Living Rehabilitation Program -- this program which is similar to the Southeastern one will provide staff, travel, equipment, supplies, and consultants to develop and implement an independent living program which will provide outreach, PCA pool, independent living training, and housing to severely physically handicapped clients.

These model programs which span the state could become alternatives to the severely handicapped in their efforts to direct their lives to the fullest degree possible and subsequently be able to live as independently as feasible with minimum supports within their chosen communities.

INTRODUCTION

Cooperative efforts by rehabilitation professionals and disabled consumers have demonstrated that community-based independent living is a medically acceptable, cost-effective, and personally rewarding alternative to long-term institutional care for severely disabled individuals. Indeed, in the years since passage of the Rehabilitation Act of 1973, Independent Living is rapidly becoming one of the bywords of Rehabilitation.

Following the initiative of centers for independent living in Champaign, Illinois, Berkeley, California and Houston, Texas, the project to establish a Boston Center for Independent Living was conceived in January, 1974 and opened its doors in September, 1974. To date, 50 individuals have been through the program. Within three years, using the Boston Center for Independent Living as precedent, other CILs were established in Worcester and Amherst, Massachusetts, and Bangor, Maine. As this report goes to press, CILs are on the drawing board in Vermont, Rhode Island, Connecticut, and Southeastern Massachusetts, with BCIL and RT-7 input.

The groundswell of interest in independent living is the result of determined efforts by disabled individuals who have demonstrated a truly pioneering spirit in breaking away from institutions--sometimes in defiance of health professionals--and in learning how to care for themselves, pursue educations and place themselves in the job market. These individuals have had the dedicated assistance of many rehabilitation professionals who were distressed by the limited futures of those for whom the promise of America was visible only on a flickering TV screen in a back bedroom or hospital ward.

The most dramatic outcome of the move toward independence was the announcement in May, 1977, by Housing and Urban Development Secretary Patricia R. Harris that HUD would sponsor an Office for Independent Living. With this type of support from the federal government for housing and expanding Health, Education and Welfare support for services, possibilities for future growth and development of CILs are greatly enhanced.

The following report is a summary of how the BCIL began and what some of the issues and problems were in its establishment. The original manuscript ran some 240 pages and included nearly every scrap of paper that went into BCIL's planning. These papers are a record of the principal milestones in BCILs development.

If readers are seriously interested in developing a center for independent living, send $5.00 (to cover printing, postage and handling) for the BCIL Report Appendix. The lengthy Appendix includes BCIL by-

laws, articles of incorporation, Medicaid contracts (for both transitional and community living programs), Massachusetts Rehabilitation Commission contracts, quarterly reports, complete staff job descriptions, brochure, news articles, descriptions of other CILs and Tufts Rt-7 project description.

The Boston Center for Independent Living Report is to serve two primary purposes: first, to give a history of the creation of the Center; and second, to provide a perspective and guide to those who wish to replicate such a Center. History, in the case of BCIL, is important because it demonstrates how various individuals, organizations, agencies, and constituencies came together to solve a long-festering problem. All too often, a problem waits for years for an implementable solution to come to the fore. In the situation of BCIL, the statement of the problem, and the design of a solution came together with the nucleus of those who started BCIL. To capture the essence of this coming together, the BCIL Report and its Appendix present the goals, objectives, hopes, detailed plans, historical documentation, results, and evaluation in one place.

The report is unique: it tells both what was planned, and what actually happened over the first two years of a CIL's operation.

Dun and Bradstreet warns that 55 percent of all new business enterprises fail in the first five years. Such ventures flame out, experts say, due to inadequate financing and lack of management talent. While both problems may have plagued BCIL staff, BCIL's success has proven a positive learning experience for others developing new CILs.

The Boston Center for Independent Living had its roots not only in the anger of disabled individuals "incarcerated" in public and private institutions, but also in the frustration of rehabilitation professionals who found the non-institutional community inaccessible to clients and patients following rehabilitation. All three co-founders had first-hand knowledge of the complexity of integrating persons with severely disabilities into the larger community. Paul J. Corcoran, M.D., now RT-7 Project Director, contributed his knowledge of medically acceptable alternative living situations and links to university support. Frederick A. Fay, Ph.D., now RT-7 Research and Training Director and a quadriplegic psychologist, brought energy and enthusiasm from first-hand knowledge of other centers for independent living. Rehabilitation Counselor Bob McHugh, with his intimate knowledge of the state vocational rehabilitation system, was a link to avenues of cooperation and funding between agencies and the idea.

For several months, these three met regularly, brainstorming their idea, mapping out ways to make it a reality. Their goal was a base of operations--a program rather than a facility--for disabled individuals to bridge the gap between total dependence on an institution and independent living. The BCIL concept envisioned a consumer-run self-help community, integrated with the able-bodied, where severely disabled persons could develop.

Enlisting the aid of state agencies and Boston University, the three founders spent the spring and summer of 1974 putting together a board of directors, arranging a contract with Medicaid and finalizing arrangements with Boston University. In September, the first resident rolled into modified quarters in BU's Theology building and BCIL was underway. In the three years since its founding, BCIL and the roughly 50 individuals who have participated in its program have demonstrated that independent living is a realistic and preferred goal for many severely disabled persons.

Today BCIL is a small, non-profit corporation coordinating three separate phases of independence that have evolved over the years:

1. Transitional living. Providing the first basic steps in training social and physical skills, transitional living began in modified dormitories at Boston University. As BCIL attracted disabled persons not necessarily interested in a full-time education this concept was expanded and in March, 1977, the first residents moved into a second transitional facility in Brookline Village, an apartment complex in a Boston suburb.

2. Cluster Housing. For those who mastered the skills of independent living, Cluster housing offers greater independence. Located in East Boston, this is an apartment building with several apartments modified for handicapped persons, with a pool of personal care assistants (PCA) and a night-time attendant.

3. Independent living. As facilities and funding for attendants became available in the greater Boston area, individuals began moving to accessible apartments, usually shared with a PCA, from which they now conduct lives as students and professionals.

MANAGEMENT

The BCIL proved to be a management challenge. Since it involved innovative use of federal and state monies, it required careful reading of--and between--the lines of federal regulations. In addition, management had to be cognizant of and responsive to the particular requirements of severely disabled individuals. Proper management of BCIL involves all of the following:

- -First hand knowledge of disabled persons
- -Ability to communicate with residents
- -Familiarity with day to day support services (PCAs, transportation, etc.)
- -Knowledge of educational institutions and state rehabilitation and social service agencies
- -The ability to deal with human problems tactfully, and to address fiscal problems aggressively.

The goal of BCIL's founders was to establish and maintain a small, grassroots operation, with resident control, a small staff and low overhead. The fiscal goal was to operate the program with Medicaid funds that were already being spent to maintain the disabled individual in a chronic care institution. Several of the people who are now in or who have graduated from BCIL came from hospitals where they had been living for several years at well over $100 per day. Put simply, the program was too complex to be small scale. Most of the people associated with BCIL will admit to management problems; they also believe that successful community development includes a transfer of power and authority to minorities and taking the risks that ensue. BCIL's founders insisted upon transferring responsibility to the "BCIL consumers" and their elected representatives. Federal and state regulations and buracracy make consumer control a continuing issue and no simple answers exist.

An examination of the funding sources will indicate the complexity of management and financial strands that must be taken into account.

For BCIL, the first year of the program requires integration of several sources of funding:

1. a Medicaid per diem contract
2. a $5,000 bank loan
3. a grant from the Massachusetts Rehabilitation Commission
4. a small grant from the Tristate Regional Medical Program.
5. Supplemental Security Income.

Before the first residents were taken in, BCIL had a preliminary contract with Medicaid. The contract specified a per diem rate of $20 that required a state Rate Setting Commission review to finalize. Prior to the review, Medicaid set and paid a rate on an emergency basis. One month after BCIL began, this rate was confirmed by the rate setting commission and that rate prevailed for the first year.

Medicaid participates in BCIL's transitional and community living programs by reimbursing BCIL for personal care services rendered to Medicaid recipients. Medicaid requires BCIL to establish and maintain a program of outreach and identification of potential candidates for independent living and to locate and arrange appropriate housing and community support services.

In the original Medicaid contract, residents of transitional housing received $12 per day for personal care services and BCIL received $8 per day for administrative overhead and consultants (The rate-setting commission has since increased the basic per diem rate from $20 to $24.). Residents of community living receive approximately $14 per day for cluster living and $16 per day for those in independent living arrangements. While the Medicaid program provided support for individuals within the BCIL program in terms of a per diem rate for PCA's and medical consultation, it did not provide program support such as supporting staff salaries.

Because of a three-month lag in time in supplying these funds, BCIL plunged into the red in January, 1975, only four months into the program. As the corporation did not have a credit rating, a bank loan for $5,000 was taken out in the corporations name with four individual co-signers. This loan was repaid in June, 1976.

When it was six months underway, and cognizant of some of the financial problems ahead, BCIL submitted a proposal for an initial grant from the Massachusetts Rehabilitation Commission. The grant was to be used for such specific items as operation of a van, some equipment, and initial staff salaries (director, secretary and daytime personal care coordinator). The grant began in July, 1975. The money came from MRC in two ways: through the Vocational Rehabilitation counselor's office, and through the Comprehensive Employment and Training Act (CETA). All told, MRC supported BCIL with funding for initial staff (executive director, secretary, daytime personal care coordinator), equipment (purchase, modification, and maintenance of a van &supplies (call systems, tools, and supplies for water closet repairs). The director's and secretary's salaries were paid out of the Vocational Rehabilitation Counselor's office as positions within his office. These individuals were actually employees of MRC and the positions were donated to BCIL. The daytime personal care coordinator was paid by the CETA program through MRC.

In addition, the MRC and other state vocational rehabilitation agencies pay for college tuition, room and board costs up to $800 per semester for their respective clients. Books, supplies, and transportation to the program are also funded by vocational rehabilitation agencies. For many residents, vocational rehabilitation provides an additional source of assistance with BCIL room and board payment. To assure a smoothly running educational program, a rehabilitation counselor from each region works with his clients and establishes an Individual Written Rehabilitation Plan (IWRP). This plan outlines the educational and/or vocational goals of the resident.

With a continuing need for funds to pay PCAs, one of the BCIL board members learned of funds available from the Tristate Regional Medical Program. Originally earmarked for the New England Spinal Cord Injury Foundation, the thousand dollar grant was made available to BCIL.

The third principal source of support came in the form of Supplemental Security Income (SSI). In January, 1974, the federal government began mailing monthly payments to people in financial need who were 65 or older or who were blind or disabled. The program assures a basic cash income for those eligible who have little or no regular cash income and do not own much in the way of assets that can be turned into cash. The basic federal payment nationwide assures that each eligible person will have an income of at least $167.80 a month and each eligible couple at least $251.80. Payment may be reduced if people have other income. The social security office provides information about payment levels. Many BCIL residents use the basic SSI grant to pay the room and board costs of living at BCIL. Most transitional housing residents qualify for SSI, as do many of the independent housing residents.

In addition to these sources of hard and soft money, people from many walks of life provided in-kind services. The total consultant staff (nurses, occupational therapists, physical therapists, psychologist, and physicians) provided professional services without compensation. One LPN who worked full-time at BCIL received some salary but also contributed many services without reimbursement. The Boston University staff also contributed in-kind services. The dean of Sargent College of Allied Health and an individual from University Housing donated much valuable time and knowledge. The Director of Buildings and Grounds also contributed much in the way of room modifications. The Massachusetts Easter Seals Society provided in-kind services of a physical therapist.

Management Requirements. The requirements of the management of BCIL include developing, setting, and monitoring policy; raising funds from various sources; hiring the executive director; establishing community support; and serving as a resource to staff and residents.

During the first years, BCIL management was somewhat chaotic, frankly more reactive rather than planned. The financial integrity of BCIL had always been a problem, but there had never seemed to be time to deal with it. The original financial management was run by a checkbook, without budgets or plans. On the positive side, BCIL management did establish and has maintained good external relations by direct ties through the Board. These good external relations have helped BCIL to obtain grants and community support.

In addition to keeping up with the paperwork required to maintain smooth financial operation, staffing BCIL involved juggling medical, allied health, vocational, administrative and other supportive personnel.

BCIL's original staff consisted of a director and a part-time bookkeeper who were paid by Massachusetts Rehabilitation Commission, and a consulting team of a physiatrist (specialist in Rehabilitation Medicine), a psychologist, a nurse, an occupational therapist, and a physical therapist. The consulting team assisted in determining the support service needs of each BCIL resident. Legal counsel was provided by MRC.

Later additions included an assistant director who acted as a personal services coordinator and alleviated much of the workload and day-to-day pressure on the director. As paperwork mounted a full-time secretary was added in the third year.

The present administrative staff includes an executive director, a personal services coordinator, a part-time bookkeeper, a secretary, and a van driver. Other supporting BCIL staff includes a housing adaptation specialist (occupational therapist) to coordinate all services pertinent to a program participant's independent living requirements. A nurse provides consultation, training, and medical support services to program participants, personal care assistants, and other staff members. The daytime attendant acts as a PCA back-up during the day and assists program participants in activities of daily living. The Night-time attendant is on call during the night to cover emergencies and to provide assistance when necessary. Responsibilities of the Personal Care Assistant are outlined in a subsequent chapter.

The majority of both the Board of Directors and the staff are persons with disabilities. Thus "consumers" are presently involved in all levels of BCIL activity--in the administration of the Center, in the planning of needed services, in program development and implementation and in decision-making--and are committed to developing and refining a community-based independent living program that best meets the needs of disabled persons.

SUMMARY

There were times during the first nine months, after the conception of the idea, when the co-founders had real doubts that the program could be developed. The first student who entered the program in September, 1974, ended those doubts. During the first year, some of the early board members and staff had doubts about the fiscal stability of the organization. BCIL is now in the black.

There were some doubts about BCIL's managerial stability, with major changes in the board and staff, yet the dozens of disabled individuals now living independently outside nursing homes and back bedrooms reflect BCIL's successful programming. Some have questioned how BCIL can be viewed as a "model" program that others might replicate. Hindsight does show lack of managerial and financial sophistication. As the first Center for Independent Living in New England, BCIL's development presented difficult attitidinal and bureaucratic barriers. The three CILs that have developed since and the four more that are in various stages of development around New England have benefitted by both BCIL's mistakes and its precedents.

The co-founders' original objectives has been achieved. The Boston Center for Independent not only exists, it enables persons who were previously institutionalized, to bridge the gap to independent living in the community. BCIL residents have experienced an improvement in the quality of their lives. BCIL has succeeded in involving consumers, including BCIL residents, in the day to day management of the organization. A major BCIL success has been establishment of a hard money program where substantial funding is assured and not solely dependent on temporary grants. Another BCIL success has been broadening its scope to include a community living program, thus enabling BCIL to serve even more people than originally anticipated.

One indication of BCIL's impact is the fact that so many different groups are asking BCIL to lecture, advise and consult with them. BCIL has provided technical assistance to such diverse agencies as Medicaid, Departments of Vocational Rehabilitation, and Housing Finance Agencies. BCIL staff have also assisted a number of groups interested in establishing CILs, not only in New England, but in states like Michigan, New York, and Maryland and Washington, D.C.. Lectures and demonstrations have been given to students in allied health programs, and a number of organizations have invited BCIL to discuss transitional housing. BCIL staff members serve on a statewide committee in Massachusetts, the Interagency Committee on Independent Living, which is now developing a state policy on participant-directed personal care services.

The county and state hospitals where many disabled individuals were living before coming to BCIL were costing well over $100 per day. Medicaid now only pays a small portion of that for the same individual to BCIL. The climbing costs of health care could be a final blow or a growth incentive to the CIL movement. Medical progress will continue to produce more and more severely physically disabled individuals who will require personal care assistance on a daily basis. These persons will continue to gravitate to hospitals and nursing homes as long as cheaper alternatives are not available to the state. The key words are "cheaper" and "available."Centers for Independent Living must remain available in every community. Cost controls must be built in to insure that they continue to represent a less costly alternative than nursing homes and chronic care institutions. If it is cheaper to warehouse disabled individuals in such institutions, then only eternal vigilance by the handicapped consumer organizations will prevent this from happening. If, on the other hand, the CIL movement can offer a cheaper alternative to the system, then the institutional system, and state governments will welcome and support the CIL alternative.

Legislation and regulations can be altered to make it easier for centers of independent living to be developed. Difficulty with recent legislation and regulations include:

1. An inappropriately large emphasis on medical input and supervision; and

2. An orientation toward institutional providers for service, whether program management or personal care services.

Regulations are needed which will encourage the provision of funds directly to the disabled individual for use in hiring and reimbursing his or her own personal care provider. This would reduce agency overhead and increase accountability of the care provider directly to the disabled person.

Legislation to provide "front money" for starting new centers for independent living is necessary.

HUD's new Office for Independent Living may help with housing.

Funds for personal care assistance may come from HEW's Medicaid or Social Services programs. HEW's Rehabilitation Services Administration gave Centers for Independent Living a boost in their manual Chapter 25 on Policy Development Consultation. Generally, the chapter lays out optional methods for consumer involvement in the planning, delivery, and evaluation of rehabilitation services. Specifically it presents the following as one of the areas where consumer representatives should work

closely with the state vocational rehabilitation agency's Director and his or her representatives:

> Assistance in the establishment of specialized facilities and programs to be operated by consumer and other groups through funding by the State agency, to meet the special needs of the severely disabled applicant or client such as peer counseling, centers for independent living, halfway houses, and other transitional living arrangements, transportation and post-employment services.

The Comprehensive Needs Study of Individuals with Most Severe Handicaps (Urban Institute 1975) presented "the setting up of consumer run self-help organizations to fill vital gaps in the disability service delivery system" as a major policy option for implementing rehabilitation for independent living.

> Our findings seem to indicate that one of the major reasons why VR rejects clients for severity is that they lack motivation. One of the factors we find in persons with severe disabilities is lack of appreciation of their own worth. Whether it is the long period of recovery from depression due to the crippling effects of a serious accident, or the young person for the first time coming out from under the overprotective environment of the home, not to mention the "attic" cases one still runs across, the severely disabled person needs role models, examples, energizing of himself to be willing to meet the difficult job of not being dependent. Public agencies are staffed with professionals. In many cases they have little time and large responsibilities. Most often they meet not with people but with clients, not with peers but with the disabled.
>
> Where does one go if one is quadriplegic in an electric wheelchair to find a job, housing, transportation, friends, and love? Not to a public agency.
>
> But there is a reservoir of strength in a group, where some, perhaps, may have "made it". Banded together they often get concessions from public programs or from reluctant political figures. They can persuade a mayor to assure that at least all new curbs will have curb cuts, or a governor to forcefully address requirements for accessibility in buildings constructed with public funds.

They can swap tales about attendants, find people to repair appliances and other devices.

We speak here of no ghetto of the disabled but of a mechanism of self-help. This type of organization can be seen as a resource to public agencies. Counselors seek them out for help with an individual; they, in turn, pressure the agencies to do more than they might for given individuals. A number of such programs are already in various stages of development. Perhaps the best example is the Center for Independent Living in Berkeley, California.

CIL grew out of the Physically Disabled Student Program at the University of California, Berkeley, in 1972. It is staffed almost entirely by people with severe disabilities. As a self-help group they have an aggressive belief that the blind and disabled have a right to be fully integrated into the community. One of their primary methods is the development of peer group support, peer counseling, and peer role modeling. As activists, in addition to being advocates, they press freely on the reluctances and limitations of legislative law-making bodies and on tradition-bound agencies whose services focus or array is adequate to meet their needs. They set up and provide services themselves, since for many of the severely handicapped the services required are not in the domain of any given agency; instruction in home remodeling, for example, or the assurance of equipment repair, or an inventory of experienced attendants.

Then, too, there are areas which many public agencies will not easily touch, such as sex counseling for the severely disabled. It is their disabilities, their lives, their passion which will insure continued pressure on social agencies to make their needs felt and met. It is unlikely that any public agency could sustain such a role.

While not all such programs need be organized and operated as CIL is, public policy-makers should investigate the potential of such a model for filling in this needed function in the rehabilitation system.

12

In May, 1977, advocates for Centers for Independent Living were well received at such diverse meetings as the Council of State Administrators of Vocational Rehabilitation, the American Coalition of Citizens with Disabilities, and the White House Conference on Handicapped Individuals.

The climate appears ripe for a major new federal legislative thru for establishing a rehabilitation for independent living program. In the past four years the percentage of VR directors supporting rehabilitation for independent living programs has climbed from 60% (NRA, 1973) to 75% (Urban Institute, 1975) to 92% (CSAVR, 1977). President Carter, in his position paper "Jimmy Carter on Americans with Disabilities", stated that "We must broaden the traditional concepts of rehabilitation to include independent living as a supported rehabilitation objective."

WORCESTER AREA TRANSITIONAL HOUSING, INCORPORATED

AN INDEPENDENT LIVING PROGRAM: ORIGINS, DEVELOPMENT AND COMMUNITY INVOLVEMENT

By Melanie Tillmanns, Executive Director

February 4, 1980

TABLE OF CONTENTS

Introduction i

I. Origins and Development 1

Transitional Housing 2

Community Based Independent Living Program Fee-For-Service 5

Community Based Independent Living Program Title VII, Part B 6

Housing Development 6

Job Training and Development 8

II. Priorities and Methods for Developing Interagency Relations and Community Resources 10

III. Philosophical Basis 12

Ms. Tillmanns is the present executive director of Worcester Area Transitional Housing, Incorporated. She has a master's degree from Assumption College, and has been employed by the Department of Public Health, Mental Health, and was the first Massachusetts Rehabilitation Commission counselor to the residents of W.A.T.H.

WORCESTER AREA TRANSITIONAL HOUSING, INCORPORATED

AN INDEPENDENT LIVING PROGRAM: ORIGINS, DEVELOPMENT AND COMMUNITY INVOLVEMENT

Worcester Area Transitional Housing, Incorporated (W.A.T.H.) is a private, non-profit organization formed in April of 1975 for the purpose of developing independent living alternatives for individuals with a severe physical disability, especially those residing in institutions or at risk of institutionalization. The first program component, Transitional Housing, began in June of 1976 when the first residents entered the nineteen (19) dormitory-style apartments. Since that time, W.A.T.H. has added three (3) other service programs and works with an average of 125 people per month. The basic service areas are Transitional Housing, Community Based Independent Living Programs, Job Training and Development, and Housing Development.

The following description of this agency will be presented in three parts:

1. Origins and Development
2. Priorities and Methods for Developing Interagency Relations and Community Resources
3. Philosophical Bases

This presentation is intended to convey the philosophical and practical orientation of all W.A.T.H. programs; Independent Living is a right and responsibility of the community and its members as a whole, not just one agency.

Our community is the city and county of Worcester, Massachusetts. Worcester, located in Central Massachusetts, has a population of approximately 175,000 individuals and the county nearly 500,000. Business is focused on manufacturing, insurance and banking industries, and a variety of educational and medical facilities are available.

This summary will mainly present the growth of W.A.T.H. and the community in developing independent living services. There were, are, and will be problems. We, so far, have maintained the commitment and support to continue and to see change.

I. ORIGINS AND DEVELOPMENT

To clearly portray W.A.T.H. interrelations with other community resources, the description of each program component will be divided to show those services provided directly by W.A.T.H. staff, and those coordinated through inter-agency agreements or availability.

Transitional Housing - Direct Services

The purpose of transitional housing is to assist severely physically handicapped individuals to leave nursing homes, hospitals and dependent living situations and to learn to live independently in the community. It is a residential program with a capacity for nineteen (19) individuals. To meet funding eligibility, participants must be at least 18 years of age, severely physically handicapped (wheelchair mobile), emotionally and physically stable, self-directive, and require physical assistance for daily living. Transition from this program to independent living is anticipated in nine (9) months. Primary services include independent living skills, training in areas such as health maintenance, personal care assistance management, budgeting, transportation, advocacy, housing, etc. Aid in meeting physical needs is provided by Personal Care Attendants (P.C.A.'s).

The personal care assistance system is consumer directed. Residents are expected to learn their own physical needs and P.C.A. recruitment and management skills. Through employment of personal care assistants, physical needs are met at transitional and later in one's own permanent residence.

When Transitional Housing began direct funding for services was from two (2) sources; Title XIX from the Department of Public Welfare (DPW) on a per diem per resident basis, and from an Innovative and Expansion Grant from the Massachusetts Rehabilitation Commission (MRC). Allocations of funds for the original program were as follows:

Personal Care Attendants	DPW Title XIX
Administrative Services	DPW Title XIX
Director	MRC Innovation & Expansion
Bookkeeper	MRC Innovation & Expansion
Registered Nurse	MRC Innovation & Expansion
Equipment & Furniture	MRC Innovation & Expansion

During the next two (2) years, other staff were added; a secretary through C.E.T.A. (Public Service Employment), a part-time education coordintor through the Massachusetts Rehabilitation Commission (MRC) Innovation and Expansion Grant. Allocation of funds available through the MRC I & E Grant to other staff was accomplished through the increase and stabilization of the resident per diem rate from Title XIX. Also through MRC funds a van was purchased to provide transportation for residents who were eligible for MRC.

