The Independent Living Service Model

Historical Roots, Core Elements, and Current Practice

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Foreword

> Independent living has the potential to emancipate not only persons with disabilities, but also millions of other disadvantage people from the servitude of unjust, unwanted dependency, and to initiate a quantum leap forward in the quality and productivity of their lives.
> However, fulfilling this historic potential will not be quick or easy. Success will require increased, often sacrificial commitments by people with disabilities, their families, advocates, service providers and all who love the magnificent dream of 1776.
> Martin Luther King has stated that, "Freedom has always been an been an expensive thing." We must be ready to pay the price. We are responsible to millions in this and future generations, who rely on us for access to a life of quality. Available to us are the vast economic, technological and human resources of the richest culture in the history of mankind. We have no excuse to fail. We cannot afford to fail. We must unite to establish the principles of independent living in the consciousness and in all the processes of our society.
>
> Justin Dart, 1988

The independent living movement has become a powerful force for change on behalf of persons with disabilities. Its core values and philosophical principles of consumer sovereignty, self-reliance, and equal access have been the foundation of the Congressionally authorized independent living program and of service models developed and implemented in community-based independent living centers across the country. Since their inception, independent living centers have been the primary organizational mechanisms for pursuing the values and goals of the independent living movement. Their program and service models reflect deeply held principles aimed at assisting citizens with disabilities to increase their personal levels of independence. In addition, there is an emphasis on eliminating the physical, architectural, and economic barriers that prevent people with disabilities from living fully integrated and productive lives.

As programs and services were initiated, centers were faced with the challenge of developing a non-traditional, consumer-oriented service model based on equality between the consumer and service provider and stressing self-help and a barrier-free society. In developing this model, centers were clear about the service approaches they would not use. It also was clear that general types of program sup- port such as information and referral, peer counseling, skills training, and advocacy should be offered.

The non-traditional, consumer-oriented nature of the independent living service approach has contributed to its success; but it has also created unique challenges faced by centers and the field as a whole. The lack of extant service delivery models appropriate to independent living meant that the development and implementation of service delivery methods within the field had to occur simultaneously.

The proliferation of centers and their services was not accompanied by definitive descriptions of the evolving service model that could be shared across centers. This fact has created an urgent need for operational descriptions that can be used to support the ongoing philosophical and programmatic integrity of the model. This resource manual is a response to this need.

The manual traces the historical and philosophical roots of the independent living service model as it has evolved over the past two decades. The essential elements of the model are described as well as the services, approaches, and activities that characterize current practice. The manual also traces the emergence of national standards for the Part B-funded (now Part C) Independent Living Program and closes with a short summary of issues and concerns that may impact on the continued development and expansion of independent living services in the future. The manual was written to provide a useful resource for staff of independent living centers and for all audiences who have an interest in understanding how the concept of independent living has been translated into a viable and comprehensive service model.

Mary Ann Lachat, Ed.D.
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Preface

Perhaps more than any other program for America's disability population, Centers for Independent Living provide a vital link between people with disabilities and their community. The vanguard of empowerment for people with disabilities in the '70s, Centers continue to derive their strength from leaders in the disability community and consumers who are eager to take charge of their own lives.

The independent living movement has attracted some of the brightest advocates. Their vision for increased opportunities and greater independence for all people with disabilities has shaped public policy and changed community attitudes. Their influence has stretched into the boundaries of rehabilitation and caused us to reflect on the effectiveness of traditional vocational rehabilitation techniques.

Thanks to the concerns that Centers for Independent Living have articulated over the past decade, bondages of isolation and dependence have decreased substantially for people with disabilities. Today, these citizens are enjoying options and taking risks that people who have never had a disability often take for granted. Choosing a career, a place to call home, or a means of travel are fundamental options in daily living for most people, but too often they had been out of reach for people with disabilities.

Centers for Independent Living encourage self-direction among consumers, and this newly acquired independence has helped to forge new avenues for our nation's disability population. The independent living movement has enlightened our nation on the strengths and abilities of people with disabilities.

Susan S. Suter, Former Acting Commissioner
Rehabilitation Services Administration

Chapter One

HISTORICAL ROOTS OF THE INDEPENDENT LIVING PROGRAM

> In its broadest implications, the independent living movement is the civil rights movement of millions of Americans with disabilities. It is the wave of protest against segregation and discrimination and an affirmation of the right and ability of persons with disabilities to share fully in the responsibilities and joys of our society.
>
> Edward V. Roberts, 1977

The Concept of Independent Living

The activism of persons with disabilities on behalf of themselves and their peers was both the seed of the independent living movement and the force that continues to fuel it. Independent living emerged as a concept in the 1960s with the creation of self-help networks among individuals with severe disabilities who were attempting to live in the community (Zola, 1983). These efforts led to a social ideology that emphasized a distinctive approach to services for persons with disabilities by society, and encouraged consumer control and self-help initiatives to achieve community integration.

From its origins as a challenge to unresponsive, restrictive, and segregating service systems, the independent living movement has grown into a national force for change --a different way of viewing an entire population and segment of our society, and a forum for those who had been disenfranchised. From the evolving political and social perspective of independent living, concrete programs and services emerged that carried a new vision of more positive and empowering ways to work

with people with disabilities (Kailes and Weil, 1985). Independent living, therefore, is many things that are intertwined. It is an ideology that spawned both a political movement and a non-traditional service program.

Independent living is a term that has been used in a wide range of contexts over the past twenty years, and as a concept it is continually evolving. Definitions have varied somewhat, but several common themes are evident: personal control over one's life, self-direction, freedom of choice, risk-taking, equal access, and significant participation in society. The Independent Living Research Utilization (ILRU) Program of Houston described independent living as:

> ...control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's own affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of psychological or physical dependence upon others. Independence is a relative concept that may be defined personally by each individual.
>
> Frieden, Richards, Cole, and Bailey, 1979

For members of the disability community, independent living means the ability to participate fully in society --to work, have a home, raise a family, and generally share in the joys and responsibilities of community life. It means lithe ability to choose where to live and how; it means the individual's ability to obtain the services necessary to carry out activities of daily living that non-disabled people often take for granted (Pflueger, 1977). Conceptually, “it implies freedom from social and physical isolation and from institutionalization. Its philosophy and ideology are grounded in people with disabilities having choices and opportunities available”. (Kailes and Weil, 1985).

The Independent Living Movement

The concept of independent living became the rallying force and the philosophical formulation for the independent living movement, a broad social and civil rights thrust that draws enormous strength from the fact that it represents all people with disabilities (Roberts, 1977). It was originally formed in response to the self-identified needs of persons with severe disabilities who were not being adequately served by traditional programs. These individuals were presented with the limited life options of institutionalization or dependency on family support because their employment potential and ability to live independently in the community either were not recognized or were grossly underestimated by the rehabilitation and social service systems. Through the independent living movement, this population designed programs and initiated advocacy efforts enabling them to achieve independence despite limits in the existing service system. For thousands of people with disabilities, the independent living movement

became a beacon of hope and an avenue of new opportunity. Moving beyond the initial concerns of people with disabilities who were being ignored by traditional service programs, the movement acquired a momentum, which took aim at a broader set of issues relating to the integration of this population into the social, political, and economic mainstream.

> It is impossible to deny either the power of economic realities or the consistency with which disabled people have emerged at the bottom of the heap after battles for priorities. But the IL movement has given hope and experience to a cadre of people for whom the issue of independence has become literally a matter of life and death. They cannot and will not resign themselves to incarceration in institutions, however benevolent, yet they cannot exist without adequate housing and attendant care services. For them, it is critical that the movement survives. Even for others who could manage to live without it, the IL movement means the difference between a life of emptiness and isolation and one of satisfying involvement with others.
>
> Crewe, 1983

More than any other writer, Gerben DeJong traced independent living's important connection to other movements. Rooted in the societal upheavals of the 1960s, the independent living movement identified with the struggles of other disenfranchised groups, absorbing reform ideas from many sources: civil rights, consumerism, self-help, de-medicalization, and de-institutionalization (DeJong, 1978, 1983). These reforms not only broke through destructive and inhibiting barriers, but also led to personal affirmation and more positive self-images for those who had been isolated and repressed by society. Independent living was thus nurtured by powerful forces, which challenged restrictive concepts and discriminating practices.

