
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 initiatives 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 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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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 Disabilities (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.

ORIGENS 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. 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. 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. 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. 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 came 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-
their consumer counterparts in the IL movement. For a different conception of independent living than do agencies.

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 non-accountability 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
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. 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. Such organizations view themselves as mutual aid groups that serve as adjuncts or as valid alternatives to established human service agencies. 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, 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. 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 and Siegler and Osmond. 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, the impaired role "carries with it a loss of full human status:"

... the impaired role does not require the exercise 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, 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 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.

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, 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.* 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 a paradigm is discarded for another. Anomalies do not automatically cause individuals to renounce one 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." Both these concepts are useful to our inquiry here.

**The Rehabilitation Paradigm**

The dominant paradigm in disability policy today is the rehabilitation 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.
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. 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\textsuperscript{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,\textsuperscript{37,38} disability research must give more consider-
I Internal vs External Locus of Control” Method of Coping with Stress

The impact of environmental variables and their measured by psychologic tests “have not account for a large proportion of the variance in behavior." 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 belabor 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.

Traditional rehabilitation research that belabor 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 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 non-disabled 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 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.

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