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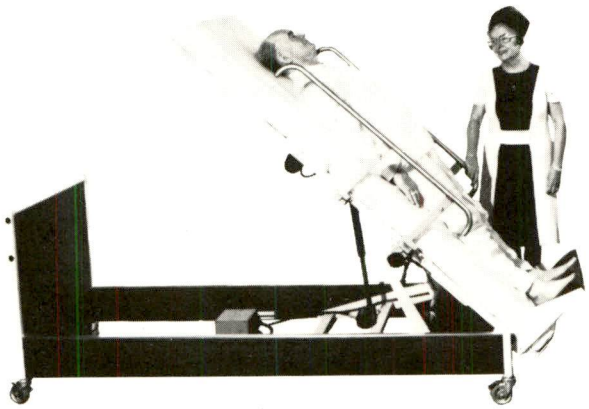

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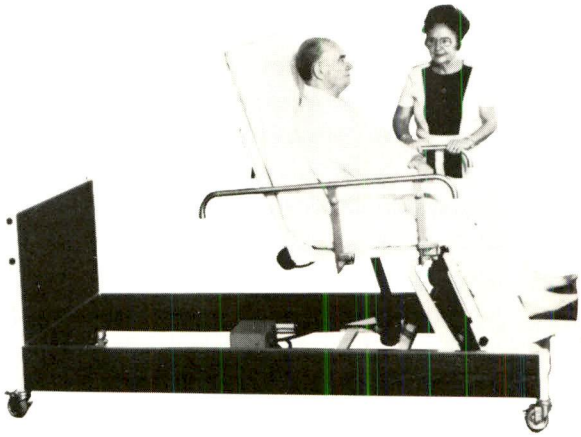

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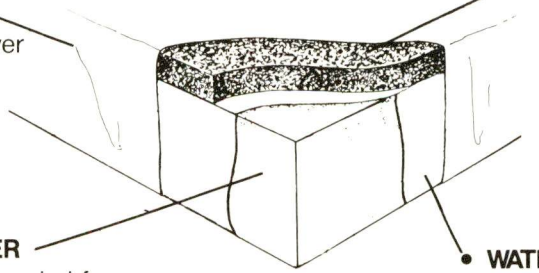

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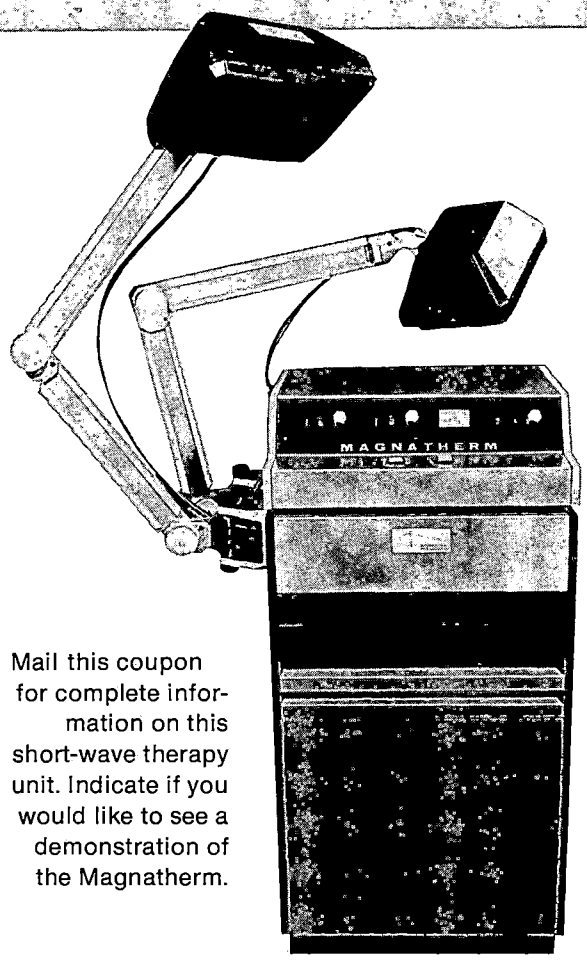

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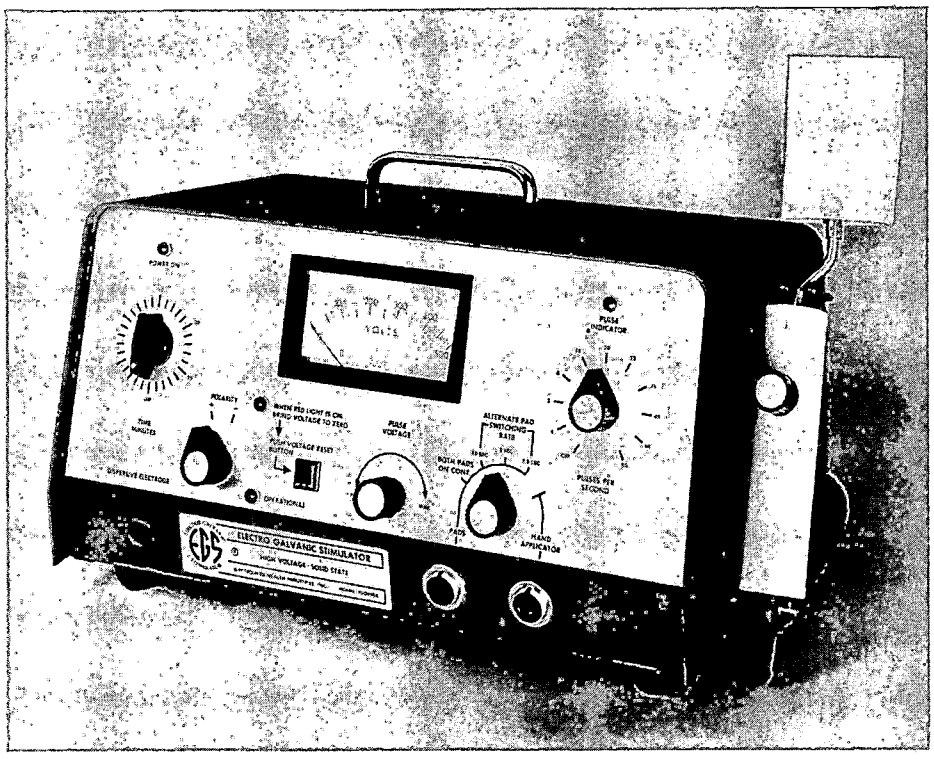

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1. Beninson J: Preliminary report on the use of a pressure gradient, elastic support in conditions associated with impaired vascular reserve. Henry Ford Hosp Med Bull, Dec 1956, 238.

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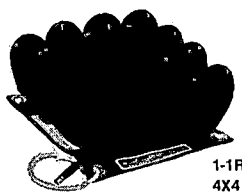

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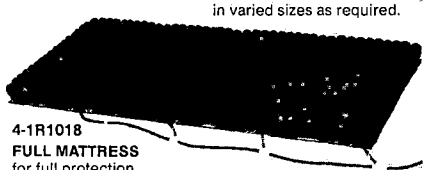

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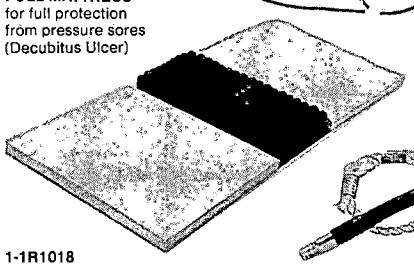

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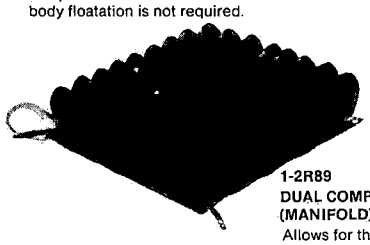

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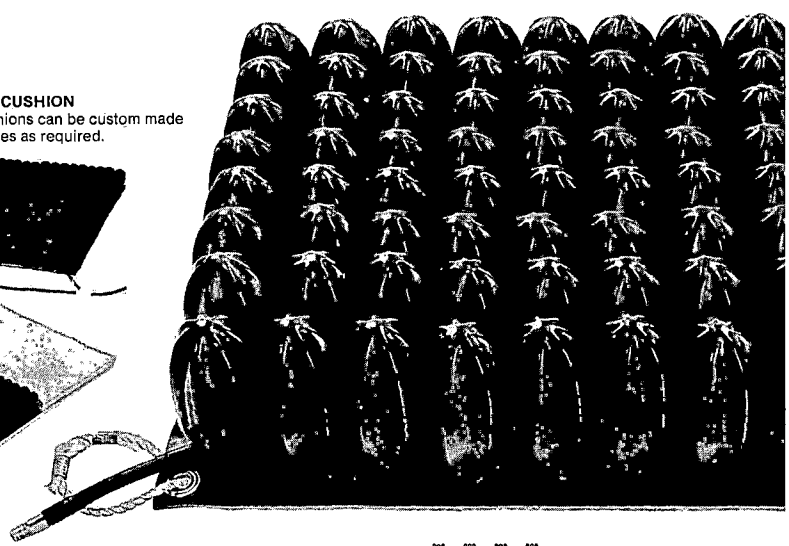

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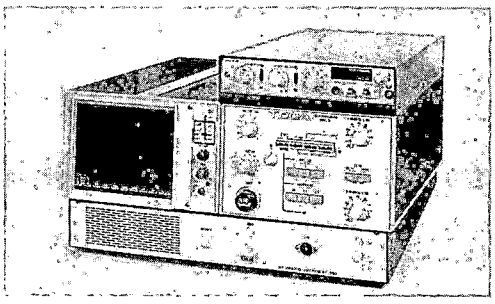

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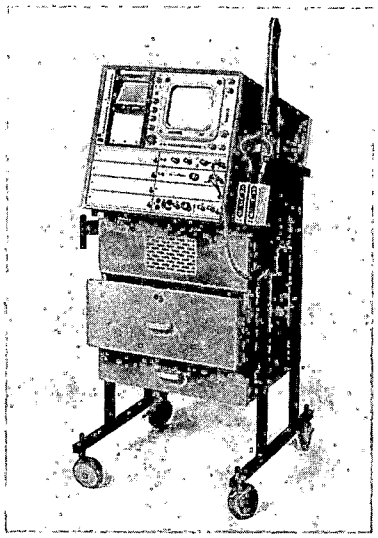

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EDITORIAL

Independent Living: An Idea Whose Time Has Come

With the passage of the 1978 Amendments to the Rehabilitation Act, the United States made a formal commitment to the goal of independent living (IL) for people with severe disabilities. This step has the potential to bring enormous changes to the lives of disabled citizens and to the field of rehabilitation. Whether the potential is realized will depend on several factors, including the extent of the financial commitment that follows the legal commitment already made. It will also depend on the cooperation of consumers and service providers, and a willingness to discard traditional paternalistic relationships and old assumptions about what living options are feasible.

Already independent living has grown so dramatically that it has become known as a movement, and every day it captures the attention of more people in rehabilitation. My own interest in IL grew from my clinical and research experience as a rehabilitation psychologist; consequently, I am particularly interested in the impact of independent living on emotional well being.

From a psychologic viewpoint, the essence of IL is captured in the word, "independent," which relates to freedom, self-determination, and individual autonomy. Specifically, it implies a belief in one's ability to make decisions and to take actions that affect the course of one's life, and willingness to accept responsibility for the experiences of life. Recognition of personal control has been found to correlate with many measures of psychologic adjustment and productivity.[1] Conversely, it is negatively related to depression.[2]

Independent living develops individual power, both as a process and as an outcome. Although independence is not a new theme for rehabilitation, the IL movement does stress in a new way the consumer's responsibility for both the identification and the achievement of specific goals. It also affirms, regardless of barriers, the right of each individual to live in a place of his own choosing and to participate as a member of the community.

Independent living also has other implications. To vocational rehabilitation it involves the responsibility for delivering services with nontraditional objectives to a new group of clients. To rehabilitation medicine it represents a challenge to become more concerned about facilitating the transition between hospital and community. This will almost surely involve allowing disabled individuals to be responsible for more decisions and activities during inpatient treatment. It may require improved programs of patient education, increased family involvement and better liaison with community resources. And for some rehabilitation centers, IL may call for development of a transitional living facility that can help prepare former patients to manage their own affairs despite continuing physical limitations.

Besides such changes in rehabilitation services, federal support of IL programs will inevitably require much research. How cost effective is independent living and for whom and under what circumstances? What changes does it make in quality of life, and how can these changes be documented? Are certain service delivery systems consistently more successful than others, and if so, what are their characteristics?

These questions are just a sample of the many that will be asked. If we are to meet the service and research challenges that will soon confront us, it is essential that we begin now to develop an understanding of the area. That is the purpose of this special issue of the ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION.

The issue approaches independent living broadly and from an interdisciplinary perspective. It encompasses the history and philosophy of the movement and also examines some of the most important IL services, including attendant care and transportation. There are omissions, of course, such as specific reference to the needs of people whose primary disabilities are intellectual or emotional rather than physical. The focus is on subjects most relevant to rehabilitation medicine and on the people who have most frequently been served by this field.

The lead article, written by Gerben DeJong, describes a new model of rehabilitation generated by the IL movement and explores the ways in which it may change rehabilitation services and research. Dr. DeJong, who is trained in economics and public administration, also explores the relationship between the growth of IL and other recent social movements in America.

At least 2 major streams of experience must be considered if one is to understand the history of the IL movement; one stream springs from rehabilitation providers and policy makers, and the other springs from the disabled community. Richard Verville, legal consultant for the ACRM, the American Academy of PM&R and related groups, looks at the 1st stream, tracing the history of legislative initiatives over 20 years. On the other hand, Dr. Irving Zola, noted medical sociologist and a founder of the Boston Self Help Center, describes the development of self help organizations.

Until recently, when the possibility of federal funding arose, many rehabilitation centers have shown scant interest in providing post-discharge services other than medical follow-up. Now that the picture is changing and rehabilitation professionals are becoming interested in independent living, they are discovering that several services are being provided by consumer organizations that emerged to meet pressing needs. In these circumstances, what is the role of the able-bodied professional—to take over, to compete with, to ignore, or to somehow cooperate with these programs? Dr. Sheldon Berrol, a physiatrist who also serves on the Board of Directors for the Center for Independent Living in Berkeley, CA, addresses this dilemma in his article on the role of the able-bodied professional.