Currently, the service and administrative staff of the Transitional Housing Program are funded almost entirely by the Department of Public Welfare (DPW), Title XIX per diem with the following staff receiving some portion of salary from this source:

Personal Care Attendants	100%
Independent Living Program Director	
Registered Nurse	
Education Coordinator	
Executive Director	
Financial Manager	
Secretary	

Residents in the program pay for their rent and food from their disability benefit incomes; SSI, SSDI, V.A., etc.

Transitional Housing - Interagency and Community Resources

The goal of Transitional Housing is to encourage community living and the individual's ability to get needs met in the community. Examples of services used by residents include, but are definitely not limited to, educational/vocational, rehabilitation and housing. Formal relationships with other service agencies vary with frequency of use and importance of the service.

A primary resource for educational and vocational services is the local Massachusetts Rehabilitation Commission (MRC) counselor and all residents are referred to MRC. Since the program's inception, a designated liaison counselor has participated as a member of the interview team for potential residents, and the monthly review team. Through their status as MRC clients, residents may become eligible for services ranging from pre-vocational evaluations through college tuition. These plans can be continued when an individual

moves to their own home in the community. Other educational and vocational resources are the Adult Learning Center (for high school diplomas via GED), C.E.T.A. and various junior and four-year colleges.

Primary needs we have found for physical rehabilitation services are basic medical coverage, occupational, physical and speech therapies and adaptive equipment. Residents are assisted in finding and developing a relationship with a primary care physician. Occupational, physical and speech therapies are provided at community based out-patient rehabilitation centers. As part of the occupational therapy evaluation, adaptive equipment may be recommended. Funding for therapies and equipment is through the individual's medicaid or medicare health coverage, or from MRC as part of evaluation and restoration services. Private organizations such as the Muscular Dystrophy Association have also provided equipment.

The Central Massachusetts Rehabilitation Center of Worcester offers two (2) services especially important to residents. These are a wheelchair clinic at which the consumer, a physiatrist, physical therapist and wheelchair vendor(s) are present. This intensive evaluation technique is used to facilitate the consumer's ability to get a wheelchair fitted to meet their physical needs and lifestyle. Also, this center offers a driver education program for a range of physically handicapped individuals who need training in specially modified vehicles.

A major resource for financial assistance with housing is the Section 8 housing certificate, through which an individual pays 25% of income for rent in a privately owned apartment that meets fair market requirements. Representatives of the Worcester Housing Authority meet with residents to determine their eligibility and to do re-evaluations. This process helps individuals to understand tenant responsibilities and provides an invaluable resource for finding permanent housing in a market where the need for barrier-free housing far exceeds the supply. W.A.T.H. has worked with the Worcester Housing Authority to modify their Section 8 orientation program for all individuals needing barrier-free housing. Assistance for housing modification comes from the MRC and, occasionally, from individual and family funds.

W.A.T.H. residents can also benefit from community recreation, entertainment, public libraries, legal services and the range of activities available

to the residents of the city. The barriers to participation and receipt of services tend to be transportation and physical accessibility. W.A.T.H. staff and residents are encouraged to advocate and to assist the community in developing greater accessibility.

Community-Based Independent Living Programs

Fee For Service - Direct Services

The purpose of this program is to assist individuals residing in the community in developing and using their independent living skills. Training and evaluation cover medical and non-medical issues, including evaluations for P.C.A. services, health maintenance, housing, transportation, etc. This program began on January 1, 1979. The geographical service area is Worcester County.

Funding is a fee-for-service basis from DPW, Title XIX for medical services and by MRC for non-medical. A state funded P.C.A. contract, with the Massachusetts Rehabilitation Commission, covers evaluation and P.C.A. payments for those individuals who are employed and no longer eligible for medicaid (Title XIX).

Staff which provides these services are the registered nurse, occupational therapist and education coordinator. Fees are intended to reflect administrative costs for bookkeeping and management. A major bookkeeping function is the processing of P.C.A. payments, which under Title XIX Regulations, cannot be directly reimbursed to consumers. A major need for development in the P.C.A. system is the speed and promptness of processing funds from the Department of Public Welfare.

Interagency and Community Resources

All of the resources mentioned in the description of the Transitional Housing Program may be used, but the availability varies considerably from town to town. It is the responsibility of the staff and participant to identify and advocate for service in their area.

Community Based Independent Living Program
Title VII, Part B - Direct Services

In October of 1979, W.A.T.H. became a recipient of a portion of Independent Living funds awarded to the Massachusetts Rehabilitation Commission under Title VII, Part B. The primary services of this program are outreach, advocacy and skills training to those severely physically handicapped individuals who may be able to live more independently, but have been considered ineligible for vocational rehabilitation services. The service area is Worcester County. Staff responsible for this program are:

Community Advocates
Independent Living Program Director
Executive Director
Secretary

The community advocates are fully funded under this program; other staff salaries are proportioned.

Interagency and Community Resources

Previously mentioned resources basic to independent living will be used. A main focus of this program is identifying eligible individuals and new resources and planning for coordination of independent living services in the community. Cooperation has been sought from other service agencies, and long-term care facilities to identify referrals. A planning group has met with representatives of groups and agencies concerned with mental health, developmental disabilities, speech and hearing, epilepsy and severe physical disability. This group hopes to meet once a month to explore resources and identify some priority needs within Worcester County.

Housing Development

Throughout its history, W.A.T.H. has identified the lack of barrier-free housing as a major obstacle to individuals achieving and maintaining an independent life style. To assist in meeting this need, W.A.T.H. has applied to state and federal sources for funding for actual construction of housing

units which are designed to be free of architectural and communications barriers. To date, funding has been awarded from two (2) sources; 689 appropriations for the Commonwealth of Massachusetts and from 202 appropriations of Housing and Urban Development (HUD).

The Massachusetts Legislature has appropriated specific funds for the development of housing for the handicapped. This program, 689, is coordinated by the Office of Communities and Development, and requires a four-member affiliation agreement between Communities and Development, a local Housing Authority, the Massachusetts Rehabilitation Commission and a sponsor, such as W.A.T.H. W.A.T.H. is currently sponsoring two (2) 689 programs, one (1) for twenty-four (24) apartment units and another for eight (8), and has begun negotiating for affiliation with two (2) other housing authorities.

The HUD program, under 202, is also designed for the development of housing for the handicapped. W.A.T.H. is in the process of developing forty-eight (48) units of barrier free apartment housing in the City of Worcester under this program.

Almost all W.A.T.H. staff, board members and many program participants have been involved in activities related to this housing, submitting applications, consulting on design and coordinating the development teams. Unfortunately, no mechanism for funding for the sponsor agency i.e. W.A.T.H. has been identified and implemented. Active planning is being done in this area, so that relatively small non-profits can continue and maintain these development efforts.

Interagency and Community Resources

The development of housing, either by new construction or rehabilitation, requires extensive coordination of agency and community resources. Formal agreements of substantial support are needed from the local Housing Authority, the Office of Planning and Community Development or other city planning office representative of city or town management, local consumer groups, local legislators, local rehabilitation and service agencies, the state planning agency (Office of Community & Development) and the Massachusetts Rehabilitation Commission, to name a few.

Community and neighborhood resources are reviewed for their ability to offer a livable neighborhood for prospective tenants. Accessibility and availability of stores, transportation, educational and employment opportunities, recreation and social rehabilitation and medical services are all considered.

Job Training and Development - Direct Services

The Job Training and Development Program began in April of 1977. The goals are to assist individuals in learning the skills necessary for a specific job, and obtaining employment. Participant eligibility is determined by the existence of a physical disability, C.E.T.A. income requirements, and preparedness for training placement. Funding is from the Comprehensive Employment and Training Act (C.E.T.A.), Title II B.

The staffing includes the following:

Program Director
Job Developers
Job Counselors
Secretary
Bookkeeper, part-time

Direct services provided by W.A.T.H. include assessment and orientation, follow-up, job development and consultation to employers regarding job modifications and general accessibility. The job training is provided via a formal agreement with a business or industry whose supervisory staff does the instruction in skills necessary to the job. This training is done at the actual job site. Trainees are paid a stipend through the C.E.T.A. Grant. Staff maintains contact with the trainee and employer to review progress and determine the trainee's readiness for an unsubsidized position.

Interagency and Community Resources

The Job Training Program uses three (3) main resources; comprehensive vocational and rehabilitation assessments, the city's Special Mobility Impaired Transportation System (S.M.I.T.S.) and employers. The assessments

usually four (4) week evaluations, performed at workshops and physical and occupational therapy reports can be critical to the job counselor's ability to work with a trainee in clarifying vocational goals. These assessments are usually made available by the MRC counselor or from previous rehabilitation records.

For many individuals, transportation becomes a major factor in obtaining and maintaining employment. The S.M.I.T.S. service, operated by the Worcester Regional Transit Authority and the local Age Center, operates five (5) days a week from 7:00 a.m. to 6:00 p.m., and is available to mobility impaired residents of the community for a minimal fare.

Industries and businesses which will provide training sites and jobs are the key community resource. The program's relationship with employers is based on our ability to assist employers in identifying and training competent employees. An incentive to employers has been that funding for trainee's stipends is prompt and requires minimal paperwork. A disincentive has been that many employers want to hire directly without the training period. Under the regulations of C.E.T.A., Title II B, all participants must participate in a training phase. A goal of the Job Training Program is to develop funding for direct placement.

II. PRIORITIES AND METHODS FOR DEVELOPING INTERAGENCY RELATIONS AND COMMUNITY RESOURCES

As W.A.T.H.'s purpose is to assist individuals with a substantial physical disability to live independently in the community, we make two (2) basic assumptions. One, participants in our program can live independently with a range of support services which are being, or reasonably can be, provided. Two, community resources available and often needed by all citizens of a community can reasonably be made available to its citizens who are handicapped. Since its beginning, W.A.T.H. has proceeded with identifying and maintaining relationships with existent agencies and resources and encouraging the development of new resources where none exist.

Program participants have consistently identified the following priority areas, although order of priority varies with the individual:

A. Physical Assistance with Daily Needs
B. Housing
C. Medical/Rehabilitation Services
D. Transportation
E. Education/Employment
F. Community Involvement - Recreation, Civic Organization
G. General Consumer Services - Mercantile, Legal, Psychological, Entertainment

W.A.T.H.'s participation in maintaining and developing resources involves program participants, members of the board and staff. The type of involvement varies depending upon the availability and accessibility of an existent service, the need to develop a new service and the level of decision-making authority--individual, local, state or federal.

The forms of participation with other agencies and resources vary from cooperation between staff members to formal staff representation in services to membership on various committees and boards. For example:

A. Intra-Staff Cooperation

In planning training sessions on sexuality the education coordinator requested and obtained participation of staff of the local Family Planning organization in facilitating the workshops. This arrangement provides informa-

tion to participants while familiarizing them directly with a resource available to all community residents, and increases the other agency's awareness of and need to respond to a client with a physical handicap. W.A.T.H. staff may also provide an accessibility survey in exchange for training services.

B. Formal Staff Representation

The local MRC office has selected a vocational rehabilitation counselor to be liaison to the W.A.T.H. program. This individual is a formal member of the team which interviews prospective residents of Transitional Housing and also the resident review team.

C. Formal Committee and Board Membership

Representatives of W.A.T.H. are members of various local and statewide boards concerned with implementation of 504, consumer coalitions, transportation, the general provision of human services, and employment of the handicapped. The intention is to assist in the documentation of need and accomplishment.

For issues regulated at a state or federal level, such as employment disincentives and requirements for barrier-free design, W.A.T.H. has coordinated with other Independent Living Programs in the state and program participants have presented public testimony and documented need to state and federal legislators.

In summary, interagency cooperation and coordination with other community resources are an absolutely essential responsibility and purpose of our program. Participation in community planning and awareness activities is a part of each staff members' job description, and each participants' orientation to independent living. It may be that because one resident from Transitional Housing was interviewed by a local reporter about the need for barrier-free housing that private landlords called who were willing to have ramps installed in their apartments. Or, it may mean that because of coordinated written testimony a statewide regulation was changed. Time and attention spent on interaction with the community, which we hope will become more accessible, is necessary.

III. PHILOSOPHICAL BASIS

The original incorporators of Worcester Area Transitional Housing, Incorporated adopted within their bylaws language which continues to reflect the philosophical orientation of the agency to its program participants and the community.

Policy decisions made by present staff and board members refer to those basic understandings. Three (3) items of the bylaws are particularly important in defining services and relationships to the community and program participants. These are:

1. The purpose of the organization is to develop alternatives for independent living for individuals with a severe physical disability.
2. These alternatives are to be developed within the community.
3. All recipients of services of W.A.T.H. programs (program participants currently almost 200) are members of the corporation and entitled to make nominations to the board and vote at the annual meeting.

The implications of these bylaws and the corresponding decisions which are made provide an underlying structure for the agency. The fact that W.A.T.H. is mandated to develop "alternatives" has been interpreted to mean that we understand that all individuals are not the same and do not need the same services, nor should an individual be required to accept more services than they need or want. Implementation of this policy is reflected in the range of services provided by the program. Should an individual need and want extensive involvement such as participation in Transitional Housing or a series of training sessions, this is available. Likewise, it is possible for the agency to provide only fiscal processing for P.C.A. payments with an annual re-evaluation. We will continue to develop programs which facilitate maximal independence from a service provider, if desired. However, the program seeks to maintain and substantially enhance the spectrum of independent living services available to participants as their lifestyles, health and/or community support systems change.

The decision that these alternatives are to be developed in the community stresses W.A.T.H.'s commitment to encouraging the responsiveness and development of the community so that able-bodied and handicapped individuals can choose to

live, work and play in the same places. Reflection of this policy can seen in the "on-site" nature of the job training program (see page 8) in the use of community resources and agencies for rehabilitation and educational services and the participation in community activities. However, practical compromises have been made in these areas. Development of housing through funds specified for occupancy by handicapped tenants is an example. This housing is being developed with as many family units as possible, and within residential community neighborhoods, and can assist in addressing the need for barrier-free housing. The agency must continue all efforts to encourage barrier-free construction in other private and public developments within the community.

The involvement of program participants as members of the corporation supports the basis of the agency's relationship with all recipients of services. This is a system of rights and responsibilities. The consumer-directed P.C.A. program, the training and advocacy procedures are structured to maximize an individual's options for lifestyles and service providers. Participants are also expected to accept responsibility for their decisions and encouraged to participate in programmatic and consumer issues. This participation may involve consultation on housing design, testimony at public hearings, membership on the board and advocacy by and for one's self.

The original incorporators of Worcester Area Transitional Housing, Inc., many of whom are still directors of the board, presented a thoughtful and sound set of guidelines which allow for programmatic growth within clear statements of purpose.

REPORT

National Center
for a
Barrier Free
Environment

Volume 5 Number 5

Washington, D.C.
September/October 1979

NCBFE to Develop Access Center; New Positions Available

The National Center for a Barrier Free Environment (NCBFE) has announced plans for a major expansion of its accessibility-related services. The new effort has been made possible by a contract recently awarded to NCBFE through an inter-agency funding agreement between HEW's Office of Civil Rights and the Community Services Administration. The contract calls for the National Center to develop, under its auspices, an Access Center which will become the nation's most comprehensive source of information, education, technical assistance and research on accessibility matters. The Access Center's programs will be an extension of the services which NCBFE has been providing since 1974.

According to NCBFE Executive Director Jack Armstrong, the Access Center will include a computerized information system/data bank, a telephone "Hot Line", technical assistance services and an extensive publications program. "The implementation of Section 504 of the Rehabilitation Act of 1973 is causing a tremendous demand from Federal fund recipients for information about accessibility and barrier free design," he said. "The Access Center will be designed to provide such information, as well as assistance with problems related to the creation of an accessible environment. We anticipate participation by other Federal agencies during the coming year, and the Access Center should eventually become a centralized resource which any Federal agency can use to respond to inquiries from its fund recipients. The Access Center's services will, of course, also be available to the general public." More detailed information about the Access Center will appear in the next issue of REPORT.

The development of the Access Center project will make available seven new positions within the National Center, and applications are being invited immediately. The following is a description of the positions, as presently envisioned, by area of responsibility:

INFORMATION SERVICES

Information Services Coordinator. Responsible for establishing computerized information system/data bank, developing information source network, reviewing existing materials and acquiring new ones. Will have overall responsibility for response to requests for information. Should have graduate degree in library science (or equivalent experience), with an orientation to information services and experience in utilizing a computerized data bank.

Information Specialist. Will assist Information Services Coordinator in all areas of responsibility and devote major effort to telephone "Hot Line" service and research on selected accessibility issues. Bachelor's degree in library science (or equivalent experience) preferred.

Information Services Secretary. Will process requests for information as directed by Information Services Coordinator and Information Specialist. Responsible for maintaining records of all inquiries and providing clerical support to other Information Services staff members. Excellent secretarial skills required.

ACCESSIBILITY DESIGN RESOURCES

Design Resources Coordinator. Responsible for developing a national network of technical

Continued on Page 8

NCBFE's New Address

As of October 15, the National Center for a Barrier Free Environment will be located in new headquarters in downtown Washington, D.C. The National Center's new mailing address is: Suite 1006, 1140 Connecticut Avenue, N.W., Washington, D.C. 20036. The Center's new telephone number will be announced in the next issue of REPORT.

Founding Members

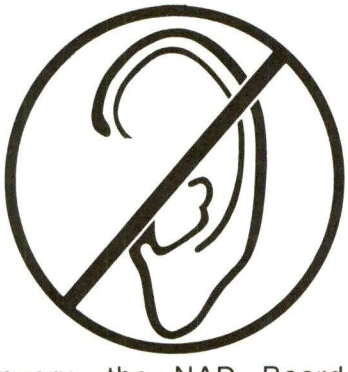
American Institute of Architects
American Society of Interior Designers
Disabled American Veterans
Gallaudet College
Goodwill Industries of America, Inc.
National Congress of Organizations of the Physically Handicapped
National Easter Seal Society for Crippled Children and Adults
National Rehabilitation Association
National Spinal Cord Injury Foundation
Paralyzed Veterans of America, Inc.
President's Committee on Employment of the Handicapped

CREATIVE CONCEPTS

Decision Near on International Symbol for Deafness

As part of a world-wide effort to increase public awareness about deafness and to assist in eliminating the communications barriers which confront people with hearing impairments, an International Symbol for Deafness will soon be approved for use throughout the world. The major push toward the development of an International Symbol came from a task force organized cooperatively by the National Association of the Deaf (NAD), Gallaudet College, and the Model Secondary School for the Deaf of Washington, D.C. The task force has been working together with groups from other countries for more than two years in an attempt to reach agreement on a universally-recognizable symbol. The culmination of their work is now within sight.

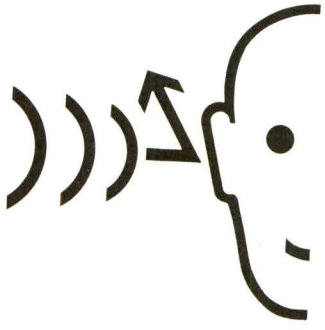
SYMBOL A



Last January, the NAD Board of Directors endorsed a conceptual design symbol (symbol A, shown on this page) for presentation and recommendation to the VIIIth World Congress of the World Federation of the Deaf, which was held in Bulgaria in June. NAD also stipulated that symbols B and C, which demonstrate "the positive side of deafness" be presented to the World Congress as secondary suggestions. After reviewing designs submitted by a number of countries, the delegates to the World Congress decided that one of the three symbols recommended by NAD will become the officially-endorsed International Symbol. Representatives of 66 participating nations are to communicate their preferences no later than this November, and the final selection will be based on those responses.

The movement to develop an International Symbol for Deafness grew in large part from the successful use of the International Symbol of Access in creating public awareness about the accessibility needs of people with physical disabilities. Deafness is still the most invisible disability, and much too little attention has been given to the communications barriers which confront people with hearing impairments. The widespread use of the International Symbol for Deafness should help in a variety of ways to reduce the social isolation which deaf people often encounter.

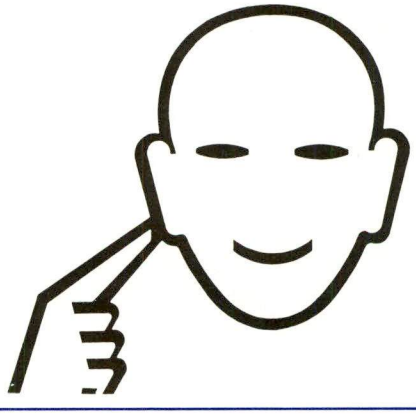
SYMBOL B



As presently envisioned, the new Symbol could be used at the discretion of a person having a hearing impairment to make others aware of his or her impairment. Examples of such use would be the appearance of the Symbol either on a card in the person's wallet or on a lapel pin. The symbol could also be used in public places to indicate the availability of TTY's or people with knowledge of sign language, to highlight movies or television programs with captions, etc. The list of uses will undoubtedly grow as the Symbol gains international recognition.

To obtain further details about the development and implementation of the International Symbol for Deafness, write Herbert C. Bounds Pearson, Model Secondary School for the Deaf, Kendall Green, Washington, D.C. 20002.

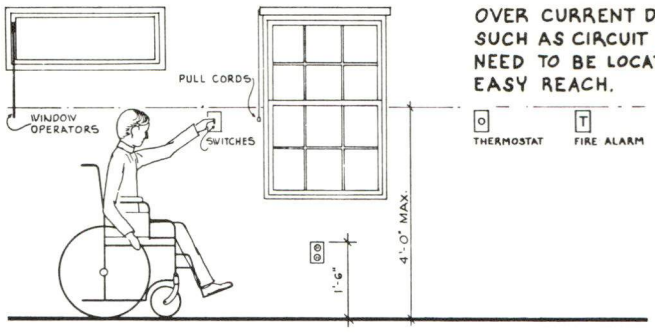
SYMBOL C



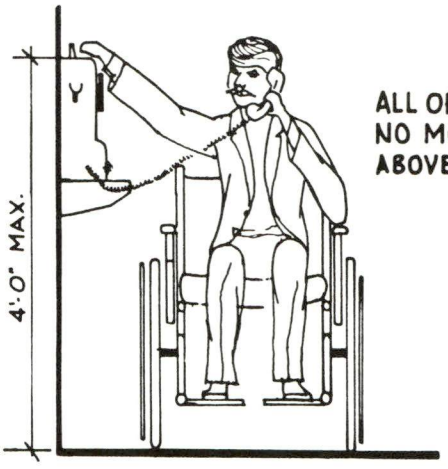
REPORT is published bi-monthly by the National Center for a Barrier Free Environment, Suite 1006, 1140 Connecticut Avenue, N.W., Washington, D.C. 20036. The contents are for informational purposes only and do not necessarily represent the opinions of the Board of Directors or the membership of the National Center. Inquiries and/or information should be addressed to Jack Armstrong, Executive Director, at the address shown above.

DESIGN DIRECTIONS

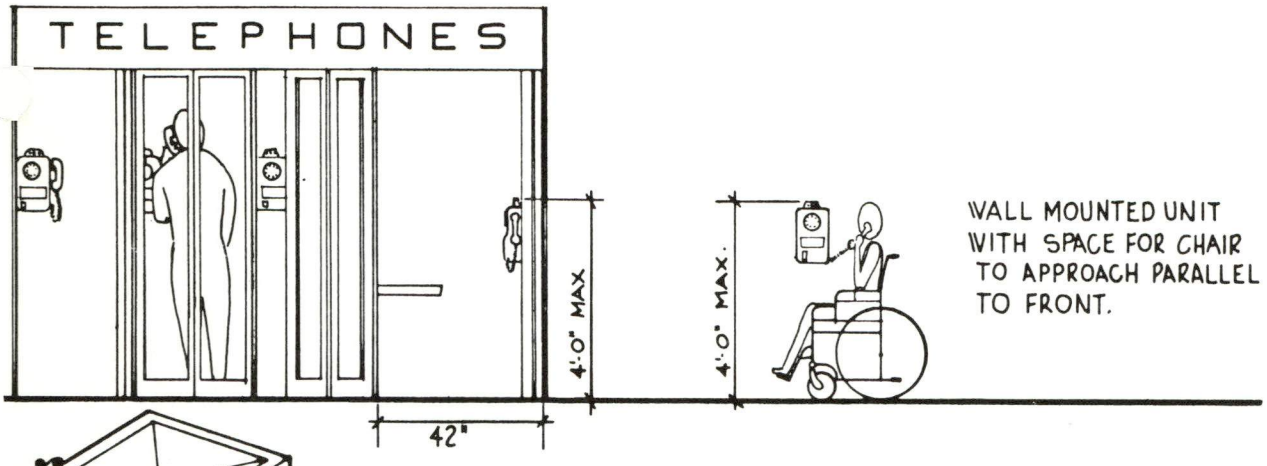
The proper placement of controls and fixtures is essential in order to insure that building interiors are usable by people in wheelchairs. All switches and controls for light, power, heat, ventilation, fire alarms, draperies, windows and doors should be placed no higher than four feet (48″) from the floor. Accessible telephones should also be mounted so that the operating mechanisms are no higher than 48″, and space should be provided to allow a wheelchair to approach parallel to the phone. In order to be usable by both disabled and able-bodied people, water fountains should be mounted so that the edge of the basin is no more than 36″ above the floor. If the water cooler is higher than 36″, a small fountain with the rim of the basin no higher than 30″ should also be provided. The accompanying drawings and specifications are accurate interpretations of accessibility requirements pending the final publication of the revised ANSI Standard. They are reprinted from "An Illustrated Handbook of the Handicapped Section of the North Carolina State Building Code".