> From these experiences, many disabled individuals emerged for the first time with a sense of themselves as members of a unique and valuable community, a sense supported by their comprehension that they had the right --hitherto denied --to participate as fully equal members of American society.
>
> The Institute for Educational Leadership, Inc., 1984

Important learnings were gleaned from the reforms of the sixties, particularly from the examples of minority groups demanding the right to define their own identities (Varela, 1983). From the black perspective on racism came the recognition that prejudice against disability is deeply rooted in cultural attitudes. This awareness underscored the need to understand and overcome societal sources of paternalistic and rejecting attitudes that were so destructive to persons with disabilities (DeJong, 1978). Zola (1983) pointed out that the American cultural emphasis on youth, beauty, and success has bred very limited tolerance of the chronic conditions that require help and assistance.

> Even today, being in need of help is not an accepted condition in the Western world, and particularly not in the United States. This attitude may be summed up in the aphorism; the Lord helps those who help themselves. ...the folk heroes of disability and chronic disease have not been 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 pitcher who played major league baseball, the great composer who was deaf, the famous singer who had a colostomy. They were all so successful that no one knew of their disability, and therein lay their glory. The emphasis on such successes has done more harm then good for the majority of people with disabilities, because it masks the real kinds of help that those with chronic conditions need. Management in daily living does not involve dramatic tasks, but mundane ones. Examples of persons who overcame their disability once and for all mask the time element required for such achievements. Most aid can neither be given nor utilized in a short series of encounters. Moreover, the problem for the majority of the disabled is not a temporary one but one that will last a lifetime.
>
> Zola, 1983

Leaders in the disability movement who struggled with cultural values that undermined their acceptance in society were stirred by the consumerism and self-help forces of the sixties that had been fueled by the same basic distrust of professionally dominated services. These forces pointed toward a new consciousness of consumer sovereignty and self-determination. "De-medicalization" was an extension of the self-help movement to the fields of health and medical care, promoting the belief that the management of medically stabilized disabilities is primarily a personal matter and only secondarily a medical matter. Finally, independent living was able to draw from the social movement for de-institutionalization which cut across many disabling conditions and challenged the dependency creating features of institutional settings (DeJong, 1978, 1983).

At a five-day leadership conference in 1982, leaders in the disability movement drafted a "Philosophy of Independent Living" which elaborated on essential core values and rights. Emphasizing that the independent living philosophy is wholly consistent with basic American political tenets, these leaders drafted the following preamble to their statement:

> Among the foundations of our society is the acceptance of certain fundamental human rights. Independent Living is based on the belief that all individuals, including those with disabilities, shall have an equal opportunity to exercise those rights. The independent living movement shall affirm the basic human rights of disabled persons:
>
> > To participate in the prerogatives and responsibilities of citizenship
> >
> > To equal employment opportunities

> To access to public facilities, transportation, and affordable housing for all disabled people
>
> To the supportive services necessary for employment opportunities and full participation in society
>
> To free, appropriate and non-segregated education
>
> To bear, raise, and adopt children
>
> To full participation in the cultural, social, recreational, and economic life of the community
>
> To live in dignified independence outside of institutional settings
>
> The Institute for Educational Leadership, 1984

What was especially significant about this preamble was that it moved beyond the service provision rights of people with disabilities to summarize a consciousness that had emerged from two decades of reform. In this sense, it captured fundamental principles that would shape the evolution of a broad community-based program of services and advocacy support for persons with disabilities. It communicated the need for a more comprehensive, consumer-oriented, non-paternalistic model that would promote the right of people with disabilities to full participation in society. This model would thus address two equally important needs --the need for individualized, responsive, consumer-directed services; and, the need for an advocacy thrust that would consciously address societal barriers to independence.

National Policy and Independent Living

The forces of the 1960s led to congressional reforms in the 1970's, which took aim at the roots of historical, prejudice and stereotypes that had isolated people with disabilities from organized society as an inferior caste. A clear summary of the overall intent of these reforms was stated in 1974:

> The Congress finds that it is essential to assure that all individuals with handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working, and service patterns be held as the final objective.
>
> White House Conference on Handicapped Individuals Act, 29 U.S.C. 270
> December 7,1974

In 1973, Congress passed a Rehabilitation Act (PL93-112) which set into motion new priorities and initiatives affecting the lives of people with severe disabilities. The 1973 Act was revolutionary in that it contained several provisions that proved critical to the movement. It required state rehabilitation agencies to establish methods of selection to ensure that persons with severe disabilities were not bypassed, thus serving notice to these agencies of their responsibility to this population. Also, while the act did not specifically designate independent living programs, it authorized six research and demonstration projects as part of a Comprehensive Service Needs Study. The demonstration projects promoted the establishment of community-based services supportive of independent living, --"disability rights activists seized the opportunity offered by the demonstration grants and began to use these funds for seed money for Independent Living Centers and for services for the disabled that were not based on vocational training" (Kailes and Weil, 1985). To these activists, the six projects symbolized the start of a new wave of community- based services to help people who previously had nowhere to turn. (Varela, 1983).

A particularly significant feature of the Act was Section 504, which prohibited discrimination on the basis of disability under any program or activity receiving Federal financial assistance. Legally acknowledging people with disabilities as a disenfranchised group needing protection from discrimination, this section of the act is often referred to as the civil rights act for the disability community. In the 1970s "504" became the kind of rallying cry for disability activists as the phrase "black power" had been to civil rights activists a decade earlier (Kailes and Weil, 1985, Varela, 1983). The passage of Section 504 represented a major shift in national disability policy away from benevolent paternalism toward the legal protection of civil rights.

The 1974 Amendments to the Act increased the impetus toward independent living by broadening service eligibility requirements. Other legislation contributed to this momentum by guaranteeing education for all children with disabilities, subsidizing housing, removing architectural barriers, and increasing the accessibility of public transportation.

Emerging as one of the leading demonstration projects; funded through the Act, the Berkeley Center for Independent Living gained national attention as an expression of the new activism among persons with disabilities, translating the independent living ideology into a community-based program integrating services with social action. This prototype center gave credibility and momentum to the movement. The Berkeley model was significant not only for its individualized approach to the needs of people with severe disabilities, it also took into account the need to modify the physical, social, and economic environments that influence independent living. Regarding residential programs as inherently paternalistic and debilitating, it extended this critique to other social service practices, which promote dependency. "Berkeley combined services and advocacy in the most straightforward and logical way; the center itself was controlled and

largely staffed by disabled people and designed to serve their needs as they saw them". (The Institute for Educational Leadership, 1984)

As exemplified in the Berkeley model, a basic premise that emerged from the community-based consumer-oriented approaches of the early 1970s is that people with disabilities best understand their needs and the needs of their communities .

In addition to better meeting the needs of their constituency, these early community-based programs, controlled and staffed by people with disabilities, also achieved other goals that included:

> Providing employment and volunteer opportunities that developed the skills and self-reliance necessary for integration into the social and economic mainstream;
>
> Emphasizing peer role modeling that encourages risk-taking and self-determination; and
>
> Establishing a community based operation that could serve as a source of support and pride to the local disability community and for a symbol of production and self-reliance for the community at large.
>
> The Institute for Educational Leadership, 1984

The independent living programs of the 1970s were not the only organizational forms, which the activism of the sixties generated. Coalitions, many under the sponsorship of or in conjunction with independent living programs, formed to advocate around special issues and to influence broad social policy through public education, community organizing, and systems advocacy efforts. These independent living programs and advocacy groups were unique for several reasons. First, they cut across traditional medical/charity distinctions to work with coalitions of people with different disabilities. Second, the new organizations were formed by people with disabilities living in the community who took on leadership roles to develop and run programs that met their needs.