Dr. Jean Cole, an anthropologist who has directed the Research Utilization Project on independent living at The Institute for Rehabilitation and Research in Houston, provides an overview of independent living in the United States. She describes several of the oldest and largest IL programs as diverse models, and also discusses the ways in which they represent a departure from older kinds of rehabilitation services.

Dr. Denise Tate, Robert Jarvis and Gerald Juhr, colleagues on the staff of the International Rehabilitation Special Education Network (IRSEN), direct our attention abroad with a description of approaches to independent living in Denmark, Sweden, England, Australia, Canada, and the Netherlands.

An accessible environment has usually been thought of solely in terms of measurements, specifications, and hardware. Berkeley architect and professor, Raymond Lifchez, has pioneered in taking architectural education beyond access at this level to a sensitive consideration of the psychologic and social impact of the physical environment on the lives of people with disabilities. His article, "The Environment as a Support System for Independent Living," is adapted from his new and exciting book, *Design for Independent Living.*

Of the several services relevant to independent living, attendant care and transportation are probably the most critical. Dr. DeJong and counselor Teg Wenker, illuminate the controversies surrounding attendant care and describe the manner in which this service is being provided in several states. Dr. Frank Bowe, director of the American Coalition of Citizens with Disabilities, addresses the other key service, transportation. After making a major commitment to integrated and fully accessible transit services, the government appears to be responding to a conservative backlash and weakening its efforts in this area. Dr. Bowe argues convincingly that a retreat cannot be tolerated.

Special thanks are due to each of these individuals who have shared their expertise for this issue. Appreciation is also due to the Editorial Board of the ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION for facilitating this special issue. In particular, the support and participation of Dr. Alfred J. Szumski, the Chairperson of the Board, and the Associate Editor, Dr. Gary Athelstan, were essential to its preparation. In addition, members of the SEAR Committee should be recognized for their creative spark that brought this project into being. The members are: Justin Alexander, PhD, PT; Kathaleen C. Arneson, MA; Sheldon Berrol, MD; Paul J. Corcoran, MD; Kathleen M. Dirschel, PhD, RN; Frederick A. Fay, PhD; Suzanne L. Harsanyi, MS; Cythia A. Koehn, MSW; Paul Leung, PhD; M. Scot Manley, PhD; Raymond L. Milhous, MD; Charles R. Poor, MS; John E. Schatzlein, BA; Irving K. Zola, PhD.

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Independent Living: From Social Movement to Analytic Paradigm

Gerben DeJong, MPA, MSW

ABSTRACT. DeJong G: Independent living: from social movement to analytic paradigm. Arch Phys Med Rehabil 60: 435-446, 1979.

• Independent Living (IL) is more than a social movement; it is also an analytic paradigm that is reshaping the thinking of rehabilitation professionals and researchers alike. The IL paradigm is contrasted with the rehabilitation paradigm that has dominated disability policy, practice, and research. This article analyzes how the shift from the rehabilitation to the IL paradigm is likely to affect the future of disability research. To gain an appreciation for the IL paradigm, the article first evaluates independent living as a social movement in terms of the movement's constituency, origins, and its relationship to other social movements.

> *"A significant social movement becomes possible when there is a revision in the manner in which a substantial group of people, looking at some misfortune, see it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable in society."*[1]

Future historians of American social policy will look back to 1973 as a year which separates 1 epoch of disability policy from another. That year Congress passed a new Rehabilitation Act which set into motion a whole set of new inititatives affecting the nation's disabled population, particularly its most severely disabled citizens.

The most visible feature of the 1973 Rehabilitation Act is Section 504, a 1-sentence statement prohibiting discrimination against "otherwise qualified handicapped" individuals "under any program or activity receiving Federal financial assistance." Because of this section's far-reaching implications, the 1973 Rehabilitation Act has sometimes been dubbed "the Civil Rights Act of the Handicapped."

The 1973 Act cannot be fully understood apart from an emerging social movement: the independent living (IL) movement. Sparked with a high degree of indigenous leadership from among the disabled population, the movement seeks a better quality of life for disabled persons.

The IL movement is more than a grass-roots effort on the part of the disabled to acquire new rights and entitlements; it is also reshaping the thinking of disability professionals and researchers, has spawned new service-delivery models, and has encouraged new research directions.

This article evaluates independent living as a social movement and as an "analytic paradigm" that is redirecting the course of disability policy, practice, and research. As a paradigm, independent living is redefining the problem of disability and is encouraging new interventions that are in marked contrast to the definitions and interventions provided by its predecessor—the rehabilitation paradigm. But to gain an appreciation of the IL paradigm, it is necessary to understand independent living as a social movement with a distinct constituency and history. Moreover, the movement is heavily indebted to a variety of other contemporary social movements such as civil rights, consumerism, self-help, demedicalization/self-care, and deinstitutionalization. The significance of independent living for the future of disability practice and research cannot be understood apart from the contributions of these other movements.

THE CONSTITUENCY OF THE IL MOVEMENT

The IL movement has always counted the "severely disabled" as its primary target group or constituency. But who are the severely disabled? How many are there? One common method used to define and measure severe disability is the inability to work or to carry on one's major activity. Based on results from its 1974 Health Interview Survey, the National Center for Health Statistics[2] estimates that 3.3% (6.8 million) of the nation's population—about 0.2% of all children, 2.6% of all working age adults, and 17.1% of all the elderly—are unable to carry on their major activity.

Core Constituency

However, the movement's core constituency is more limited than that suggested by these national data. The movement has concentrated its energies on a relatively few major disability groups: those with spinal cord injury, muscular dystrophy, cerebral palsy, multiple sclerosis, and postpolio disablement. Moreover, the IL movement has concentrated its energies on a selected

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From the Medical Rehabilitation Institute, Tufts-New England Medical Center, Boston.

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Updated and condensed from a paper presented at the 55th Annual Session of the American Congress of Rehabilitation Medicine, New Orleans, November 17, 1978 and disseminated by the University Centers for International Rehabilitation, Michigan State University, East Lansing, MI.

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

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

Notably absent from the movement's constituency are older persons with severe physical impairments resulting from stroke or other degenerative conditions. While the movement's philosophy may have direct relevance to older disabled persons, the movement has focused its concern elsewhere. The movement's present age bias is one that cannot last indefinitely. Medical science is not only enabling severely disabled persons to survive initial trauma but is also enabling severely disabled persons to live longer. Thus, as the movement's initial adherents grow older we can expect the movement to enlarge its present age focus.

Also absent from the movement's constituency and leadership are racial minorities. This is noteworthy, since disability statistics indicate that blacks have a higher prevalence of disability than do their white counterparts. The absence of racial minorities deserves special analysis. Given the similarities among the civil rights movement, the black movement, and the IL movement, one would expect the IL movement to attract disabled persons from racial minorities.

Disability Professionals and Special Interest Organizations

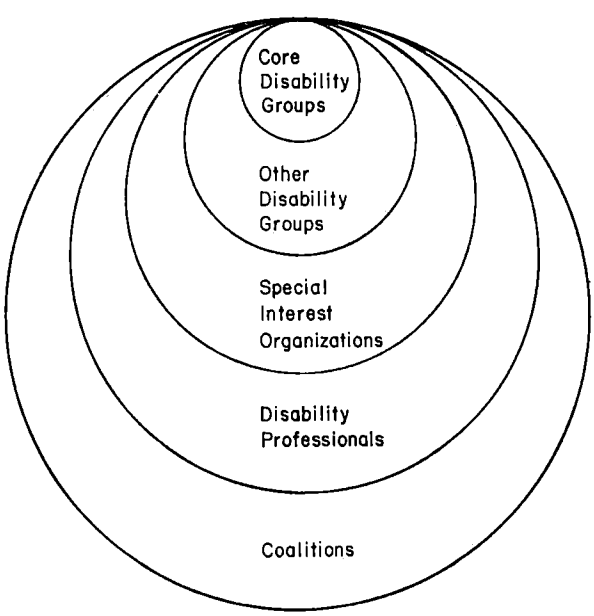
There is another part of the movement's constituency that deserves mention: disability professionals and special interest organizations. The disability professionals include physicians in physical medicine and rehabilitation, physical therapists, occupational therapists, nurses, rehabilitation counselors,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

In defining the movement's constituency one should not overlook the overlap between disabled "consumers" and disability professionals. Many disabled persons are themselves disability professionals. The participation of able-bodied professionals in the movement can to some degree be explained by the influence and the consciousness-raising impact of their disabled professional peers.

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

Thus it can be seen that the movement's constituency is difficult to define. National survey data enable us to identify that portion of the population most likely to come within the scope of the movement's concern. We can identify a core constituency but there are many other interested parties—professionals and special interest groups—who have come to recognize the movement and have joined forces to one degree or another (figure). Moreover, common interests with other disability groups enable the movement to extend its influence beyond the boundaries of the core disability groups.

The movement's constituency is defined not only by *who* participates but also by *what* it advocates. The constituency, in some respects, extends to others who do not actively participate but who nonetheless come



Constituency of the movement for independent living.

under its consciousness-raising spell and thus become informal advocates of its philosophy and ideology.

ORIGINS AND LEGISLATIVE BACKGROUND

It is difficult to point to an exact time when or place where the IL movement began. The movement has sprung from 2 main sources: (1) the efforts of disabled persons to seek a more fulfilling life in an able-bodied world, and (2) the efforts of rehabilitation professionals to reach disabled persons for whom a vocational goal was, until recently, unthinkable. While the efforts of both groups often converge on specific legislation, their interests and origins are sufficiently different to warrant separate consideration.

Indigenous Origins

The disabled students program at the University of Illinois at Champaign-Urbana was among the first to facilitate community living for persons with severe physical disabilities. In 1962, 4 severely disabled students were transferred from a campus-isolated nursing home to a modified home closer to campus. The disabled students program has since emerged as a significant self-help effort and has helped to make the University one of the most architecturally accessible institutions of its kind.

It was not until the early 1970s that the movement gained greater visibility and momentum with the creation of the Center for Independent Living (CIL) in Berkeley, California. The Berkeley CIL incorporated itself in 1972 as a self-help group, to be managed primarily by persons who were themselves disabled. The Center provides a wide range of related services, such as peer counseling, advocacy services, van transportation, training in independent living skills, attendant care referral, health maintenance, housing referral, wheelchair repair, and others.[3,4] Unlike other centers that have since emerged, the Berkeley CIL has no residential program and serves persons with a greater variety of disabling conditions than do many other existing centers.

On the East Coast, the Boston Center for Independent Living (BCIL) began its activities in 1974. BCIL emphasizes transitional housing and attendant care services.[5] Similar centers and organizations have sprung up in Houston, Columbus, Ann Arbor, and elsewhere. Each center offers its own unique blend of advocacy and consumer services; together the various centers have given the IL movement both an organizational focus and a vehicle for realizing some of the movement's more important goals.

The movement's organizational efforts have not been limited to centers for independent living. Allied organizations such as the ACCD, mentioned earlier, have been instrumental in monitoring federal legislation affecting disabled persons. The ACCD also helped to organize the coast-to-coast demonstrations that goaded the US Department of Health, Education and Welfare (HEW) to promulgate regulations implementing Section 504 of the 1973 Rehabilitation Act.

Professional Origins

Developing concurrently with the organizational initiatives of disabled persons were the efforts of rehabilitation professionals in the formulation of national legislation. In 1959, HR361 was introduced containing language that would extend IL services to individuals for whom employment was not an obtainable objective.[6,7] That attempt failed and in 1961 a new bill, written largely by the National Rehabilitation Association, was introduced. The new bill contained a separate title on IL services. That bill also failed.

If adopted, the 1961 bill would have authorized $15 million in the 1st year and $25 million in the 2nd year for IL rehabilitation services. The new title was to be administered by state vocational rehabilitation agencies. The reasons for Administration opposition to the bill are unclear but anecdotal evidence has it that HEW was unable to determine which of its component agencies should administer the new title.

The 1973 Rehabilitation Act

In 1972, Congress passed HR8395 amending the Vocational Rehabilitation Act to provide IL services to those individuals "for whom a vocational goal is not possible or feasible." The bill was twice vetoed by the President on the grounds that it "would divert the (vocational rehabilitation) program from its basic vocational objectives" toward more ill-defined medical and welfare goals.[6] Eventually, the President did sign what became known as the 1973 Rehabilitation Act, albeit with the IL provisions deleted.

The 1973 Rehabilitation Act contained other breakthroughs important to the IL movement. First, it mandated that those who were most severely handicapped were to receive 1st priority for services under the Act. Second, title V extended new statutory rights to handicapped persons. Sections 501 and 503 mandated affirmative action programs for the employment of disabled persons within the federal government and by organizations contracting with the federal government. Section 502 created the Architectural and Transportation Compliance Board. And Section 504 banned discrimination on the basis of handicap in any program or activity receiving or benefiting from federal financial assistance.

The 1978 Amendments

A statutory authorization for IL services finally come into being when President Carter signed PL95-602 in 1978. This law created a new title VII—"Comprehensive Services for Independent Living," which establishes a 4-part program: (1) an IL services program to be administered by the state vocational rehabilita-

tion agencies; (2) a grant program for IL centers; (3) an IL program for older blind persons; and (4) a protection and advocacy program to guard the rights of severely disabled persons. Title VII authorizes $80 million for fiscal year 1979; $150 million for 1980; $200 million for 1981; and "such sums" in 1982. Given the Administration's current efforts to hold down federal spending, it is very unlikely that the amounts appropriated by Congress will approach authorized spending levels.

Differing Views of Independent Living

Two things need to be said about the concept of IL services as advocated by vocational rehabilitation professionals.

First, the concept of IL rehabilitation has changed since it was originally introduced to Congress almost 2 decades ago. Since then, medical and rehabilitation technology has advanced significantly. Those who would have been targeted for IL rehabilitation services 15 years ago are now routinely prepared for gainful employment by state vocational rehabilitation agencies.

Second, vocational rehabilitation professionals, as reflected in the legislation reviewed here, have a different conception of independent living than do their consumer counterparts in the IL movement. For many vocational rehabilitation professionals, IL services are for those for whom a vocational goal is thought to be impossible. Independent living is seen as an alternative to the vocational goal–thus, the term "independent living rehabilitation" as distinct from "vocational rehabilitation." IL rehabilitation refers to those medical and social services that enable a disabled person to live in the community short of being gainfully employed. From this perspective, independent living and rehabilitation are seen as competing policy goals. Throughout the history of the legislative debate on independent living, there has been the fear that independent living would dilute the specificity of the vocational outcome. Some professionals feared the IL services would result in the same charges of nonaccountability often levied against more ill-defined social services such as those administered under title XX of the Social Security Act.