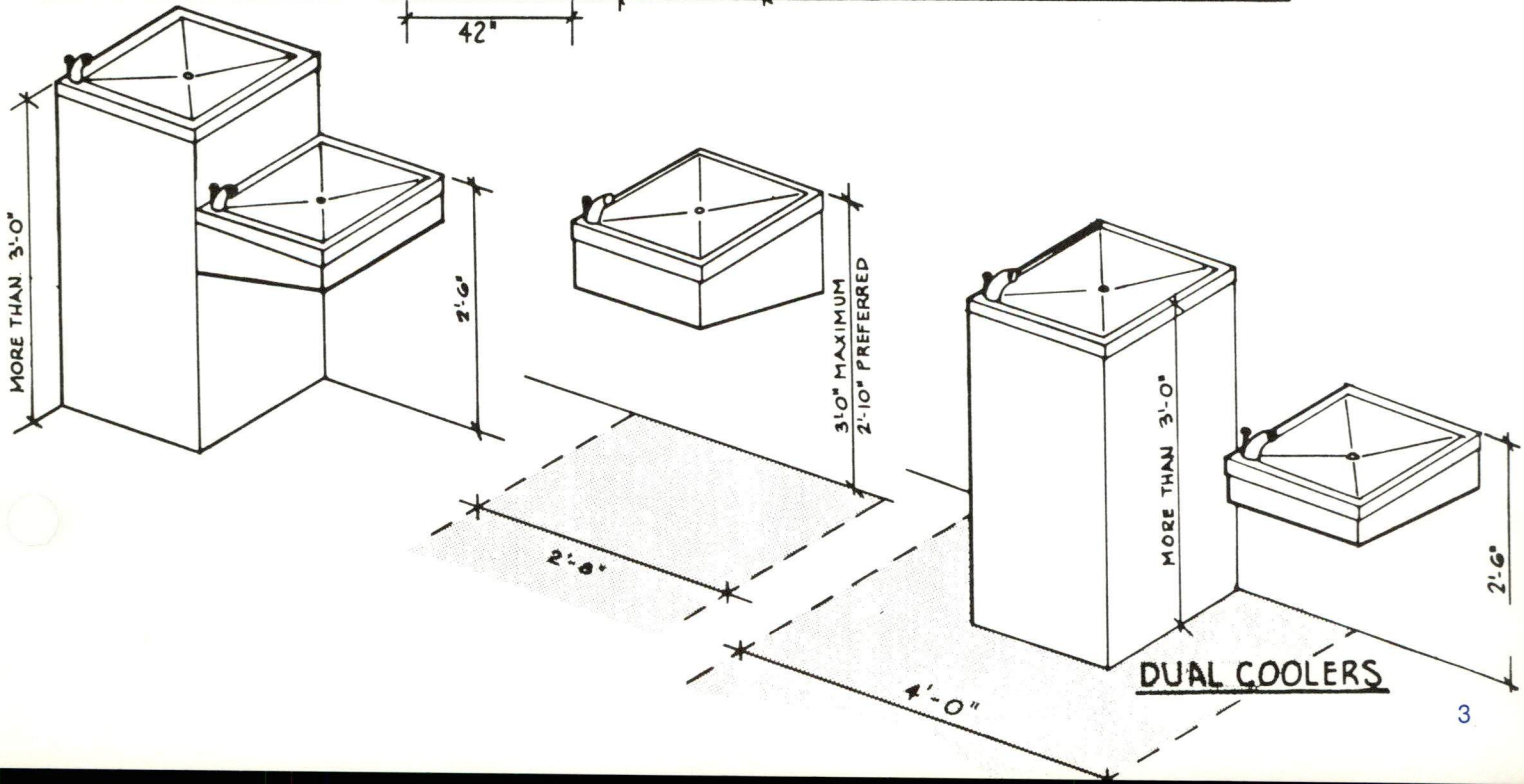
OVER CURRENT DEVICES, SUCH AS CIRCUIT BREAKERS, NEED TO BE LOCATED WITHIN EASY REACH.



ALL OPERATING MECHANISMS NO MORE THAN 4'-0" ABOVE THE FLOOR.



WALL MOUNTED UNIT WITH SPACE FOR CHAIR TO APPROACH PARALLEL TO FRONT.



DUAL COOLERS

ACCESSIBILITY ACTION

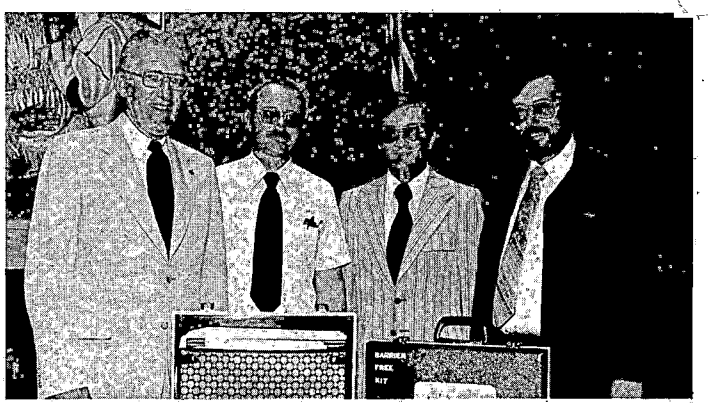
1980 International Meetings. Two major international gatherings at which accessibility issues will be important topics of discussion have been scheduled for 1980.

Houston, Texas, will be the site of the Third International Congress on Physically Handicapped Individuals Who Use Assistive Devices. The theme of the Congress, which will be held from April 10-15, is: "Improving the Quality of the Handicapped Person's Community Life: Today and Tomorrow". The program will include issue forums on a wide range of topics (including environmental design, mobility, living arrangements, and equal access to full citizenship), plenary sessions, roundtable groups, paper sessions, a film festival and an exposition area. An additional feature will be a design competition open to both students and professionals. For detailed program information, write: William A. Spencer, MD, President, Scientific Program Committee, 1333 Moursund Avenue, Houston, Texas 77030.

The 1980 World Congress of Rehabilitation International will be held from June 23-27 in Winnipeg, Manitoba, Canada. The week-long program will feature plenary sessions, seminars, sectional meetings, workshops, an exhibition and a photography contest. Included on the program are extensive discussions on means of integrating disabled persons into education, housing, transportation and the workplace. Information about the Congress is available from the Congress Secretariat, 1980 World Congress, c/o Canadian Rehabilitation Council for the Disabled, P.O. Box 1980, Winnipeg, Manitoba, Canada R3C 3R3.

Access Hotline. The City of Charlotte, North Carolina, is taking a new approach to the traditional community access guide. Rather than publish a directory, three organizations are working together to develop a 24-hour telephone hotline service with accessibility information on all types of facilities throughout the community. The service, which will be operational next March, will be maintained by the Charlotte-Mecklenburg Information and Referral Service and will give a caller specific information about accessibility features in restaurants, office buildings, department stores, specialty shops, parks, churches and other public places. Businesses considered accessible by the hotline service will display the International Symbol of Accessibility on the premises, as well as in newspaper and yellow page advertisements. Sponsoring organizations for the service include the Mayor's Committee on Employment of the Handicapped, North Carolina Rehabilitation Association, and the Metrolina Chapter of the National Spinal Cord Injury Foundation. For additional information about the hotline, write: Peggy Matheny, Mayor's Committee on Employment of the Handicapped, 600 East Trade Street, Charlotte, North Carolina 28202.

Wyoming Governor's Task Force. Governor Ed Herschler of Wyoming has set in motion a series of activities designed to ensure that all state owned and leased buildings are accessible to persons with disabilities. After a survey of state agencies indicated a lack of awareness about accessibility requirements, the Governor's 504 Task Force held seminars around the state, distributed a brochure explaining the impact of Section 504, began to publish a quarterly newsletter, and offered technical assistance services to state agencies. During the past summer, two three-member survey teams representing the Governor's Task Force made on-site assessments of more than 500 of the highest priority state buildings. Each day during the survey, photos and site reviews were mailed to a central office, where they were reviewed and assessed by a contracted architectural team. The architects estimated retrofit costs and traveled to those sites where major architectural changes were necessary. The activities of the task force have generated considerable interest from private sector businesses and organizations as well. Many private sector groups have voluntarily submitted plans for construction and/or renovation to the task force office to insure that their facilities will be accessible. For more information about the activities and plans of the Task Force, write David C. Andrews, Special Services Supervisor, State Division of Vocational Rehabilitation, Hathaway Building, Cheyenne, Wyoming 82002.



Wyoming Governor Ed Herschler (left) joins survey team members Dave Reng, Stan Torvick, and David Andrews in preparation for site visits.

New Tax Deduction Bill. Senator Robert Dole (R-Kansas) has introduced the newest and strongest bill to date concerning the extension of the tax deduction now available to businesses for making facilities accessible to disabled people. While a number of bills introduced earlier would make the deduction a permanent provision of the Internal Revenue Code (see REPORT, May/June, 1979), Senator Dole's bill—*S.1694*—would both make the deduction permanent and increase the allowable deduction in a given year from $25,000 to $100,000. The existing provision, which is considered to be an important incentive for accessibility modifications in the private sector, will expire at the end of 1979 unless it is extended by Congressional action.

News Services. Three innovative news services, designed for visually and hearing impaired constituencies, have come to REPORT's attention in recent weeks. In Denver, news items of interest to the area's deaf and hearing impaired population are made available through a TTY news service called TTY Dial-A-News. The Dial-A-News program, operated by the Denver Center on Deafness, covers a variety of available services, as well as local and national news items of interest to deaf people. The TTY service supplements a monthly newsletter published by the Center on Deafness. Equipment for the program was purchased through a major gift from the "Donate Once Club" of Rocky Flats, a division of Rockwell International. The telephone number for Dial-A-News is (303) 758-8542. For additional information, write the Denver Center on Deafness, Room 105, 2120 South Holly, Denver, CO 80222.

In New York, a radio information service is provided for an estimated 100,000 visually and physically print-handicapped adults through the In Touch Networks. Special radio receivers are provided to handicapped persons, and volunteers read newspapers, magazines and books, and give details on supermarket and department store sales, employment opportunities, community events etc. Regular features include call-in shows, radio drama, health programs and independent living courses. A new series of consumer education programs, made possible under a grant from EW, will offer tips on consumer rights, inflation-ighting shopping skills, tax deductions, insurance, tenants' rights, money management and a host of other topics. Information about the service may be obtained from In Touch Networks, Inc., 322 West 48th Street, New York, NY 10036.

The Xavier Society for the Blind offers a Deafblind News Summary which is mailed bi-weekly to deaf-blind adults. The newsletter is published in both Grade I (uncontracted) Braille and large print. Written in easy-to-read English, the Deafblind News Summary is intended to assist deafblind persons who have a limited knowledge of the English language to keep abreast of current events. A typical edition will feature basic background information on several major national and international news stories. There is no charge for the service, To receive the News Summary, or to learn more about the Xavier Society, write to Karen Jernigan, Deafblind Department, Xavier Society for the Blind, 154 East 23rd Street, New York, NY 10010.

Telephone Services. The Bell System has issued a booklet entitled *Services for Special Needs* to inform persons with hearing, visual, speech or motion impairments about telephone equipment and services which can be of assistance. The 24-page brochure presents a wide range of options for persons who have difficulty using the telephone, and it also suggests possible aids for homebound students who wish to keep up with their studies. Copies of the booklet, as well as additional information about telephone services for handicapped people, may be obtained by contacting a local Bell Telephone business office.

Accessibility Update. The National Easter Seal Society has announced plans for an "Accessibility Update" program as part of its annual convention. The program is scheduled for 9:00 a.m. on Friday, November 16, at the Philadelphia Marriott Hotel in Philadelphia. Highlights will include a preview of the revised ANSI Standard A 117.1, a discussion concerning compliance with Federal 504 regulations, and an examination of provisions for accessibility in model Building Codes. A special feature of the session will be the first presentation of the Leon Chatelain Award, which was recently established by the Society in order to recognize the outstanding contributions of individuals who are working toward the development of a barrier free environment. The award is named in honor of the late Leon Chatelain, Jr., who was one of the driving forces behind the approval of both the original ANSI Standard and the Architectural Barriers Act of 1968. Mr Chatelain, who died during 1979, served as president of both the National Easter Seal Society and the American Institute of Architects and as chairman of the National Commission on Architectural Barriers and the Barrier Free Design Committee of the President's Committee on Employment of the Handicapped. The award will be presented periodically to individuals who have provided outstanding leadership to a national effort having a positive influence on the accessibility movement. For additional information about the program, contact: Rita McGaughey, National Easter Seal Society, 2023 W. Ogden Avenue, Chicago, Illinois 60612.

Barriers Game. A board game, intended to capture the frustrations encountered by people in wheelchairs, has been developed for use as an awareness tool in schools around the country. *Barriers, the Access Game* gives players an opportunity to travel around six city blocks where they will encounter architectural and transportation barriers of various kinds. The first person to make the circuit successfully is the winner, but doing so will require that that person overcome such problems as curbs without curb cuts, inaccessible buildings, narrow doorways, plush carpeting and ramps with excessive inclines. The game does not deal with other types of disabilities. To learn more about *Barriers,* contact Message Management Consultants, P.O. Box 20010, Indianapolis, IN 46220.

Address Notations

Two articles in the July/August issue of REPORT have resulted in a number of inquiries about the addresses of organizations which were mentioned.

The address which appeared in the article about the Museum Access Planning Sources (MAPS) package was incorrect. The correct address for Skye Pictures, Inc., is: 2225 Floyd Avenue, Richmond, Virginia 23220.

The new address for the U.S. Council for the International Year of Disabled Persons is: 1156 15th Street, N.W., Washington, D.C. 20005.

PUBLICATIONS

Product Inventory. The National Handicap Housing Institute has developed a catalogue of products which will assist persons who are designing or building barrier free housing to choose intelligently among the wide variety of appliances, hardware items, bath and plumbing fixtures and other equipment necessary for accessibility. The *Product Inventory of Hardware, Equipment and Appliances for Barrier Free Design* contains more than 400 pages of listings organized into general product headings. The listings include pictures, summaries of features and approximate prices of 500 manufactured products available for residential, commercial and industrial use. Each section begins with general comments about the values and problems of the product for people with disabilities. A check-list of available features is presented for many of the products, as are evaluative comments resulting from the Institute's survey of the products. The cost of the Product Inventory is $12.00 per copy for consumers or nonprofit organizations and $20.00 per copy for professionals. Write the National Handicap Housing Institute, 12 South Sixth Street, Suite 1216, Minneapolis, Minnesota 55402.

Bibliographies and Listings, Three new listings of materials on accessibility-related topics are now available.

Transportation for the Handicapped is a 32-page annotated bibliography listing those holdings of the Institute of Transportation Studies Library at the University of California at Berkeley which refer to the transportation needs of handicapped citizens. The listing is divided into subject areas, including general information, case studies, theoretical works, design considerations, technical studies and foreign sources. The document may be obtained for $3.00 per copy from Vance Bibliographies, P.O. Box 229, Monticello, Illinois 61856.

The U.S. Library of Congress has issued two documents of interest. *Accessibility: Designing Buildings for the Needs of Handicapped Persons* is a 17-page annotated bibliography intended as an introduction to the subject for architects, administrators and other persons planning accessible facilities. It includes subject headings such as The Law, Standards, Public Buildings and Institutions, Domestic Architecture, and Travel and Transportation. *Information for Handicapped Travelers,* an 11-page reference circular, lists travel information centers and special transportation services in the United States, sources of travel information in foreign countries, and a bibliography of published travel guides. Both documents are available free of charge from the Reference Section, National Library Service for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20542.

Design for Deafness. A new booklet published recently by the Physical Plant Department at Gallaudet College offers a general orientation to the kinds of environmental modifications which can help deaf and hearing impaired persons overcome communications barriers. The 13-page document, entitled *Breaking Through the Deafness Barrier,* explains the importance of visual and acoustic factors in the environment and offers design guidelines on such matters as communication devices, emergency and warning signal systems, lighting, visual cues and the reduction of background noise. Individual copies of the booklet are available free of charge, and additional copies may be obtained for fifty cents each. Contact Thomas A. Lillis, Director, Physical Plant Department, Gallaudet College, Kendall Green, Washington, DC 20002.

Barriers Information. The Architectural and Transportation Barriers Compliance Board has made available two pamphlets to assist in the orientation process for persons who are exploring the issue of accessibility for the first time. *About Barriers* is a 23-page document which describes barriers, discusses their costs, and provides information on recent activity by the Compliance Board, the impact of federal legislation on accessibility, and available information resources. *Selected Resources for Accessibility* is a ten-page listing of sources of information on accessibility including codes and standards, design specifications, audio visuals and a variety of publications and periodicals. Both documents are available free of charge from the Architectural and Transportation Barriers Compliance Board, Washington, DC 20201.

Accessible Housing. *Wheelchair Accessibility: Opening the Door to Housing,* by Marilyn Wittmeyer and Jim Barrett, is a combination slide/tape presentation and illustrated manual which offers a thorough, yet easily-understandable orientation to the housing needs of persons in wheelchairs. It is particularly designed for persons who are new to wheelchair use and who are attempting to arrange housing opportunities for themselves. Both the slide/tape presentation and the manual clearly illustrate the basic concepts of mobility as well as specific barriers which are encountered in the typical home. Areas covered include parking, entryways, floor surfaces, room arrangements, bathroom design, and appropriate positioning of appliances, furniture, electrical controls, etc. Both the manual and the tape are available in either English or Spanish. The slide/tape presentation (with written script) may be previewed for $9.50 or purchased for $95.00, and the manual may be purchased for $4.00 from the Health Sciences Learning Resources Center, T-252 Health Sciences Building SB-56, University of Washington, Seattle, Washington 98195.

GUEST EDITORIAL

The Where and Why of the New ANSI STANDARD

by Ronald L. Mace, AIA

Ronald L. Mace, who is President of Barrier Free Environments, Inc., of Raleigh, North Carolina, is a nationally-recognized authority on barrier free design and has been actively involved in the revision process for the ANSI Standard A 117.1.

Since 1961 the basis for most building codes and agency regulations on accessibility has been the American National Standards Institute ANSI Standard number A117.1, *American National Specifications for Making Buildings and Facilities Accessible to and Usable by Physically Disabled People.* In the 17 years since its adoption, the 1961 ANSI Standard has been recognized as insufficient to meet recent needs. Most codes and regulations have, in these years, included provisions well beyond the ANSI Standard. The result of this has been a proliferation of widely differing state and federal requirements. At times these regulations apply to the same building and contradict each other. This situation puts the architect and the administrator in an untenable situation and often results in no accessibility.

Five years ago the monumental task of researching and revising the ANSI Standard, A117.1, was undertaken at the School of Architecture of Syracuse University. The idea was once and for all to find out, and include in the ANSI Standard, what is necessary as a minimum to make facilities accessible to disabled people. The goal was to produce the one uniform guiding Standard so badly needed to replace the earlier (1961) version—one which would be the basis for regional, state, and local building codes and federal agency building regulations. Five years ago, few people anticipated the complexity of the task, the broad range of human diversity or the widely differing opinions which would be encountered.

The review process through which the proposed revised Standard has gone involved 53 voting committee members representing industry, expert, professional, and consumer interest groups. In addition to expert and industry review, each of the drafts has been put out for public review. The comments have been numerous and the suggestions incredibly diverse, contradictory and controversial. Such is the way with a democratic concensus process.

Any of the many "experts" or regulatory agencies could have written a Standard in a fraction of the time had they the authority to force others to accept it and comply with it; but that is not the way a national Standard is developed.

Today after five years of research, review, negotiation, disagreement, hostility, and resolution, involving approximately $600,000 in HUD research money and countless thousands in professional, consumer, and industry review time, that new Standard is nearing completion—almost. It has received a positive vote from most of the voting review members despite their fears and concern for its overall and long-term effect. It is now in its final editorial stage.

Because of the seriousness of the new Standard's impact, we all want a complete and perfect document. These goals may be impossible. The revised Standard in its present state must not be thought of as "finished" and its development must go on. Some items have been deleted because little or no research was available to justify their inclusion. Some items remain because the reviewers conceded out of frustration with the disagreement, feeling that to hold out for perfection on one item was detrimental to the whole. Others are included because of compromises between affected groups, and most are there because research indicated that they were the best for the most people.

Some people feel the Standard is too large; some that it is not complete enough. Some question the quality of the research; some dislike the writing style or the format. Some dislike everything, and some do not understand what a Standard is.

There has been talk of starting over, talk of continuing the current development process and working for perfection. The Standard is needed now. The review committee is in agreement that it has gone far enough to be acceptable. It does not appear that the Standard can be significantly improved by continuing the current concensus process.

The Standard is needed now. The time has come to put personal preferences aside and to accept it, at least for a trial period. Since the American National Standards Institute requires that its Standards be reviewed and updated each five years, it must soon receive further review and revision. The 1961 Standard received no such update, and almost fifteen years went by in which its requirements were found to be increasingly inadequate. This new Standard is too important to let that happen again.

It is important to understand that the ANSI Standard provides only technical specifications, and that there is plenty of opportunity for those adopting it to modify and apply it as they see fit. Like all national Standards, the ANSI Standard is voluntary and only becomes mandatory when it is adopted by reference or inclusion into a law, code, or regulation. The adopting agency, building code authority, etc. has the option of adopting the Standard in whole or in part. It is also important to note that any national Standard tells one *how* to do something—not when or how many to do. The ANSI Standard (1979) tells one how to make an accessible toilet stall, etc. and recommends that a "reasonable number" (but always at least one) toilet stall, parking space, ramp, etc. be installed. The authority adopting the revised Standard must be responsible for specifying in which of the facilities under their jurisdiction the specifications must be met, and how many accessible toilet rooms, stalls, parking spaces, etc. must be installed. Although some people feel that the ANSI Standard must take this responsibility, there is no way that it could or should specify these numbers. For example, the number of toilet rooms that would be appropriate for a 1.5 million square foot government building would be totally inappropriate for a small theater.

The regulatory agency with authority for enforcement must decide what are "reasonable numbers" of accessible facilities. This must be done at the time the Standard is adopted. For example, the Architectural and Transportation Barriers Compliance Board (A&TBCB) might want to adopt the ANSI Standard and require that all federally funded facilities must have all of their spaces in compliance. On the other hand, a state building code authority might want to adopt the ANSI Standard specifications and require that only some specific spaces within buildings under their jurisdiction must be in compliance.

Handicapped people and their organizations should be involved in those decisions. Building types, local conditions, program activities, civil rights laws, and applications to new construction or remodeling will also affect reasonable numbers.

Failure of an adopting authority to specify numbers will result in only one mandatory accessible toilet room per building or will leave the decision to the architect or administrator. These agencies must not pass the buck and expect the ANSI Standard to provide all the answers. They must accept this responsibility.

Continued on Page 8

Access Center *(Continued from Page 1)*

assistance providers, establishing a reference file of all existing codes and standards on barrier free design, planning training programs for technical assistance providers and other professionals charged with implementing accessibility requirements, developing and maintaining a liaison with schools of architecture and design, etc. Should have a professional degree and experience in architecture, engineering, code developing or enforcement, or the construction industry, with particular expertise in barrier free design.

Design Resources Secretary. Will provide clerical support to Design Resources Coordinator on all areas of responsibility. Excellent secretarial skills required.

PUBLIC INFORMATION/PUBLICATIONS

Public Information/Publications Coordinator. Responsible for establishing a public information program on accessibility issues, developing an outreach program to promote use of Access Center services, editing and producing all Access Center publications, writing and editing REPORT, and planning a long-range publications program. Should have an academic degree or equivalent experience in communications, journalism, or publication design and production. Excellent writing skills are essential.

Editorial Assistant. Will assist Public Information/Publications Coordinator in all areas of responsibility. Should have excellent secretarial and writing skills, as well as some experience in public information and/or publications programs.

Knowledge of accessibility issues and barrier free design principles will be given strong consideration in the selection of candidates to fill all seven positions. People with disabilities are specifically urged to apply. All applicants must be willing to relocate to the Washington, D.C., area. Salaries for each position will be competitive with salaries for similar positions in the Washington area. The National Center for a Barrier Free Environment is an Equal Opportunity Employer.

Resumes and letters of application (including information on salary requirements) should be sent immediately to the National Center for a Barrier Free Environment, 1140 Connecticut Avenue, NW, Suite 1006, Washington, D.C. 20036.

Guest Editorial *(Continued from Page 7)*

One method of accomplishing effective application of the revised Standard is for the adopting agencies to develop applications manuals for the Standard. These manuals would specify numbers of facilities in each building type and could add or delete technical specifications for application in facilities under the agency's jurisdiction.