The growing influence of the community-based independent living movement led to direct Congressional support through the 1978 amendments to the Rehabilitation Act of 1973 which added Title VII, Comprehensive Services for Independent Living. As expressed in the legislation, Title VII was intended to assist in the development of community-based service centers to provide information and referral, peer counseling, transportation, attendant care, and other services which would facilitate the integration of adults with severe disabilities into the mainstream of community economic and social life. These centers would decrease the dependence of persons with severe disabilities, and increase their self-determination and ability to be productive and contributing members of society.

Title VII represented a significant change in national policy and established a base of federal programmatic support for independent living. Part B (now Part C)of Title VII established a grant program to establish Centers for Independent Living. Under Part A (B) of Title VII, state rehabilitation agencies were authorized to provide comprehensive

services to any disability groups whose ability to engage or continue in employment or whose ability to function independently in family or community is severely limited. Comprehensive services were defined in the act as "any service that will enhance the ability of handicapped persons to function better in employment or live more independently in the home or community.” Part C (now Chapter II) of the act authorized grants to provide independent living services to older blind persons.

Initially, only Part B (C) of the act was funded, and at levels that were shockingly below the amount authorized in the amendments. Nevertheless, Title VII was a remarkable milestone for the independent living movement. It reflected many of the consumer-oriented services that had emerged in the 1970s, and, most importantly, meant that Congress had finally endorsed the principle of consumer control. The independent living movement had achieved Congressional support for a program of community-based services that would be offered by private, non-profit organizations (Varela, 1983).

Chapter Two

A PROGRAM DESIGN FOR INDEPENDENCE

> "The Independent Living Movement goes beyond the attempt to secure new rights and entitlement for disabled persons. It also represents an attempt to reshape the manner in which the problem of disability is defined and to encourage new interventions. We are witnessing the emergence of a new paradigm designed to redirect the thinking of disability professionals and researchers alike."
>
> Gerben DeJong, 1979

The Independent Living Service Paradigm

Today, the consumer-oriented values and concepts that are associated with community-based independent living centers are widely accepted and have influenced traditional approaches within the rehabilitation field. During the 1970s, however, the independent living service approach represented a significant alternative to professional rehabilitation services. Independent living produced a very different service delivery paradigm, which contrasted significantly with the traditional rehabilitation paradigm (DeJong, 1978, 1979, 1983).

In the late 1970s, Gerben DeJong presented a very perceptive and incisive analysis of the contrasting assumptions underlying the two approaches. By doing so, he provided the independent living field with an important analytic framework for depicting core values that influence the delivery of services to persons with disabilities. DeJong's analytical paradigm is depicted below.

A Comparison of the Rehabilitation and Independent Living Paradigms

Item	Rehabilitation Paradigm	IL Paradigm
Definition of problem	Physical impairment; lack of vocational skill; psychological maladjustment; lack of motiva- and cooperation barriers;	Dependence on professionals, relatives, and others; inadequate support services; architectural tion economic barriers
Locus of problem	In individual	In environment; in the rehabilitation process
Social role	Patient -client	Consumer
Solution to problem	Professional intervention by	Peer counseling; advocacy;

	physician, physical therapist, occupational therapist, vocational counselor and others	self-help; consumer control; emoval of barriers and disincentices
Who controls	Professional	Consumer
Desired outcomes	Maximum ADL; gainful employment; psychological adjustment; improved motivation; completed treatment	Self-direction; least restrictive environment; social and economic productivity

DeJong, 1978 and 1983

The most important theme that emerged from DeJong's independent living paradigm was that the locus of the problem was not the individual, "but the environment that includes not only the rehabilitation process but also the physical environment and the social control mechanism in society at large" (DeJong, 1978). Emphasis on the importance that the environment or factors external to the individual play in handicapping an individual reflects the distinction made by Roberts (1977) between disability and handicap. Disability is a condition, which the person can learn to deal with and assimilate. Handicap reflects the negative effects resulting from gaps in services and environmental barriers. Independent living services were seen as a way to close these service gaps and eliminate environmental barriers.

The core values underlying the independent living paradigm are reflected in three major propositions that have influenced the evolution of the independent living program at the national level. These are:

> Consumer Sovereignty --the actual consumers of the services, not professionals, are the best judges of their own interests. They should ultimately determine how services are organized on their behalf.
>
> Self-Reliance --people with disabilities must rely primarily on their own resources and ingenuity to acquire the rights and benefits to which they are entitled.
>
> Political and Economic Rights --people with disabilities are entitled to pursue freely their interests in various political and economic areas.
>
> DeJong,1978

Developing The Independent Living Service Model --Essential Features

The essence of the independent living movement and its core values became the foundation for a consumer-oriented service model that emphasized individual choice,

personal control, and the need for self-determination. In commenting upon the evolution of this model, DeJong (1983) stated, "The dignity of risk is the heart of the independent living movement. Without the possibility of failure, the disabled person lacks true independence and the ultimate mark of humanity, the right to choose." As leaders in the movement translated philosophical principles into actual service programs and community advocacy efforts, they recognized that there would be a rich and necessary diversity in service approaches across centers. However, it was also clear that as centers evolved, certain key elements were essential to designing and maintaining effective community- based independent living services. These included:

Consumer control over policy and management decisions. Persons with disabilities would control decisions governing organizational policies and procedures, the provision of services, and community activities. In this sense, the term "consumer" is defined broadly to mean persons with disabilities who may be direct recipients of services as well as those who are not but who are secondary beneficiaries of advocacy efforts. Consumer control in decision-making is intended to ensure that policies, procedures, services, and activities are responsive to the needs and respectful of the rights of the disability population.

Consumer control over service objectives and methods. This aspect of independent living services places primary responsibility for identifying service needs, setting independent living goals and objectives, and making decisions about service participation with the consumer who is receiving services. This means that the service provider role shifts from that of controlling and providing the services to one that consciously seeks to promote the independence and self-sufficiency of the consumer within the context of service participation selected by the consumer.

Cross-disability emphasis. Independent living emphasizes a responsiveness to the needs of all persons with disabilities. At the national level, this separates the independent living programs from programs that emphasize services to a particular disability group.

Community based and community responsive. Independent living centers are designed to be responsive and accessible to the disability community in their service locale, and to involve the community significantly in setting program priorities.

Peer role modeling. The emphasis on peer role modeling in independent living reflects a belief that people with disabilities can greatly benefit from the perspectives and support of others with disabilities who have successfully struggled to lead productive and meaningful lives in their communities. Peers serve as strong role models and facilitators to consumers in their efforts to achieve desired levels of independence.

Provision of a range of services. Because independent living is responsive to the varied dimensions of knowledge, skills, options, and support associated with achieving personal independence, a range of services is provided. These include such core services as information and referral, skills training, advocacy, and peer counseling as well as others such as attendant care services, housing services, transportation services, educational services, vocational services, equipment services, communication services, legal services, and social/recreational services.

A community advocacy thrust. Independent living recognizes that in order for consumers to achieve independent lifestyles, environmental and social barriers in the community must be eliminated. There is thus a dual commitment to both individual services and community advocacy --activities conducted to enhance opportunities for people with disabilities to have equal access to all aspects of community life and to achieve meaningful integration into society.

Open and ongoing access to services. Independent living is not a closure-oriented program. Services are open and available to consumers on an ongoing basis, reflecting consumers' evolving and continuing needs and interests.

These key features of the independent living service model underscore the importance of constituency control, the power of peer support, and the fact that independent living centers were established to meet the needs of specific disability populations that had been underserved and segregated by traditional rehabilitation services. Also, the independent living service model has been characterized by the dual thrusts of individualized support services to promote self-determination and community advocacy to promote integration into the social and economic mainstream.