Others in the IL movement, whose involvement does not originate in the vocational rehabilitation tradition, reject the conception of independent living and employment as competing policy goals. To them, such a conception is potentially sinister in that it implicitly places an undesirable arbitrary upper limit to the goals a disabled person might set for himself; the vocational objectives should be seen as an integral part of the IL goal, not as a competing goal.

RELATION TO OTHER SOCIAL MOVEMENTS

The IL movement has flourished at a time when several other complementary social movements have also developed; these include:

- Civil rights
- Consumerism
- Self-help
- Demedicalization/self-care
- Deinstitutionalization/normalization/mainstreaming

While these movements share common values and assumptions, each arises from a somewhat different source in response to different social problems. Each has influenced the IL movement in its own unique way. The origins and ideology of the IL movement cannot be fully appreciated without also noting the contributions of other social movements.

Civil Rights

The civil rights movement of the 1960s has had an impact far beyond the racial minorities it sought to benefit. The movement made other disadvantaged groups aware of their rights and of how their rights were being denied. During the initial stages, the movement was mainly concerned with *civil* rights as opposed to *benefit* rights. Civil rights include the right to vote, to hold elective office, to be tried by a jury of one's peers, and so forth. Benefit rights include the entitlement to income and medical assistance benefits, educational benefits, and other entitlements. The benefit rights issue was taken up later in the civil rights movement by the Poor Peoples' Campaign and by spin-offs such as the National Welfare Rights Organization.

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

The IL movement has been similarly concerned with both civil and benefit rights. The movement's interest in civil rights is reflected in title V of the 1973 Rehabilitation Act prohibiting various forms of discrimination, particularly in the area of employment. However, the concern for civil rights has not stopped there. Persons with severe mobility impairments are insisting that architectural barriers in effect deprive them of their civil rights when these barriers prevent them from participating in the political life of the community. In like fashion, disabled persons have become aware that their benefit rights are prerequisites for living in a community setting. Without income assistance benefits or attendant care benefits, many disabled persons would be involuntarily confined to a long-term care facility.

The civil rights movement has not only had an

effect on the securing of certain rights but also on the *manner* in which those rights have been secured. When traditional legal channels have been exhausted, disabled persons have learned to employ other techniques of social protest such as demonstrations and sit-ins.

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

Consumerism

The parameters of the consumer movement are hard to define. It is a movement that affects nearly all social classes and groups. It is most personified by Ralph Nader but also includes public interest lawyers representing various disadvantaged groups and embraces both the person who devotedly reads *Consumer Reports* and the person who campaigns for new consumer protection legislation.

A more profitable venture here would be to briefly evaluate the movement in terms of its ideology and in terms of its expression in disability policy. Basic to consumerism is a distrust of seller or service provider. It is up to the consumer to become informed about product reliability or service adequacy. Consumer sovereignty has always been the hallmark of free market economic theory. In practice, however, it is often the professional who has been sovereign.

With the rise of consumer sovereignty, professional dominance in disability policy and rehabilitation is being challenged. In vocational rehabilitation, for example, the professional counselor does not necessarily have the final word in case planning as he/she once did. Instead, the Rehabilitation Act of 1973 provides for an "individualized written rehabilitation plan" (IWRP) to be drawn up jointly by client and counselor. Outside vocational rehabilitation, the IL movement has spawned new advocacy centers to advise disabled persons of their legal rights and benefits. With the awareness generated by the IL movement, the disabled person with several years of disability experience is often better informed about governmental benefits and regulations than his/her professional counterpart in the human services system.

The doctrine of consumer sovereignty, sometimes referred to as "consumer involvement," is now very much a fixture within the IL movement. The doctrine asserts that because disabled persons are the best judges of their own interests, they should have the larger voice in determining what services are provided in the disability services market.

Self-Help

The self-help movement embraces a large variety of groups: from the Female Improvement Society to Alcoholics Anonymous.[8] There now appears to be a self-help group for almost every conceivable human condition or problem—drugs, gambling, death, homosexuality, child abuse, women's health, old age, sex, neighborhood crime, cigarette smoking, childbirth, and of prime interest here, physical disability.[8-12] Such organizations view themselves as mutual aid groups that serve as adjuncts or as valid alternatives to established human service agencies.[8,13-16] They usually address problems and needs not dealt with by other institutions in society.

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

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

Demedicalization/Self-Care

"Demedicalization" is a trend that is challenging the dominance of medical professionals in selected spheres of human life. The trend is exemplified by well-known critics such as Ivan Illich,[17] who have expressed the concern that too many social problems and life conditions are being unnecessarily "medicalized."

Over the last several decades, an increasing number of behaviors considered sinful or criminal have come to be considered illnesses.[18-25] Alcoholism and mental disorders, for example, have been removed from the categories of sin or crime and are now labeled illnesses. Some have begun to call child abuse a "disease." Similarly, life events such as birth and death now almost always entail a considerable degree of medical intervention.

Many have begun to react to the excesses of medicalization and have urged that certain conditions and life events be demedicalized. One example is pregnancy and childbirth. Some urge that pregnancy be removed from the category of illness and that childbirth be

supervised by a midwife rather than a physician. Another example is death.[26-29] "Death with dignity" is the phrase being used for allowing the terminally ill to die at home rather than in a hospital, wired to the latest array of monitoring devices.

Implicit in the argument for demedicalization is the assumption that individuals can and should take greater responsibility for their own health and medical care. In many ways, demedicalization is an extension of the self-help movement to the fields of health and medical care, and is so referred to in some quarters. The movement goes beyond the keep-fit, watch-your-weight, stop-smoking, and drink-less campaigns of the recent past. The self-care movement encourages people to administer their own treatment for minor health problems and to avert potential complications arising from chronic health conditions.

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

Central to the goals of the IL movement is the belief that the management of medically stabilized disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the lives of disabled persons is said to entail behavior on the part of both medical practitioners and patients that induce dependency and thus are in conflict with rehabilitation and IL goals.

The Medical Model. To understand how such behavior arises, it is helpful to turn to the concept of the "medical model," a loosely used concept that often varies with the context in which it is discussed. As used here, the medical model consists of the following assumptions and role expectations in the provision of medical care:

- The physician is the technically competent expert.
- Medical care should be administered through a chain of authority wherein the physician is the principal decision maker; accountability for the care of the patient is centered on the attending physician.
- The "patient" is expected to assume the "sick role" that requires him/her to cooperate with the attending medical practitioners.
- The main purpose of medicine is the provision of acute/restorative care.
- Illness is muted primarily through the use of clinical procedures such as surgery, drug therapy, and the "laying on of hands."
- Illness can be diagnosed, certified, and treated only by trained practitioners.

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

Before evaluating the role expectations of the medical model, it is worth noting some of the model's other features that have been unpalatable to the IL movement. One important reason for demedicalizing disability, the movement implicitly argues, is that many of the assumptions of the medical model do not fit or apply to the needs of disabled persons. For example, the model's emphasis on acute/restorative care is not in keeping with the needs of long-term disabled persons well beyond the acute phase. Likewise, once beyond the acute phase, and living independently, many disabled persons are not in need of surgery, drugs, or the laying on of hands that characterizes clinical medicine. Moreover, experienced disabled persons often do not need the diagnostic, certification, or treatment services of medical professionals, since they have developed sufficient familiarity with the idiosyncrasies of their own condition to be able to do much of their own medical monitoring and treatment.

The Sick Role. The IL movement has been particularly critical of the behavioral expectations of the medical model as defined in the sick role, which, in this context, has a very specific meaning. This concept, originally formulated by Talcot Parsons,[30] is considered the single most important concept in medical sociology. By understanding its requirements we can gain a better insight into the position advocated by the IL movement.

The sick role consists of 2 interrelated sets of exemptions and obligations:

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

These exemptions are granted conditionally. In exchange:

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

The sick role is intended to be a temporary one. But for the long-term or permanently disabled person there is no immediate recovery in the sense of being re-

stored to one's original physical condition. Because the disability is often an irrevocable part of his/her existence, the disabled person, as a result of the sick role, begins to accept not only his/her condition but also his/her own very personhood as "aberrant" and "undesirable." Moreover, he/she begins to accept the dependency prescribed under the sick role as normative for the duration of his/her disability. Thus, the sick role removes from the disabled person the obligation to take charge of his/her own affairs.

The Impaired Role. This critique of the sick role is affirmed in the concept of the "impaired role" articulated by Gordon[31] and by Siegler and Osmond.[32] The impaired role is ascribed to an individual whose condition is not likely to improve and who is unable to meet the 1st requirement of the sick role, the duty to try to get well as soon as possible. Occupants of the impaired role have abandoned the idea of recovery altogether and have come to accept their condition and dependency as permanent. In the words of Siegler and Osmond,[32] the impaired role "carries with it a loss of full human status:"

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

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

The impaired role is fictionalized in Thomas Mann's Nobel Prize-winning *The Magic Mountain,*[33] a novel about patients living at the Berghof, an international tuberculosis sanitarium for the well-to-do. Here patients abandon the sick role for the impaired role. Siegler and Osmond's[32] description of the impaired role at the Berghof is informative:

> The impaired role has a lower status than the sick role, but in return for this childlike status, they are allowed to spend their days as children do, playing card games, taking up hobbies, having meals served to them, "playing" with each other, or, most often, doing nothing at all.

Mann's fictionalized account of the Berghof presents us with 1 variant of the impaired role as it is found in a particular institutional setting. His account provides a glimpse of the tendencies toward childlike dependency inherent in the impaired role.

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

Deinstitutionalization/Mainstreaming/ Normalization

The dependency-creating features of the medical model and the impaired role are most pronounced in institutional settings. Institutions are self-contained social systems that allow house staff and various practitioners to exercise a substantial measure of social control with little outside interference.

Prolonged institutionalization is known to have harmful effects:

> Patients are encouraged to follow instructions, rules and regulations. Compliance is highly valued, and individualistic behavior is discouraged. The "good" patient is the individual who respectfully follows instructions and does not disagree with staff. On the other hand, the patient who constantly asks for a dime for the pay phone, a postage stamp, or a pass to leave the institution on personal business, tends to be treated as a nuisance or labeled "manipulative." Patients do not make their own appointments, keep their own medical charts, or take their own medications. Responsibility for these things is legally vested in the institution. Yet on the day of discharge, the patient is expected suddenly to assume control of his own health care and life decision making.[34]

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

The deinstitutionalization movement has been backed by the political argument that institutional care is expensive and that community care will save taxpayer money. Proof of this argument has been hard to establish, especially when studies overlook the ever-present tendency of institutions to increase utilization to meet capacity.

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

The IL movement has adopted many of the same money-saving arguments for deinstitutionalization used by other groups. The only problem is that many of these arguments are beginning to wear thin with representatives of the taxpaying public who have not witnessed any significant decrease in human service expenditures. As latecomers to the deinstitutionalization thrust, severely physically disabled persons are less

likely to benefit from the money-saving argument. Public cynicism about deinstitutionalization may prove to be yet another barrier to independent living.

Closely related to the deinstitutionalization movement are the concepts of normalization and mainstreaming. These concepts have been discussed mainly in connection with developmentally disabled children and young adults. At one time it was thought that the interests of disabled children were best served by confining them to institutions or segregating them into special education classes. Now, thinking is that a disabled child or young adult becomes more "normal" when "mainstreamed" with able-bodied counterparts. However, normalization goes beyond mere deinstitutionalization. According to Dybwad,[35] it assumes that: normal on our earth is trouble and strife, trial and tribulation and the handicapped person has the right to be exposed to it. Normalization . . . includes the dignity of risk . . .

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

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

INDEPENDENT LIVING AS AN ANALYTIC PARADIGM

Social movements eventually find their expression in public policy or professional practice. While neither policy nor practice may totally embrace all the tenets of a movement's philosophy, a significant impact can be discerned. The IL movement is no different. We began our discussion by saying that independent living is more than a social movement seeking new rights and entitlements for disabled persons but is also having an impact on disability professionals. The movement, as we said, is reshaping the manner in which the problem of disability is being defined and encouraging new interventions. What we are witnessing in American disability policy is the emergence of a new "paradigm" that is redirecting the thinking of disability professionals and researchers alike.

Kuhn's Conception of Paradigm

My use of the word paradigm is borrowed from Kuhn's oft-cited work, *The Structure of Scientific Revolutions.*[36] As a historian of the natural sciences, Kuhn observed that scientific facts did not emerge by simple accumulation or evolution, but were the products of new ways of thinking—new scientific paradigms. Paradigms define reality for the scientist. They provide the framework by which problems are identified and solved. A paradigm also prescribes the technology needed to solve a given problem.

Kuhn's historical frame of reference is not only applicable to the natural sciences but is appropriate to public policy and professional practice as well. The concept of a paradigm can be useful here in helping to understand the debate that has been precipitated by the IL movement.

Two other concepts are important in Kuhn's analytic frame of reference. First is the concept of an *anomaly*—an event or observation that cannot be adequately explained by the dominant paradigm of the time. When a sufficient number of anomalies appear, a crisis is precipitated, and disaffected individuals begin to search for an alternative explanation or paradigm. Second is the concept of *paradigm shift*—when 1 paradigm is discarded for another. Anomalies do not automatically cause individuals to renounce 1 paradigm for another. A paradigm shift does not occur unless there is a new paradigm to replace the old. "[A] scientific theory is declared invalid only if an alternate candidate is available to take its place."[36] Both these concepts are useful to our inquiry here.

The Rehabilitation Paradigm

The dominant paradigm in disability policy today is the rehablitation paradigm, which is evident in both medical and vocational rehabilitation. It could be argued that there are sufficient differences between medical and vocational rehabilitation to speak of 2 paradigms, but there are also a sufficient number of similarities to consider them as one. Since my main interest is to contrast rehabilitation and independent living as paradigms, the differences between medical and vocational rehabilitation are less important.