The revised ANSI Standard is needed now, and should be adopted even though it needs additional work. The agencies adopting it should accept their responsiblity and develop the applications manuals that will make its technical specifications workable for their facilities and programs. Its use should be monitored carefully by an independent body such as the National Center for a Barrier Free Environment, to which disabled people and others could send comments, complaints, or suggestions. In a short time, the Standard should be brought up for review and—based upon the comments received—it should be revised.

Also during this monitoring period, those agencies or organizations with responsibility for accommodating disabled people should move on with their efforts to identi not only the Standard's deficiencies but also those compe tent to conduct the additional research necessary to correct them. The results of this research should also be contributed to the Standard's periodic revision.

In this way, the Standard can continue to develop in conjunction with research and increased awareness of the needs and abilities of disabled people. Perhaps we can come closer to perfection, even if we don't quite achieve it.

National Center for a Barrier Free Environment
Suite 1006
1140 Connecticut Avenue, N.W.
Washington, D.C. 20036

Non-Profit Organization
U.S. Postage PAID
Permit No. 46428
Washington, D.C.

REHAB BRIEF

BRINGING RESEARCH INTO EFFECTIVE FOCUS

Choosing An Independent Lifestyle: Housing Alternatives for Severely Handicapped Persons

Vol. I, No. 5 May 25, 1978

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

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

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

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

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

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

SEVERAL HOUSING SOLUTIONS ARE POSSIBLE

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

A nationwide campaign for the elimination of architectural barriers is necessary for the achievement of community accessibility. Such a campaign is not effectively underway, although some recent developments point to growing recognition of the need for accessible community facilities. And the Architectural Barriers Act (Public Law 94-80), which requires accessibility in Federally financed housing built after 1968, is being more strictly enforced. Sections of the Rehabilitation Act of 1973, as amended, hold promise for increased accessibility to community activities (504) and strong compliance procedures (502).

Revised Accessibility Standards

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

CAMPUS-BASED HOUSING ALTERNATIVES

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

The University of Illinois—Urbana-Champaign

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

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

REHABILITATION SERVICES ADMINISTRATION • OFFICE OF HUMAN DEVELOPMENT SERVICES

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

attendants automatically, but only if they really need assistance.

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

The University of California—Berkeley

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

The Boston Center for Independent Living (BCIL)

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

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

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

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

GROUP RESIDENCES

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

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

Eastern Paralyzed Veterans Associations (EPVA)

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

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

Individual-Created Programs

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

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

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

COMBINED GROUP RESIDENCES AND COMMUNITY INTEGRATION

Cooperative Living—Houston

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

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

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

TOTAL COMMUNITY INTEGRATION

Center for Independent Living (CIL)—Berkeley

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

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

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

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

PROBLEMS IN FINDING HOUSING ALTERNATIVES

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

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

Attendant Care

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

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

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

Transportation

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

RESULTS OF EXPERIMENTS IN ALTERNATIVE HOUSING

- Sheltered housing is a viable alternative to institutionalization. A HUD project, the Highland Heights Experiment with barrier-free apartments found that type of housing more efficiently utilized medical care facilities and services and reduced unnecessary and costly institutional care. Results of the other housing projects support this finding.

- Social contacts and activities, functional status, and health status improve with independent living. The results of the Houston Cooperative Living project clearly support this conclusion. And the most dramatic results reported by the Berkeley Center for Independent Living were in the area of preventive care. The incidence of pressure sores and urinary infections dropped to almost zero.

- Independent living costs less than institutionalization. In 1975, total monthly living costs for a resident of Houston's Cooperative Living project were $570. The monthly cost of nursing home care was $743, and an apartment with private attendant cost $840. These costs include rent, meals, attendant, transportation, and personal expenses.

- Independent living affords more employment opportunities than institutionalization. Of the 40 residents in Houston's Cooperative Living project, none had jobs before entering the project, but 28 had either full or part time jobs after entering the project.

- Independent living in a group facility gives residents more social closeness, providing emotional support and modeling opportunities. But many persons object to being segregated from the rest of society. Houston's follow-up study found that residents of the Cooperative Living project, dorms, and nursing homes had more social closeness, which fostered group cohesion and some degree of conflict. Frequently, as they gain self-confidence, group residents outgrow the need for closeness and choose to move out into the community.

- There are advantages of both shared and private attendants. In the Cooperative Living project, private attendants gave the resident control over the attendant's time, but with shared attendant services, there was less conflict because no two persons spent a lot of time together, and costs were reduced.

- The location of a group residence in the community is important. Most of the Cooperative Living residents felt that part of the solution to transportation problems lay in locating their residence in a neighborhood that offered contact with the mainstream of society and that was within wheelchair rolling distance of business and community facilities.

- The successes of all the housing alternatives indicate the need for diversity of housing options. There is no one best alternative. Different individuals are comfortable in various settings, and it is important that handicapped persons have a range of choices.

IMPLICATIONS

- Legislation and regulations should be altered to make it easier to establish independent living facilities for handicapped individuals. Legislation to provide front money for staff and services could assist in starting new centers. And providing funds directly to the disabled individual would enable him to select and hire his own personal care provider.

- Large group facilities are undesirable because they become institutional as their residents grow gradually more dependent and isolated.

- A correlation exists between a handicapped person's housing situation and vocational productivity. The results of the Houston project support the trend toward helping persons with severe handicaps move out of institutions and into the community. They also indicated, however, that making the transition into the community can be difficult.

- The degree of physical disability is not a way of predicting success in independent living situations. First to be placed in the Boston Center for Independent Living were quadriplegic persons. One could move only his head, and another needed a respirator.

- Each community should attempt to offer severely handicapped persons an opportunity to get out of nursing homes and into more independent living.

- Rehabilitation programs should teach more effective independent living skills. The Houston project found necessary the ability to manage finances, to locate community resources and manage these contacts skillfully, and to manage social relationships with persons who provide physical assistance.

- Rehabilitation practitioners should work with self-help organizations of disabled persons to develop community-based independent living programs. President Carter's position paper "Jimmy Carter on Americans with Disabilities" states, "We must broaden the traditional concepts of rehabilitation to include independent living as a supported rehabilitation objective."

REFERENCES

Corcoran, Paul, et al. *The BCIL Report*. Boston, Mass.: Tufts/New England Medical Center, 1977.

Fay, Frederick A. *Housing Alternatives for Individuals with Spinal Cord Injury*. Tufts New England Medical Center Rehabilitation Institute, 1977.

Greenstein, Deborah, Charles Gueli, and Edmond Leonard. No One at Home—A Brief Review of Housing for Handicapped Persons in Some European Countries. *Rehabilitation Literature*, 1976, 37(1), 2-9.

Laurie, Gini. *Housing and Home Services for the Disabled: Guidelines and Experiences in Independent Living*. Hagerstown, Maryland: Harper & Rowe, 1977.

McEwen, Jan. Center for Independent Living: An Overview. *Rehabilitation Counseling Bulletin*, 1976, 19(4), 616-619.

Pflueger, Susan. *Independent Living: Emerging Issues in Rehabilitation*. Washington, D.C.: Institute for Research Utilization, 1977. (RSA Grant 22-P-59019).

Copies of the BRIEF are available from UF-RRI.

Prepared by Rehabilitation Research Institute • College of Health Related Professions

University of Florida • Gainesville, Florida 32610

HUD PROGRAMS THAT CAN BE USED FOR THE DISABLED

OFFICE OF INDEPENDENT LIVING FOR THE DISABLED

U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

HUD PROGRAMS THAT CAN BE USED FOR THE DISABLED

The disabled, as a special user group, can benefit from many of HUD programs because these programs are targeted at low and moderate income people, of which the disabled make up a substantial component. It is well known that housing without supportive services is not sufficient to meet the needs of many disabled. Therefore, it becomes necessary to determine some mechanism(s) whereby an appropriate matching of housing and services may be assured.

All efforts must not be concentrated on one program such as Section 8 Rental Assistance. There are several programs listed below which could, with some creative thinking, be utilized in the best interests of the disabled.

Homeownership Assistance Section 235

Program Objective: To enable eligible families to afford new or rehabilitated homes by providing them with a homeownership subsidy.

Program Operation: Direct cash subsidy payments are made by HUD to a mortgagee on behalf of a participating family to reduce mortgage interest costs to as low as 5 percent. The homeowner must contribute at least 20 percent of adjusted gross income toward monthly mortgage, insurance, and tax payments on a newly constructed or substantially rehabilitated home which can be a single-family detached, townhouse, condominium, cooperative unit, or mobile home.

How It Can Be Used For The Disabled : Since the goal of deinstitutionalization is to return to the community those disabled individuals who should not be in institutions, the Section 235 program provides for homeownership for those capable of independent living.

Eligibility : Any family with an adjusted income of up to 95 percent of the area median income.

Budget:

	1978 (est.)	1979 (est.)
Units reserved:	30,000	50,000
Units started	19,000	27,500

Community Development Block Grants

Program Objective: Development of viable urban communities, including decent housing and a suitable living environment, and expanding economic opportunities, principally for persons of low and moderate income.

Program Operation: CDBG funds are distributed on a formula basis to units of general local government and states to be spent according to local priorities.

How It Can Be Used for the Disabled: Grant assistance may be used for the following activities:

1. Acquisition, construction, reconstruction, rehabilitation or installation of centers for the handicapped defined as any single or multipurpose 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.

2. Removal of Architectural Barriers
   Special projects directed to the removal of material and architectural barriers which restrict the mobility and accessibility of elderly or handicapped persons to publicly owned and privately owned buildings, facilities, and improvements including residential and non-residential structures.

3. Planning activities which may include surveys and plans for removal of architectural barriers to the handicapped and elderly.

4. Rehabilitation of publicly owned or acquired properties for use or resale in the provision of housing including:

   a) Permanent housing units, both single family and multifamily, for rental or sale, and

b) Residential facilities, including group homes, halfway houses, and emergency shelters.

5. Acquisition by private entities (profit and non-profit) of privately owned properties for the purpose of rehabilitation or for rehabilitation for use or resale in the provision of housing including:

a) Permanent housing units, both single family and multifamily, for rental or sale, and

b) Residential facilities, including group homes, halfway houses, and emergency shelters.

Eligibility:

1. Metropolitan cities: A metropolitan city is the central of a SMSA or any city of 50,000 population or more.

2. Urban counties: Any county within a SMSA which is authorized to undertake essential community development and housing assistance activities, or enabled to through cooperation agreements, and has an eligible population of 200,000 or more, excluding the population of metropolitan cities and others not wishing to participate.

Budget:

	1978	1979
Program Level -	3,894,644,000	3,750,000,000
Distribution of Funds:		
Metropolitan Areas:	2,804,227,000	2,891,760,000
Non-Metropolitan Areas:	601,273,000	656,690,000
Secretary's Discretionary Fund:	94,500,000	101,550,000

Comprehensive Planning Grants Section 701

Program Objective: To support State, areawide and local comprehensive planning and management programs concerned with urban and rural development.

Program Operation: The 1979 program will provide funding to prepare State, areawide planning organization and local governmental strategies to help revitalize urban areas, provide necessary shelter and freedom of choice in housing for all persons, manage growth, conserve energy, maintain and expand economic development and inprove the environment

How It Can Be Used for the Disabled:

Grants can be used to plan barrier removal for areas and facilities used by handicapped people. Examples include:

Natural resource planning, such as location of accessible and usable wooded areas including trails and restrooms, and interpretive nature trails for the blind; studies of the impact of environmental policies on the handicapped population.

Physical land use planning, such as surveys of the type, amount and distribution of housing, community facilities and employment centers accessible to the physically handicapped population; projection of land use needs including the number and probable distribution of the handicapped population.

A portion of the funds under this program may be used for planning research and demonstration projects that serve the needs of handicapped people.

Eligibility: Assistance may be provided to States, areawide planning organizations municipalities and counties, and Indian tribes to cover up to two-thirds of the project cost.

Budget:

	1978 (est.)	1979 (est.)
Grant Reservations:	60,368,000	57,000,000

Rehabilitation Loans Section 312

Program Objective: To make loans for the rehabilitation of single and multifamily residential property and business properties.

Program Operation: Loans currently bear an interest rate of three percent for terms not exceeding 20 years, or three-fourths of the remaining life of the structure after rehabilitation, whichever is less.

How It Can Be Used For The Disabled : As a result of Section 504 the disabled will be encouraged to make use of Section 312 loans. The removal of architectural barriers can be funded through this program.

Eligibility : Property owners in urban renewal or concentrated code enforcement areas and business tenants of such property whose leases have at least as long to run as the terms of the loan.

Budget :

1979 (est.)
$95,000,000

Section 202 - Housing for the Elderly or Handicapped

Program Objective: To provide for rental housing for the elderly or handicapped which may include essential service facilities such as dining facilities, community rooms, and small treatment centers.

Program Operation: Private nonprofit sponsors may apply for direct 40 year Federal loans at interest rates equal to the Treasury's average borrowing rate on all debts to construct, rehabilitate or alter rental housing for the elderly or handicapped. Applicants submit their request for fund reservations in response to an invitation appearing in the Federal Register on a yearly basis.

How It Can Be Used for the Disabled : It became unwritten policy in FY 77 that projects for the handicapped funded under this program would be small scattered site group homes serving no more than twelve residents. This policy will continue which is in line with the concept of deinstitutionalization. This year, Fiscal Year 1978, the program will be decentralized to the HUD Area Offices. Therefore, it will become necessary for sponsors to develop good working relationships with HUD Area Office staff and also to make them aware of the housing needs of the disabled.

Eligibility : Limited to provate nonprofit sponsors with new Section 202 loans being made in conjunction with the Section 8 Housing Assistance Payments program.

Budget :

	1978 (Est.)	1979 (Est.)
Units:	23,600	25,000
Amount:	750,000,000	800,000,000

Out of $800 million of loan reservations proposed for 1979, at least $50 million is reserved for housing designed expressly for handicapped persons (primarily non-elderly). This will provide approximately 1,400 units for the non-elderly handicapped.

Nonprofit Sponsor Assistance
(Section 106 (b))

This program provides interest-free loan assistance ("seed money") for start-up costs to private nonprofit sponsors of Section 202 Housing for the Elderly or Handicapped projects. "Seed Money" loans may not exceed 80 percent of the total start-up costs. The sponsor must provide at least 20 percent of the start-up costs which is repaid from the initial proceeds of the Section 202 loan.

Section 8 Rental Assistance Program

Program Objective: To aid lower income families in obtaining decent, safe and sanitary housing in private accommodations and to promote economically mixed housing through existing, newly constructed, and substantially rehabilitated housing.

Program Operation: The Section 8 program provides a flexible subsidy which covers the full cost of providing housing assistance, including debt service and operating costs attributable to the construction and operation of rental housing for lower income families. Subsidy payments are equal to the difference between the contract rent and the amount of rent paid by the eligible family. The family contribution toward rent is determined by formula and may vary between 15 and 25 percent of income depending upon such factors as income level, family size and extraordinary expenses such as high medical costs which the family must support.

How It Can Be Used For the Disabled: Single disabled individuals and families in which a member may be disabled are eligible for Section 8 assistance as long as they meet the income limitation. In addition, 5 percent of Section 8 newly constructed units will be designed to be barrier free. The Section 8 existing housing program has been amended to allow eligibility for independent group residences for the elderly, physically handicapped and the developmentally disabled.

Eligibility: Applicant - Profit and non profit organizations, public housing agencies and state housing finance and development agencies.

Beneficiary - Very low income families (whose income does not exceed 50 percent of the median income for the area), and lower income families (whose income does not exceed 80 percent of the median income for the area).

Budget :	1978 (est.)	1979 (est.)
	(Units)	
New construction:	105,010	110,000
Substantial rehabilitation:	56,050	70,000
Existing housing		
Moderate rehabilitation:		39,000
Regular rental housing:	117,810	115,000

Moderate Rehabilitation

The Program: Federal rent subsidy funds are available for the housing needs of the handicapped under the new Moderate Rehabilitation Program. Public Housing Authorities may designate up to five percent of their rental assisted housing units for the handicapped. This funding is available for the specific purpose of renovating otherwise standard housing units if the work to be done involves the removal of architectural barriers to the handicapped. Under the Act, 39,000 apartments are expected to be rehabilitated and nearly 2,000 of these made usable for use by disabled tenants.

How It Can Be Used For The Disabled: The Moderate Rehabilitation Program, involving a new use for HUD's Section 8 rental assistance funds, will provide advance commitment of rental subsidy to private owners for buildings, enabling owners to carry out the limited repair work needed to bring their buildings up to acceptable standards. In the case of units designated for the handicapped, this could involve removal of any architectural barriers to handicapped people. Rental subsidies for these units could cover the cost of renovation necessary to remove such barriers, permitting easy use of the quarters by eligible disabled individuals. Under the Section 8 program, HUD pays to the owner the difference between what an eligible tenant can afford to pay (generally 25 percent of his income) and the rent charged by the landlord for his apartment. Fair Market Rents, which act as a ceiling on how much rent an owner can charge for the unit, can be exceeded if necessay to provide for the renovation of units for handicapped tenants.

Eligibility: Tenant eligible for Section 8 assistance, including the handicapped, are those whose income does not exceed 80 percent of the median income in their localities.

Public Housing Program

Program Objective: To provide federal aid to local public housing agencies to provide decent shelter for low income residents at rents they can afford.

Program Operation: Through the use of an Annual Contributions Contract, HUD provides financial assistance to cover the debt servcie on bonds and notes issued for the construction of projects to be owned and operated by local public housing agencies.

How It Can Be Used For The Disabled : Disabled individuals and families with disabled members may reside in public housing provide they meet the income limitations. In addition, 5 percent of newly constructed public housing units will be designed barrier-free. The public housing modernization program has established as one of its priorities the retrofitting of public housing projects to make them accessible to physically handicapped persons.

Eligibility : Applicant - Public Housing Agencies

Beneficiary - Low income families including a single person who is elderly, disabled, displaced, or the remaining member of an eligible tenant family.

Budget :

	1978 (est.)	1979 (est.)
Unit reservations:	58,935	50,000

Modernization: In 1979, the Budget proposes the use of $37.5 million of contract authority and $750 million of budget authority. In addition, there have been discussions with the Office of Budget to set aside contract authority equivalent to $5 million for retrofitting public housing to make it accessible to the disabled.

Mortgage Insurance - Rental Housing

for the Elderly or Handicapped Section 231

Program Objective: Federal mortgage insurance to facilitate financing of rental housing for the elderly or handicapped.

Program Operation: HUD insures lenders against loss on mortgages used to finance construction or rehabilitation of detached, semi-detached, walk-up or elevator type rental housing designed for occupancy by elderly or handicapped individuals and consisting of 8 or more units. The sponsor submits a formal application through an FHA approved mortgagee to the local HUD Area or Insuring Office.

Eligibility : Applicant - Investors, building developers, public bodies, and nonprofit sponsors.

Beneficiary - All elderly or handicapped persons.

Budget :

	1978 (est.)
Mortgages Insured:	$104,395,000

Property Disposition Program

Program Objective: To reduce the inventory of acquired properties in such a manner as to ensure the maximum return to the mortgage insurance funds consistent with the need to preserve and maintain urban residential areas and communities.

Program Operation: See Attached

How It Can Be Used For The Disabled : With a little creativity this program could provide a valuable resource for the disabled especially when it is used in conjunction with other programs such as CDBG, Section 312, or Section 8.

Eligibility : Brokers, prospective purchasers, and other interested parties are permitted to attend bid openings.

Budget: HUD-Owned Property Inventory

	1978 (est.)	1979 (est.)
Homes:	25,701	22,559
Multifamily	37,418	19,348

Urban Homesteading Program

Program Objective: To utilize existing housing stock to provide homeownership, thereby encouraging public and private investment in selected neighborhoods and assisting in their preservation and revitalization.

Program Operation: The local governments selected for the program sell the properties for a token sum (as low as $1.00) to individuals or families called "homesteaders". The homesteader must make repairs to meet minimum health and safety standards, then occupy the property as a principal residence for at least 3 years.

How It Can Be Used For The Disabled : Since $16 million in Section 312 funds has been reserved for low interest rate rehabilitation loans to support this program, the disabled could make use of this to be provided with accessible housing.

Eligibility : Homesteaders must be equitably selected by each participating city.

Budget :

1979 (est.)
$20,000,000

SPECIAL USERS: ELDERLY AND HANDICAPPED

Policy, Development and Research (PD&R) is addressing how best to provide housing and housing-related services to people who have special requirements caused by age or physical condition. What are the optimal strategies for assisting these people? What service package is essential to the success of special programs designed to reach them? Specifically, PD&R wants to examine HUD's role in helping elderly people keep their own homes and in helping handicapped people have access to buildings. PD&R is looking at the housing-related services that elderly people consume and the housing maintenance decisions that they must make. PD&R is inventorying the current housing situation to determine the extent to which people with disabilities have access to federally subsidized housing. PD&R is also examining the need for and costs of retrofitting public buildings so that handicapped people will be assured of access.

PART V: DEVELOPING ALTERNATIVE LIVING ARRANGEMENTS

Chapter 8: *Important Dimensions and Considerations*
- Physical Structure
- Relationship to the Larger Community
- Supportive Services
- Management
- Social System
- Funding

Chapter 8: *Important Dimensions and Considerations*

The development of the Cooperative Living concept resulted in the definition of several comparative dimensions that significantly affected life-styles of residents.

Consideration of these dimensions is important for persons who intend to develop new housing alternatives, for rehabilitation professionals who suggest placement of clients or patients, and most importantly, for severely disabled persons who are seeking housing alternatives. It is important to recognize that the needs of physically disabled persons vary greatly depending upon such factors as degree of mobility, age, life-style before the onset of disability, family arrangements, economic levels, and traits of personality. An environment that requires great personal responsibility in managing affairs and self-confidence in being alone may seem challenging and exciting to one disabled individual, but isolated and frightening to another. Careful consideration of the factors discussed below should be useful in determining the best environment for a severely disabled person so that the individual can function comfortably at his level of independence.

Physical Structure

Careful design of spaces and fixtures can permit severely physically disabled persons to become significantly more physically independent than they are able to be in typical residential buildings. Standards for the design of accessible buildings have been published by ANSI and are currently being reevaluated in a study at Rutgers University.* Design features used most frequently are wide doorways and halls, ramped changes in level, electrical switches and outlets at waist height, bathrooms and kitchens with space for manuevering wheelchairs (often including roll-in showers), and cabinetry with space below for wheelchair accessibility and with hardware designed for persons with limited use of their hands.

Beyond this straight-forward use of design to increase physical capabilities, a structure used to house disabled persons should provide both opportunities for socialization and opportunities for privacy. Persons who are insecure when isolated from direct voice contact with other persons are more comfortable in a dormitory-style structure. Those who prefer greater privacy find apartments and single-family dwellings more comfortable and compatible with their needs. Many severely disabled persons are more sensitive to the social-contact features of a residence than are able-bodied persons because they are dependent upon the physical assistance from others, and the importance of this consideration may be much greater than is immediately apparent.

It is also important to note that the individual resident's needs change with

*Contract H-2200R, U.S. Department of Housing and Urban Development, 1975.

his or her ongoing adaptation to new circumstances. If one were to consider an individual resident over a period of time, it would be reasonable to assume that the individual would initially desire a very structured experience after his acute care and first discharge to the community, then a semi-protected dormitory arrangement, next an apartment complex with other residents, and finally, his own setting. Viewing these requirements as a continuum gives some indication of the many options in terms of privacy and socialization open to each resident as his individual needs change over a period of time.

Relationship to the Larger Community

Adaptive housing for the disabled person is usually only one of many requirements. In order to establish an independent and productive life-style, an individual also needs a number of other elements including opportunities to obtain schooling or job training, find employment, shop for material needs, pursue a variety of leisure activities, and obtain ongoing medical services. It is often preferable that sites of such activities (shopping, leisure activities, schooling) are located within wheelchair range of a residence so that individuals may reach them without arranging more elaborate transportation. A good transportation system can make the other opportunities readily available if the residence is located in a well-chosen area rather than isolated at an unreasonable distance for convenient travel. In the effort to make a wide variety of opportunities accessible, it is important to recognize that if all these opportunities are provided under one roof, the residential environment becomes a self-contained institution. Evidence indicates that most disabled persons prefer to be integrated, and meeting all of the person's needs internally prevents his or her integration into the mainstream of the community.

There is a tendency among residential planners, vocational counselors, and other professionals to believe that medical services must be an integral aspect of the residence itself. While this is undoubtedly true for some disabled persons, a great proportion of the severely disabled population can maintain stable health while obtaining needed medical services in the same way they are obtained by the able-bodied population in the community. Locating a residence too close to a medical facility may impart an institutional atmosphere that many residents purposely seek to avoid.

Neighborhood acceptance of a residence for severely disabled persons is a concern among rehabilitation professionals who feel that there will always be citizens in the community who will not approve of a special residence in their neighborhood. It has been our experience throughout the life of this project, however, that these apprehensions are over-exaggerated, and only in rare instances have citizens expressed concern over living near a group of handicapped individuals. If the resistance does become significant, it might be necessary to seek legal assistance. In most cases, however, it is possible to guard against getting into a difficult encounter with the community if a few simple steps are taken prior to the actual construction or opening of a residence.