Variations in Independent Living Program Models

Over the past decade, the number of programs providing some type of independent living service has increased remarkably. However, the initial lack of specific definitional criteria or guidelines for establishing independent living programs led to significant variations in organizational structures and service approaches. Differences in the interpretation of legislative intent and how consumer service needs should be met resulted in entirely different service patterns in spite of the fact that each program might be identified as an independent living program. In short, the independent living literature reveals a myriad of definitions and models, some reflecting consensus across the field and some reflecting sharp divisions. The 1985 Directory of Independent Living Programs published by the Independent Living Research Utilization (ILRU) Research and Training Center in Houston, Texas includes three major types of programs:

1. Independent Living Center --a community-based non-residential program characterized by consumer control and substantial consumer involvement. It provides directly or coordinates indirectly, through referral, services which

persons with severe disabilities need to increase their self-determination and to minimize dependence on others. (Frieden et. al., 1979). Core Services offered by Independent Living Centers include information and referral, peer counseling, independent living skills training, and advocacy assistance. Centers also conduct community advocacy activities and provide other services, which might include housing assistance, attendant care, readers and/or interpreters, and transportation assistance.

2. Independent Living Transitional Program --an independent living program that facilitates the movement of persons with severe disabilities from comparatively dependent living situations to comparatively independent living situations. The primary service provided by these programs is skills training. Services of transitional programs are usually goal-oriented and/or time-linked. A transitional independent living program is community-based and offers opportunities for substantial consumer involvement.

3. Independent Living Residential Program --a live-in independent living program that provides directly or coordinates through referral shared attendant services and transportation. Related services, which increase personal self-determination and minimize unnecessary dependence on others may be provided. Similar to other independent living programs, a residential program is community-based and offers opportunities for substantial consumer involvement.

The ILRU Registry also describes an "Independent Living Service Provider" -- an organization which provides several discrete services which can be used to in- crease an individual's ability or opportunities to live independently.

Frieden's (1983) analysis of the three prototype programs pointed out their similarities as well as major differences. 'They are all community-based, allow for consumer involvement, and provide services designed to promote independent living for persons with severe disabilities." Significant differences among them are tied to three important factors: 1) whether they provide ongoing or transitional services; 2) whether they are residential or non-residential; and, 3) whether they are controlled by consumers or merely provide opportunities for substantial consumer involvement. Frieden summarized points of debate around these differences as follows:

> Some people argue that independent living programs must be controlled by consumers in order to be viable. Others argue that consumer involvement on a lesser scale is sufficient. Some people hold that residential programs are institutional, segregated, and do not promote optimal normalization in the community. Others argue that they provide suitable alternatives to institutionalization for severely disabled people, that they represent one step on a continuum of independence, and that they need not necessarily be segregated.

> Some people argue that transitional programs are simply residential programs in disguise, that they are too much like traditional rehabilitation programs, and that they do little to insure the long-term support of severely disabled people in their communities. Others hold that transitional programs differ significantly from residential programs in that they force participants to move into the community after a specified period of time, or after the participants have met certain goals. They argue that transitional programs are much more cost -effective than other sorts of independent living programs and that they enable severely disabled people to live independently in their communities without the need for ongoing services other than those provided to the general population.
>
> Frieden, 1983

The variations reflected in the major program models described above created serious policy tensions within the independent living field. Leaders in the field cited this problem at a leadership conference funded by the Mott Foundation in the summer of 1982.

> The use of the concept "independent living" under federal legislation and the application of the concept to a wide range of program models which are not run and directed by disabled people and do not include community advocacy have created major political issues for community-based programs. Can independent living be a mere provision of services without undermining the overall goal of empowerment and advocacy? What is the value of federal funding if it creates another form of dependency and the loss of community control?
>
> The Institute for Educational Leadership, 1984

Regardless of the arguments for or against the major types of independent living programs, it is clear that community-based independent living centers most closely reflect the core values of the independent living movement and the essential features of the service delivery approach that emerged from this movement. Providing independent living services within residential or transitional structures may indeed benefit and lead to increased independence for people with disabilities who are served by these programs. However, these frameworks do not reflect the full intent of the philosophical principles associated with the independent living movement and its translation into an innovative, empowering, and highly promising service paradigm for people with disabilities.

The legitimacy of the community-based independent living center model has been strongly reinforced through the emergency of federally mandated national standards for the independent living program funded under Title VII, Part B (C). The standards which

were approved by the National Council on the Handicapped in 1985 are described in detail in Chapter 5 of this manual. It is significant to note here, however, that these standards require a community-based non-residential program.

Chapter Three

ORGANIZING AND PROVIDING INDEPENDENT LIVING SERVICES TO CONSUMERS

> As for other Americans, life for people with disabilities involves striving, working, taking risks, failing, learning, and overcoming obstacles. We have all had the experience of seeking something that eludes us, of trying to reach a goal that seems to dance just out of reach. Most of us have also had the rewarding experience of surmounting obstacles to achieve a goal or accomplish a task, succeeding even though someone else or even ourselves doubted we could do it.
>
> Toward Independence, 1986

Key Elements

Over the past two decades a very solid conceptual foundation has emerged for organizing and providing independent living services to consumers. Board members, staff, and consumers of existing and new independent living centers, vocational rehabilitation representatives, and other service providers can now draw from a rich experiential knowledge base on independent living. This knowledge base enables us to describe the key elements of providing independent living services to individual consumers.

As discussed previously, what is most unique about independent living services to consumers is an intense commitment to a core set of philosophical principles. Among all human service systems, independent living is without doubt, one of the most value-driven in design and operation. What is also unique about this service system is its comprehensiveness and complexity. While most national programs are characterized by a single major focus and a limited array of services, independent living addresses every human dimension associated with living a full and productive lifestyle. Therefore, independent living embraces a wide range of direct services to consumers.

The strong philosophical orientation that places the locus of control with the consumer in independent living, is very unlike service approaches that are more directive and prescriptive in nature, allowing the service provider to control service objectives as well as the flow of services. The independent living commitment to consumer sovereignty reflects a complex service relationship wherein the service provider has the responsibility to make the consumer aware of options without. usurping control over the selection and exercise of those options.

Organizing independent living services for individual consumers means giving attention

to three major elements: 1) the specific categories or areas in which consumers experience a need for services and seek to achieve independent living goals (outcomes) -- this represents the content of services; 2) the philosophy which guides the organization and delivery of services; and, 3) the types of services that are provided in response to consumer needs and goals for independence. These primary elements are depicted in the framework on the following page.

The Content or Focus of Independent Living Services to Consumers

As noted, independent living is responsive to a wide range of areas connected to persons with disabilities achieving a productive and independent lifestyle --these areas represent the content or focus of independent living services. While centers vary in the types of services offered, the content is similar across centers. Each content area may be addressed through different types of services. For example, an independent living center may provide information and referral, peer counseling, and skills training services to respond to consumer needs/goals in the content area of attendant care. The primary service content areas reflected in the independent living service model are defined below.

Attendant Care: (Self-care goal)	Consumers learn how to use personal care attendants in order to live independently. Attendant care management includes such topics as advertising, interviewing, hiring, scheduling, training, supervising, firing, employer- employee relationships, reporting requirements, arranging for substitute attendants, and having live-in attendants. Consumers are also assisted in acquiring funding support for attendant care.
Civil Rights/Law: (Self-advocacy/ self-empowerment)	This content area is concerned with helping persons with disabilities understand their legal and consumer rights according to federal and state laws and regulations. Included in this area is information concerning basic human rights, the rights of persons with disabilities, and consumer rights. Consumers are informed about fair employment practices and affirmative action. Information is given/available on organizations that provide legal information and services, and guidance is provided to consumers who wish to take legal action. Consumers also learn about the process of appealing an agency decision, filing suit, or changing guardianship.
Communication: (Communication)	This area focuses on increasing an individual's ability to effectively communicate with others, as well as to read and write as independently as possible. Developing effective communication skills includes the use of aids and reader and interpreter assistance.
Education/training: (Education)	This area focuses on helping consumers access available educational or training opportunities. Consumers are assisted in