In the rehabilitation paradigm, problems are generally defined in terms of inadequate performance in ADL or in terms of inadequate preparation for gainful employment. In both instances, the problem is assumed to reside in the individual. It is the individual who needs to be changed. To overcome his/her problem, the disabled individual is expected to yield to the advice and instruction of a physician, physical therapist, occupational therapist, or a vocational rehabilitation counselor. The disabled individual is expected to assume the role of "patient" or "client." While the goal of the rehabilitation process is maximum physical functioning or gainful employment, success in rehabilitation is to a large degree determined by whether the patient or client complied with the prescribed therapeutic regime.

The Severely Disabled Person as an Anomaly

In recent years anomalies have appeared that cannot be explained by the rehabilitation paradigm. The most important anomaly was the fact that very severely physically disabled persons were achieving independence without the benefit of, or in spite of, professional rehabilitation. In fact, some were considered too disabled to significantly benefit from rehabilitation

Table 1: Comparison of Rehabilitation and Independent Living Paradigms

Item	Rehabilitation paradigm	Independent living paradigm
Definition of problem	Physical impairment/ lack of vocational skill	Dependence on professionals, relatives, etc
Locus of problem	In individual	In environment; in the rehab process
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, voc rehab counselor, etc	Peer counseling advocacy self-help consumer control removal of barriers
Social role	Patient/client	Consumer
Who controls	Professional	Consumer
Desired outcomes	Maximum ADL Gainful employment	Independent living

services. It became evident that cooperation with professional rehabilitation was not a prerequisite for independent living. As a result, an increasing number of individuals, particularly among the most severely disabled, have become disaffected and have sought an alternative paradigm.

The IL Paradigm

The IL paradigm has emerged, in part, as a response to the anomaly of the severely physically disabled person. According to the IL paradigm, the problem does not reside in the individual but often in the solution offered by the rehabilitation paradigm—the dependency-inducing features of the physician-patient or professional-client relationship. Rehabilitation is seen as part of the problem, not the solution. The locus of the problem is not the individual but the environment that includes not only the rehabilitation process but also the physical environment and the social control mechanisms in society-at-large. To cope with these environmental barriers, the disabled person must shed the patient or client role for the consumer role. Advocacy, peer counseling, self-help, consumer control, and barrier removal are the trademarks of the IL paradigm (table 1).

Although the IL paradigm is now well beyond the embryonic stage of development, the rehabilitation paradigm remains strong. We can expect the IL paradigm to strengthen as movement leaders continue to refine its basic principles. In this period of paradigm shift, we see individuals with loyalties to both paradigms. There are some rehabilitation professionals who have introduced IL concepts within their practice but have not totally abandoned the rehabilitation paradigm for the IL paradigm. This analysis differs somewhat from Kuhn's.[36] He argues that "[the] decision to reject one paradigm is always simultaneously the decision to accept another..." The analysis here suggests that the shift or transition to another paradigm is not necessarily abrupt or exclusive.

Implications for Disability Research

Paradigms not only define problems and the range of appropriate interventions; they also determine what is relevant for purposes of research. Kuhn holds that there is no such thing as research in the absence of any paradigm. Underlying each paradigm is a theory of causation spelling out the relevant set of dependent and independent variables.

In traditional rehabilitation research, the emphasis has been on outcomes such as gains in carrying out ADL, mobility, and employment. The intervening variables thought to be critical have generally centered around patient/client characteristics and various kinds of rehabilitation therapies. Patient/client characteristics typically include age, sex, physical impairment, and the psychologic makeup of the individual. The inclusion of these characteristics reflects the assumption in rehabilitation research that the problem to be addressed resides in the individual. The issue for rehabilitation research is not whether rehabilitation works, but which therapy or intervention works best for which groups of patients or clients.

Independent living as a paradigm of research has only begun to emerge. Much of the research incorporating IL concepts has yet to find its way into the published literature. Nonetheless, given the values and assumptions posited by the IL movement, we can at least begin to identify some of the variables considered relevant for research.

The theory of causation implicit in the IL paradigm asserts that environmental barriers are as critical as, if not more so than, personal characteristics in determining disability outcomes. This theory of causation is implicit in Trieschmann's[37] conceptual framework attempting to explain the behavior and outcomes of spinal cord injured persons. Trieschmann hypothesizes that behavior is the function of 3 sets of variables—person variables, organic variables, and environmental variables, as shown in table 2. According to Trieschmann,[37,38] disability research must give more consider-

Table 2: Trieschmann's Hypothesis of Behavior Functions in Spinal Cord Injury (B=f(PxOxE))

P = Person variables	E = Environmental variables	O = Organic variables
Repertoire of Habits	Hospital Milieu	Age
Personality Style	Stigma Value of Disability	Severity of Disability
Types of Rewards	Family and Interpersonal Support	Medical Complications
Internal vs External Locus of Control	Financial Security	Congenital Anomalies
Method of Coping with Stress	Social Milieu	Strength
Self-image	Urban vs Rural Residence	Endurance
Creativity	Access to Medical Attention & Equipment Repair	
	Access to Educational, Recreational, & Avocational Pursuits	
	Socioeconomic Status	
	Architectural Barriers and Availability of Transportation	
	Legislation	
	Cultural and Ethnic Influences	

ation to the effect of environmental variables and their measured by psychologic tests "have not account for a large proportion of the variance in behavior.[38] Her list of environmental variables is not exhaustive but does illustrate the research directions proposed by the IL paradigm.

Moreover, the IL paradigm differs from its rehabilitation counterpart in defining outcome variables relevant for research. While rehabilitation has stressed the importance of self-care, mobility, and employment, independent living has emphasized a larger constellation of relevant outcomes. In addition to the 3 outcomes considered desirable in rehabilitation, independent living has emphasized the importance of living arrangements, consumer assertiveness, outdoor mobility, and out-of-home activity. In some instances the IL paradigm would reject the significance of self-care as an outcome variable. The fact that a disabled person needs more assistance from a human helper does not necessarily imply that he/she is more dependent. If a person can get dressed in 15 minutes with human assistance and then be off for a day of work, that person is more independent that the person who takes 2 hours to dress and remains homebound.

The challenge for disability researchers is to operationalize the concepts introduced by the IL paradigm. In particular, we need to operationalize both the outcomes and intervening variables deemed important by the IL paradigm. In terms of outcomes we need to identify and weight a set of variables that are most reflective of IL values. In terms of intervening environmental barriers we need to define meaningful measures of environmental constraint.

One might ask whether the consideration of environmental variables belabors the obvious. "Ask any disabled person," one might say. While the importance of environmental variables appears to be self-evident, we are not certain about the relative contribution of each environmental constraint in explaining IL outcomes. Nor do we know the collective importance of these environmental variables relative to individual characteristics. We need to go beyond mere statistical significance to show what percentage of the variance in outcome can be explained by variables considered important by the IL paradigm.

But there is a more important reason to consider the impact of environmental variables. There is a growing public debate about the extent to which society should subsidize the removal of environmental constraints—inaccessible public transportation, architectural barriers, unmet personal care needs, and others. If it can be empirically demonstrated that these barriers are predictive of disability outcome, then the IL movement will be considerably strengthened in making its case before various public forums.

Environmental variables, unlike individual characteristics, can be rectified through legislative and administrative action. In his follow-up study of spinal cord injured veterans, Eggert, in an unpublished dissertation, makes this observation:

> Environmental and individual characteristics. . . have qualitatively different degrees of potential manipulation. Demographic characteristics such as age, sex, and race cannot be altered. Other individual characteristics, such as degree of independence in ADL are subject to slight modification through a program of physical therapy. The nature and level of veterans benefits, an environmental variable, is subject to drastic alteration by the stroke of a pen on a piece of federal legislation.[39]

Traditional rehabilitation research that belabors the significance or insignificance of individual patient/client characteristics has little policy relevance—and in many instances, has little clinical relevance as well. As a paradigm of research, independent living offers us an opportunity to steer away from the myopic preoccupation with unalterable individual characteristics that divert our attention from the larger institutional and environmental context in which disabled people live. The institutional and environmental context has for too long been accepted as given.

THE FUTURE

In a mere 7 years, the IL movement has grown

from a small band of disabled persons struggling for simple rights to a significant political force shaping the future of disability policy. With its meteoric rise, can we predict how the movement is likely to shape the future of disability policy? Can we predict what the movement will look like in another decade? While these questions cannot be answered directly, we can discern some trends and issues.

The Role of the IL Paradigm

The concept of paradigm can be useful in predicting how the IL movement is likely to affect disability policy. Paradigms are more than analytic frames of reference; they also serve important latent social functions. They prepare students, scholars, and practitioners for membership in a particular discipline, help to define the boundaries of professional practice, and help to confer legitimacy upon professional groups.

Up till now the field of disability policy (for physically impaired persons) has been the captive of the rehabilitation paradigm and rehabilitation professionals whose limited frame of reference in many ways narrowed the options available to disabled persons. The emphasis on one-to-one clinical practice often excluded the contributions of other disciplines. By broadening the problem of disability to include a wide variety of environmental variables, the IL paradigm is opening the field of disability policy to other disciplines. The emphasis on rights and entitlements is encouraging the participation of legal professionals; the matter of architectural barriers is stimulating new interest on the part of architects; and the problem of work disincentives arising from various public assistance programs is sure to invite economists who have plowed similar ground in income transfer programs geared to nondisabled groups.

Furthermore, the infusion of new perspectives precipitated by the IL movement will undoubtedly invigorate the field of rehabilitation and enlarge its awareness of related areas. For example, it may lead vocational rehabilitation counselors to learn more about the rest of the human service system with resulting benefit to their clientele.

The Role of Able-Bodied Persons

One of the most vexing issues in the future will be the role of able-bodied persons in the movement. In some quarters, there are strong feelings that only disabled "consumers" should hold the majority of leadership positions. The issue is reminiscent of the civil rights movement when whites were asked to relinquish their leadership roles in black-advocacy organizations. The debate on this issue is likely to intensify over the next few years. The issue of consumer involvement will become less controversial as able-bodied persons begin to realize the significant role they have outside movement organizations, especially in the development of public policy affecting disabled persons.

Another unresolved issue is the question of who is a "consumer." This question is particularly relevant to parents of disabled children. Parents have often identified themselves as surrogate consumers on behalf of their children. The movement has been somewhat anti-parent, since parents of disabled children often perpetuate childhood dependency into adult life. The movement has often viewed parents as a major barrier to independent living.

New Legislation

The new authorizations for IL services under PL95-602 present both opportunities and risks for the movement. The new law gives an opportunity to strengthen existing IL programs and to extend IL services to parts of the nation where none exist. The new law also affirms the political credibility of the movement. The risk is that new funding could bureaucratize the movement and blunt its cutting edge as it becomes involved in organizational maintenance activities at the expense of advocacy. Moreover, IL funds may be diverted into activities that are only marginally associated with independent living, thus diluting the meaning of what independent living is all about. Finally, since new funding will come through the Rehabilitation Act, there is the danger that the movement may become a captive of the rehabilitation establishment.

We can also expect new legislation on other fronts. Legislation has been pending in the Congress to remove certain work disincentives for disabled persons receiving benefits under the Social Security Disability Insurance and the Supplemental Security Income programs. Disincentives under these programs are most serious for severely disabled persons, who not only lose their income benefits but also their related medical and social service benefits when becoming gainfully employed. If passed, the legislation should enable many disabled persons to become more independent through gainful employment. As of this writing, it appears likely that Congress will pass some legislation in this area. This problem has been in existence for some time and has compromised the ability of state vocational rehabilitation agencies to move severely disabled persons toward gainful employment. Yet, rehabilitation professionals have, till recently, ignored the disincentives problem as a serious disability policy issue —even though the disincentives facing disabled persons have been far more serious than those facing persons participating in other more controversial welfare programs. The disincentives issue illustrates how the IL movement may liberate the formation of disability policy from the assumptions that have governed the rehabilitation establishment.

CONCLUSIONS

The IL movement represents a new chapter in American disability policy. Considering its brief history,

its accomplishments in legislation, services, and raising of consciousness have been truly remarkable. But the movement has only begun. We can expect it to reach out to new disability groups and to enlarge its base as its initial adherents grow older. We can also expect it to produce a growing and sophisticated disability literature as it continues to redefine its concepts, programs, and services.

The movement's most significant contribution is that it has given disabled persons a voice in their own future and has fostered a new sense of dignity and pride that for too long has been denied them. This will continue to be its most important contribution in the years to come.

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

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Federal Legislative History of Independent Living Programs

Richard E. Verville, LLB

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• In some respects, passage by the US Congress of the 1978 Amendments to the Rehabilitation Act (PL95-602) marked the beginning of federal involvement in the independent-living movement. For the 1st time a program was created whose primary goal is to help disabled persons to live independently; previous programs have been designed to help such persons become employable. This paper briefly examines the roots of PL95-602 and identifies how this new law represents a major new direction in the rehabilitation movement. The purposes and goals of the advocates of independent living have changed in the past decade and the new law reflects those changes.

A productive discussion of independent-living programs must, like any discussion of a complicated matter, begin with some elaboration of the concepts, terms, and issues involved. In the context of the vocational rehabilitation laws and programs of the past 60 years, the term "independent living" has generally referred to attempts to establish programs of rehabilitation services with the purpose of improving the disabled individual's ability to function independently to the extent possible. The disabled person would not have to have a reasonable likelihood of being employed as a result of the services provided but would have a reasonable likelihood of being able to live outside of an institutional setting.

Confusion has existed as to whether the independent-living program and policy are conceptually based on the goal of the services provided, the types of services financed, or the type of individual eligible for services. Often, all 3 concepts have been involved, but basically it is the first which distinguishes independent living from other rehabilitation policies or programs. However, because the goal is to enable the patient to function independently, the individuals eligible are likely to be different from persons eligible for traditional vocational rehabilitation services. The difference may be in age as well as in the severity of the disability.

In addition, the services may also vary between an independent living program and a vocational rehabilitation program, although both are comprehensive service programs in that any health, social, psychologic, vocational, or other services or aids can be provided to meet the established goal. Comprehensive services for independent living are defined in PL95-602 as all services provided under the vocational rehabilitation program plus any other services necessary to achieve the goal of independent living. However, in an independent-living program, social services may be the primary service element, with health services next and vocational training services being the least utilized. In vocational rehabilitation, the order might well be reversed.