1. It is helpful to meet with neighborhood leaders and local legislators to discuss the purpose and operating plans for the project.

2. It is important to explore with a local planning agency or zoning board the limitations that might be faced and to request a special use permit as indicated.

3. It might be impossible to receive a full or open endorsement of the project from persons in the neighborhood. Receiving a position of neutrality could very well be enough and acceptance can come after the program is operational.

Supportive Services

For many severely disabled persons, having reliable attendant assistance (as distinguished from nursing care) is a prerequisite to living outside an institution. Recruiting attendants, training them, and managing the intensive social relationships involved are major problems that continually face those who are physically dependent upon assistance. Arrangements for providing this service include a model in which each resident has one attendant, a model in which attendant service is shared among a group of residents, and a hybrid model in which one-to-one attendants are supplemented by shared attendants. In some projects, the recruiting, training, and management of attendants is done entirely by each resident. In other cases, an attendant pool may be maintained by the project to assist individuals in finding attendants. Occasionally, the project provides a staff of shared attendants and performs recruiting, training, and managing functions for the residents.

Intensive relationships between a disabled person and his attendants seem to have great potential for conflict, and most persons find it difficult to learn an appropriate interaction style, often going through a number of attendants before a stable and lasting relationship is developed. Experience in this area is often gained by living in a group residence and observing other disabled persons interact with their attendants.

Obtaining food service is another requirement of the severely disabled person. This service has been structured in various ways, ranging from having attendants prepare food in private kitchens to sharing meals in group dining facilities. The provision of meals must be considered in a more general way, since dining usually has social significance in our culture. It is therefore important to most disabled persons to consider not only the quality of food, cost effectiveness and convenience of preparation, but also the setting and context in which meals are eaten.

The availability of transportation is essential for disabled persons who wish to lead active life-styles. Shared transportation services can be organized for residential projects at various cost levels. Some projects own their own vehicles, and others use specialized transportation for the handicapped provided by other agencies. Still other residences are able to utilize the services of the City of Houston special mini-bus system, which transports

the residents from their apartments to the downtown sector of the city as well as to university and medical services.

The need for periodic medical services can also be met in various ways. Some residential projects provide medical consultation through professional staff personnel. In other cases, residents are expected to utilize the medical service systems of the community. Most disabled persons in the Cooperative Living residence managed to have their routine medical maintenance needs met by non-medical staff. Staff representing various backgrounds, many of whom had no medical or nursing familiarity, were trained to assume the necessary attendant nursing care responsibilities. Staffing with non-medically oriented personnel is very important in maintaining and promoting an atmosphere that is non-institutional in nature. Judgments regarding an individual resident's capacity to function in the setting or regarding the requirements for definitive care must, of course, be assumed by medically trained personnel. Even though daily care functions are assumed by attendants, medical care and check-ups in an outpatient facility are also essential to prevent complications. In facilities or residences where medical services are not provided internally, a resident should be encouraged to make plans in advance for coping with acute medical emergencies, and project personnel must have access to this information.

Management

In Houston projects that offer shared attendant services or attendant pools, management of the program is usually done by disabled residents, perhaps with outside supervision. This system may be overseen by a single, full-time manager, though the manager's position of authority over the staff may be weakened because he himself is dependent on their services and good will. Alternatively, various tasks, such as recruitment of personnel, accounting, or building management, may be assigned to different persons. There are many advantages in having the project managed by residents who are familiar with their own problems. In some projects, groups of residents as a whole play an active part in decision-making, effectively involving each resident in the project's operation. In others, the individual resident may purchase services and have only a business relationship with the managerial structure.

Experience has shown that several different types of management can be effective and can maintain the necessary communications with the residents under their care. It is important to be aware, however, of the strengths of the individual residents as well as the group of residents as a whole in choosing the most appropriate management style. Through the life of the Cooperative Living project, it was found that different management styles were required and depended upon the resources of the group residing in the project at a given time. For example, during some periods a necessary single manager-leader type person was required since many of the residents were not ready, able, or willing to participate in management and simply wanted services provided to them. During other times during the life of the residential program, it was found that the residents were becoming more active in the daily operation of the facility and were interested in negotiating and bringing about change in the system since it would affect

6

their situation personally. Overall, involving the residents in management allowed them to begin gaining skills that served them well as they began to approach competitive employment in the community. In essence, the experience as a resident manager, or an individual involved in the group management, seems to have provided a good training ground and preparation for future employment.

Social System

The social system of a residential project has a more significant impact on the life-styles of the residents than may be readily apparent. Living with other disabled persons can provide the opportunities for strengthening one's capabilities in communicating, as well as providing opportunities for modeling. Modeling was found to be particularly important for persons whose disabilities occurred after they had established a life-style as an able-bodied person. In adapting to disability, persons learn about new equipment, ways of handling medical problems such as skin breakdowns, and new physical techniques for performing various tasks through observation of fellow residents. They may also learn how to manage social interaction with attendants, potential dating partners, and personnel of various organizations such as vocational rehabilitation counselors or potential employers. Seeing a fellow resident arrange transportation for a date, open a checking account, secure a part-time job, or buy a car, may provide the motivation as well as the know-how to encourage a disabled individual to try new activities.

In a shared residence, certain roles may emerge within the social system which last beyond the tenure of a specific individual who plays the role. Some roles are specific to the project, but others seem to be more general. Among these are the role of "contact broker," who is a person experienced in dealing with outside agencies such as social security offices, university registrar's offices, housing authorities, and personnel of medical facilities. The contact broker serves an important linkage function between residents and outside agencies since he "knows the ropes" and has personal contacts which can be of great benefit to other less sophisticated residents. Another general role is that of "goat," an individual who asks for more help than the other residents feel he requires. In general, there seems to be little tolerance of such behavior in the residential settings studied, and "goats" are usually the object of joking and criticism. Ridicule of dependent behavior seems to be an important element of social interaction as it discourages dependency among other residents and supports the ideals of independence and productivity that are shared by most persons who move into independent living arrangements. Persons who are labeled as "spoiled" by other residents often can never become fully accepted members of the social system and may feel very isolated and lonely.

Group residences may become close in-groups with solidarity promoted by sharing activities such as out-trips within the community. This solidarity may be an important supportive force for many residents. In other projects, most persons "go their own way" and interact infrequently with other residents.

The social system is also important in terms of the opportunities it provides for developing external relationships. If persons are able to leave the project and become involved in activities, and if they are comfortable entertaining guests, outside friendships are developed which prevent the environment from becoming an ingrown social system.

Funding

An adequate financial base is essential for any group residence, and various combinations of sources of support have been utilized. Financial sponsorship of group projects with shared services has been provided by contributions from private individuals, by foundations, by HEW funds through Research and Training Center and Research and Demonstration grants, by establishment grants from state vocational rehabilitation agencies, and by non-profit corporations formed by groups of residents. The Department of Housing and Urban Development has provided funds to construct accessible apartment buildings but usually does not fund the necessary support services such as attendant assistance and transportation. Cash payments to individual residents may be provided by maintenance payments from departments of vocational rehabilitation, supplemental security income, or social security disability insurance. Specific services may be subsidized by homemaking and chore services from state departments of public welfare, or by rent subsidies through agreement with housing authorities. In Massachusetts, a special arrangement was developed to permit supportive services such as attendant care to be purchased under Medicare for persons in facilities other than nursing homes. Since no currently existing funding program alone provides a consolidated approach for purchase of independent living, a major task of all residential projects must be to coordinate the several sources of support that exist within state and federal agencies as well as from local programming. Development of these resources requires a considerable amount of effort, diplomacy, and continuing persistence on the part of project personnel.

HUMAN FACTORS, 1978, 20(3), 365—370

A Small Group Independent Living Experiment for the Physically Handicapped

DON M. RICE[1], HARRY E. HINTON, *and* DONALD W. CONOVER, *San Diego, California*

This article describes an experimental attempt to provide family-like housing accommodations for a small group of handicapped persons. It presents an insider's view of the residential facility itself and of some of the factors relating to small group living, resident selection, and staffing.

BACKGROUND

During the past few years a number of severely physically disabled persons across the country have been banding together in an attempt to live in small groups for economic and emotional reasons. Many of these handicapped people are young college students who are otherwise unemployed. Their limited income is provided primarily by the Social Security Administration, the Veterans Administration (United States Code), and various welfare programs. This income limitation has forced countless mentally active, but physically disabled, young and middle-aged adults into nursing homes or other institutions.

The advantages of living as independently as possible within a small-group residence over living in an institution are many and profound. Perhaps the most fundamental of the differences are the opportunity to perceive oneself, and to be perceived by others, as a responsible private citizen rather than as a patient, and to function in an environment that is not unduly restrictive. To operate a large institution such as a nursing home efficiently, many rules, regulations, and schedules are essential. In the large institution it is usually impossible to treat each person as an individual. Even to the individual who is responsible, mentally competent, and relatively able-bodied, these limitations can be very annoying. To the individual who is responsible, mentally competent, and severely physically disabled, these same limitations can be demeaning, maddening, and terrifying (Mendelson, 1974).

The purpose of this article is to describe one attempt to provide low-cost, wheelchair-accessible housing that shows promise of continuing economic and social success. The intent is to present the problem and the attempted solution from the point of view of the handicapped person with special residential needs, inasmuch as two of the authors are handicapped people living in the facility to be described. Moreover, while attention is given to the design of the residence itself, social and economic aspects of the general problem of providing appropriate housing for the handicapped are also noted.

[1] Requests for reprints should be sent to Mr. Don M. Rice, 5544 Madison Avenue, San Diego, California 92115, U.S.A.

© 1978, The Human Factors Society, Inc.
All rights reserved.

HANDICAPPED INDEPENDENCE PROVEN (HIP)

In 1973 a builder in San Diego, California, became aware of the lack of appropriate housing for wheelchair-bound people while trying to locate a suitable residence for a friend. After contacting a local disabled businessman who put him in touch with other individuals, the builder arranged meetings with members of the California Association for the Physically Handicapped, disabled students from San Diego State University, their Coordinator of Disabled Students Services, and other interested citizens.

From these and other contacts within the community, the builder ascertained that there was a significant and immediate need for reasonably priced wheelchair-accessible housing. The overwhelming consensus of the disabled persons contacted also convinced him that they were not enthusiastic about the prospect of large facilities; institutionalization was precisely what they wished to avoid. Most of the handicapped people queried definitely preferred small-scale residences which would be able to provide a friendly and family-like environment. Such home-like surroundings would enable them to pursue more productive lives regardless of their disability. Specifically, all disabled residents wished to be provided with private bedrooms.

For the above reasons it was decided that the first experimental residence would be limited so as to accommodate about six wheelchair-bound persons. Subsequent experience has shown that this size group preserves the family-like environment and effectively minimizes the feeling of institutionalization. On the assumption that the development and operation of reasonably priced housing for the disabled could be economically feasible, this small-unit building program was initiated in mid-1973 (Rice and Hinton, 1977).

The first residence was ready for initial occupancy in February, 1974, at which time the coordinator moved in. This individual had been involved in a somewhat similar living arrangement for several years and had developed some skills in account keeping, food buying, and unit management. An attendant was employed and the "small group independent living experiment for the severely physically disabled" concept was started. To characterize their experiment, the handicapped residents chose the descriptor "Handicapped Independence Proven," and its acronym HIP, because both reflect the positive attitude as well as the ideal toward which they strive.

FACILITY DESIGN

For the most part, only basic architectural accessibility and convenience innovations have been incorporated into this first residence (Federal Law Related to Public Housing). These basic design features enable quadriplegics requiring special care to live more comfortably and to be as independent as their physical disabilities permit. Several other additional features are necessary in order for wheelchair-bound paraplegics to be able to function adequately in complete independence. These features are being incorporated as rapidly as demand and circumstances permit (Federal Law Related to Public Housing, 1968; American National Standards Institution, Inc., 1961).

The exterior sidewalks in this new place are concrete and are level or ramped with a maximum grade of 5%, and safety railings have been installed where necessary. Most doorways are at least 91 cm wide. Wall plugs are 61 cm, light switches are 91 cm, and thermostat controls for the electric heaters are 122 cm above the floor level. The heaters are recessed high on the walls to avoid accidental burns. Attendants can be contacted from each bedroom with an emergency call buzzer. The emergency call system is a 24-volt

DC system. Normally, it is powered by the standard 110-volt AC system through a step-down transformer, to 24 volts DC. However, in case of a power failure, a special relay immediately actuates the 24-volt DC backup system.

Each bedroom has two entrances (California Civil Code). All bedrooms have an outside private entrance, except one. Bedroom closet clothes poles are 122 cm from the floor. The bathrooms have ramped showers with both conventional shower-head and hand-held sprays. Water temperature in the showers can be preset to avoid burns. Bathroom sinks are positioned to permit knee room beneath. With the exception of the bedrooms and the bathrooms, most of the remaining residence interior is open and unobstructed by walls.

There is another important design consideration which is related to the provision for knee space under lavatories and kitchen sinks. If there are exposed drain or supply pipes under these units, they can become hot enough to burn knees and legs. These pipes must be wrapped with insulation materials. Remember, paraplegics and quadriplegics cannot feel the burn at all. They just see it—too late!

Specifically, for the paraplegic—one who who has use of one set of extremities but not both—certain special and often additional interior design features are required. Those paraplegics who have full use of hands usually do not require complete bio-care (catheterization, etc.), but they must be provided with standard grab bars around the toilet as well as other special design features required for all wheelchair users (American National Standards Institute, Inc.; California Civil Code; Laurie and McGwinn, 1977).

The "upper paraplegic," often a polio victim, who may be able to walk but has little use of arms and hands, poses a very special and often unique problem to the human factors engineer/designer. As with the quadriplegic, the "upper paraplegic" often requires some form of bio-care and may have considerable difficulty in lowering himself to a toilet stool despite inclusion of standard grab bars. Use of toothbrush, comb, eating utensils, and the like, is almost precluded without special arm/hand-operated attachments—truly a design job specific to the particular handicapped individual.

It is the little things that count in the practical living situation, especially for the quadriplegic. For example, most quadriplegics have limited use of their hands except for gross movements; however, they often can handle a telephone hand set if it is especially adapted for their use. In some instances, the Veterans Administration or rehab-hospital bioengineering shops have made some handicapped people special prosthetic devices which attach to their hands for holding such things as eating utensils, toothbrushes, combs, and pencils.

Minimum shower stall dimensions intended for the handicapped are generally provided, but they seldom offer enough "turn-around" space for both the handicapped person in a special wheelchair and for the attendant who quite often must be present. (A 1.8-m diameter "turn-around" space is recommended.) Furthermore, the floor-riser, which keeps shower water from spilling out over the bathroom floor, must still be flat enough for the handicapped person to maneuver the chair over the riser without excessive arm-force requirements. Nonslip floors in bathroom and kitchen are a must. Wet, slippery floors, despite powered chairs or the strong arms of many paraplegics, make maneuvering of the wheelchair nearly impossible.

Kitchen sink and lavatory height above floor level should be limited to 81 cm. Imagine trying to wash one's hands or to dry a dish while hands are near eye level! Despite specifications to the contrary, this design feature is too often disregarded by builders of homes for the disabled. The high sink is

satisfactory for the attendants, but useless to the handicapped.

Even though 91-cm doors and 107-cm hallways are usual features in homes designed for handicapped people, often little or no consideration is given to "turn-around" clearance between such things as beds and desks. Rarely is interior design consideration given as to how many wheelchairs can be placed around a table. A good rule to go by for seating is: two wheelchairs to three ordinary chairs.

As a final example, for the disabled who have very little use of hands, even a specially designed doorknob presents an almost impossible manipulation task. Our group has partially solved this problem by tying short lengths of nylon rope to the doorknob extension handles. Using the rope, the quadriplegic can insert an arm or wrist in the loop at the end of it and tug the handle "down" to open the door; by backing away from the door with the wrist or arm again in the loop, he can cause the door to close.

The foregoing minor design innovations, to suggest a few, are offered for their practical use by those who are concerned "beyond the call of mere specifications" about making life just a little more meaningful to the handicapped person. Although the scope and intent of this article does not include discussion of specific details per se, suggestions are made in the several documents (Federal Law Related to Public Housing; American National Standards Institution; Aulger, 1974; California Civil Code; Laurie and McGwinn, 1977).

REGULATIONS AND POLICIES

As was noted above, the efficient operation of a large institutional facility necessitates adherence to a set of rules and regulations that to many individuals may be unduly restrictive. At HIP, the sole regulation is: "do nothing illegal on the premises." Specifically, this prohibits such things as the possession of illegal drugs. Everything else can be adequately handled by the common-sense application of the Golden Rule. With any group, no matter how small, minimal schedules are necessary. At HIP, the evening meal is provided at a specific time. To ensure that the residents are ready on time each morning to be picked up by the school vans, there are scheduled times at which they receive personal attendant care. These times are flexible and are worked out between the residents and the staff to their mutual convenience (Rice and Hinton, 1977).

There are no restrictions on adult visitors or hours. However, all residents make every effort not to infringe upon the rights of their fellow residents. The residents also cooperate with the staff and try not to disrupt their busy routine, especially regarding bedtime activities. For example, when residents plan to be out late, arrangements are made in advance with the staff. If possible, persons who are taking them out for a late evening should be able to put them to bed.

Residents who are parents may have their children stay several days at HIP provided they are responsibly supervised. The presence of small children entails an additional workload for the staff. The resident is expected to make some sort of agreement with the staff for their assistance in looking after the children.

All out-of-the-ordinary plans are arranged for in advance with the staff and the coordinator. When guests are invited to dinner, advance notice is necessary to ensure that additional food is available and prepared. Each resident is charged a nominal fee to cover the cost of meals consumed by their guests.

It is normally difficult for several persons to live together without some personality conflicts now and then. Nevertheless, this group makes a conscious effort to minimize conflicts which do arise. Attempts are made to settle these problems with patience,

understanding, and compromise. In order to maximize this feeling of being a close family, the current residents also make an effort to select only those new residents and staff members who appear to be equally responsible and compatible.

RESIDENT SELECTION

At HIP, small group living has been demonstrated to be suitable for a variety of disabilities. To assist in selecting persons who will be able to function successfully here, each applicant should ideally meet the following criteria (Rice and Hinton, 1977).

(1) Be a reasonably intelligent young or middle-aged adult who is highly motivated toward self-improvement and who intends to lead as productive a life as possible.
(2) Be considered by his physician to be able responsibly to direct his daily activities, including the training and supervision of his attendants.
(3) Be knowledgeable enough about his specific disability to recognize minor medical problems and use sound judgment in determining when professional medical help is needed.
(4) Be disabled to the degree that he requires at least 20 hours of attendant care per week. (This is the minimum number of hours required to qualify for the California State Chore and Homemaker Services, a program that provides funds to those adults who are current applicants for, and recipients of, Federal Supplemental Security Income [SSI] and/or State Supplementary Program [SSP] benefits. Its purpose is to enable adults to remain in, or return to, their own homes in cases where they are unable to perform essential housekeeping tasks, and/or to help maintain or strengthen their capacities in the areas of limited personal care and household management.)
(5) Be considered favorably by the other residents and staff.
(6) Be approved by the coordinator if he is convinced that the applicant seems likely to fit into the existing group with minimal personality conflicts, and if it appears that becoming a resident will be in the best interests of the applicant and the group as a whole.

STAFF CONSIDERATIONS

The staff is selected and hired by the coordinator; however, the coordinator is supported in this task by the residents, since they are most familiar with their own care requirements. Generally, HIP residents have favored college students as attendants. Several of the HIP residents and staff attend San Diego State University which is less than 3.5 km away. This common interest tends to increase the closeness of the HIP family group. Proximity to the university, plus the close rapport with its students and staff, facilitates locating those students who are interested in part-time work. HIP is also located within 16 km of several other potential sources of attendants, such as other colleges, universities, hospitals, as well as Veterans Administration facilities. Attendants have an excellent opportunity to learn the different types of care required by each of the diverse physical disabilities of the HIP residents.

Although staff attrition will always cause temporary inconveniences, it can, with proper planning, be handled as a productive portion of a stable program. HIP encourages the staff family to take advantage of all opportunities for professional improvement.

A primary reason that so few severely physically disabled persons live alone with an attendant is that this is a "luxury" which they cannot afford (Mendelson, 1974; Rice and Hinton, 1977). This, of course, is the same reason that so many end up in nursing homes. In small groups, lack of sufficient money is still a problem; however, by sharing common expenses, it has been possible for this particular group to function successfully to date.

At HIP, provision for staff living quarters was made in the original plan. By this means, it is possible to employ higher caliber persons, yet pay them a more moderate salary, because they are also provided with room, board, and utilities. This, in turn, enables the owner/manager to provide the physically disabled residents with the 24-hour-per-day attendant care most of them require.

It is often the case that wage scales for service providers who are supported by the state are close to the legal minimum. In general, if a manager cannot provide room, board, and utilities as part of a package agreement, the caliber of prospective attendants often deteriorates. Many disabled people know too well that they usually get what they can afford. They also know that the attrition rate of the lowest wage-scale employees can be very high. To date HIP has minimized these problems through staff live-in arrangements.

Part-time helpers are used on a regular basis during peak workload periods, especially during early morning and late evening hours, and on weekends. They assist the residents in dressing, transferring to wheelchairs, grooming, and preparing and serving meals. In the evenings, they assist in transferring residents to beds and in undressing them. The part-time helpers are also used in numerous other capacities, such as driving or minor internal maintenance work. Their wages vary, depending on their duties and experience.

One of the three full-time staff members is the special weekend attendant. This person is on call from 6:00 a.m. Saturday until 6:00 a.m. Monday. The special weekend attendant also helps supervise the part-time staff, and often assists in dressing, undressing and, in the more detailed bio-care, as required.

Locating competent and responsible attendants is a chronic problem for the severely physically disabled. Attendant hiring is also a problem for the elderly and the convalescing in many places, so this makes it a widespread community problem. City-wide, centrally located offices may prove to be the solution. Such offices could provide attendants of many types, such as companions, drivers, housekeepers, counselors, para-legals, and several years. Those who are participating in this precedent-setting concept enjoy the challenges with which they are continually confronted. They realize that small group handicapped housing is no different from any other experimental program. Regardless of its advantages, challenges are to be expected, and constant efforts toward improvements must be made for continuing successful operations.

As of November, 1977 the name of Handicapped Independence Proven has been changed to Mi Casa, Su Casa, and it is under new management. All questions regarding current status should be directed to: Mi Casa, Su Casa, 5333 El Cajon Blvd., San Diego, California 92115, U.S.A.

REFERENCES

American National Standards Institute, Inc. American national standard specifications for making buildings and facilities accessible to, and usable by the physically handicapped. Washington, D. C.: The President's Committee on Employment of the Physically Handicapped, ANSI-A117.1, 1961 (reaffirmed 1971).

Aulger, A. A. A pilot study of selected curricula and facilities to determine their appropriateness and accessibility for orthopedically handicapped students. San Diego, California: Department of Education of San Diego County, October 15, 1974.

California Civil Code—As amended by the 1972-1975 legislatures. Division 13 of the Health and Safety Code Part 5.5.—Access to public accommodations by physically handicapped persons. Sections 19955-19959; also Chapters 2, 5, 7, and 15.

*Cheever, R. C. (Ed.) *Accent on living, Inc.* Bloomington Ill.: R. C. Cheever.

Federal law related to public housing for the handicapped and elderly. P.L. 90-480, 1968.

*Laurie, G. and Laurie, J. (Eds.), *Rehabilitation Gazette.* St Louis, Missouri.

Laurie, G. and McGwinn, D. *Housing and home services for the disabled and elderly.* Hagerstown, Maryland: Harper and Row, 1977.

Mendelson, M. A. *Tender loving greed.* New York: Alfred A Knopf, 1974.

Rice, D. M. and Hinton, H. E. Handicapped independence proven. Chapter in *Housing and home services for the disabled.* New York: Harper and Row, 1977.

United States Code: Section 802, Chapter 21, Title 2 Formula for determining maximum grant to veteran qualifying for specially adapted housing. Implemented by Veterans Administration Regulations (C.F. 36.4406-36.4410).

*Webb, R. L. (Ed.) *Paraplegia News.* Seal Beach, Ca

EPILOGUE

Chapter 9: *The Residents Revisited*

Chapter 9: *The Residents Revisited*

Cooperative Living had a special meaning for each resident who participated in the program. To some, it meant being able to leave a nursing home or family home; to others, it provided the opportunity to go to school or consider employment. But to each resident, the Cooperative Living experience provided a setting to test his or her independence in new ways.

As a result of the Cooperative Living experience, most of the residents were able to consolidate both personal and agency resources to improve their life-styles and create options and opportunities that were not formerly available. The following case narrative describes this difficult process, and highlights the role of the Cooperative Living concept in helping integrate all the resources required to help persons achieve personal goals and expectations that are commensurate with their abilities.