	identifying their personal educational needs and interests in acquiring additional education and training.
Employment: (Vocational)	In this area, assistance is provided regarding career options. Consumers are helped to learn job-seeking skills and to pursue employment opportunities suited to individual needs and interests.
Equipment: (Information Access, technology)	This content area focuses on various equipment options, their costs, how to acquire them, and how to use them. Acquiring adaptive aid(s), and/or acquiring equipment repair or maintenance is addressed.
Finances/Benefits: (Personal Resource Management)	This area ensures that consumers learn about benefits programs and how to apply for them. Assistance may be provided in acquiring necessary and appropriate financial assistance. Skill development in personal financial management is also included in this area.
Health Care/Medical: (Self care)	This area focuses on increasing a consumer's knowledge of individual health needs in order to manage preventive health care or to address existing health problems. Consumers may be trained to establish daily routines and to develop exercise and nutritional habits that are most beneficial to their health. Other topics relate to the specific health situations that could arise related to disability.
Housing: (Community Services)	This important content area includes helping consumers become knowledgeable about their housing options, locate desired housing, move to housing situations better suited to their needs, or make home improvements to increase accessibility.
Self-Care/Daily Living: (Self Care)	This content area covers knowledge and skills that enable consumers to manage daily living tasks in ways that are safe and efficient. Skills relate to such tasks as bathing, dressing, and eating, as well as carrying out and managing household and shopping chores.
Self-Help/Personal Growth: (Self Advocacy/ Self Empowerment)	The self-help/personal content area focuses on persons with disabilities recognizing their own strengths to achieve fuller participation in life activities. This involves development of a positive self-image, problem-solving ability, and coping with disability and attitudes toward disability in making a transition from restrictive and dependent situations to a more independent lifestyle. It includes such areas as sexuality, family life, and

	understanding public attitudes and expectations toward persons with disabilities.
Social/Recreation: (Personal Growth)	This content area relates to persons with disabilities in- creasing their social contacts and developing positive perspectives about many forms of recreation. Consumers are encouraged to take advantage of available social and recreational opportunities and to become more active in the community.
Transportation: (Mobility/ transportation)	Transportation options are the focus of this area. Support is provided in choosing and becoming skilled in using the most appropriate transportation options. Support also relates to van modification and acquisition of a driver's license or handicapped license plates.

Independent Living Service Framework
Consumer Services

Content Of Consumer Services And Goal Areas	Service Philosophy	Types of Services
Attendant Care (Self Care)	Consumer control of development of own independent living objectives and services.	Information and Referral
Civil Rights/Law (Self advocacy/ self empowerment)		Peer Counseling
Communication (Communication)	Self-help and self-advocacy	IL Skills Training
Education/Training (Education)	Development of peer relationships and peer role models	Advocacy
Employment (Vocational)	Cross-disability emphasis	Attendant Care Services
Equipment (Information Access Technology)	Equal access to programs and physical facilities	Communication Services
Finances/Benefits (Personal Resource Management)		Educational Services
Health Care/Medical (Self Care)		Equipment Services
Housing (Community services)		Housing Services
Self Care-Daily Living (Self care)		Legal Services
Self -Help/Personal (Self advocacy/ self empowerment)		Other Counseling
		Social/Recreation

Social/Recreation
(Personal Growth)

Transportation
(Mobility/transportation)

Transportation Services

Vocational Services

CONTENT OF SERVICES AS DEFINED BY CONSUMER NEED: Independent Living is responsive to a wide range of areas that relate to persons with disabilities achieving a productive and independent lifestyle. Unlike many human service programs, the focus on independent living is broad, encompassing the varied dimensions of knowledge, skills, options, personal growth, and support associated with living independently.

SERVICE PHILOSOPHY: Independent Living Services are characterized by a service approach, which emphasizes consumer control, self-help and self-advocacy, peer role modeling, a cross-disability focus, and equal access.

TYPES OF SERVICES: Independent living services to consumers include core offerings such as information and referral, peer counseling, skills training, and individual advocacy. Additional services include attendant care, equipment, communication, housing assistance, and transportation.

Consumer Goals for Independent Living

In independent living, consumer needs are translated into goals through a supportive consumer-controlled goal setting process. This process is influenced by two major principles: 1) that taking control over one's life and participating more fully and productively in society is dependent upon many interrelated goals and, 2) that goal setting must take into account the individualization required for consumers who vary widely in their needs, interests, and abilities.

The Independent Living Service Philosophy

As noted previously, independent living services are delivered through a service approach, which emphasizes key philosophical principles. These include consumer control, self-help, peer role modeling, equal access, and a cross-disability emphasis.

Consumer Control and Self-Help

The consumer control and self-help elements of the independent living service philosophy are intertwined. They are both related to a commitment to consumer sovereignty and empowerment, and they are based on the belief that achieving independence requires that consumers internalize and demonstrate a personal sense of

control, responsibility, and self-direction. Also inherent in the philosophy is the belief that consumers can and must act on their own behalf in achieving their independent living goals. This philosophical approach runs counter to service approaches where the onus of the problem is placed on the consumer and the locus of control over service objectives and services rests with the service provider.

Implementing the consumer control concept in independent living services requires very clear procedures, which emphasize that consumers (not staff) make the major decisions about their independent living goals as well as their participation in services. To provide a structure, which meaningfully guides and enhances the consumer's development of goals and identification of service priorities, many centers use a goal-setting process that is recorded in an independent living plan. The independent living plan usually includes goals set by the consumer, activities and services for accomplishing the goals, the mutual responsibility of the consumer and staff person in completing agreed upon activities and services, and information related to progress on goals and goal achievement.

In independent living, use of a written plan can serve as a positive and powerful tool for ensuring provision of consumer controlled services. It provides a means for planning relevant and focused services based on consumer needs and goals, a means for effectively reviewing progress, and a written record of the consumer's control over service goals and service participation.

Promoting the self-help and self-advocacy concepts means that an independent living center continually emphasizes attitudes of self-reliance among consumers and seeks to develop consumers' confidence and ability to control their own lives. This process implies existence of a developmental approach where consumers are actively encouraged to take on more and more responsibility for decisions. What is essential is that consumers feel that their participation in services reflects their personal priorities. The developmental process associated with self-advocacy and self-determination may seem slow and inefficient because consumers may be accustomed to assuming a dependent role in receiving services (Nosek, Dart, and Dart, 1981). Specific methods which are often used to promote consumer self- determination include advocacy training and decision-making skills training. Using problems that consumers present, problem-solving skills and skills associated with confronting and resolving inhibiting situations are taught as strategies that can be generalized to many life areas.

Peer Role Modeling and Peer Relationships

The central theme of peer role modeling and peer relationships is that persons with disabilities who have struggled for independence can best help others who are trying to cope with that struggle. Peer role modeling is also linked to the concept of self-help. It recognizes the power of peer empathy in overcoming the array of life issues faced by people with disabilities, which a non-disabled person can never fully grasp. Effective peer relationships are characterized by mutual respect and understanding, a sharing of

experiences, concrete problem solving, and positive modeling.

In dependent living, peer role modeling is frequently linked to the core service of peer counseling and is directly affected by the extent to which persons with disabilities are employed at the center on a full-time, part-time, or volunteer basis to act as role models, provide support, and foster peer relationships. This philosophical concept is also reflected in the efforts of staff members with disabilities who serve as leaders or contributors in community groups to promote role modeling.

Cross-Disability Emphasis

A distinguishing feature of the independent living service model is its emphasis on the common threads of service support that should be available to all persons with disabilities. In a nation where the number of Americans with disabilities is estimated at 35 to 36 million, this philosophical commitment to reducing artificial and bureaucratic segmentation of services to the disability population is noteworthy. It should be noted that cross-disability responsiveness not only involves sensitivity to the diversity of needs experienced by persons with physical, sensory, and mental disabilities, but also sensitivity to needs that vary according to a consumer's particular life situation.

> The social category of people with disabilities encompasses a wide diversity of individuals. It includes the neighbor who has just had heart by-pass surgery, the boy down the street with cerebral palsy, the business executive who has been hospitalized for severe depression, the blind woman who works in the office downstairs, the mentally retarded landscaper at the local nursery plant, and last year's champion diver at the local high school who now uses a wheelchair because of a spinal cord injury.
>
> Toward Independence, 1986

Independent living recognizes that all people with disabilities face a myriad of barriers in seeking to achieve personal goals, community acceptance, and community integration. While the specifics and complexity of the barriers may vary for particular disabilities, the goals and intents of the independent living service model are relevant to helping all people with disabilities overcome these barriers.