BACKGROUND HISTORY

In reviewing the literature dealing with the history of rehabilitation legislation, one finds only an occasional reference to independent living as a part of the arsenal of rehabilitation programs. In an article marking the 50th anniversary of the vocational rehabilitation program, Smith[1] observed: "There has been, at various stages in the program's history, discussion of changing the program to one in which services could be given for the purpose of improving the disabled individual's functioning to make it possible for him to gain the status of independent living other than mere economic independence." A main thesis of Smith's article is "the consistency with which the Congress and the different administrations have, through the years. . . , maintained the goal of employment for the persons found eligible for the services."

Thomas, in 1970, was unable to cite an instance prior to that year of expansion of nonvocational programs of rehabilitation, but he did suggest that a possible trend for the 1970s would be the provision of "life enriching experiences to all handicapped people, whether related to employment or not."[2] In that same edition of the *Journal of Rehabilitation,* Mary Switzer and E.B. Whitten, two of the intellectual and political leaders of rehabilitation during the 1950s, 1960s, and early 1970s, attempted to forecast the future of rehabilitation, with no mention of independent living. Perhaps the most revealing commentary of all on independent living programs is the thoughtful paper of Mary Switzer,[3] on the need in the decades after 1970 to constructively reform the rehabilitation program to provide vocational opportunities for classes of people overlooked traditionally by rehabilitation: public offenders, alcoholics and drug addicts, and welfare recipients. Her major point was that the rehabilitation program always maintain its vocational objective:

Mr. Verville is the legal counsel for the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation. His office is in Washington, DC.

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"The challenge of the future will be to maintain the dual characteristics of rehabilitation as we have known it for they are the essential ingredients of its success. First, the personal, committed, devoted relationship of the counselor to the person being served; and second, *the service to be directed to the goal of work.*"[3] (Emphasis supplied).

That statement was made 2 years before President Nixon vetoed HR8395 and the S7 on the grounds, among others, that the bills strayed too far from the essential vocational objective of the program.

Perhaps the best account of the history of rehabilitation legislation is Russell Dean's book *New Life for Millions.*[4] In the account of the history of the rehabilitation movement and federal legislation there is no mention of independent living programs as important federal legislative considerations.

The 1st rehabilitation legislation involved vocational rehabilitation for World War I veterans and then similar legislation for civilians. The focus of both laws was so narrowly vocational that physical restorative services were not included in either law as rehabilitation services.[4] While the fear of socialized medicine had something to do with this reaction, it also reflected the very narrow focus of the new laws. Not until 1943 was restorative medical care a service for which rehabilitation agencies could pay with federal funds. However, there were some, such as Douglas McMurtrie, head of the Red Cross Institute for Crippled and Disabled Men, who argued even at the beginning for broader programs.[4] But according to Dean,[4] even the flexible definitions and programming recommended by McMurtrie in 1918 were related only to services to those having prospects for ultimate employment.

Some general consideration of social goals for rehabilitation was given by President Hoover and his staff in 1928 during a national conference on the health and protection of children.[4] In the President's opening speech, he classified the 3 major problems of children as "the protection and stimulation of the normal child; second, aid to the physically defective and handicapped child; third, the problem of the delinquent child."[4] Obviously, aid to handicapped children would not be assistance of a vocational nature primarily. Rather, it would be health, social, and educational services. However, no new federal laws developed to provide programs for these problem areas. It was not until the enactment of titles IV B and V of the Social Security Act that social and health services to children, including handicapped children, were authorized, and these were not established, organized, or provided as part of rehabilitation.

In 1943, the amendments to the rehabilitation legislation added physical restorative services, or medical rehabilitation, to the program. Congressman Walter Judd, a Minnesota physician, was most responsible for this major achievement.[4] The concept of rehabilitation services was becoming more comprehensive, but the goal was still clearly a vocational one. With respect to rehabilitation, the 1940's were clearly most notable for the major expansion of medical rehabilitation programs. While the 1943 amendments to rehabilitation legislation (PL78-113) were being developed, Dr. Howard Rusk was developing medical rehabilitation care in the military health system.[5] Also, the Baruch Committee on Physical Medicine was established by Bernard Baruch and had immediate effect on the expansion of this field of medicine.[5] Dr. Paul Magnuson led a major overhaul in the VA health system which emphasized rehabilitation care.[5]

The amendments of 1954, PL83-565, added research, training, and facility grants to the array of programs in rehabilitation legislation but did not deal with questions of direction or goals for rehabilitative services. These amendments, as did the 1943 amendments, expanded the programs available in rehabilitation. PL83-565 did not expand the services which rehabilitation could finance, for the 1943 amendments had essentially made the program comprehensive with respect to the scope of services,[2] but the 1954 amendments made rehabilitation a multiprogram approach by adding research, training, innovation, and facility support to the federal-state service program.[5]

THE 1960s

In the late 1950s, the rehabilitation program came under the exciting and creative leadership of Mary Switzer, whose background had been in the Public Health Service. By 1960, the program was one of the major social programs financed by the federal government. We had not then yet witnessed the growth of federal social programs which later produced Medicare, Medicaid, major federal aid to elementary and secondary education, social services for the elderly, and title XX of the Social Security Act. The rehabilitation program had by 1960 developed most of its major elements except independent living: comprehensive services, innovation grants, research and training programs, and facility support. At the same time, substantial growth in federal programs and responsibility for the poor was clearly in evidence. The effect on vocational rehabilitation was a broadening of its clientele without change in its program goals. In fact, when major social programming was enacted for the disabled in the 1960s, vocational rehabilitation was not the legislative or program instrument utilized.

Under President Kennedy in 1960, the nation was urged to focus upon the problems of perhaps the most neglected of disabled citizens, the retarded. In 1963, the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 was enacted. It established the foundation for what is presently the Developmental Disabilities Act. The goal of the effort for the retarded or those with developmental disabilities was not and is not limited to vocational activity. Assistance in improved independ-

ence of function was, at least implicitly, an important policy of the law. These programs were not enacted as part of rehabilitation legislation, nor was the Rehabilitation Services Administration (RSA) the administering agency. Thus, when a social, nonvocational goal and program was developed for a group of severly disabled, it was clearly not established as part of the rehabilitation program structure, though it might have been.

The major issue of rehabilitation policy in the 1960s did, however, relate to the populations served. This is evidenced by the 1970 paper by Ms. Switzer, cited above.[3] The book, *50 Years of Rehabilitation in the U.S.A., 1920-1970,* put it aptly:

> "Now the vocational rehabilitation program faced a challenge of unprecedented size—of bringing to the problems of the poor and disadvantaged the concepts, philosophy and the methods on which vocational rehabilitation had grown. . . . "[5]

The decade of the 1960s reflected an extraordinary concern at the national political level for the poor and economically disadvantaged, not evidenced since the depression when there was no alternative but to be concerned and act. In the 1960s the poverty programs of the Office of Economic Opportunity (OEO), aid to disadvantaged children in the schools (title 1 of the Elementary & Secondary Education Act), and Medicaid, were all enacted to assist the poor. Rehabilitation was expected to fulfill a role as well. It was placed organizationally in a new federal agency, the Social and Rehabilitation Service (SRS).[4] The name of the agency is reflective of the view of the times. Ms. Switzer's role as first SRS Administrator is evidence of not only her skill but the importance Wilbur Cohen, then secretary of HEW, placed on vocational rehabilitation in dealing with the poor and their needs. But, as Ms. Switzer wrote in 1970, the rehabilitation program was a vocational one and she intended it to remain that way.[3]

Another noteworthy event of 1968 was the completion of a study of rehabilitation programs, first called for by Congressman Fogarty in 1963 and done by a prestigious National Citizens Advisory Committee (NCAC) on Vocational Rehabilitation which began its work in 1966.[4] The 1968 Report was similar in tone and theory to Ms. Switzer's 1970 paper. Its thrust was on the need for broadening of vocational rehabilitation to serve the disadvantaged of all types.[5] It also called for a special program aimed at correctional institutions and special local centers for rehabilitation in poor urban neighborhoods.[5] These findings were perfectly consistent with the general political climate of the 1960s. According to the NCAC, the focus of rehabilitation was still to be on vocational goals.

THE 1970s

Most histories of rehabilitation end at about 1970 but personal recollections generally suffice for a period as recent as 10 years. The 1st years of the Nixon Administration saw continued interest in the problems of poverty which concerned prior administrations, but the program response to those needs focused essentially on income support and jobs. The Adminstration began phasing out the social service programs of OEO. Rehabilitation was given a leadership role in providing vocational training and jobs for welfare recipients as part of major welfare reform initiatives. However, while this may have been consistent with the 1965 and 1968 amendments, reflecting a need to provide extended evaluation and work adjustment services and broadening the focus to the behaviorally handicapped, many people in the field believed that the effort on behalf of the physically disabled was being vitiated.

The Congressional hearings of 1972 on rehabilitation and related deliberations raised 2 major questions about the vocational rehabilitation program: (1) "creaming," or taking easy cases to develop good statistics; and (2) serving those without real physical or mental handicaps in the traditional sense. Both these criticisms led to concern with tightening the law to require vocational rehabilitation service primarily to those with the most severe handicaps, a trend noticeably inconsistent with Ms. Switzer's and the NCAC views.

In 1972, the Administration submitted its rehabilitation legislation, which did not propose any major new programs, only technical amendments. The House Committee on Education & Labor did recommend major reform and new programs in its bill HR8395, sponsored by Chairman Carl Perkins and John Brademas. That bill included a proposed major program of comprehensive rehabilitation services for those who might not reasonably have a vocational goal in life, but for whom rehabilitation would be of assistance in living independently. In large part, this idea arose because of concern that some severely disabled individuals who might benefit from vocational rehabilitation services were so disabled that a vocational goal seemed unlikely, at least in the short term, and they were therefore not served at all. Like much of the history of the 1970s and 1960s, this philosophy was a vocational one.

The Administration attacked this independent-living proposal on the ground that it diverted rehabilitation from its quantitative and measurable goal of vocational outcomes, thereby weakening the program, and because there were social services available to the handicapped under title IVA, now XX, of the Social Security Act. It was also argued that HR8395 would create 2 program tracks and divert the severely handicapped to a 2nd track, which did not offer vocational services, thereby defeating the purpose of serving that population when work was feasible. HR8395 and its successor, S7, which included the same independent living program, were both vetoed for the above reasons and because of cost.

The Senate Committee Report on S1875, the rehabilitation legislation enacted as PL93-112 in 1973, Senate Report 93-318,[6] clearly evidenced the fairly

narrow Congressional view of independent living as a vocational program for the severely disabled. It summarized the problems highlighted by the 1972 hearings as: (1) failure of vocational rehabilitation to respond to the needs of the severely handicapped and (2) lack of services in the community for those who might not presently have a vocational potential *"but who would be brought to that point through the provision of self help services and training"*. [6] (Emphasis supplied.)

The legislation finally enacted, S1875, resulted in the Rehabilitation Act of 1973, PL93-112. While it did not include the independent living program that had been title II of HR8395, it did have some provisions of great significance to nonvocational services to the severely handicapped: (1) the civil rights provisions of title V or PL93-112;(2) special projects for certain classes of severely disabled such as the spinal cord injured where the emphasis was upon nonvocational services; and (3) special demonstrations to determine the total needs of severely handicapped individuals. PL93-112 also required vocational rehabilitation services to be targeted on the severely handicapped.

The pressures for independent living programs seemed to change substantially from 1970-1972 to the years 1974-1978. Between 1974 and 1978, 2 major movements are noteworthy in the rehabilitation field that also affected independent living programs: the consumer movement, including the White House Conference on the Handicapped, and civil rights for the handicapped. Civil rights issues often focused on transportation, housing, and living arrangements, matters essential to independent-living programs. Also, the consumer movement resulted in the establishment of consumer-managed centers for independent living throughout the United States, whose focus was more social than vocational.

In addition, a major national movement largely unrelated to rehabilitation but affecting it directly developed in the years just after 1972: the concern with deinstitutionalization. This concern arose around the needs of the mentally ill, but rapidly spread to include those of the elderly and eventually physically severely disabled people. It created pressures for community-based living arrangements and social services for the severely handicapped. These pressures and concerns were not necessarily with the future employment of the individuals needing such community-based services, but rather with their independent function. Unfortunately, behind this movement of deinstitutionalization there was also the deft hand of budgeteers who saw deinstitutionalization as a cost-saving device for federal and state governments.

The major interest of consumers and the White House Conference on the Handicapped was with the full scope of needs of handicapped people: transportation, housing, health care, income support, and civil rights. While employment was still important, the consumer movement, the civil rights movement for the handicapped, and the deinstitutionalization doctrine served more than anything else to emphasize program needs which were not traditional to vocational rehabilitation. This effectively laid a foundation for a fully new approach to independent-living activity.

LATER DEVELOPMENTS

With the coming of the late 1970s, the pressure was off from rehabilitation to serve all of the disadvantaged, as the Johnson and Nixon Administrations, Mary Switzer, and the NCAC had all urged. New programs had been authorized or expanded to meet the needs of the disadvantaged, such as title XX of the Social Security Act, the Older Americans Act Amendments of 1973 and 1974, and programs in alcoholism and drug abuse at the National Institute on Mental Health. However, the pressures of severely handicapped people for expanded service had grown immeasurably during the 1970s, as evidenced by the effective formation of the American Coalition of Citizens with Disabilities and the White House Conference on the Handicapped, which were as much for social goals and programs as vocational ones. Also, the 1973 PL93-112, had already targeted vocational rehabilitation services on the severely handicapped. As a result, the focus swung drastically from expanding the persons served by bringing new groups of needy into the traditional vocational rehabilitation system, to expanding the service goals and programs available, but limiting those served to only the severely disabled. The 1973 Act had narrowed the target group and the 1978 Act would expand the service program to include independent-living services and centers.

Thus, in 1978, PL95-602 produced title VII of the Rehabilitation Act, "Comprehensive Services for Independent Living," the 1st major, nonvocational program of federal rehabilitation legislation. Its details have been elaborated many times. At this time, RSA is struggling with regulations for the program. That struggle makes Sisyphus look like a great achiever. While the regulations are being worried over, HEW is requesting only $10million to finance a program authorized for funding at $150million. A $150million program cannot possibly achieve its objectives when financed at $10million. The serious general budget situation generally leads most knowledgeable people to conclude that while Congress will be more generous than HEW, it will not provide anything near $150million. It is likely then, that the program will begin as one of support to centers for independent living on a small scale and not expand into a major national service program for some years.