> John Lopez (fictitious name), a 17-year-old Mexican-American, lived with his parents and 11 siblings in a small town about 15 miles outside of Houston, where his father worked on an irregular basis. In 1965, John became quadriplegic as the result of a diving accident. John had never liked school and had just completed the eighth grade prior to his accident. His spinal cord injury, at the level of the sixth cervical vertebra, left John facing abrupt changes in his life-style.
>
> After the accident, John was taken to a county hospital in Houston where he spent two months, and was then transferred to the Texas Institute for Rehabilitation and Research, a comprehensive medical rehabilitation facility.
>
> During the comprehensive rehabilitation process, John benefited from a number of services beyond those required to restore function, use residual movement, and stabilize his health and physical condition. In physical therapy and occupational therapy, he learned to use his residual physical capabilities so that at discharge he could push his wheelchair on a level surface, perform grooming activities, feed himself, and write slowly using special reciprocal wrist splints. He also began some new leisure activities, including painting. Social service counseling and therapy were important in helping him resolve some of his feelings about the hopelessness of his situation and finally in working out some future plans for his life. This was tedious and often frustrating because of his precarious and uncertain physical condition and his awareness of its meaning to his survival and range of options.
>
> After leaving the Institute, John returned to his rural

family home. His personal life centered about his brothers and cousins. Transportation out of his isolated setting was seldom available for a wheelchair-dependent person. As a result, in spite of his earlier dislike of education, John developed an interest in reading which became his major pastime. During the next seven years, John lived with his family and returned to the Institute every six months to be followed in outpatient clinics.

John eventually became dissatisfied with his existence and sought a vocational evaluation to explore other alternatives. This examination revealed an intellectual potential for college and also indicated that with proper equipment, John now had enough hand and arm function to perform some manual shop tasks. He was accepted as a client of the Texas Rehabilitation Commission (TRC) and made the decision to enter a work adjustment and vocational training program at the Institute's Work Activities Program.

In order to begin involvement in vocational training, John had to find a living arrangement in Houston, since his family was unable to provide daily transportation. Initially he agreed to live in a nursing home which had other young disabled residents, and where shared transportation would be available. He had strong feelings of dread about moving to this environment, and it was a difficult compromise to make. Fortunately, before he entered the nursing home, an opening became available in the Cooperative Living project. John moved into the project in the fall of 1973, and began to reassess his personal goals. Following extensive vocational exploration, in January, 1974, he entered a training program in micrographics developed by the Work Activities Center.

The contacts John experienced with young, active, working disabled persons and the availability for social and vocational involvement stimulated important changes in his lifestyle. In May, 1974, John moved into an apartment cluster with shared attendant and transportation services developed as an outgrowth of the residential program. At this time (December, 1976), he is living with a significant other in this setting.

After being employed a year and a half in the micrographics project, John decided to enter the University of Houston where he is presently enrolled, and plans to graduate soon.

John's needs for a complex array of rehabilitation services during the years since his injury have varied greatly as his

personal development has evolved. Without the availability and appropriate coordination and timing of a number of key elements of comprehensive rehabilitation, such as medical restorative services, follow-up services, adaptive housing, vocational evaluation and training, attendant assistance, and transportation, John's progress would have been stifled. Access to only one of these elements would have been of little benefit.

In this case example, it becomes clear that understanding and negotiating services, many with conflicting entitlements, was essential for success. Also, the timely availability of a housing alternative in the sequence of events was extremely important. Without the Cooperative Living alternative, it is questionable whether the goals of independent living, involvement in school and work, and active social participation would have been attainable.

The Cooperative Living concept, which combines physical arrangements and assures personal physical assistance, vocational training experiences, and personal growth services, must be a part of the rehabilitation process that extends beyond the formal institution. The full impact of this concept is further illustrated by a follow-up study conducted in January, 1977, on the 40 residents who participated in the Cooperative Living project.

In the follow-up study, it was determined that one resident had died, and three were lost to follow-up, giving a reportable N of 36. Thirty-three of the 36 persons interviewed now live in urban settings, and three reside in rural homes. Of the 33 persons living in urban settings, 17 currently live in apartment clusters with shared services, four reside with personal attendants in apartments or apartment clusters, five reside with their spouses in apartments or apartment clusters, three live in homes with their spouses, one person lives in his own home with an attendant, two residents have returned home to their families, and one person currently resides in a nursing home.

The current mean income level of the residents has increased from $122.59 at admission to the project to a current mean of $496.91. This increase is primarily due to the active vocational involvement of 17 former residents. Chart 8:1 lists the job classifications and reports full and part-time employment.

Chart 8:1
Current Job Classifications of Former Cooperative Living Residents

Part-time	Full-time
1 – real estate salesperson	2 – switchboard operators
1 – writer	1 – intermediate school teacher
1 – products salesperson	1 – receptionist
1 – communications clerk	1 – accountant
	1 – civil engineer
	1 – social work administrator
	1 – vocational evaluator
	1 – products salesperson
	1 – research director
	1 – college professor
	2 – residential managers
n = 4	n = 13

Of the 19 persons who are not employed, 13 are attending college or are involved in vocational training, and six persons are inactive. Two are inactive due to medical problems, and four are in the process of reformulating plans.

Chart 8:2 offers a comparison of the residents' sources of income at admission with current sources. Several significant conclusions can be drawn. The employment status, both full and part time, demonstrates that employment gains were maintained. Secondly, the role of Vocational Rehabilitation in the process of helping residents achieve vocational independence was successful; therefore, vocational rehabilitation support has decreased from 15 persons being sponsored at admission to seven at the time of the follow-up study. Thirdly, the dependence on state welfare programs, Supplemental Security Income, and Social Security has decreased from 37 persons being sponsored to 24 currently receiving these types of benefits. Finally, the shift in dependence from parents is significant from the standpoint of individual independence.

Chart 8:2
Residents' Sources of Income

	ADMISSION	CURRENT STATUS
EARNINGS		
Part Time	1	4
Full Time	0	13
SOCIAL SECURITY	17	9
SUPPLEMENTAL SECURITY INCOME	4	15
STATE VOCATIONAL REHABILITATION	15	7
HOUSING AUTHORITY	0	0
VETERAN'S ADMINISTRATION	1	1
STATE WELFARE	16	0
PARENTS	28	2
SPOUSE	0	3
OTHER (Investments, etc.)	3	3

The follow-up study also included a question about the former residents' feelings about their current life-styles and their future goals and plans. Thirty-one of the residents indicated that they are content with their current life-styles, four feel their life-styles could be improved, and one

person indicated dissatisfaction with his life-style. When asked about future goals or plans, 12 persons expressed a desire to go to work, nine said they wanted to complete their education or vocational training and begin work, six wanted to obtain a higher degree or pursue a post-graduate professional degree (i.e., law), two said they would like to purchase a car, and six persons indicated that they had achieved their goals and were content. Four persons had no future plans or goals.

The findings in this follow-up study serve to reinforce the permanance of the benefits of the Cooperative Living experience upon individual residents. The Cooperative Living model offers hope for the disabled segment of our population. The experience in Houston, Texas, only serves to typify the need existing across the nation for unique living arrangements for the severely handicapped. Independent living for the severely disabled must become the rule, not the exception, in the United States. The Cooperative Living concept can serve as a national model for residential developments of this type. Therefore, the significance of this venture and others to follow can only be measured after viewing the opportunities offered.

INDEPENDENT LIVING CURRICULUM

OBJECTIVES

1. To provide a list of resources and materials relevant to the development of an IL Curriculum.

2. To feature materials which may assist facility personnel in training and teaching skills to their program participants.

SUMMARY

The materials presented in this section are portrayed in accordance with the selection process used in gathering sources for this manual. The first part of this section contains materials that have been personally reviewed by the project staff. The second part of this section offers suggested references which have been reviewed by various professionals involved with IL services or research.

The majority of the materials selected utilize behavioral techniques in developing methods of assessment, training, or teaching. This approach involves initiating written objectives, lesson plans, and methods for the evaluation of results. We would like to caution the reader, however, from using these kinds of materials in isolation. The philosophy of IL stresses not only the development of certain competencies, but a "state of mind" whereby the individual feels "in control" of his/her own life and is able to make decisions without undue dependence upon others. The psychological aspects of IL can also be evaluated through personal interviews, personal counseling, and observations of actual experiences in daily living.

It is also recommended that the professional involved with IL services explore alternative resources that have not been well-publicized up to the present time. For example, the Boston Center for Independent Living (BCIL) is in the process of writing a manual on staff development and IL service delivery. The Center for Independent Living (CIL) in California provides technical assistance to many facilities and centers who are in need of information on the development and implementation of services. CIL, along with the Texas Institute of Rehabilitation and Research, (TIRR), strive to provide continuing research and resources on IL. TIRR plans to offer training in developing Individually Written Rehabilitation Plans

and Programs (IWRP'S) in Independent Living, which will most likely come about in June or July of this year. And lastly, many hospitals who provide care for severely disabled individuals may have information on staff development and services for their patients.

There is a need for continued research and development in service delivery for Independent Living. It is hoped that facilities and centers will make their programs known through publication of their IL curriculum and program materials.

(1) De Jong, Gerben and Sager, Alan. Meeting the Personal Care Needs of the Severely Disabled Citizens in Massachusetts. Waltham, Massachusetts, Levinson Policy Institute, Brandeis University 02154, 1977. To order, please contact Gerben at Tufts-New England Medical Center, 171 Harrison Avenue, Boston, Massachusetts 02111.

This 220 page manual is a detailed exposé on personal care services for the severely physically disabled. The concept of consumer-directed personal care attendant (PCA) has emerged as one of the key focal points in the provision of IL services. The PCA is an individual who assists a disabled person in bathing, dressing, toilet care, skin care, and other daily activities. They may also lend assistance in meal preparation and housekeeping chores. In this model, the PCA is viewed as a regular employee and not as an assistant. The disabled person is solely responsible for hiring and terminating his attendant's employment.

For the professional who is responsible for, or involved with, the provision of attendant care or attendant care referral services, this information can facilitate the following:

(1) An awareness of the complexities of funding mechanisms for PCA services, and potential avenues of support for their own particular program.

(2) An education in the various PCA systems in use, and the specific elements therein. This includes eligibility criteria, employee selection, services needed, and attendant care training.

(2) Fry, Ronald R., and Smith, Bradley C. Instructional Materials in Independent Living. Menomonie, Wisconsin 54791, Materials Development Center, University of Wisconsin, Stout, 1978.

In response to the need for instructional materials in Independent Living, this annotated list of resources has been developed for the rehabilitation professional. The majority of the selections are written with the developmentally disabled individual in mind. Topic areas such as personal care and money management, however, may be applicable and necessary in meeting the needs of various disabled populations. For a preview of materials, here are some examples of the resources listed:

Baker, Richard and Sawyer, Horace. Adjustment Services in Rehabilitation: Emphasis in Human Change. Auburn, Alabama 36830, Auburn University, Rehabilitation Services Education, 216 Petrie Hall, 1971.

This publication examines the concepts of adjustment as perceived by rehabilitation facilities, and offers information on developing goals, implementing services, and defining training areas. In addition, an extensive reference section on adjustment and vocational evaluation is offered.

Adjustment programs typically concern themselves with client behavior and competencies in work or work-related areas. This process is directed towards the enhancement of vocational potential. This document may provide a basis for structuring an IL service component, however as skills development in IL also focuses on behavior and client change.

Kreps, A., and Redden, C. Ongoing Classes for Developmentally Disabled Adults in the Denver Area: Working Curricula 1975-76. Denver, Colorado, Metropolitan State College, 1006 11th St., Box 92, Denver, Colorado 80204.

The Stout publication lists this source and 13 others from Denver which deal with the following areas: Homemaking, family living, hygiene, money management, transportation, and methods of program evaluation. For each area in the curriculum, goals are established, objectives designed, and pre- and post-tests are administered.

These publications may serve as a guide in developing service areas and in designing assessment tools for an IL program. Since the material is geared towards developmentally disabled adults, the information may be easily adapted for use with the disadvantaged disabled population.

(3) Georgia Division of Vocational Rehabilitation, Overview: Adjustment Services, Milledgeville, Georgia 31061 Rehabilitation Center, Central State Hospital, 1976.

This collection of materials includes a series of manuals which cover the following adjustment areas: community living, social and personal skills, and work adjustment training. The development and implementation of the center's program is explained, and its functions described. For each area of programming the referral process, methods of evaluation, and the reporting system utilized are outlined.

The procedures used in adjustment services training may be revised for adaptation to an IL curriculum. For example, for the section on Community Resources, a complete lesson plan is provided. This plan includes objectives, methods, activities, and subject matter to be learned. The information offered from this set of manuals claims to be designed for the occupational and personal fulfillment of the participants, all of which intersect with the concepts of IL rehabilitation.

(4) James, Muriel, and Jongeward, Dorothy. Born to Win: Transactional Analysis with Gestalt Experiments. Menlo Park, California: Addison-Wesley Publishing Company, 1977. Transactional Analysis Association, 1772 Vallejo Street, San Francisco, California 94123.

The authors provide a detailed interpretation of transactional analysis which is a psychological construct that proposes a rational method for analyzing and understanding human behavior. TA believes that man is capable of directing his own life, of making decisions without persuasion from others, and is capable of being a "winner" in life. To "win" at life, an individual must learn to develop certain aspects of his/her own personality. These include being able to give and receive love, be responsive to the needs of others, and to be able to assume responsibility for his/her own life. The concept of IL for the disabled echoes these descriptions.

(5) Johnson, Stuart R., and Johnson, Rita B. Developing Individualized Instructional Material. Palo Alto, California: Westinghouse Learning Press, 1970. 2680 Hanover Street, Palo Alto, California 94304.

One of the challenges in delivering IL services is the necessity for the reconciliation of individual needs and capabilities with general service provisions. The client is asked to assume control in developing his own program goals and objectives. IL services, however, may be

limited and/or general in approach, depending upon such factors as available funding and community resources.

This booklet provides a method for developing an instructional system which emphasizes individual learning. This approach is based upon an analysis of the specific behavior desired, and a task analysis of that behavior. Included in this manual are sections on specifying and analyzing objectives, measuring the attainment of objectives, arranging instructional activities, designing methods and materials, and refining the instructional system. This material may be a valuable resource for those professionals who require a step-by-step procedure in providing IL services.

(6) Laurie, Gini. Housing and Home Services for the Disabled: Guidelines and Experiences in Independent Living. St. Louis, Missouri: Medical Department, Harper and Row Publishers, 1977. Gazette, 4502 Maryland Avenue, St. Louis, Missouri 63108.

Gini Laurie is often referred to in IL circles as the "person in the know" when it comes to possessing a long-time understanding of the needs of the severely disabled. As the Editor and Founder of the Rehabilitation Gazette, Ms. Laurie has been keeping her readers informed on relevant issues for the disabled, since the magazine's inception in 1958. As the Gazette has become internationally based, the concepts and experiences generated by its readership have kept the material relevant, and a global perspective has been provided.

The purpose of this book is to provide the professional with a worldwide assortment of housing situations, complete with solutions to problems encountered and model programs to follow or adapt for use. The areas covered include kitchen adaptions, attendant care, apartment living arrangements, and resources for architects and planners. This material offers a definitive analysis on the needs of the disabled and the housing alternatives available for them. For those involved with providing housing alternatives or housing referral services, this book stands as the editor's choice.

(7) Means, Bob L., and Roessler, Richard. Personal Achievement Skills Training: Instructor's Manual. Fayetteville, Arkansas 72701, Arkansas Research and Training Center, University of Arkansas, 1976.

The authors have designed this manual for individuals who are in need of skills in the area of goal setting and communication, and who are in the process of

adjusting to some "major disruption" in their way of living. PAS training claims to be successful for the blind, spinal cord injured, juvenile delinquents, and other disabled groups.

The skill areas that are covered in the manual include the following: Communication, self-examination, values clarification, valuing, goal definition, problem exploration, and program development. Objectives, activities, and the necessary equipment are listed for each area. This information appears to be an excellent source for assisting individuals in learning to appreciate themselves and their abilities, and to receive this recognition from their friends and community. For those newly injured, it may provide a positive direction for personal and vocational growth in the face of a traumatic situation.

(8) The National Easter Seal Society for Crippled Children and Adults. Rehabilitation Literature, 2023 West Ogden Avenue, Chicago, Illinois 60612, 1979.

The Easter Seal Society publishes a list of references and sources of information for the professionals who are working with disabled children or adults. In regards to Independent Living, the Society offers a number of publications that may be relevant for curriculum development.

The following are examples which may be of interest. Any orders for the materials must be addressed directly to the individual publishers.

A Resource Guide To Habilitative Techniques And For Cerebral Palsied Persons of All Ages, by Elizabeth Codman High. 1978. 150 p. illus. Job Development Laboratory, Rehabilitation Medicine, George Washington University, 2300 Eye St., N.W., Room 420, Washington, D.C. 20037.

A comprehensive guide and reference tool to technical aids and sources. The sections include general references and audio-visual sources, references on positioning and seating, feeding, dressing, hygiene, household and community involvement. The appendix includes suppliers of aids and equipment, publishers and organizations.

Aids For The Severely Handicapped, edited by Keith Copeland. 1974. 152 p. illus. Grune & Stratton, 111 Fifth Ave., New York, N.Y. 10003.

Aids To Independent Living: Self-Help For The Handicapped, by Edward W. Lowman and Judith Lannefeld Klinger. 1969. 896 p. illus. Blakiston Div.,

McGraw-Hill Book Co., 1221 Avenue of The Americas, New York, N.Y. 10020.

International Guide To Aids And Appliances For Blind and Visually Impaired Persons. 1977. 254 p. Paperbound. American Foundation for the Blind, 15 W. 16th St., New York, N.Y. 10011.

Rehabilitation Techniques In Severe Disability: Case Studies, by John G. Cull, Ph.D. and Richard E. Hardy, Ed.D. 1974. 238 p. (American Lecture Series in Social and Rehabilitation Psychology) Charles C. Thomas, Publisher, 301-327 E. Lawrence Ave., Springfield, I.L. 62703.

Case studies are included of persons with mental retardation, epilepsy, visual impairment, diabetes and diabetes with blindness, spinal cord injury, hearing disabilities, amputations, cancer, rheumatoid arthritis, drug dependency, cardiovascular disease, and pulmonary disabilities.

(9) New Options Transitional Living Project, The Institute for Rehabilitation and Research, 1333 Morusund Avenue, Houston, Texas 77030, 1979. (Refer to Appendix)

There are two publications that appear to be relevant for the professional who is in the process of developing IL services in his facility or center. "New Options" explores the process by which severely disabled persons become independent, and examines the functions of the program in a detailed, informative manner. The "New Options Training Manual" offers information on teaching strategies for the development of community living skills.

In the training manual, the areas of development include functional skills, living arrangements, mobility, and time management. Each area is designed as a training module, and includes a statement of purpose, orientation information for the group leader, instructional objectives, lesson content, and outline aids.

The New Options project was designed for those individuals who are medically stable and who have a major mobility impairment. This project has functioned as one of the leading model IL programs in the country. Judging by the quality of these publications, their reputation has most certainly been well-deserved.

(10) Schalock, Robert L., and Gadwood, Linda. Program Handbook. Hastings, Nebraska 68901, Mid-Nebraska Mental Retardation Services, 1979.

This handbook introduces the approach used by the Mid-Nebraska Center, in developing and implementing their programs. In reference to IL services, the authors have also developed the following materials: IL Screening Test, Standardization manual, and the IL Teaching manual.

This material is designed primarily for mentally retarded individuals. The techniques that are presented, however, may be utilized by any professional who is involved with developing IL services for various disability groups.

Among the areas to be covered are Time Management, Home Maintenance, and Community Utilization skills. A systematic analysis of steps to be completed, taken from a task analysis, comprises the first step in the center's approach. From this analysis, individual objectives and training methods are designed. Task analysis can be an effective tool in working with mobility or sight impaired persons, whose limitations may inhibit "normal" learning processes, so that it becomes necessary to provide a step-by-step learning process based upon individual ability.

(11) The Sourcebook for the Disabled. Hale, Gloria, (ed.) New York: Paddington Press, Ltd., 1979. 95 Madison Avenue, New York, New York 10022.

This manual covers a wide range of concerns advanced by disabled persons. Its intent is to explore attitudes, options, and aids which can enable them to maintain a more comfortable, independent lifestyle. Areas covered include aids for daily living, the environment (eg. transportation), home, adaptions, personal care needs, sexuality, parenting, and a resource section on references pertinent to the aforementioned areas. This source book could be called the "encyclopedia of the world of the disabled," and would be an ideal first choice in developing a library of curriculum materials.

(12) Van Hooser, Jack and Rice, B. Douglas. Report from the Study Group on the Rehabilitation of the Severely Handicapped Homebound. Hot Springs, Arkansas 71901, Institute on Rehabilitation Issues, Arkansas Rehabilitation Research and Training Center, 1977.

This manual presents an overview of rehabilitation efforts in servicing severely handicapped homebound persons. Areas covered include service delivery, program planning and development, job placement and modification, and staff training procedures.

The homebound individual is one whose physical, intellectual, or emotional condition is so disabling that they cannot function effectively in an employment situation. Recommendations are offered and procedures are outlined for enabling the homebound to become employable. These suggestions include developing viable work opportunities, such as self-employment, or work activities in the home. For those in need of IL services, this manual offers guidelines for taking the beginning steps towards living independently.

(13) Walls, Richard T; Zane, Thomas; Thuedt, John E. Independent Living Behavior Checklist. West Virginia Rehabilitation Research and Training Center, 509 Allen Hall, West Virginia University, Morgantown, West Virginia 26506, 1979.

The ILBC is an extensive list of 343 independent living skill objectives carefully specified in terms of conditions (antecedents or givens), behaviors, and standards (criteria for correct performance).

The development of this Behavior Checklist began with more than 200 behavior checklists collected from rehabilitation facilities and schools throughout the United States and some other countries. Of these checklists, 53 checklists were selected which contained items found to be constructed well enough to suggest ways to assess independent living behaviors. Thus, the ILBC encompasses the collective experience and judgment of an impressive array of training personnel.

This publication covers the following six areas: Mobility Skills, Self-Care Skills, Home Maintenance and Safety Skills, Food Skills, Social and Communication Skills, and Fuctional Academic Skills.

Along with the checklist a skills summary chart is provided for each area. It contains the following information: trainee selection, skill objective, initial assessment /Mastered (+) or (-)/ and dates for training (date begun and completed).

In using this checklist the trainer or evaluator for independent living skills will find clear standards for determining client skills in various areas. The professional responsible for writing Individualized Education Programs or Individualized Written Rehabilitation Plans will find objective documentation for legislative requirements, as well as a means for goal setting and evaluation of client progress. Based on a review of the manual and its contents, this appears to be a valuable publication for pinpointing specific

behaviors to assess in an Independent Living Program. The content appears to be designed for a mentally retarded population, but its approach to IL assessment could possibly be revised for other disability groups in mind.

(14) Wehrum, Mary S. Techniques of Daily Living. Pittsburgh, Pennsylvania: The Greater Pittsburgh Guild for the Blind, 1977.

This manual is designed for the instructor of adventitiously and congenitally blind adults who are in need of developing skills in areas associated with daily living activities. The intent of this information is to provide a strategy which could assist in structuring curriculum based on individual need. Areas addressed in this manual include eating skills, personal grooming, special needs, shopping, and marketing. Objectives for training, and suggested learning procedures and experiences are outlined for each section. For those who are newly blind, or who have been homebound or institutionalized, this material may provide assistance to the IL practitioner in developing Individually Written Rehabilitation Plans (IWRP'S) for his/her blind clientele.

(15) Wolfensberger, Wolf. Normalization: The Principle of Normalization in Human Services. Toronto, Canada: National Institute on Mental Retardation, York University Campus, 4700 Keele Street, 1972.

In this book, the normalization principle is defined, and its major implications are reviewed. Application of the principle to social service areas and strategies for implementation are offered. Normalization, within the context of human management, refers to the process whereby the individual seeks to adopt personal behaviors and characteristics which are as culturally normative as possible, given his/her own capabilities.

IL rehabilitation seeks to provide normalizing experiences for severely disabled individuals, so that they can become active contributors to their home, family, and community. Wolfensberger provides a basis for understanding the various facets of this philosophy. For the professional who is developing an IL curriculum, this material can provide a framework and philosophical basis from which to begin.

SUGGESTED REFERENCES

(1) Becker, Elle F. Female Sexuality Following Spinal Cord Injury. Bloomington, Illinois: Accent Special Publications, P.O. Box 700, Bloomington, Illinois 61701, 1978.

(2) Bregman, Sue. Sexuality and the Spinal Cord Woman. Minneapolis: Sister Kenny Institute, Chicago Avenue, 27th Street, Minneapolis, Minnesota 55407.

This material offers frank advice on social and sexual adjustment, and counters stereotyped attitudes toward the sexual potential of women with spinal injuries.

(3) Galbreath, Patricia. What You Can Do for Yourself. Drake Publishers, Inc., 801 2nd Ave., New York, New York, 1977.

This manual offers practical tips and ideas for achieving independence inside and outside the home.

(4) Gilbert, Arlene E. You Can Do It From a Wheelchair. New Rochelle, New York: Arlington House, Publishers, 1979.