Approaches that support a cross-disability emphasis include: a range of services and methods that are responsive to the varying needs of different populations; seeking a cross-disability mix on the board of directors and across staff positions; and, ensuring program access for all disability groups as discussed below.

Equal Access to Programs and Facilities

The independent living program is committed to ensuring easy and equal consumer

access to services. In independent living centers, part of this commitment is expressed through outreach efforts, which inform consumers, how they can access services and in prompt response to consumers who seek services. Centers are located in the communities they serve and strive to provide services in ways that make it easy for consumers to access them. This often includes providing services to consumers in their homes or in locations that are close to particular groups of consumers.

Centers are expected to meet applicable portions of the Uniform Federal Accessibility Standards (UFAF*)* to ensure physical access to programs and services and to accommodate access for persons with visual and hearing impairments. This includes ensuring availability of qualified interpreters and readers; TDD equipment; and brailled, large print, and tape-recorded materials as needed.

Issues that Influence the Implementation of Consumer-Oriented Concepts

The national evaluation study of the Title VII, Part B (C)-funded independent living program condl1cted by Berkeley Planning Associates (BPA) in collaboration with the Center for Resource Management, Inc. (CRM) and the Research and Training Center on Independent Living at the University of Kansas examined the extent to which an emphasis on consumer-oriented service concepts might be influenced by such factors as: size (level of funding as well as total number of consumers served); type of center (independent vs. part of a larger agency); percentage of staff with disabilities; majority vs. non-majority consumer board; type of service locale (urban, rural, suburban); and extent to which center was supported by Part B (C) funds (percent of total funding). The findings revealed no significant differences in how different types of centers claimed to emphasize the consumer-oriented service concepts associated with independent living. Site visit data did reveal differences, however, in the interpretation and manifestation of such concepts.

Site visit findings indicated variations in center emphasis on consumer control and self-help concepts. In some centers, staff felt passionately about these concepts and struggled with the fear that certain service delivery approaches will diminish and dilute commitment to them. In other centers, staff were able to discuss these concepts but did not seem as aware of the complexities associated with putting them into operation and sustaining them. In short, it was determined that most centers have literature that describes these concepts, but there are great differences in the interpretation of how they should be operationalized. Center staff who strongly adhere to these beliefs as primary principles of independent living resist trends toward more traditional approaches that may dilute consumer control and self-help. Moreover, the site visit data suggested that these staff tend to be associated with independent living centers that had strong histories of consumer involvement, staffing practices that favor the hiring of persons with disabilities, and a strong community advocacy orientation.

Site visit data also revealed a dilemma tied to the maturation of the independent living service model-- as services become better defined, structured, and organized in ways that

contribute to a more focused approach, there is a danger that staff may lose sight of consumer control and self-help concepts, i.e., services become driven more by the structure and less by the consumer. Also, there is an issue that is emerging in urban centers which, as they become more effective in attracting consumer are beginning to experience backlogs --consumers on waiting lists. This creates a pressure to move consumers more quickly through services to allow other consumers to be served. In these centers, staff felt that it becomes more difficult to let the consumer's interest, pace, and way of working on tasks control the service process.

Another issue that affects consumer control and self-help concepts relates to consumer ability to understand and sort through different options and decisions. A lot of individualization is needed to accommodate significant differences in capability across consumers and variations in their level of independence and sophistication.
National study site visits also indicated that peer role modeling and peer relationships are linked to staffing considerations in independent living centers as well as to how peer counseling is defined by the center. There were some issues regarding extent to which peer role modeling has to be formalized in the staffing structure, i.e., is it necessary to have paid staff acting as peer role models or is it equally effective when consumers or volunteers act as peers. The centers that felt the most strongly about peer role modeling as a staffing requirement were those that also felt most strongly about the hiring of persons with disabilities in key administrative and direct service positions.

The "professionalization" of independent living services also was identified as an issue that affect how centers carry out role modeling. Center staff experienced a dilemma that as they become more skilled in defining, structuring, and delivering independent living services, they feel less able to act as peers in the pure sense of the movement --"as we become better service providers there is a danger that we will forget our early commitment to peer role modeling and sensitivity to the consumer's situation."

Finally, it must be recognized that implementation of consumer-oriented concepts in the overall service design of an independent living center is closely tied to other aspects of center operations. It is significantly influenced by capability in recruiting, hiring, and maintaining qualified staff who understand and espouse independent living tenets. Difficulty in sustaining commitment to core concepts occurs where there is high staff turnover or where hiring policies do not result in maintenance of staff who understand and are able to implement philosophical principles associated with independent living.

Types of Services Offered Through Independent Living

There are few national programs that match the breadth and scope of services offered through independent living. Moreover, there is a rich and necessary diversity both in methods of service delivery of centers across the country and in the range of services provided. For example, service methods may vary from center to center somewhat in response to the different needs of individuals with mobility, sensory, emotional, or cognitive disabilities.

> In order to live independently, disabled persons require a wide range of support services according to their disability type. Persons with severe physical disabilities usually require assistance with personal care, domestic tasks, transportation, equipment maintenance, and modifications of home and work place for architectural accessibility. Those with sensory disabilities may require assistance with interpersonal communication such as that provided by readers and interpreters. Persons with mental impairments who wish to live independently may require some degree of supervision and assistance with cognitive tasks. All persons with disabilities and their families can benefit from a single source of information and referral about services and service providers.
>
> Toward Independence, 1986

Cutting across these differences are a set of core services that include information and referral, peer counseling, independent living skills training, and advocacy. Other independent living services include housing, transportation, attendant care, equipment, communication, legal, educational, vocational, counseling, and social/recreational services. The types of services provided through independent living are described below.

Information and Referral

Access to information and referral services is essential for people with disabilities. In addition to varied types of direct services, individuals need information on options, resources, and the issues that influence their abilities to achieve independent lifestyles. Referral assistance is also essential since achieving independence most often requires involvement of a variety of agencies and community organizations. Information and referral services are also provided to other service providers and the community at large. This assistance is instrumental in increasing public awareness of disability issues and knowledge of the service options and resources available to people with disabilities from the center and the community.

The results of the national evaluation study of the Part B (C)-funded independent living program indicated extensive provision of this service in centers across the country. Regardless of level of funding, staffing arrangements, or location, most in- dependent living centers provide information and referral assistance not only to people with disabilities but to other service providers and to the general public. Also, this service area serves as an entry mechanism into other center services for consumers seeking broader assistance. Thus, while this service is designed to respond to consumers' information needs and to increase knowledge about issues and resources associated with independent living, it also involves a process which helps consumers assess their situations and identify the services and resources they need.

Independent living centers vary in how they organize and deliver information and referral

services, with the major variation reflecting the extent to which the service is fully staffed and supported by a resource collection. Some centers have a fully developed system with staff specialists and a centralized resource library of materials. Most centers provide this service through a more informal mode in which all center service staff assume some responsibility for responding to calls. In these centers, problems can arise around the extent of staff time and energy needed to provide information and referral assistance when there are not resources to support it adequately.

Maintaining updated directories and resource listings and a collection of information resources on a wide range of topics is essential to providing effective information and referral services. Centers provide information related to the major content areas associated with independent living --architectural accessibility, attendant care, civil rights, communication, community barrier removal, education and training, employment, equipment and aids, finances/benefits, health care and nutrition, housing, self-care and daily living, self-help and personal growth, social/recreation, and transportation. A complete information data base also includes disability-specific information and information on advocacy issues, including the major federal, state, and local laws affecting the lives of people with disabilities.

Referral assistance involves developing a network of contacts and referral relationships with a variety of agencies, which make referrals to centers in addition to receiving referrals. These agencies include vocational rehabilitation, primary care, medical, and rehabilitation facilities, housing and transportation agencies, mental health and mental retardation agencies, social and welfare agencies, and disability-related organizations. Referral services require that centers develop an information base about the various types of agency services that are available in their locale as well as an awareness of how consumers can access such services.