CONCLUSIONS

The history of 60 years of rehabilitation legislation indicates an inexorable movement to expand services in this field: from strictly vocational services in 1920; to comprehensive medical, social, and vocational services

but all with a vocational goal in 1943; to vocational rehabilitation services directed toward independent living as a program goal in 1978. However, the first 50 years of the program were all concerned only with employment as the goal of the services and programs. Only in the past decade have nonvocational goals become especially significant to the leadership of the rehabilitation movement. Even in this decade, the concept of independent living has shifted in a dramatic way from essentially one of expanding vocational rehabilitation services to those with severe handicaps and unlikely employment goals, to providing primarily social services to those, including the aged and children, who may never work.

The lesson of this history is whether, in such a short time, a very old program with all of the inhibitions of age can respond constructively to a major new program area. While independent-living activity has been underway in a few states for the past 5 years, it in no way has been a major national program such as that called for in PL95-602. If funding consistent with the authority and scope of PL95-602 is provided for independent living, the challenge will be significant; if it is not, the frustration for handicapped people will be equally significant. The challenge will be to demonstrate that rehabilitation agencies and professionals can organize and deliver rehabilitation services to effectively and measurably improve independent function and living for those for whom work is a far-removed, if not impossible, goal. Many people, from President Nixon and his OMB to Mary Switzer and other great leaders of rehabilitation, have had their doubts.

ADDRESS REPRINT REQUESTS TO:
Richard E. Verville, LLB
1156 15th Street, NW
Washington, DC 20005

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Helping One Another: A Speculative History of the Self-Help Movement

Irving Kenneth Zola, PhD

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• The Independent Living Movement represents a direct challenge to current notions of rehabilitation (see the article by Gerben DeJong in this issue). It is a unique challenge, spearheaded not by new technical advances but by a new social awareness, and not from within by medical personnel but from without by lay groups. In another sense, however, it is but the latest evolution of an old theme in American life—the notion of self-help. This paper traces the history of self-help, to illuminate the problems and prospects of the Independent Living Movement.

The roots of mutual-aid groups harken back to the frontier days of the United States. As early as the 1st part of the 19th century, Alexis de Toqueville noted the American penchant for joining groups,[1] and by 1900 a directory listed over 250 independent national voluntary lay organizations. For most of these organizations, be they men's service clubs, women's clubs, or others, the goal of helping, though often central to their avowed reason for being, was rather external to the members themselves. Those to be helped were the community in general or some specific cause or disease.

The shift from voluntary associations for helping others to mutual-aid organizations to help each other was, however, not an easy one. Though some have found examples of such activities in early agricultural cooperatives,[2] the mass waves of immigration of the late 19th and early 20th century were the clearest stimuli to their proliferation.[3] Thrust into a nation in which there were few formal services to aid in their survival, the new arrivals turned to one another. Their response was the creation of mutual-aid societies where membership was based primarily on sharing some explicit social characteristic: race, religion, country of origin. Interestingly, by far the most "popular" of their services, though basic to life, came at the end of it: namely burial and funeral rites. A far-distant 2nd service was the lending of money. Thus, in these early self-help groups, the aid given to one another was of the most material sort. From this tangible kind of service, aid of a more social or psychologic nature was truly a giant step.

The difficulty of this step is illustrated in the history of that best-known of illness-oriented voluntary organizations: The March of Dimes. For here, where the rehabilitation problems of young children were enormous as well as controversial, there was no "coming together" of the afflicted. When it is remembered that polio patients were not isolated from one another and even had clinics, wards, and hospitals devoted to their exclusive treatment, then the fact that no support organization, however informal, ever arose or was encouraged is even more surprising. In retrospect it seems that there was a kind of undertone that such activity might be considered inappropriate. Everything that could be done was being done *for* you. In a distortion of the recent slogan, "Do your own thing," it became, "Do your own suffering and managing, and keep your problems to yourself."

Three Barriers To Self-Help

From such examples I infer that there must have been a number of barriers which impeded the development of medical self-help organizations. Three barriers that seem most basic were: 1) the nature of the problems to which such groups were devoted; 2) the nature of the help required in dealing with the problems; and 3) the nature of the personnel best suited to give that help.

On several levels the diseases with which mutual-aid societies dealt were long considered socially unacceptable. Most concretely the groups dealt with issues of "loss" and "deficiency," from a missing body part or function—the ability to walk, to see, to hear, to speak, to urinate, to defecate—to the most taboo of psychologic traits, the inability to control certain aspects of one's behavior, such as gambling, drinking, drugs, sexuality, mental illness, obesity. There is no doubt a continuum of taboo problems, with several, such as hearing, seeing, and walking, being far less stigmatized than others, such as facial disfigurement or colostomy.

But toleration for being less than perfect even in these respects is a very recent phenomenon. Only in the current generation of teenagers is the taunt, "Boys never make passes at girls who wear glasses," a ludicrous one. On the other hand we, the older generation, are still "hung up" on even the "most accepted" of handicaps: We speak louder to the deaf, avoid mentioning the beauty of scenes to the blind, and reprimand our children for staring at someone with a limp. All of this is complicated by our country's commitment to a belief that there is *no* problem that cannot be ultimately overcome. Thus unsolved problems or diseases come to represent a failure, and the bearers or survivors be-

From the Department of Sociology, Brandeis University, Waltham, MA, and the Boston Self Help Center, Brookline, MA.

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come constant reminders of this inadequacy. As such, a general response was to put them as far as possible out of sight and out of mind.

A 2nd barrier, the nature of the help that such problems entailed, was also threatening. For the idea of being in need of help is not an accepted theme in the Western world. No aphorism regarding help is known so well as "The Lord helps those who help themselves." Independence was the byword. Achievement against all odds and all comers was the measure of success. Horatio Alger was for many years the embodiment of the American ideal—a person who overcame his background to attain success. So too the folk heroes of chronic disease were not the millions who came to terms with their problems but those few who were so successful that they *passed*—the polio victim who broke track records, the one-legged baseball pitcher who made the major leagues, the great composer who was deaf, the famous singer who had a colostomy. They were all so good that no one knew, and therein lay part of their glory.

In fact, it may be that the emphasis on such successes has done more harm than good for the majority of people with disabilities. For it masks the real kinds of help that the sufferers of chronic conditions need. Management in daily living does not involve doing dramatic tasks, but mundane ones. And these examples of someone overcoming a handicap once and for all certainly masks the time element required for such help. Most of this aid can neither be given nor utilized in a single encounter or short series of encounters. And the problem is not, for the majority, a temporary one but one that will last for *life*. That is what chronic means! How uncomfortable this makes people feel is frequently seen in the negative response to mutual-aid organizations which state this lifetime commitment explicitly, such as Alcoholics Anonymous, Synanon, Re-Evaluation Counseling, and the current Independent Living Movement.

The 3rd barrier to any widespread acceptance of mutual aid was the nature of the personnel involved in giving help—our enormous worship of the technical expert, especially the physician. For modern medical care has been, and to a large extent still is, the exclusive province of the physician. It has been hard enough for the physician to give up tasks, and inevitably some responsibility, to a growing army of allied health professionals. But these were at least nominally under his authority. Self-help organizations, on the other hand, were essentially lay groups and as such were largely outside medical control. As a result, any good that they could do was scarcely examined. Even when positive results of mutual aid were reported, as in group therapy and encounter groups, they were given little professional recognition and were dismissed as second-choice alternatives. At best they might be viewed as nice things for patients to do to keep themselves occupied and out of trouble. Such forms of help represented self-treatment and this, next to the use of chiropractors, was regarded by the ordinary providers of medical care as perhaps worse than no help at all.

Ameliorating Factors

With such formidable forces ranged against the mutual-aid organizations, how did they ever get off the ground? There is no single answer, but a number of events certainly pried open the door. For example, World War II had an enormous impact upon our ability to ignore the seamier aspects of life. Once and for all our insulation was broken. All of us, but particularly those in the Armed Services, confronted different cultures and thus different ways of defining as well as handling problems. In short we saw viable alternatives. Certainly one could argue that the civil rights movement truly got under way here as blacks and whites were forced to come to new definitions of themselves and others. (One might have expected this to have taken place much earlier with the great waves of immigration which inundated our country, but their influence was mitigated both by the vastness of America which permitted great isolation of most "natives" from these groups and by the philosophy of Americanization, which, accepted by the immigrants and encouraged by the residents, consciously attempted to extinguish all salient aspects of the heritage from which they came.)[4]

World War II, however, did more than this. It forced a confrontation with the most massive job of rehabilitation we have ever faced and this made certain kinds of physical handicaps no longer a personal but a national responsibility.

The A-bomb itself and its successor, the H-bomb, provoked the deepest questioning of who we were and what life was all about. At least 1 outcome of this searing of our social conscience was a financial commitment to the solving of life's problems. So in the postwar era, the National Institutes of Health flourished and some form of national health insurance became increasingly inevitable.

The change in the nature of help that might be needed was being challenged also by certain undeniable realities. With a host of infectious diseases coming under control, more and more people were surviving to middle age and beyond. Thus many latent or previously "numerically insignificant" disorders became more manifest—arthritis, diabetes, mental illness, heart disease, multiple sclerosis, stroke, cancer. Moreover, these were disorders which were more often disabling than immediately fatal, and for which no "magic bullet" either in prevention or in care was forthcoming. In short, they were problems which should require medical management for extended periods of time, some for life.

But there was something more to these disorders; they fundamentally altered the doctor-patient relationship. There was a shift from cure to care. No longer did

treatment take place with the doctor doing and the patient receiving. To succeed at all, the patient had to help and, as in psychotherapy, to be an active participant. In short, treatment was something in which the patients themselves had a role—something that had to be recognized by them as well as their former "caretakers."

The Advent of Psychiatric Impact

The coming of age of psychiatry had another impact, for it made abundantly clear the importance of behavior in all aspects of disease—from how one gets sick to whether or not one recovers. In a sense it reemphasized the oneness of a person's mind and body—a phenomenon so evident in the almost ever-expanding category of disorders called psychosomatic. Thus, terms like "support" and "relationship" could no longer be something in medical care to be done if one had the time, but were at the very core of helping. And yet this was not an activity for which many health personnel felt trained or inclined. Even were they willing to actively undertake such a role, it is not clear that numerically they would ever fill the need.

For given the current demand, the shortage of physicians is insurmountable and we are too committed to a line of scientific inquiry and specialization to ever turn back. No matter how many doctors now choose the path of primary care or community medicine, doctors in general continue to be more specialized rather than less. Thus partly by default and partly by delegation, many medical tasks—from history-taking to prescribing drugs, from giving injections to performing certain forms of surgery, from teaching to counseling—ultimately came to be done by people who were not MDs. The biggest jump, however, was not in the delegation of responsibility to less-trained personnel but in the taking over of many therapeutic tasks by people who had "been there" or were still "there." In short, the "expertise" of patients to help themselves and others began to be recognized.

The recognition of such expertise is at best a struggle. The world in general and the medical world in particular still too often feel they are in the best position to know what is in the best interests of the disabled. Often they contend it is their years of experience and lack of personal involvement which makes them see our needs more clearly. A personal experience shows how occasionally ludicrous this claim can be:

> I entered the workshop of a prosthetist who had been in the business for over 50 years. Noting that I had had polio and use a cane to walk, he motioned me to come near.
>
> He: "I wonder if you'd try this cane." I did so.
>
> He: "Well, what do you think?"
>
> IKZ: "It seems solid enough."
>
> He: "Now watch this." He then proceeded to take the cane from me and pushed a little button about 3 inches from the handle, and out popped a 12-inch blade.
>
> Before I could say another word, he went on: "This one is even handier; look!" Taking another cane, he also pressed a button and now brandished what might be called a 10-inch iron blackjack. "You know," he went on, "in times like these, crime in the streets and all, things like this self-defense cane should be pretty handy."
>
> IKZ: "Yes," (in my best tongue-in-cheek fashion) "particularly if the thief lets me lean on him for support while I dismantle my cane."

In a certain basic sense I feel that no matter how sophisticated or even understanding the unafflicted become, the sufferers will ultimately have to see to their own needs by banding together and pushing. This is not merely because the general public does not care but because, in a real sense, they do not know. It is not accidental that major changes in the architecture of public buildings have been pushed by paraplegics, reduction of drug maintenance costs by "mended hearts," extension of medical insurance coverage by ostomates, new speech therapies by the laryngectomies, or a new profession, enterostomal therapy, largely created and staffed by former patients. Thus public interest is not stirred by large members of "problem-bearers" alone. There have always been millions of poor, of black, and of consumers, as Michael Harrington has pointed out in "The Other America."[5] It has always taken something more to stir society to action.

Thus while there is some recognition of the legitimacy of the self-help movement and the people it represents, the acceptance of the voices of the disabled is grudging at best. Even with the greater attention to problems of chronic disease and disability, there is a way society speaks of them which perpetuates a separation and a distancing. It seems that, to justify rising health costs as well as the financial expenditure that it will supposedly take to remove current architectural and programmatic barriers, we must quantify the extent of the problem. And yet in so doing we distort an important reality. By trying to find strict measures of disability we make into dichotomous categories what are indeed a series of blurry, continually changing continua. By agreeing that there are 20 million disabled or 36 million, or even half the population, in some way affected by disability, we delude ourselves into thinking there is some finite (no matter how large) number of people. In this way, both in the defining and in the measuring, we try to make the reality of disease, disability, and death problematic, and in this way make it at least potentially someone else's problem. But it is not, and can never be. Any person reading the words on this page is "at best" momentarily able-bodied. But everyone reading them will, at some point, suffer from at least one or more chronic diseases and will be disabled, temporarily or permanently, for a significant portion of his or her life.

That we persist in this denial means that the necessary steps to undo this process are likely to be difficult to acknowledge as well as to undertake. But at least 3 steps suggest themselves. First, we with handicaps and chronic disabilities must see to our own interests. We must free ourselves from the "physicality" of our conditions and the dominance of our life by the medical world.[6] In particular, I refer to the number of times we think of ourselves and are thought of by others in terms of our specific chronic conditions. We are polios, cancers, paras, deaf, blind, lame, amputees, and strokes. Whatever else this does, it blinds us to our common social disenfranchisement. Our forms of loss may be different, but the resulting invalidity is the same.