This booklet is authored by a paraplegic mother of four, and offers advice on homemaking, financial matters, and raising children in light of a personal experience with a disability.

(5) Gordon, Sol. Sexual Rights for People Who Happen to Be Handicapped. Syracuse, New York: Human Policy Press, 1978.

(6) Gregory, Martha Ferguson. Sexual Adjustment, A Guide for the Spinal Cord Injured. Bloomington, Illinois: Accent Special Publications, 1978.

(7) Hayes, Jim, and Smith, Shannon. Live-In Attendant Care Manual. Arlington, Texas: University of Texas at Arlington and Texas Rehabilitation Commission, South College Avenue, Arlington, Texas 76019, 1978.

(8) Hradesky, Patricia L.; Callas, Gwen H.; Cranston, Dr. Jay; and Kile, Margaret H. Attendant Care Manual. Kent State University Office of Handicapped Students, East Main and Lincoln, Oxford, Ohio 45056, 1978.

(9) Klinger, Judith L., O.T.R., M.A. Self-Help Manual for Arthritis Patients. New York: The Arthritis Foundation, 221 Park Avenue, South, New York, New York.

(10) May, Elizabeth; Hotte; and Waggoner, Neva R. Independent Living for the Handicapped and the Elderly. Boston: Houghton Mifflin Company.

This book offers information on aids and techniques to assist the disabled in coping with the problems of daily living.

(11) Sex and Disability Project, Institute on Attitudinal, Legal and Leisure Barriers, 1828 L Street, Washington, D.C. 20036, 1979.

This manual supplies information on a project which has been set up to provide a model for sexual adjustment counseling services for people with disabilities.

(12) Taggle, J. M., and Manley, M. S. A Handbook on Sexuality After Spinal Cord Injury. M. Scott Manley, 3425 S. Clarkson, Englewood, Colorado 80110, 1978.

(13) Towards Intimacy. "Family Planning and Sexuality Concerns of Physically Disabled Women." New York, Human Sciences Press, 1978. Task Force on Concerns of Physically Disabled Women, 72-5th Avenue, New York, New York 10027.

(14) Zilbergeld, Bernie. Male Sexuality: A Guide to Sexual Fulfillment. Boston, Massachusetts: Little, Brown and Company, 34 Beacon Street, 1978.

Attendant Management

Purpose

The Attendant Management module is intended to help participants explore a variety of ways to meet their needs for daily attendant assistance. It is also intended to teach practical information about attendant services and to provide an opportunity to practice specific skills important in managing this aspect of ones life. (In **New Options**, attendance at this module is optional for paraplegics and other persons who do not require daily attendant assistance.)

This subject is included in the **New Options** program because most participants formerly received attendant care either from family members or nursing home personnel prior to entering the project. Consequently, they usually have had little direct responsibility for self-directed care in the past and may not have had an opportunity to hire and supervise attendants, manage the financial resources to pay for this service, or confront problem areas such as the need for a back-up system. These management skills are essential if independent living and a self-directed lifestyle are important to the individual.

The Attendant Management module also emphasizes personal interaction between a disabled individual and an attendant. It seeks to foster an awareness of the attendant's perspective, and also points out the practical importance of the many skills taught in the Social Skills module, including assertiveness, listening skills, and conflict resolution.

Requirements of the Group Leader

The group leader for this module should be a handicapped person who needs daily attendant assistance and has personal experience with several different types of attendant arrangements. This background can help the leader provide examples of problems that may occur and offers a comparative perspective to the participants. The leader should also be sensitive to social interaction skills so that he can help participants become aware of the effects of their behavior on other persons.

Orientation for Group Leader

In preparing to teach this module, the group leader should familiarize himself with a wide variety of alternative attendant arrangements. He might talk to other disabled persons who use arrangements he has never experienced personally to learn about the pros and cons.

The leader should also be knowledgeable about sources of funds to pay for attendant assistance. This information is available from local agency personnel who work with attendant care programs. Primary contact agencies include the State Department of Vocational Rehabilitation, the Department of Human Resources, and various welfare agencies.

The leader should consider experienced attendants as good sources of insight for this module. Attendants obviously vary greatly in their ability to articulate feelings about their job, and it is helpful to invite someone skilled in this area to talk with participants.

It is also useful for the group leader in this module to communicate closely with the leader of the Social Skills module. Participants will be learning many relevant skills in Social Skills that can be applied in attendant management situations, and it is important that the two group leaders use this overlap to advantage. If the Attendant Management module is taught as a separate entity, two sessions from the Social Skills module may be incorporated into this module. These are the sessions on assertiveness and conflict resolution. Attendant Management also relates directly to the Living Arrangements module. As participants visit disabled persons in a variety of living situations on Living Arrangements field trips, it is important that they learn as much as possible about the host's attendant arrangements as an important part of an overall independent living plan.

Linkages With Other Modules

Important relationships with the Social Skills and the Living Arrangements modules have been discussed. Also, the Attendant Management module is closely related to the Financial Management module since costs of attendant services are usually a substantial item in a disabled person's budget. Questions about sources of funds, accounting requirements, tax obligations, and other issues should be generally addressed in financial management. These can also be explored on an individual basis in the fifth Financial Management session in which each participant reviews his personal budget with the Financial Management group leader.

Module References and Suggested Resources

Printed Materials

Hayes, Jim and Shannon Smith. *Live-In Attendant Care Manual.* University of Texas at Arlington and Texas Rehabilitation Commission, Arlington, Texas, 1978.

Hradesky, Patricia L., Gwen H. Callas, Dr. Jay Cranston and Margaret H. Kile. *Attendant Care Manual.* Kent State University Office of Handicapped Students, 1978.

Larson, Maren R. and Daniel E. Snobl. *Attendant Care Manual: Rehabilitation Services.* Southwest State University, Marshall, Minnesota, n.d.

Films and Videotapes

Geyer, Robert and Delma Brown. *Attendant Management: The Attendant's Perspective* (60 minute 3/4" videotape). The Institute for Rehabilitation and Research, Houston, Texas, 1977.

Materials Obtained Locally

Materials from local agencies on attendant care programs such as the Attendant Care Program administered by state Departments of Welfare.

Suggestions for Possible Sessions in Attendant Management

- Alternative Attendant Arrangements
- Interviewing a Potential Attendant
- The Attendant's Perspective
- Asking for Help and Turning Down Unnecessary Help (located in the Social Skills module outlines)
- Conflict Resolution (located in the Social Skills module outlines)

Attendant Management Module Outline

Title: Alternative Attendant Arrangements

Format: Group meeting

Purpose: To consider the pros and cons of various attendant arrangements and to discuss various ways of locating and paying for attendant services.

Instructional Objectives:

1. By the end of the session, each participant will be able to list three alternative attendant arrangements and the pros and cons of each.
2. By the end of the session, each participant will be able to list three ways they might find an attendant and two sources of funds to pay for attendant care.

Planning and Materials:

Secure copies of handouts on locating an attendant and paying for an attendant (included in this section).

Estimated Time: 1-1/2 hours

The Lesson:

Instructional Set:

1. Ask participants to discuss what they would do if their present attendant care system ended tomorrow. Ask what alternative arrangements they can think of, where they might look for an attendant, and how they would pay for these services.
2. Introduce purpose of the session.
3. Review the instructional objectives.

Content:

1. Ask each participant to state the hours he routinely needs attendant help and the types of assistance required.
2. Discuss alternative ways of managing attendant needs including private attendants who come at scheduled hours, live-in attendants, shared attendant services, family members, friends, nursing home services, visiting nurses, and any other alternatives the participants can identify. Ask the group to list pros and cons of each alternative, keeping their personal needs in mind.
3. Have participants identify the back-up systems needed for each of these alternatives.
4. Ask participants to discuss ways they might find a private attendant. Have the group write a sample advertisement to be placed in a newspaper or sample bulletin board notice. Distribute handout on locating an attendant.
5. Review possible sources of funds to pay for attendant services and distribute handout. Discuss how much attendants should be paid and any constraints on salary level imposed by funding sources.

Closure:

1. Summarize the session by asking participants to complete tasks in instructional objectives.

Outline Aid

Suggestions for Locating an Attendant

1. College bulletin boards and placement offices (including schools of nursing and medical schools).
2. Hospital bulletin boards.
3. Nursing home bulletin boards.
4. Health care agencies (Medical Personnel Pool in Houston).
5. Local newspapers, including college papers.
6. Public health departments.
7. State and private employment offices.
8. Friends who use attendants.
9. Mormon Church.

Outline Aid

Possible Funding Sources for Attendant Services

1. State Department of Vocational Rehabilitation. (Texas Rehabilitation Commission has paid for attendants in dormitories and in private and shared living arrangements. Must be DVR client to qualify.)
2. Attendant Care Services. (Title XX funds, usually administered by State Welfare Department. Maximum monthly amount in Texas is $212; supplemented in some states including California and Minnesota. Family members can be care providers. Must be SSI recipient to qualify.)
3. In some states such as Massachusetts, Title XIX funds (Medicaid) can be used to pay for attendant services. This is not available at the present time in Texas.
4. Charitable or voluntary organizations may give "scholarships" to help with costs of attending school. In Houston the Houston Clergy Association is an example. Will require research in local community.

Attendant Management Module Outline

Title: Interviewing a Potential Attendant

Format: Group meeting

Purpose: To practice interviewing techniques for hiring an attendant

Instructional Objectives:

1. Each participant will list three questions which should be asked of an attendant applicant.
2. Each participant will role play an interview situation with a potential attendant.

Planning and Materials:

1. Make arrangements for one or two people from outside the group to play the part of "attendant" in interview situations. These people should be prepared by the group leader to portray typical applicants. They should request clarification on any duties they do not understand and portray indifferent, hostile, or partronizing attitudes in different interviews.
2. Secure copies of handout on considerations in interviewing potential attendants (included in this section).

Estimated Time: 2 hours

The Lesson:

Instructional Set:

1. Introduce the purpose of the session.
2. Ask participants to state reasons it might be important to select an attendant carefully. Have them identify possible consequences of a bad choice.
3. Review the instructional objectives.

Content:

1. Ask participants to list questions which they feel need to be asked of potential attendants. If participants have had some negative experiences with attendants, ask them to identify questions that might help anticipate potential problems and identify positive traits. For example, they might ask how many sick days the applicant has had in the last six months of work. Another line of questions might address the kinds of things that make the applicant angry and what he does when he gets angry.
2. Discuss basic interviewing techniques. Review suggestions in interviewing handout.
3. Practice role play situations. Each participant will interview an attendant applicant and the group will then comment on the interview.

Closure:

1. Ask participants what they now feel are the most important things to look for in an attendant.
2. Ask them to discuss what they learned from the practice interviews.

Outline Aid

Interviewing Techniques

1. Have person fill out an application documenting previous work experience health record, convictions, type of transportation, driving record, and references.

2. Personality is very important. Think in advance about the kinds of traits you think are important to look for.

3. Discuss previous work record (dependability, how long stayed on a job, pay, responsibility, how got along with other employees, how got along with supervisors).

4. Discuss convictions, driving record, health record, and drug and drinking problems in detail.

5. Discuss mode of transportation to and from work in detail.

6. Discuss job in detail (bowel care, bladder care, dressing, time spent on each task). Provide detailed written job description.

7. Discuss hours, rate of pay, time off, and weekend responsiblities.

8. Ask open ended questions. (Example: Why would you like this job? Poor example: Would you like this job?)

9. Check out references.

Attendant Management Module Outline

Title: The Attendant's Perspective

Format: Group meeting with either guest speaker or videotape

Purpose: To assist participants in developing an awareness of attendants as people and to sensitize participants to typical feelings that attendants have about their jobs.

Instructional Objectives:

1. Each member of the group will state two situations they have been involved in or observed which an attendant might have viewed as a problem.
2. The group will list topics they have discussed in the social skills module that could be useful in interacting with an attendant.

Planning and Materials:

Invite one or two people who have varied experience as attendants and who are articulate and willing to share their feelings. Preferably the attendants and participants should not have worked together before. (If attendants are not available, a videotape of this session is available from New Options.)

Estimated Time: 1-1/2 hours

The Lesson:

Instructional Set:

1. Introduce purpose of the session.
2. Ask participants to spend a few minutes thinking about how they would feel about playing the role of attendant. Ask them to identify things they would find rewarding about this job and the things they would consider problems.
3. Review plans for the session to (a) talk with an attendant about his job, or (b) watch a videotape of an attendant discussing his role with a group of handicapped people.
4. Review instructional objectives.

Content:

1. Introduce the guest speaker and ask him to discuss his background, his job experiences, and his feelings about the role of attendant. Alternatively, show videotape on this subject.
2. Encourage a roundtable discussion following the presentation. This should cover what attendants like and dislike about their jobs, the kinds of training attendants should have, and interpersonal interaction between an attendant and a disabled person.
3. As part of the discussion, ask participants to relate incidents they have been involved in or observed that may have been difficult for an attendant because of a disabled person's behavior or attitude. Ask them to suggest kinds of behavior that probably make an attendant feel angry or resentful. Also, ask them to suggest kinds of behavior that probably make an attendant's job seem enjoyable or worthwhile.
4. Ask participants to list any topic they have talked about in the social skills module that they think would be useful in interacting with an attendant. Examples might include assertiveness in asking for help, listening skills, steps in conflict resolution, or awareness of perceptions of other persons.

Closure:

Ask participants to try to use what they have learned in this session as they interact with attendants during the coming week.

ANNOTATED BIBLIOGRAPHY

OBJECTIVE

To provide additional information and reference materials on Independent Living programs and services.

SUMMARY

Although this bibliography is not intended to be all-inclusive, it is the result of a comprehensive literature search in the area of Independent Living. These materials can assist the professional in the planning, research, and implementation of programs. The references selected have been previously reviewed in other publications pertaining to IL, work, and personal adjustment services. It is believed that these materials have been shown useful and effective for rehabilitation programs. Many of these publications can be located at a material's clearinghouse or rehabilitation research and training centers that disseminate rehabilitation information.

The sections of the bibliography correspond to the sections outlined in the manual. These sections are as follows:

I. Legislation, Funding, and Federal Documents.

II. Consumer Involvement.

III. Developing/Implementing Independent Living Programs.

IV. Housing.

V. Evaluation of Programs.

VI. Sources of Information.

VII. Periodicals and Newsletters.

I. Legislation, Funding, and Federal Documents

1. American Society of Landscape Architects Foundation. Barrier Free Site Design. Washington, D.C. 20013, U.S. Government Printing Office, 1974, p. 82.

   This pamphlet on the results of research conducted by the American Society of Landscape Architects Foundation, and sponsored by HUD, Office of Policy Development and Research. Aspects of barrier free design, including federal and local legislation, costs, architectural considerations, and information sources are discussed.

2. Catalog of Federal Domestic Assistance. Office of Management and Budget, Superintendent of Documents, Washington, D.C. 20402.

   Describes all federal support programs offered by federal agencies; includes eligibilities, deadlines, funding levels, and contact names.

3. Clelland, Richard. Civil Rights for the Handicapped. American Association of School Administrators, 1978.

   This book includes an overview of the Rehabilitation Act of 1973 and its relationship to Employment Practices and Program Accessibility. It includes an accessibility checklist complete with required measurements and building codes.

4. Eckstein, Burton J. ed. Handicapped Funding Directory. Research Grant Guides, P.O. Box 357, Oceanside, New York 11572.

   Designed for fund seekers for the handicapped, this directory includes lists of foundations and agencies which grant funds for handicapped programs and services.

5. Turem, Jerry and Nau, Louis Y. "Comprehensive Needs Study, Part II," American Rehabilitation 1 (4). Mar.-Apr. 1976, pp. 6-9.

   The results of the Comprehensive Needs Study which focused on ILR--architectural barriers, transportation problems, equipment needs, long term care, income and health transfers, residential mobility, isolation, recreation--are briefly discussed. Several programmatic options for making services accessible to the handicapped are proposed. Commitment of financial support is identified as the primary ingredient currently needed to initiate a program of independent living.

6. U.S. Architectural and Transportation Barriers Compliance Board. Freedom of Choice: Report to the President and to the Congress on Housing Needs of Handicapped Individuals. Washington, D.C. 20013, 2 vols., 1975.

The national Public Hearing on Housing for Handicapped Individuals conducted by the Board in Chicago on June 9 and 10, 1975 is summarized in Volume I. Documentation of existing federal legislation and programs affecting housing for the disabled, and recommendations for actions essential to a national commitment to meet the housing needs of the disabled, are summarized. Viewpoints, observations, and recommendations of the hearings are categorized under 19 major topics. A transcript of the oral and written testimony presented at the hearing is contained in Volume II.

7. Urban Institute, The. First Year Report on Section 130 Demonstration Projects. Washington, D.C. 20013, July 1976.

There were six demonstration projects funded as a part of the Comprehensive Needs Study, which was a result of the Rehabilitation Act of 1973. This first year report describes the background and purpose of the six demonstration projects and the initial population served, and presents an analysis of the data available at the end of the start-up year.

8. Urban Institute, The. Report of the Comprehensive Service Needs Study. Washington, D.C. 20013, Rehabilitation Services Administration, June 1975, p. 854. Contract #HEW 100-74-0309.

In the Rehabilitation Act of 1973, Section 130, Congress called for a comprehensive study of service needs of the most severely disabled individuals. The study was conducted by The Urban Institute and a consortium of other firms and individuals. The report on the study results details a number of problem areas for the disabled: architectural barriers, transportation, employment, and social interaction. In addition, there is discussion of special problems of mental retardation, of the blind and visually impaired, the deaf and the mentally ill.

II. Consumer Involvement

1. Bowe, Frank G., Ph.D. Handicapping America: Barriers to Disabled People. New York: Harper and Row Publishers.

   This book is concerned with the attitudes toward disabled people that handicap their ability to be productive citizens. It is a hard-hitting inspiring study.

2. Bruck, Lilly. Access--The Guide to a Better Life for Disabled Americans. New York: Random House, David Obst Books.

   This guide is a compendium of valuable information on ways that people with disabilities can get into the mainstream of American life. With emphasis on consumer protection, the book covers physical access, media images, consumer movements, communication, civil rights, recreation, and travel. This manual explains how to take action to achieve what is needed and wanted from government agencies and private organizations.

3. Flynn, Mike; Pickle, Linda; Bean, William J.; and Sigman, Susan. "I1: Consumers & Government Join Hands." Informer, 8 (2), May 1979, pp. 5-7.

   Included in this article is (1) an interview with Lex Frieden regarding the technical assistance in IL provided by the Independent Living Research Utilization (ILRU) project of which he is co-director; (2) a brief discussion of Title VII with regards to what services can be offered and who constitutes the appropriate recipients; and (3) a set of definitions related to the concept of IL developed by the ILRU project.

4. Integrating the Disabled. The Report of the Snowden Working Party. Surrey: National Fund for Research into Crippling Diseases. Vincent House, Springfield Road, Horsham, West Sussex, England, RH 122PN.

   An important study of the extent of the disabled's integration into the community, and their status in such areas as education, employment, housing, community and personal relationships.

5. Lewis, Sylvia. "The Disabled Are Tired of Being Pushed Around," Planning 43 (6). July 1977, pp. 9-13.

   Lewis reviews recent advances in creating barrier-free environments, citing the Center for Independent Living in Berkeley as "perhaps the nation's most comprehensive

service organization for the disabled" and noting the organization's success in eliminating barriers in the community. The article provides an analysis of recent programs to improve the environment, and discusses problems in the implementation of the Rehabilitation Act of 1973, including Section 504 and the Architectural and Transportation Barriers Compliance Board.

6. Thursz, Daniel. "Consumer Involvement in Rehabilitation," Rehabilitation Record. Washington, D.C.: DHEW Rehabilitation Services Administration, September-October, 1969.

Dr. Thursz' remarks appeared in a special issue of Rehabilitation Record that reported on the National Citizens Conference on Rehabilitation of the Disabled and Disadvantaged, held in June, 1969. He warned that unless disabled people were given a meaningful voice in decision-making and new career opportunities in the service delivery system that they would continue seeing that system as "uncaring," ineffective bureaucracy.

7. U.S. Department of Health, Education and Welfare, Rehabilitation Services Administration. Rehabilitation Services Manual. Washington, D.C. 20013, 15 October 1975.

Chapter 25 of this manual provides guidelines to state vocational rehabilitation agencies for the involvement of consumers and consumer representatives in the rehabilitation service delivery system. The guidelines outline a variety of methods for utilizing persons with disabilities and their self-help organizations in the planning, delivery, and evaluation of rehabilitation programs.

8. Varela, Rita A. "Self-Advocacy and Changing Attitudes," Public Awareness Viewpoints. Richman, Gary and Trohanis, Pascal (eds.) Chapel Hill: Developmental Disabilities Technical Assistance System, University of North Carolina 27514, Spring 1978.

This article reviews how telethons and public service announcements have depicted disabled people, and argues that self-advocates must be consulted and involved whenever agencies embark on community awareness campaigns.

9. Varela, Rita A. Self-Help Groups in Rehabilitation. American Coalition of Citizens with Disabilities, 1346 Connecticut Avenue North West, Washington, D.C. 20036, 1979.

The book offers a panorama of what disabled self-advocacy groups throughout the country have done in such fields as peer services, rehabilitation policy development, and politics. It also discusses the implications of the self-help movement for the service delivery system.

10. White House Conference on Handicapped Individuals Final Report, Vol. 2, Part A. Washington, D.C. 20013, DHEW Rehabilitation Services Administration, 1977.

This historic document reflects the views of hundreds of disabled persons, parents, and rehabilitation providers. Delegates to the White House Conference were chosen for meetings and caucuses held throughout the country. The volume also contains a minority report which reveals many of the attitudes of the militant sector of the disabled self-advocacy movement.

III. Developing/Implementing Independent Living Programs

1. Barrett, Linda W. Legislative Review of the Specific Provisions for Priority to Individuals with Most Severe Handicaps and the Individualized Written Rehabilitation Program. Berkeley Planning Associates, 1912 Bonita Avenue, Berkeley, California 94704, 1975.

   This manual reviews the provisions of the Rehabilitation Act of 1973 relevant to priority to the severely handicapped (IMSH), and for implementation of the individualized written rehabilitation program (IWRP). The review covers the legislative history and intent, and the RSA Regulations and Program Guides relevant to the IWRP.

2. Frieden, Lex; Richards, Laurel; Cole, Jean; and Bailey, David. ILRU Sourcebook: A Technical Assistance Manual on Independent Living. TIRR (The Institute for Rehabilitation and Research), 1333 Morsund Avenue, Houston, Texas 77030, 1979.

   Assembled in a looseleaf notebook, the manual is designed to be a resource handbook on Independent Living. It includes:

   -A glossary related to independent living and a description of alternative programs and the range of possible models;

   -An annotated registry of existing independent living programs that provides a profile of each listing to facilitate further inquiry about specific programs;

   -Matrices portraying federal, state, and local resources for independent living as well as a listing of several existing independent living programs that have used these resources successfully;

   -A section on community organizing;

   -An annotated bibliography; and

   -A section on consumer involvement.

3. The Handicapped Person in the Community. David M. Boswell and Janet M. Wingrove (eds.). London: Tavistock Publications in association with the Open University Press).

Informative material about the situation, services, and needs of people with disabilities, this book is intended primarily for students and for those in professional contact with disabled people.

4. Independent Living Evaluation. Training Program Reprint Series No. 16. Materials Development Center, Stout Vocational Rehabilitation Institute, University of Wisconsin, Stout, Menomonie, Wisconsin 54751, August 1979.

5. Report from the Study Group on The Role of Vocational Rehabilitation in Independent Living. Arkansas Rehabilitation Research and Training Center, Arkansas Rehabilitation Services, Hot Springs, Arkansas 71901, 1978.

   This is an excellent source for those wanting a Vocational Rehabilitation view into Independent Living (IL) and how it could be implemented within a rehabilitation setting. It covers the following areas: Overview of rehabilitation efforts to provide IL services to severely handicapped persons, administrative issues and concerns, rehabilitation counselor courses, provision of IL services through vocational rehabilitation, program evaluation methods and staff training guidelines.

6. "Transportation for the Disabled: What is the Government Doing: When? Where? With What?" Accent on Living, 20 (1), P.O. Box 700, Bloomington, Illinois 61701, Summer 1975, pp. 40-42.

   Government sponsored programs and organizations focusing on transportation for the disabled are described. The five major programs of the Urban Mass Transportation Administration (UMTA) for aiding mass transit are represented: the Research and Development Program; Operational Demonstration Program; the Capital Assistance Program; the Planning Assistance Program; and the Rural Public Transportation Demonstration program.

IV. HOUSING

1. Arneson, Kathaleen. "Residential Choices and the Handicapped," American Rehabilitation 2 (1), Sept.-Oct. 1976, pp. 25-29.

   The myths and assumptions related to housing for the handicapped are discussed. The national character of the housing issue and the need for a national policy on housing for the handicapped is emphasized. Selected recommendations of the National Conference on Housing and the Handicapped (Sept. 1974) are listed, and suggestions for the future are proposed.