Information and referral is usually a very personalized process in independent living, involving a dialogue between the caller and staff person that includes the following:

a determination of the caller's reason for calling, specific information need(s) or type of referral assistance needed, and who or what agency referred the caller

in some cases, the caller's name and address is obtained for purposes of follow-up or building a mailing list

if the caller is a person with a disability, a dialogue usually occurs about the individual's particular situation, nature of disability, and need for other types of service assistance

information and/or referral assistance is immediately provided or the staff person provides the assistance through a follow-up contact.

While providing information and referral assistance is a straightforward process, what distinguishes it in independent living is a commitment to supporting consumer self-reliance. This service area can also be a valuable data source on consumer and community needs. By keeping accurate records and statistics on information and referral requests, a center can determine trends and unmet needs. This data can be used to develop a funding proposal as well as for planning new programs and advocacy efforts.

Peer Counseling

Emphasizing the direct involvement of persons with disabilities as role models in the service process, peer counseling has been a cornerstone of independent living services to consumers. A basic premise of peer counseling is that by virtue of their disability-related experiences, people with disabilities are uniquely qualified to assist their peers. Through this core service area, a "peer counselor" or "peer advocate" who has achieved a desired level of independence and community integration shares knowledge and experiences with a consumer. The process facilitates consumer awareness of independent living options and how to approach certain situations and seeks to motivate confidence in overcoming external barriers that inhibit independence.

A 1981 resource document developed under the sponsorship of the Arkansas Rehabilitation Research and Training Center cited several important qualities and skills associated with effective peer counseling. At the heart of the process are effective interpersonal and communication skills which include empathy, respect, genuineness, concreteness, self-disclosure, a focus on the immediate "here and now", and the ability to confront (Pankowski, et. al. 1981). As noted in a Resource Directory of the New England Spinal Cord Injury Foundation, the caring and empathetic nature of peer interaction is one of the most important aspects of the peer counseling process.

> The presence of a caring person, skilled or not, can be the strongest, most effective support available in helping an individual realize and work out his feelings about his injury and himself a committed person with whom to share your feelings and re-establish the process of feeling OK and comfortable about who you are.
>
> New England Spinal Cord Injury Foundation Resource Directory (no date)

Problem solving skills and trustworthiness have also been identified as essential aspects of effective peer counseling. In addition, the process requires specific types of knowledge and advocacy skills.

> In addition to having experienced a disability, demonstrated coping skills, and shown an ability to interact facilitatively with others, effective peer counselors will have knowledge of disability-related issues. Their behavior will exemplify what has been described by some as a "rights bearing" attitude

> This involves an understanding and acceptance of the fact that disabled people have the same rights and the same responsibilities as all other individuals. Knowledge of these rights and responsibilities is not enough since there must be a meshing of knowledge with a positive, assertive attitude. Peer counselors not only advocate on behalf of their helpees, but more importantly, assist them to assertively advocate on their own behalf. It is also imperative that peer counselors be familiar with services available to disabled people in their community and procedures for obtaining these services.
>
> Pankowski, et al. al., 1981

While peer counseling is an important core service of independent living, approaches vary from center to center. A 1987 resource document published by the ILRU Research and Training Center on Independent Living discusses characteristics and variations of peer counseling programs that were identified through the national evaluation of the Title VII, Part B (C)-funded independent living program (Barker, Altman, and Youngdahl, 1987). One area of variation is in the definition of "peer" or who should deliver peer counseling services. In some centers, peer counselors are unpaid volunteers who work with consumers under the supervision of center staff or as part of a network of peers who are available to each other for mutual support within the disability community. As unpaid volunteers, they remain true peers by remaining distinct from paid staff. In other centers, paid staff with disabilities provide peer counseling and in some cases are required to have counseling or other professional qualifications. There are also varied degrees of emphasis on the disability of the peer counselor, with some centers carefully matching like-disability types, others encouraging consumers to get to know individuals with other types of disabilities, and still others determining the importance of disability- matching according to the consumer's specific objectives for the peer relationship.

A second area of variation in peer counseling approaches is in how services are provided. Centers appear to be evenly split on whether they offer peer counseling as a discrete service or view it as a process that supports and is integrated with some or all other services. In the latter case, these centers often emphasize peer relationships as the primary method for working with consumers.

Peer counseling occurs through both individual and group interactions, and centers tend to emphasize the method that works best for their types of programs, community, and consumer populations (Barker et.al., 1987).

National study findings also indicated that variations in approaches and methods also influence the content of peer counseling. When offered as a discrete service it usually incorporates information and referral assistance, sharing of personal experiences, emotional support, problem solving, role modeling, and advocacy. When it is viewed as a process within other service areas, peer counseling may also involve specific skills training and community advocacy activities.

Significant benefits result from the peer counseling process in independent living. Most noteworthy are the development of coping skills, increased assertiveness and self-reliance, and enhanced self-worth. Peer counselors themselves often benefit through improved interpersonal and communication skills and the sense of accomplishment that results from helping another person (Pankowski, et. al., 1981).

Advocacy

Independent living centers also provide advocacy support to individual consumers. The central themes that run through this advocacy assistance are consumer control and self-reliance. Reflecting such basic tenets as the right to control one's own life and to make choices, this core service area involves a process that em- powers consumers to act on their own behalf and resist accepted norms of dependency.

> The concept of individual and group self-advocacy is to most of society a self-evident reality of day-to-day existence. The average American adult recognizes that advocating for one's own needs is essential to participate viably in the political, social. and economic arenas of community life. This concept underlies the basic philosophical and political tenets of American society: self-reliance; freedom to make choices on how best to meet one's own needs; freedom to pursue one's own interests in social, political and economic areas.
>
> Robert J. Funk, 1986

Consumer advocacy incorporates an array of approaches aimed at helping people with disabilities to take charge of their choices in life and overcome situations that reduce their potential for being independent. Advocacy support has two dimensions. In the preferred approach, a center staff member encourages consumer self- advocacy through a problem-solving process that identifies alternative strategies and when and how to use them to overcome inhibiting or destructive situations. In many centers, advocacy training may be provided on a one-to-one basis to individual consumers as well as in group settings where peer interaction enhances the process.

In another approach to advocacy, a center staff member might take direct action on behalf of the consumer when this seems appropriate, i.e., makes calls to or meets with parties involved in a dispute or otherwise intercedes in a problem situation. In all cases, however, there is always the intent to motivate individual consumer action in coping with problems and difficulties and in seeking greater levels of independence.

Self-advocacy programs often include training in communication and problem- solving skills and in effective strategies for confronting agencies and decision-makers.

Examples of the kinds of knowledge and skills consumers acquire through the core

service of advocacy include the following:

understanding personal legal status and legal rights;

understanding disability laws and how they protect personal rights and independence;

learning about organizations, which provide legal information and assistance;

learning about affirmative action, fair employment practices, and reasonable accommodation laws;

learning how to appeal an agency decision;

increasing ability to advocate for individual rights;

recognizing and confronting infringement of rights;

applying problem-solving and decision-making skills to particular situations;

improving ability to communicate with and negotiate confidently with agency representatives and other individuals;

increasing advocacy ability to get a job, and maintain or advance in employment;

increasing advocacy ability to acquire a desired housing situation; and,

increasing advocacy ability to acquire benefits or financial assistance.

Successful advocacy training methods often incorporate peer role modeling and emphasize reinforcement through group sharing and interaction.

Independent Living Skills Training

Skill development is an important feature of achieving or enhancing an independent lifestyle. The national evaluation study determined that almost all Part B (C)- funded independent living centers offer some type of skills training, but variation. exists in who conducts the training, range of skill areas covered, where training occurs, and extent to which the training is formalized.

Some centers view skill development as a key element of other core services such as peer counseling and advocacy rather than as a discrete service component. In centers where skills training is a separate service, it may be provided on a one-to- one basis, through groups to address the common needs of consumers, or both.

There is a trend for centers that offer more structured types of skills training to develop

formal written curricula or training sequences, especially if they offer training in groups.