While organizing around specific diseases may have great benefits for raising research monies, it has divided our strength and pitted one disease group against the other. Not only has this led to an overspecialization of services but to an underdevelopment of our consciousness. It has made us feel so dependent on others (the medical world for treatment, the general public for money) and so personally accountable that it has made us feel that we have no rights. We, patients all, perhaps the last and potentially the largest of America's disenfranchised, must organize on our own behalf. Cutting across specific disease entities, we must create advocacy, consciousness-raising, counseling, resource groups.[7] And wherever and whenever possible, staff members alike must have a chronic disease and/or physical handicap. I am not claiming that no one else can help or understand, but that, as with women and blacks, we are at a point in history where "having been there" is essential in determining where to go.

The self-help movement is, however, but 1 part of the struggle. It is a prerequisite for change, but neither the sole nor the sufficient avenue. We must deal as much with social arrangements as with self-conceptions; one, in fact, reinforces the other. Thus the problems of those with a chronic disability should be stated not in terms of the individual defects and incapacities affecting our *physical* functioning, but in terms of the limitations and obstacles placed in the way of our daily *social* functioning. What should be asked is not how much it will cost to remake a society completely, so as to be accessible to all with physical difficulties but rather why a society has been created and perpetuated which has excluded so many of its members.

There is a growing awareness that this exclusion is not an accidental byproduct of industrial society. There is an ideologic compatibility between the rise of capitalism and certain Western religions which have continually justified the hierarchical arrangements of people through "hard work" or "the grace of God." When the notions of religion and law were beginning to lose their power as absolute arbiters of important social values, Darwin, perhaps unwittingly ushered in the age of biologic determinism. One critic of the times realized the social import of his work by exclaiming in surprise: "Sir, you are preaching scientific Calvinism with biological determinism replacing religious predestination." The fixity of the universe and/or hierarchic relations once attributed to God was now being justified by scientific inevitabilities. In the ensuing hundred years, there has been an expansion of the influence of science in general and in particular of "medical science," until they have in some ways replaced religion and law. Where once a social rhetoric made reference to good and evil, legal and illicit, now it is to "healthy" and "sick."

We are now experiencing a medicalization of society, and with it medicine as an agent of social control. And while some have argued that this is a more humane and liberal way to deal with social problems, the notions of health and illness still locate the source of trouble and treatment in individual capacities, not social arrangements.[8]

In the most concrete terms, to have a portion of our population declared physically unfit serves many important social functions. In still another way it is important to recognize in this country that health occupations are the fastest growing category of employment, the medical world is in the highest income bracket, and health-related industries are amongst the most profit making.[9] Crassly put, "Some people are making money off of the sufferings of others." In these 2 ways, economic and political motives of the society have come to reinforce one another. And until the day that no one benefits economically, socially, or psychologically from someone else being beneath them, there will always be categories of exclusion.

CONCLUSIONS

Regardless of whether we join activist groups, support those who do, or seek in other ways to change the sociopolitical-economic structure of America, we must at the very least look into ourselves. For if morality or justice is not sufficient as a motivating force, perhaps personal survival will be. All of us must contend with our continuing inevitable vulnerability. Not to do so can only make us further unprepared for the exigencies of life. For when we grow old, and with today's technology "survive," sick and disabled, for increasingly longer periods of time, we will experience a triple sense of powerlessness: First, because of our very condition, we will indeed be more physically and socially dependent. Second, through our previous denial, we will have deprived ourselves of the knowledge and resources to cope. And third, from the realization of what we will have done to those who have "aged" before us, we feel we have lost our right to protest.

To the extent that we at all feel we are receiving our "just deserts," it is very hard to demand any redress of the situation. We are left to the largesse of others to forgive us and to help us. Is it thus any wonder that study after study reports many of the elderly as

feeling that their life has been worthless? A sour ending to any story cannot help but result in a depreciation not only of the present but of the past.

In this light, it is especially important to remember what Erik Erikson said[10] about society's continual denigration and isolation of the aged:

> Any span of the [life] cycle lived without vigorous meaning at the beginning, in the middle, or at the end, endangers the sense of life, and the meaning of death in all whose life stages are intertwined.

So too what we do the physically handicapped and chronically ill, we do only to ourselves.

ADDRESS REPRINT REQUESTS TO:
Irving K. Zola, PhD
Department of Sociology
Brandeis University
Brookline, MA 02154

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

Sheldon Berrol, MD

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

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

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

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

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

From the Department of Physical Medicine and Rehabilitation, the Ralph K. Davies Medical Center, San Francisco, CA.
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only feasible, but is their basic right even in the absence of vocational goals. The independent living movement established the concept of a coalition of persons with disabilitites working toward a unifying goal of permitting an individual, regardless of impairment, to participate to the maximum extent possible in normal activities of everyday life.

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

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

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

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

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

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

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

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

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

ADDRESS REPRINT REQUESTS TO:
Sheldon Berrol, MD
Department of PM&R
Ralph K. Davies Medical Center
San Francisco, CA 94114

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"What's New About Independent Living?"

Jean A. Cole, PhD

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

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

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

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

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

MODELS OF INDEPENDENT LIVING

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

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

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

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

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From The Institute for Rehabilitation and Research, Houston.

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

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

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

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

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

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

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

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

DIFFERENCES BETWEEN INDEPENDENT LIVING PROGRAMS AND TRADITIONAL REHABILITATION MODELS

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

Goals

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

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

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

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

Methods of Service Delivery

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

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

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

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

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

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

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

Program Management

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

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

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

WHAT CAN WE LEARN FROM INDEPENDENT LIVING PROGRAMS

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

FUTURE ISSUES AS INDEPENDENT LIVING BECOMES A STANDARDIZED SERVICE ENTITLEMENT

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

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

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

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ADDRESS REPRINT REQUESTS TO:
Jean A. Cole, PhD
The Institute for Rehabilitation and Research
1333 Moursund Avenue
Houston, TX 77030

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International Efforts in Independent Living

Denise G. Tate, PhD, Robert L. Jarvis, MA, Gerald D. Juhr, MA

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

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

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

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

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

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

SWEDEN

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

From the University Centers for International Rehabilitation, College of Education, College of Osteopathic Medicine, Center for International Studies and Programs, Michigan State University, East Lansing.

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

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

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

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

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

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

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

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

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

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

THE NETHERLANDS

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

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

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

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

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

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

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

DENMARK

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

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

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

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

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

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

ENGLAND

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

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

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

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

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

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

CANADA

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

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

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

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

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

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

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

AUSTRALIA

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

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

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

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

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

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

CONCLUSIONS

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

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

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

ADDRESS REPRINT REQUESTS TO:
Denise G. Tate, PhD
D-201 West Fee Hall
Michigan State University
East Lansing, MI 48824

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The Environment as a Support System for Independent Living

Raymond Lifchez, MA

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• 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.

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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-

GENERALLY RELATED LIFE CYCLE STAGES

THE TOTAL SET OF BEHAVIORALLY DEFINED ARCHETYPAL PLACES

TASKS	A INFANCY: Reflex control; orientation; communicate with siblings and parents.	B CHILDHOOD: Gain motor, social, verbal, intellectual, emotional competence.	C ADOLESCENCE: Forge identity; establish peer group regulations; social/sexual exploration.	D COURTING-MATING: Group with peers; pair-bond; obtain sexual privacy.	E REPRODUCTION, CHILD CARE: Nesting/nurturing: symbiosis; socialization.	F MIDDLE LIFE: Care of aging parents: re-emphasis on worldly affairs; redefine indentity.	G 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 cliché, the presence of a visible heat source like a fireplace or a sunny, protected patio is an important element in the concept of dwelling. Heating 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

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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).

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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

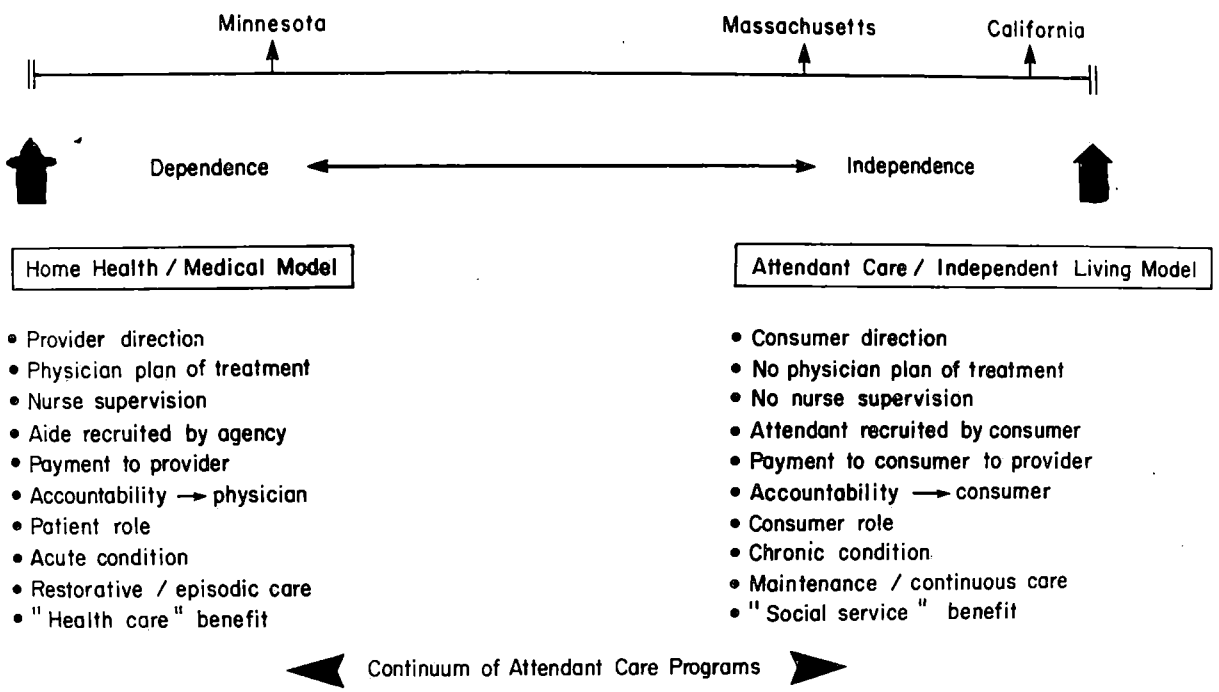
The attendant care model assumes that disabled individuals who are well versed in their own health care needs have the necessary ability and skill to direct and monitor their own personal care. The concept of self-direction is not widely accepted or supported by health professionals. Presently, opportunities 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 movement for independent living, attendant care has acquired unusual symbolic significance. It has become a premier issue for independent living advocates because this model incorporates many of the values and concepts cherished by the movement. Elsewhere in this issue, we have noted how the movement for independent living has been indebted to the contributions of other social movements—the civil rights, the consumer, the self-help, the demedicalization, and the deinstitutionalization movements. The attendant care model, incorporates the values and assumptions that characterize each of these movements.

In our society survival needs such as food, shelter, and health care are often elevated to benefit rights or entitlements. Attendant care is viewed as a survival right, a benefit necessary to the physical survival of the individual, since a severely physically disabled person cannot participate in school, work, recreation, or the political life of the community without it. Because of its indispensable nature, attendant care takes on the character of an inalienable right with status comparable to a civil right.

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

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

The demedicalization debate centers around the concern that there is too much unnecessary medical intervention into various problems and life conditions whose etiologies are social and economic rather than medical. In the case of physical disability, the movement for independent living asserts that a continuous medical presence is unnecessary once an individual is medically stable. The role expectations of the attendant care model are in marked contrast to the behavioral assumptions of the medical model and the sick role that come with medical intervention. In the attendant care model, accountability is centered on the consumer, not the physician. The attendant care model assumes that he does not require the acute/restorative care assumed in the medical model or in home health services. Disabled persons are assumed to be 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

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Transportation: A Key to Independent Living

Frank G. Bowe, PhD

ABSTRACT. Bowe F: Transportation: key to independent living. Arch Phys Med Rehabil 60: 483-486, 1979.

• Accessible transportation is essential if people with disabilities, particularly persons who are severely disabled, are to live independently in the community. The development of transportation services has moved from a focus upon special and separate "dial-a-ride" programs to an emphasis upon making fixed-route, mainstream systems accessible. The current state of the art, supported in large part by federal regulations, features a combination of mainstream accessibility and supplemental special services. Future progress in transportation for disabled people depends largely upon resolution of complex, politically explosive cost-benefit arguments on the federal and local levels, and on community acceptance of disabled persons as people deserving a spectrum of transportation services.

Transportation has been recognized as a critical component of independent living from the onset of serious discussion on deinstitutionalization of severely disabled individuals. This debate has continued, sometimes waxing and at other times waning, for nearly 2 full decades before making its 1st appearance in federal legislation.[1]

The concept of independent living surfaced in the testimony presented in the US House of Representatives and the US Senate during consideration of vocational rehabilitation legislation in the early 1960s, but the term itself was not used. More specific, detailed agendas appear in some of the Kennedy Administration's legislative proposals for research and treatment for mentally retarded individuals. The Urban Mass Transportation Act (PL88-365 Umt Act) set a policy that would require more than 10 years to mature into a program of activities when it announced, "It is hereby declared to be the National policy that elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services. . . [and] that special efforts shall be made in the planning and design of mass transit facilities and services so that mass transportation, which they can effectively utilize, will be available for the elderly and handicapped."

The Umt Act was ahead of its time in making this declaration and 3 others. It defined independent living, again without using the term, as encompassing senior citizens, physically disabled persons, and retarded individuals. It stressed the mainstream "mass" program at a time when disabled and elderly persons were restricted in virtually all areas of public services—education, housing, treatment—to segregated, "special" programs. And it tied independent living directly and inseparably to transportation.

When 4 severely disabled students at the University of Illinois moved from a nursing home to a barrier-free apartment in 1969, and when several mobility-impaired students at the University of California at Berkeley began an equipment repair and peer-counseling program in 1970, it was natural for them to look to the policy statement for support in their demands for transportation services allowing them to live "independently." The efforts they initiated stimulated similar programs in Boston, Houston and other urban areas across the country, and, in 1972, the Rehabilitation Act authorized a program of "independent living," thus introducing this term in the political arena. When President Richard Nixon vetoed the bill, this language was dropped from the subsequent bill, the landmark Rehabilitation Act of 1973 (PL93-112), which he signed. It was not until 1978, in the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments (PL95-602) that independent living finally made its appearance in federal legislation, culminating 20 years of effort by disabled people to establish independent living as a supported rehabilitation objective.