2. Baker, M. Fischetti; M.A. Williams, L.A., and Young, E.M. State and Local Efforts to Eliminate Architectural Barriers to the Handicapped. Washington, D.C.: National League of Cities, Department of Urban Studies, 1974.

   In response to questionnaires sent to 349 cities and towns and to 272 counties, only 95 cities and 42 counties reported local efforts to eliminate barriers.

3. Cole, J.A., and Frieden, Lex. Transitional Living: A Program Fostering Community Integration of Severely Physically Handicapped Persons. Houston: The Institute for Rehabilitation and Research, June 1977. Interium Report on RSA Project Grant #13P57889/6-01 (RTA). TIRR, Houston, Texas 77030.

4. Farber, Douglas A. Housing and Related Services for Exceptional Persons: A Source Book. Monticello, Illinois: Council for Planning Libraries, 1973, p. 176.

   This book contains information about the characteristics of the aged, physically handicapped, and the mentally retarded. It offers descriptions of existing programs and facilities, a discussion of models of optimum care, and an analysis of the constraints interfering with the improvement of present conditions. Lists of associations, foundations, federal agencies, research institutions and periodicals, and a bibliography of 796 indexed items are also included.

5. Fay, Frederick. Housing Alternatives for Individuals with Spinal Cord Injury. Boston, Massachusetts: Tufts Rehabilitation Research and Training Center, 185 Harrison Avenue, Boston, Massachusetts 02111, 1974, p. 37.

Dr. Fay summarizes the problems of housing for spinal cord injured persons and presents two housing alternatives: 1) total accessibility in all residences for individual living and 2) accessible group residences. Five group housing residences reflecting five different approaches are examined, and efforts being made to eliminate architectural barriers are reported.

6. Fink, Charlotte; Manus, Muriel R.; and Manus, Gerald I. Housing for Disabled Persons: Annotated Bibliography. New York: United Cerebral Palsy Association, 122 East 23rd Street, New York, New York 10016, 1975.

Forty journal articles and books are included in an annotated list; sixty additional references are listed.

7. Frieden, Lex. "Independent Living Arrangements for the Severely Disabled," Report on the State of the Art Conference, Center for Independent Living. 2539 Telegraph, Berkeley, California 94704. October 21-23, 1975. RSA Grant 45-P-4584/9-01.

This article discussed the philosophical and ideological basis of independent living arrangements. Physical and social aspects of the housing facility are also considered, as are life support systems (attendant care) and the managerial skills necessary for attendant affairs. The author also gives examples of various housing modes and offers a two-dimensional analysis of these programs. Funding, accountability, social relationships, and community relationships are briefly discussed.

8. Mobile Homes: Alternative Housing for the Handicapped. U.S. Department of Housing and Development, n.d. Available from Superintendent of Documents, Washington, D.C. 20402.

9. Mobility in the Wheelchair Home. The Craig Hospital Family Service Department, 3425 South Clarkson, Englewood, Colorado 80110, 1977.

10. Thompson, Marie McGuire. Housing for the Handicapped and Disabled: A Guide for Local Action. National Association of Housing and Redevelopment Officials, 2600 Virginia Avenue North West, Washington, D.C. 20037.

This is "required reading" for any group planning a housing project, for Ms. Thompson discusses the method by which to achieve community cooperation among building, financial and disability groups.

11. Van Bechten, Doris, and Pless, I. Barry. "Housing and Transportation: Twin Barriers to Independence," Rehabilitation Literature 37 (7), July 1976, pp. 202-207, 221.

Results of a community wide survey conducted by the Genesee (N.Y.) Region Health Planning Council to identify the housing and transportation needs of the disabled are discussed. The data analysis is focused on 261 individuals, aged 20-50 years, with major physical disabilities.

12. Wittmeyer, Marilyn, and Barret, Jim. Wheelchair Accessibility: Opening the Door to Housing, An Illustrated Manual. University of Washington, Seattle, Washington 98105, 1977.

V. Evaluation of Programs

1. Berkeley Planning Associates (BPA). Vocational Rehabilitation Program Evaluation Standards: A Critique of the Art. 1912 Bonita Avenue, Berkeley, California 94704. 7 January 1977, 177 p. RSA Contract #105-76-4116.

   This manual offers a review of developments, to date, in program evaluation standards for vocational rehabilitation services. This includes an overview of analytical work in the development of standards and a report on the impact of the current standards on state vocational rehabilitation facilities. Among the issues discussed are: Alternative uses of standards in service programs, the problem of defining severity of disability, and problems of reporting and measurement in the existing standards system.

2. Collignon, Frederick C.; Dobson, Richard; and Skaburskis, Andrejs. An Evaluation of the Costs and Effectiveness of Vocational Rehabilitation Service Strategies for Individuals Most Severely Handicapped, (IMSH). Berkeley: Berkeley Planning Associates, May 1975. Subcontract to the Urban Institute, Comprehensive Needs Study HEW-SRS-74-54-3.

   Data on the characteristics and expenditures for various kinds of services are analyzed for the individual cases closed in the Michigan and Washington vocational rehabilitation programs in FY of 74. The definition of Individuals Most Severely Handicapped (IMSH) was based on a classification system of primary diagnostic codes used in the Federal Vocational Rehabilitation R-300 records. The analysis revealed that the combination of certain degrees of old age, and lack of education, and being female and non-white were more predictive of difficulty in being employed, than the type and severity of impairment.

3. Everett, Todd H. and Collignon, Frederick. Cost and Policy Considerations in Improving the Capacity for Independent Living of the Most Severely Handicapped. Berkeley: Berkeley Planning Associates, May 1975.

   The results of a study conducted to evaluate the cost and impact of services to severely handicapped individuals are reported. The service areas considered by this study include: transportation, relocation, housing, medical care, and employment. Policy design, goals, and recommendations are also discussed.

4. Jones, F. Ron. Cost Analysis of Alternative Transportation Systems for the Handicapped. Berkeley 94704, Institute of Urban and Regional Development, University of California, 1975. Working paper No. 256.

There are approximately 7,6000,000 persons in the U.S. who suffer chronic mobility limitations as a result of physical disabilities. This paper discusses various ways of improving the mobility of these individuals, and analyzes the impact and cost of each alternative. The alternatives discussed are: curb modification; wheelchairs; modified automobiles and vans; fixed-route transit systems; demand-responsive systems; and mobility counseling.

5. Puth, Alvin D. "Independent Living: How Independent," American Rehabilitation 4 (6), July-August 1979, pp. 28, 29.

In this article, the author observes that there is no explicit goal for independent living rehabilitation stated in Title VII of the rehabilitation act, and discusses why it is essential to articulate functional and measurable goals for independent living rehabilitation, and suggests areas that these goals may cover.

6. Schmidt, Bruce L. An Alternative Approach to Assessing Client and Social Benefits Resulting From Services Provided by the California Department of Rehabilitation. A working paper written for the California Department of Rehabilitation, 830 K St., Sacramento, California 95814, 1976.

Benefit cost analysis of rehabilitation is reviewed in terms of accuracy and resulting implicit and explicit policy. The author presents an alternative mechanism for measuring client gain in not only vocational benefits, but independent living benefits in general.

VI. Sources of Information

1. Lowman, Edward W., M.D., and Klinger, Judith L. Aids to Independent Living: Self-Help for the Handicapped. New York: McGraw-Hill Book Company, Inc.

   This now classic compilation of aids and advice is the result of more than twenty years of research and practical experience in rehabilitation at the Institute of Rehabilitation Medicine, New York University School of Medicine. More than seven hundred pages of information and fully illustrated with photographs and drawings, the book covers almost every area of daily living.

2. Access Travel: A Guide to Accessibility of Airport Terminals. By Public Transportation, U.S. General Services Administration, Washington, D.C. 20405, 1979.

   This manual lists sixty-nine accessibility features of more than two hundred airport terminals around the world and includes information on the way to make advance arragements if you have special needs.

3. Center for Independent Living, Berkeley, California. Report of the State of the Art Conference, Center for Independent Living, 2539 Telegraph, Berkeley, California 94704, 21-23 October 1975. RSA Grant 45-P-45484/9-01.

   This report contains a listing of all the papers presented at the first conference on the Independent Living Movement; it was sponsored by Berkeley CIL under a grant from RSA. The four conference papers reproduced in the report volume are:

   Vash, Carolyn L., Ph.D. "The Psychology of Disability."

   Zukas, Hale. "CIL History."

   Galvin, Donald E. "The Role of the State VR Agency."

   Baird, Ralph E. "Progressive Inclusion, An Approach to Mainstreaming."

4. Council of Better Business Bureaus, Inc., 1150 17th Street North West, Washington, D.C. 20035.

   Will send, on request, a list of private companies that offer correspondence courses in many fields. Send for Tips on Home Study Schools.

5. Federal Job Information Centers, maintained by the Civil Service Commission are located throughout the country and provide information on local federal jobs. Dial 800-555-1212 for the toll-free number of the nearest Federal Information Center.

6. Federal Information Centers. These centers in seventy-seven major cities will direct you to the correct federal, state or local agency you need. Look in your telephone directory under U.S. GOVERNMENT, FEDERAL INFORMATION CENTER or write to General Services Administration, Washington, D.C. 20405 for the leaflet Federal Information Centers.

7. Helping Hand Service for the Handicapped, Free leaflet from Greyhound Lines, Greyhound Towers, Phoenix, Arizona 85077.

8. Home Study Educational Opportunities, booklet providing information about home study courses for high school or college credit. It is free from the President's Committee on Employment of the Handicapped, Washington, D.C.

9. Human Resources Center, Willets Road, Albertson, New York 11507.

   This private nonprofit organization provides vocational and educational training for severely disabled children and adults, and conducts research evaluation and training programs.

10. In the United States for information about getting odd or different size shoes write to Handicappers of America, R.R. 2, Box 58, Camby, Indiana and the National Odd-Shoe Exchange, 1415 Ocean Front, Santa Monica, California 90401. For lightweight or extra large shoes write to King Size Company, Brockton, Massachusetts 22402.

11. More Than Choosing a Chair, booklet offering guidelines in wheelchair selection. The booklet may be obtained through Sister Kenny Institute, Chicago Avenue at 27th Street, Minneapolis, Minnesota 55407.

12. National Association of the Physically Handicapped, 2810 Terrace Road South East, Washington, D.C. 20020.

    Membership is open to anyone with a physical disability who will join forces to fight to eliminate barriers and solve problems common to all disabled people.

13. National Center for a Barrier-Free Environment, Information Clearinghouse, 8401 Connecticut Avenue, Washington, D.C. 20015.

This center can provide information and bibliographies on housing and architectural barriers.

14. National Congress of Organizations of the Physically Handicapped, Inc., 6106 North 30th Street, Arlington, Virginia 22207.

This strong lobby group promotes employment, education, equal rights and rehabilitation of people with physical disabilities, as well as legislation and social integration. Publishes the COPH Bulletin.

15. Office for Handicapped Individuals, Department of Health, Education and Welfare (HEW), 200 Independence Avenue South West, Washington, D.C. 20201.

This offers information on the OHI, which runs a clearinghouse to disseminate information to individuals and organizations on all matters pertaining to the handicapped community. OHI will answer questions on the many federal programs for the handicapped and direct individuals to the appropriate federal or private organization.

16. Office for Independent Living for the Disabled, The Department of Housing and Urban Development (HUD), 7th and D Streets South West, Washington, D.C. 20410.

This office will provide information on HUD housing programs for disabled people and will refer specific inquiries to the appropriate local authority.

17. Physically Handicapped. Available from Extension Service, U.S. Department of Agriculture, North Carolina State University at Raleigh, North Carolina 27607.

This pamphlet offers aids to self-help in homemaking, grooming, and clothing.

18. President's Committee on Employment of the Handicapped, 1111 20th Street North West, Washington, D.C. 20036.

Established in the mid 1940's, this agency publishes many useful booklets and leaflets. Write for their publication list.

19. "Planning a Wheelchair Vacation," Accent on Living. Bloomington, Illinois: Cheever Publications, Summer 1978, pp. 22-29.

20. Klinger, Judith L., O.T.R., M.A. Self-Help Manual for Arthritis Patients. New York: The Arthritis Foundation.

This booklet includes a selection of the self-help devices shown in Aids to Independent Living and is of use to people with various disabilities.

21. Social Security and Supplemental Security Income (SSI) information is available in free leaflets from local Social Security offices--Disabled? Find Out About Social Security, If You Become Disabled, Disability Benefits for Blind People, Pocket History of Social Security, Supplemental Security Income for the Aged, Blind and Disabled, Pocket Guide to Supplemental Security Income, Helping the Aged, Blind and Disabled.

22. Social Security notices can be sent to blind people in braille. If desired, a printed letter, which can be read by a sighted person, will be enclosed. Make the request to: Department of Health, Education and Welfare, Social Security Administration, Baltimore, Maryland 21235.

VII. Periodicals and Newsletters

1. Accent on Living, in its twenty-second year, is providing timely and relevant information to the disabled community. Published quarterly, AOL covers news of national interest. It is also attuned to the daily living needs of handicapped persons, covering such topics as bathing, eating, homemaking, and communication. Articles in AOL frequently outline methods to overcome barriers that hinder effective services and therefore help the disabled reader understand how to make use of community resources. Annual subscription is $3.50. Write: Accent on Living, P.O. Box 700, Bloomington, Illinois 61701.

2. Achievement proclaims itself "the voice of the handicapped serving South Florida and the nation." It is known for its candid, hardline look at issues facing the disabled population. Appearing in a newspaper format, this publication frequently reports on what it considers unfair or inadequate performance in the rehabilitation community. Achievement is generally considered a controversial and outspoken advocacy publication. It is available by writing: Achievement, 13855 North West 17th Avenue, Miami, Florida 33054.

3. American Coalition of Citizens with Disabilities, Inc. (ACCK), 1346 Connecticut Avenue North West, Washington, D.C. 20036.

   A nationwide umbrella association of sixty-five organizations, including many activist groups of and for disabled people. The coalition has assumed a major role in promoting equal opportunities and civil rights for individuals with disabilities. Members receive information on these activities and a monthly newsletter, ACCD Action.

4. Disabled U.S.A. (The President's Committee on Employment of the Handicapped, Washington, D.C. 20201).

   Formerly called Performance and now revamped and enlarged, this free monthly magazine reports progress in the nationwide program to provide employment opportunities for people with disabilities. It gives general information about developments in rehabilitation and placement and about new promotional and educational ideas and activities.

5. The Green Pages is a comprehensive quarterly publication outlining medical, rehabilitation, and adaptive equipment and their sources. Subscription information can be obtained from The Green Pages, 641 West Fairbanks, Winter Park, Florida 32789.

6. The Independent. 2539 Telegraph Avenue, Berkeley, California 94704.

   Subtitled A New Voice for the Disabled and Blind, this well-written and informative action periodical is published quarterly by the Center for Independent Living.

7. National Center for Law and the Handicapped, Inc., 1235 North Eddy Street, South Bend, Indiana 46617.

   Gives active support for the legal rights of people with disabilities through legal assistance, research and public and professional education. Publishes a newsletter and Amicus, a bimonthly magazine which gives information about current litigation on issues of concern. Both are free.

8. Paraplegia Life is a publication of the National Paraplegia Foundation. It is published bimonthly and features articles on environmental barriers to disabled persons, sports and recreation, opinions of members, new products and research in spinal cord injury. It is available from Paraplegia Life, 333 North Michigan Avenue, Chicago, Illinois 60601.

9. Paraplegia News is published by the Paralyzed Veterans of America, Inc. Articles in this monthly publication range from issues of civil rights to human sexuality from traveling to homemaking. Available from Paraplegia News, 935 Coastline Drive, Seal Beach, California 90740.

10. Rehabilitation Gazette is an annual publication which seeks to inform and update the disabled community on issues relevant to their welfare. New developments in the field as well as articles of a personal nature are included. Rehabilitation Gazette is available by writing 4502 Maryland Avenue, St. Louis, Missouri 63108.

IMPLEMENTATION OF STATE PLANNING FOR INDEPENDENT LIVING

AGENDA

Wednesday 8:30- Registration

9:00 Introduction (Mr. Decker, Dr. Shinnick). Includes introduction to the resource manual and TEK evaluation.

9:15 Federal Implications (Dr. Steven Cornett).

9:30 Introduction to Model Programs (Lex Frieden and Laurel Richards).

10:15 Coffee Break

10:30 Model Programs

12:00 Lunch

1:30 Model Programs (Melanie Tillmanns, Beverley Chapman).

2:30 Break

2:45 Consumer Involvement (Jim Ledbetter, Beverley Chapman).

3:45 ILR/VR Concerns (Panel discussion of Mary Andre, Paul Knight, Jack Van Hooser, and Don Wedewer. Moderator, Martha Carrick).

4:45 Evaluation and Adjournment.

Thursday

Emory Group

9:00 Program Development (John Halliday).
10:15 Break
11:15 Housing (Louis Baine).
12:00 Lunch
1:30 Transportation (Roger Krohl).
1:50 Attendant Care (Sandra Smith and Jake Smith).
2:30 Employment (Charles Larkin).
3:00 Break
3:15 Health Care (Ronald Niswander).
3:35 Community Mental Health (Robert W. Carrick).
3:55 Recreation, Public Attitude (Ben Rickman).
4:45 Evaluation and Adjournment.

Auburn Group

9:00 Practical Application of Independent Living Concepts: A Review and Discussion of Fundamental Objectives and Associated Methodologies. (Lex Frieden and Laurel Richards).

12:00 Lunch

1:30 Small Group Work Sessions: Developing Strategies that Meet Program Objectives in Individual States.

4:00 Work Group Closure and Evaluation.

Friday

8:30 Program Evaluation Concerns from a State and Facility Viewpoint (Jack Schmidtt).

9:45 Break

10:00 Independent Living Strategies (Panel discussion of John Halliday, Mary Andre, John Dalyrumple, Ben Rickman, and Lex Frieden. Martha Carrick, Moderator).

11:15 Evaluation and Wrap-Up (Dr. Michael Shinnick).

COURSE FACULTY

Course Directors: Roger S. Decker, Ed.S.,
Assistant Professor,
Department of Rehabilitation Medicine
Emory University,
Atlanta, Georgia

Michael D. Shinnick, Ed.D.,
Assistant Professor,
Auburn University
Auburn, Alabama

Course Coordinators: Sara Hoffman,
Coordinator,
Independent Living Short-Term Training Project
Auburn University
Auburn, Alabama

Phyllis Stegall,
Associate Faculty,
Emory University,
Department of Rehabilitation Medicine,
Atlanta, Georgia

Course Contributors: Martha Carrick,
Assistant Regional Representative for Vocational Rehabilitation, Region IV,
Office of Rehabilitation Services,
Atlanta, Georgia

Mary Andre,
Associate Regional Representative for SSI-SSDI,
Region IV Representative

Elton Moore,
Doctoral Candidate,
Mississippi State University

Mervyn Willoughby,
Assistant Project Coordinator,
Independent Living Short-Term Training Project
Auburn University,
Auburn, Alabama

Faculty: Beverly Chapman,
Executive Director,
Center for Independent Living in Central Florida
Orlando, Florida

Lex Frieden,
Project Director,
Texas Institute for Rehabilitation and Research
Houston, Texas

John Halliday,
Director of Client Service Programs,
Massachusetts Rehabilitation Commission,
Boston, Massachusetts

Jim Ledbetter,
Deputy Director,
Georgia Division of Vocational Rehabilitation,
Atlanta, Georgia

Jack Van Hooser,
Director, Client Services
Division of Vocational Rehabilitation,
Nashville, Tennessee

Laurel Richards,
Training Coordinator,
Texas Institute for Rehabilitation and Research,
Houston, Texas

Melanie Tillmanns,
Executive Director,
Worcester Area Transitional Housing, Inc.
Worcester, Massachusetts

Don Wedewer,
Director,
Florida Division of Blind Services,
Tallahassee, Florida

John Dalrymple,
Specialist for Special Projects for the Severely Disabled
Raleigh, NC

Paul G. Knight,
Director, Independent Living Program
Columbia, SC

Jack Schmidt,
Georgia Warm Springs Hospital
Warm Springs, GA

Dr. Stephen Cornett,
Director, Office of Rehabilitation Services
Atlanta, GA

Participant List

Jack Schmidtt,
Roosevelt Rehabilitation Research Institute
Georgia Warm Springs Hospital
Warm Springs, GA 31830

Jim Miller,
Regional Continuing Education Program
1814 Lake Avenue
University of Tennessee
Knoxville, TN 37916

John Grimes,
Regional Continuing Education Program
1814 Lake Avenue
University of Tennessee
Knoxville, TN 37916

Sam Burton, Director of Field Services
932 N. State St.
P.O. Box 1698
Jackson, MS 39205

Ben Rickman, Director
Metro-Liner ILC
909 S. College St.
Charlotte, NC 29202

Perry Levinson, Asst. Director for Management Services
Office of Rehabilitation Services
101 Marietta St.
Suite 903
Atlanta, GA 30323

Carl McCoy, Program Director of Client Services
Florida Division of Blind Services
2571 Executive Center Circle
Tallahassee, FL 32301

David Sellars, Director
Office of Vocational Rehabilitation
1309 Winewood Blvd.
Tallahassee, FL 32301

Bill Toomey, Administrator of Client Services
1309 Winewood Blvd.
Tallahassee, FL 32301

Paris Hopkins, Director
Bureau of Rehabilitation Services
Capital Plaza Office Tower

Frankfort KY 40601

Jim L. Carballo, Director, Ms. Vocational Rehabilitation
for the Blind
P.O.Box 4872
Jackson, MS 39216

Tim Milligan, Training Coordinator
Hot Springs Rehabilitation Center
P.O. Box 1358
Hot Springs, AR 71901

Walter Blalock, Jr., Program Specialist - Voc. Rehab.
P.O. Box 1698
Jackson, MS 39205

J.W. Cowen, Director, Rehab. and Crippled Children
2129 East South Boulevard
P.O.Box 11586
Montgomery AL 36111

James M. Searcy, Coordinator: Homebound & Hemophilia Program
2129 East South Boulevard
Montgomery, AL 36111

Stewart Gatewood, Unit Director, Planning
102 Georgia
Versailles, KY 40383

Pinkney C. Seale, Director, Div. of Services for the Blind
Room 209 State Office Building
Nashville, TN 37219

Roger Patton, Program Director, Special Services
Room 209 State Office Building
Nashville, TN 37219

Louis G. Strikland, Direcor,
Addie McBryde Rehabilitation Center
for the Blind
P.O. Box 5314
Jackson, MS 39216

James R. Brooks, Supervisor of SSDI/SSI Programs
Division of Vocational Rehabilitation,
1808 West End Building, Room 424
Nashville, TN 37203

Jenelda Yurt, Program Coordinator
Bureau foro the Blind,

Division of Field Services, Homebound Program
201 Breckinridge Lane,
Louisville, KY 40207

Jeanne Pherson, Director of Jobs for the Blind
Bureau for the Blind,
Jobs for the Blind
1900 Brownsbooro Road
Louisville, Ky 40206

Joe S. Dusenbury, Commissioner
Vocational Rehabilitation Department
P.O. Box 4945
Columbia, SC 29240

P. Charles LaRosa, Jr., Special Services Coordinator
Vocational Rehabilitation Department
P.O. Box 4945
Columbia, SC 29240

Charles S. Chandler, Ph.D., Supervisor, Research and Planning
Vocational Rehabilitation Department
P.O. Box 4945
Columbia, SC 29240

Paul G. Knight, Director, Independent Living Program
Vocational Rehabilitation Department
P.O. Box 4945
Columbia, SC 29240

Cathy Bruce, Coordinator for Independent Living Program
632 State Office Building
47 Trinity Ave. S.W.
Atlanta, GA 30334

Jim Ledbetter, Director, Division of Vocational Rehabilitation
610 State Office Building
47 Trinity Ave. SW
Atlanta, GA 30334

Donald H. Wedewer, Director, Florida Division of Blind Services
2571 Executive Center Circle, East
Tallahassee, FL 32301

Leonard A. Cooper, State Rehabilitation Supervisor
S.C. Commission for the Blind,
1430 Confederate Avenue
Columbia, SC 29201

Nancy L. Buchanan, Deputy Commissioner
S.C. Commission for the Blind

1430 Confederate Avenue,
Columbia, SC 20201

Bob H. Philbeck, Deputy Director
Div. of Vocational Rehabilitation Services
P.O. Box 26053,
Raleigh, NC 27611

Donna L. Holt, Administrative Assistant to Specialist for
Special Projects for the Severely Disabled
Vocational Rehabilitation Services
P.O. Box 26053
Raleigh, NC 27611

John W. Dalrymple, Specialist for Special Projects for the
Severely Disabled
P.O. Box 26053
Raleigh, NC 27611

Herman Gruber, Administrator
N.C. Rehabilitation Center for the Blind
P.O. Box 33,
Butner, NC 27509

James D. Roberts, Deputy Chief, Rehabilitation Services
Division of Services for the Blind
P.O. Box 2658
Raleigh, NC 27602

Jack M. VanHooser, Director of Client Services
Division of Vocational Rehabilitation
1808 West End Room 424
Nashville, TN 37203