The Department of Transportation (DOT), in response to the Congressional mandates, initiated a 9-year, $27 million program to develop "Transbus," an accessible standard-size bus. DOT also funded a large number of demonstration projects to provide special "dial-a-ride" services for use in the interim before Transbus became available and to supplement this bus for the severely disabled who would be unable to use even accessible mass-transit systems. DOT Secretary Brock Adams announced in May, 1977 that only the Transbus would be funded by the department after September 30, 1979. One year later, after his order had been challenged in the Congress by representatives of the bus manufacturing industry, he reasserted the "Transbus mandate."

The stage seemed set, then, by late 1978 for a convergence of the 2 threads of federal policy, one providing for fully accessible transportation programming and the other authorizing a broad range of other programs, including housing, peer counseling, and advocacy for independent living. So promising did the developments appear that one veteran of the disability-rights movement exulted: "We have seen the future, and it works."

From the American Coalition of Citizens with Disabilities, Inc., Washington, DC.

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Scarcely 6 months later the flame that once burned so brightly flickered badly. Both threads appeared to be unraveling. To understand what happened, we must understand the importance of transportation to independent living, which will provide us with a clue as to what the future holds.

A HUB AND A SPOKE

Accessible transportation serves both as a practical necessity and as a philosophical basis for independent living. Without means of transportation to educational, vocational, cultural, recreational, and commercial facilities in the community, it is virtually impossible for most severely disabled people to live outside an institutional environment. In this sense, transportation is the hub of independent living. Its availablility expands the alternatives from which a disabled individual can design his or her life; accessible transportation makes possible creativity and spontaneity, training that qualifies the person for employment commensurate with his abilities, provision of life-support functions and services including medical care and daily sustenance, feasibility of employment remote from the place of residence. Yet transportation is a spoke in the independent living wheel, too, because it both reflects and sustains the very philosophy of living "in" the community, providing the handicapped with the same services and facilities accessible to others, allowing the handicapped to pay neither more nor less than they do, and requiring neither obeisance to others nor dependence upon them.

Pressed by these considerations, the leaders of the burgeoning independent living movement stress the design, where possible, and the retrofit, where necessary, of the mainstream, fixed-route system as the major thrust in transportation for disabled and elderly people. The alternative, segregated, "special" services restrict the range of choices available and, consequently, limit the ability to live independently in the community. "Dial-a-ride" services must be planned 24- to 48-hours in advance, cannot be changed en route, and cost too much–fares go as high as $50 for a one-way, one-stop trip. These services, then, do not offer the hub needed for independent living. Nor do they provide the spoke: the very concept of accepting services no one else in the community uses violates the entire spirit of independent living.[2]

So the leaders of the movement designed "centers for independent living" that offer a broad variety of support services, including wheelchair maintenance, financial counseling, advocacy in the search for benefits, and other forms of assistance which are tied to political activities designed to produce, in time, a more accessible community in which to live, a community featuring mass transportation disabled and elderly persons could use. This was to be the "future" that "works."

And it could–in the right environment. The mid-60s might have been such a setting, one in which this movement could have flourished. America then seemed willing to tackle large social problems with equally large expectations of success; we declared "war" on poverty and on racial discrimination. But the spring and summer of 1979 was not the right kind of environment. People were more interested in rapid and painless solutions than in longterm ones, more interested in themselves than in others, more interested in saving than spending, and more interested in turning inward to pursue happiness than in relying on government and institutions for this end. When Tom Wolfe called the 1970s the "Me Decade," he had in mind a despairing belief that many problems could not be solved, regardless of how much money was thrown at them, but he saw, too, a self-protecting retreat from these problems, as though we felt that they would somehow go away if only we would not look.

The prevailing attitudes toward disabled and elderly people–most Americans still do not accept the idea that these people can and should be independent–combined with the anti-spending and isolationist waves crystallized in California's "Proposition 13" stayed the bold thrust toward accessible mainstream transportation and the independent-living movement itself.

AN "EMOTIONAL BLOCKBUSTER"

Transbus stirred massive, prolonged controversy. B.R. Stokes, executive vice president of the American Public Transit Association (APTA), a national organization of transit authority officials, called Adams' mandate "absolute nonsense." The opposition of the bus manufacturers was no less heated. Waging a nationwide public relations attack on Transbus, APTA and General Motors charged that the bus was not only unworkable but frighteningly expensive. When DOT published its proposed regulation implementing section 504 of the Rehabilitation Act of 1973, centering its rules around Transbus, the assault accelerated and the charges mounted. So successful were the bus manufacturers in convincing the media that the regulation was "rule-making gone amok," and the transit operators in deriding the detailed requirements as "ridiculous," that the Washington *Star* ran a front-page screamer, "Transportation's Emotional Blockbuster," when the proposed rules appeared. Columnist Neal Pierce called upon President Carter to "cease and desist" with the DOT rule-making process. The attackers followed up with written and oral testimony during DOT's public-comment period. New York City Mayor Ed Koch testified that the rules would cost the city $2 billion, saying that "Such a burden would literally bankrupt us." The Chicago transit spokesman claimed that the regulation would cost $910 million and pointedly remarked that this sum would exceed the total invested in the system since 1890. Privately, the city officials admitted they were guessing; no one had actually calculated the costs on a station-by-station, vehicle-by-vehicle basis. Never-

theless, the huge numbers had their intended effect: the Department relaxed the requirements.[3]

The most devastating attack, however, came when the bus manufacturers flatly refused to bid on the 1st orders to build Transbus. Their decision has effectively halted the 9-year effort to produce a fully accessible bus. Although DOT Secretary Adams has asked the National Academy of Science to review the Department's Transbus specifications, a process which might result in bids the manufacturers would accept, the fact remains that the future of Transbus is very much in doubt.

A WHIMPER, NOT A BANG

The 1978 amendments to the Rehabilitation Act set forth a broad program of independent living in title VII of the bill. The law authorized up to $80 million in fiscal year (FY) 1979, ending September 30, 1979, and $150 million in FY 1980. It specified that no state rehabilitation agency would receive less than $200,000 for independent living services. Also authorized was a program for independent living of older blind individuals. The Congress was determined that the long awaited start of federal involvement in this area be a strong one, that independent living start with a bang. It authorized the federal share of independent living costs, not at the 80% level characterizing most rehabilitation programs, but at 90%; it also allowed the states to match this with a 10% contribution in kind, that is, through the donation of space or other resources, and did not require that the states actually contribute cash as their share.

Then, barely 9 months later, the Congress did an abrupt turnabout: it appropriated less than $2 million for independent living for 1979 and only $15 million for 1980. These sums are barely sufficient to support a few small projects in scattered locations across the country. Certainly, they will not permit a program to begin; even a minimal program based upon a $200,000 allotment per agency and modest funds for the centers and programs, for the elderly and the blind would cost at least $25 million. The irony of this reversal is that the original bill passed the House with only 12 votes against, and the Senate with just one. Yet the margins on the appropriations bills were equally impressive in the opposite direction less than one year later. What had happened, simply, was that the Congress had decided to respond to the voters' desire for greater governmental responsibility by slashing the budget drastically. The demands by many states for a constitutional convention and/or amendment requiring a balanced budget was another powerful factor. Whatever the reason, the turnabout ensured that independent living would begin with a whimper.

Combined with the confusion over the future of Transbus, the federal failure to support independent living means that it will be only partially available for disabled and elderly persons in only a few urban areas for several years to come. There is reason to hope, though, despite the setbacks. For all of the manufacturers' objections, Transbus can not be dismissed, nor do disabled and elderly persons appear likely to allow this. The bus remains the only vehicle offering full accessibility to disabled and elderly Americans while at the same time providing able-bodied riders with a faster, safer, and more convenient trip than is now possible. It is certain to make a comeback, perhaps with some modifications in the design specifications, but essentially intact. And the current anti-spending mood is likely to pass in the classic "swing of the pendulum" fashion: within 3 or 4 years at most, the Congress will have to restore some of its huge cuts in basic social programs, including independent living for disabled people.

We may not have to wait even that long. DOT's final section 504 regulations, combined with other laws requiring accessibility in transportation, lay out a schedule of events which, by law, must be followed. Progress toward transportation accessibility may have been slowed considerably, but it will continue. Among the steps mandated by law are the following:

1. By January, 1980, transit operators must develop plans for nondiscriminatory practices with respect to disabled people.
2. By July, 1982, structural changes needed for access must be made in most transportation facilities; longer periods are allowed in some cases.
3. By July, 1984, at least one railroad station in each major metropolitan area must be made accessible; all other stations must be accessible by July, 1989.
4. By July, 1984, at least one car on each passenger train must be accessible. All new passenger cars must be fully accessible.
5. All buses ordered after July 2, 1979 must be lift-equipped. Three to 10 years are allowed for all bus routes to become accessible. Half of all buses used in rush hour must be accessible by July, 1985; accessible buses must be used before inaccessible buses at all other times.
6. The Transbus mandate will become effective promptly upon production by any manufacturer of the bus. DOT has not wavered from its commitment to Transbus.
7. Special services, such as dial-a-ride programs, must be made available immediately.
8. New airport terminals and facilities must be accessible; existing terminals have up to 3 years to become accessible.
9. Disabled people must be consulted on rail system accessibility plans, particularly when a city desires to provide special services rather than retrofit its subways.
10. Employment discrimination is prohibited by any transportation authority receiving federal financial assistance.

These new steps enhance existing requirements from

earlier legislation (notably PL94-352, which prescribed access features for airports) and regulations, particularly Interstate Commerce Commission rules on access to interstate bus facilities and vehicles.

The current state of transportation and independent living, then, can fairly be described as one in which movement is slowly taking place toward accessible mainstream systems. During this interim period, special services, however distasteful to many advocates, are all that are available in many sectors of the country. These services will be needed even after all mainstream systems have been made available because several millions of Americans are so severely disabled as to be unable to use fixed-route systems and must be transported literally from door to door.

CONCLUSIONS

Whether the present trend toward mainstream services continues, however haltingly, depends largely upon the American public's perception of our disabled and elderly citizens. For investments in transportation and independent living to reach the necessary levels, America must see these people as capable of living independently. Unfortunately, the slow progress in mainstream services is causing this perception to evolve slowly.[4]

The facts, however, cannot be disputed. When disabled and elderly people are self-sufficient tax-payers rather than dependent tax-users, the entire country benefits both from their contributions and from lower social security and other taxes. Transportation accessibility and independent living programs are needed so that these people can reach their potential as productive citizens. It will be expensive to make these necessities available. But it will be much more expensive not to.

ADDRESS REPRINT REQUESTS TO:
Frank G. Bowe, PhD
Director, ACCD, Inc.
1200 15th Street, N.W.
Washington, DC 20005

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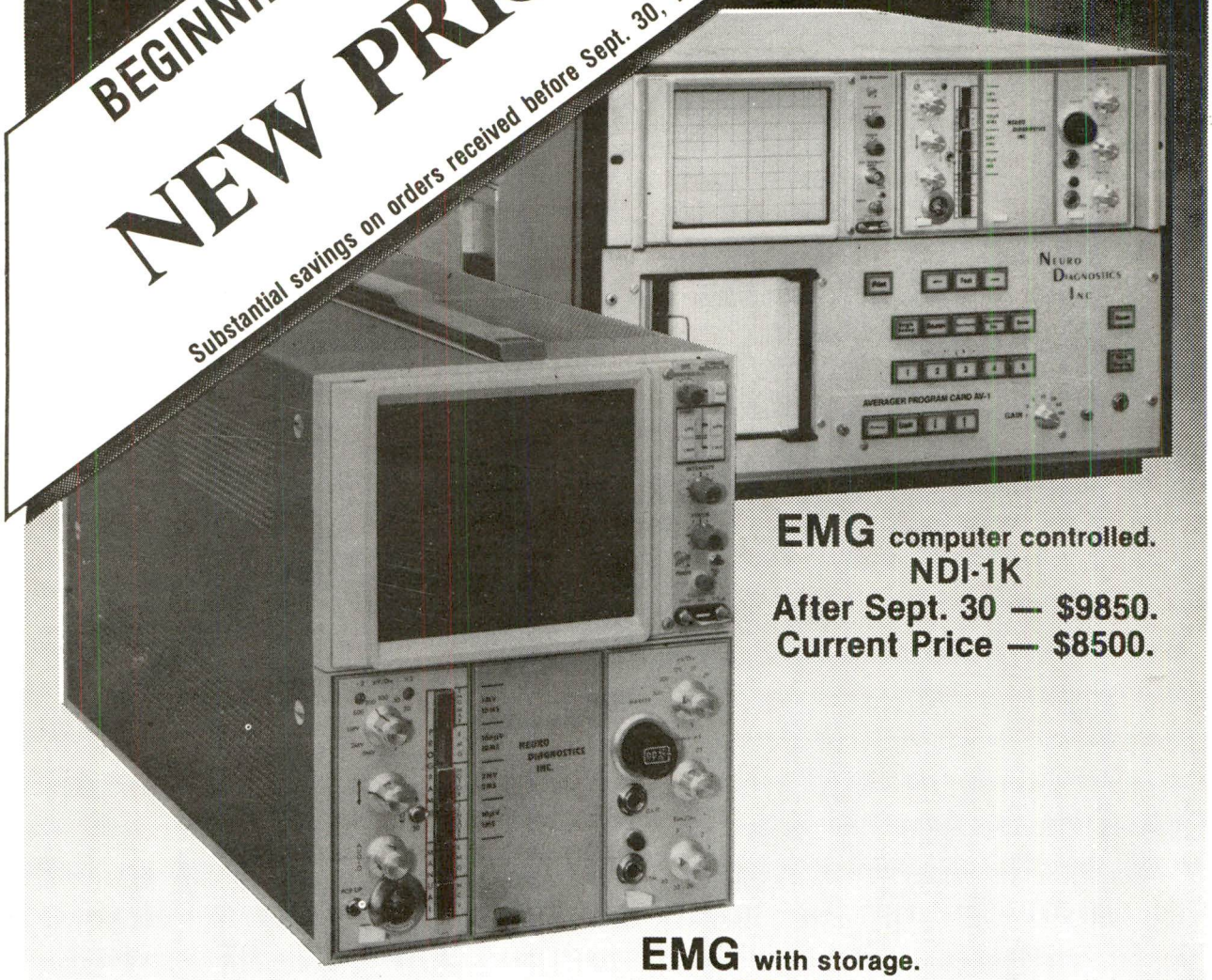

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