Skill development cuts across all of the content areas associated with independent living including personal care, self-care and daily living skills, communication, financial management, and personal growth. Examples which illustrate the great variety of skills associated with independent living are the following:

managing personal care assistance effectively, e.g., recruit, interview, hire, schedule, and maintain;

carrying out personal care and daily living routines; .
using appropriate aides or equipment effectively;
carrying out household and shopping tasks;

developing sensory mobility skills to move safely and independently within home;

developing sensory and mobility skills to travel as independently as possible in locations outside of home;

using message relay services;

communicating comfortably in groups or social situations;

managing personal finances -benefits and other income, PCA funds, bank and credit accounts, and budgets;

using available public or private transportation;

acquiring a license to drive; and

coping with disability and attitudes toward disability.

Independent living skills training may be provided at the center, in consumer's homes, or at a community location. The national evaluation study identified a trend in some centers toward hiring registered nurses and occupational therapists to provide training in the areas of health and self-care. Other staff cover non-self-care areas related to consumer rights, financial management, or coping with personal issues.
Issues surrounding skills training approaches will intensify as Title VII, Part B (C)-funded centers are required to comply with national standards that mandate the provision of this core service. Centers will increasingly feel the need for qualified staff who are competent in skills training methods as well as knowledgeable about independent living.

There is also a need in the independent living field for skills training modules that will ensure more consistency and quality in the provision of this service across centers. In short, availability of qualified staff, appropriate training and resource materials, and

Better-defined methods of service delivery will significantly influence the extent to which centers will be able to provide this core service area effectively in the future.

Other Independent Living Services

Independent living centers offer various other services which are designed to meet the needs of their consumer population, their service locale, priorities established by their boards of directors, and available funding resources. Other services provided by Title VII, Part B (C)centers were identified by the national evaluation study. These are described below.

Attendant Care. (Self Care) Many centers maintain a registry of available personal care attendants. However, while the center may recruit and screen a potential attendant, it is the consumer's responsibility to select and to approve the attendant. Most centers provide consumer training in selecting and managing attendants, and some run training programs for attendants to increase attendant knowledge of disability- related issues and attendant care skills. A few centers administer state funds to support personal care attendant services directly and determine consumer eligibility for such services.

Communication Services.(Communication) The most common communication service provided by centers is telephone assistance for hearing-impaired consumers through TDD relay. Often, the center is a hearing-impaired consumer's primary mechanism for information exchange. Increasingly, centers are providing interpreter services for hearing-impaired consumers and maintaining referral lists of interpreters. In addition, many centers assist consumers who have visual impairments through braille, services and reader referral.

Education Services. (Education) Most centers provide referral services to available educational and training programs, but few centers offer extensive education-related services. Centers often assist consumers in defining their educational goals and identifying educational options. Some centers assist families of children with disabilities with the Individual Education Plan (IEP) process while others provide educational counseling and learning support services.

Equipment. (Information Access/Technology) Centers help consumers learn about available equipment and aids and how to obtain and use such devices. Equipment services to consumers also involve loaning or maintaining and repairing mobility and assistive aids such as wheel- chairs, walkers, and commodes. Centers also serve as referral sources for consumers interested in obtaining or selling used equipment.

Legal and Paralegal Services. (Self-advocacy/self-empowerment) Legal and paralegal services are provided to assist consumers involved in administrative appeal processes. Often the matters of concern relate to financial benefits or social assistance programs that have clearly specified appeal processes. Some centers provide consumers with the information needed to enable them to act on their own behalf in matters that involve an appeal or legal process. In some centers, staff assist more directly, acting on behalf of the consumer. Centers also may have consulting arrangements with an attorney in the community for more complex issues.

Housing. (Community Services) Referral services to accessible and/or subsidized housing in the community is an important form of housing assistance. Also, this service often includes assisting consumers to obtain eligibility for subsidized housing and developing extensive relationships with property owners and housing assistance agencies. Some centers have special funds to assist consumers in making necessary home modifications while others refer consumers to available resources in the community. Some centers maintain directories of emergency housing services and hotels. Emergency housing vouchers, often coordinated through local welfare agencies, are provided in emergency situations for short-term stays. A few centers provide housing directly, either on-site (often as part of a program coordinated with an umbrella agency) or in selected housing facilities in the community.

Other Counseling. In addition to peer counseling, some centers provide more formal types of professional counseling support to consumers and their families. Centers also frequently maintain referral relationships with professional counselors.

Social and Recreational Services. (Personal Growth/Self Help) Centers are important clearinghouses for information about recreational activities on community and state level that are specially adapted to encourage the participation of people with disabilities. Many centers regularly schedule social or recreational events for consumers, actively encouraging them to engage in activities they might not pursue ordinarily because of their disabilities.

Transportation. (Mobility/Transportation) Some centers provide transportation services directly and operate vehicles to transport consumers to the center for appointments and activities. In some centers, a van may also be used to transport consumers to medical appointments. However, insurance and maintenance costs have forced some centers to discontinue provision of this service. Instruction and information about available, accessible private and public transit services is an important transportation service offered to consumers.

Vocational. (Vocational) Rather than offering vocational services directly, most centers coordinate their services with other agencies, such as the state vocational rehabilitation agency and local employment development programs. Centers that do provide vocational services do not have multi-level vocational programs that work with consumers at all stages of vocational development. The few that do are often part of umbrella agencies with long-standing vocational programs. A few centers offer pre- vocational adjustment programs to prepare consumers for training. Other centers assist consumers with resume writing and job search skills and provide placement follow-up services. A few centers have received grants to start specialized training programs in areas such as computer training and telephone answering or to develop training programs for specific disability groups.

Chapter Four

COMMUNITY ADVOCACY --A BROAD AGENDA FOR CHANGE

> It is of critical importance to this Nation that equality of opportunity, equal access to all aspects of society and equal rights guaranteed by the Constitution of the United States be provided to all individuals with handicaps; …it is essential that all individuals with handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working, and service patterns be held as the final objective.
>
> United States Congress 29 Section 701 Note (1976)

In Toward Independence (An Assessment of Federal Laws and Programs Affecting Persons with Disabilities --with Legislative Recommendations), it was under- scored that equality and independence have been fundamental elements of the American form of government since its inception. "The right to equality of opportunity and to personal independence have been recognized and protected in the Declaration of Independence, the Constitution of the United States, the Constitution of the individual states, and the laws enacted by the U.S. Congress and the States." The report emphasized that, while the nation's goals about the rights of citizens with disabilities may be clear and honorable, there has been considerable deviation and retreat from the programs and laws that should serve as paths toward these goals.

There has been a strong tendency for society at large to believe that the major problems faced by people with disabilities are primarily connected to the nature of the disability. The disability community has made it very clear, however, that their major obstacles arise from external barriers rather than from limitations associated with particular disabilities.

> Despite everything we can do, or hope to do, to assist each physically or mentally disabled person achieve his or her maximum potential in life, our efforts will not succeed until we have found the way to remove the obstacles to this goal directed by human society --the physical barriers we have created in public buildings, housing, transportation, houses of worship, centers of social life, and other community facilities --the social barriers we have evolved and accepted against those who vary more than a certain degree from what we have been conditioned to regard as normal. More people are forced into limited lives and made to suffer by these man-made

> obstacles than by any specific physical or mental disability.
>
> Report of the United Nations Expert Group Meeting on Barrier-Free Design, International Rehabilitation Review, vol. 26, p. 3 (1975)

Because of the widespread existence of external barriers that limit equal access and equal opportunity for people with disabilities, independent living centers, since their inception, have undertaken broad-based community advocacy efforts. The primary intent of these efforts is to increase and to improve options for independent living in society, to increase the availability and accessibility of essential services and resources, and to create broader community awareness and understanding of disability issues.

A thrust toward changing the system is at the heart of community advocacy as well as influencing the shifts in societal attitudes and behavior that must occur.

> For people with disabilities, the need for institutional change as a precursor to freedom is especially clear. No laws forbid people in wheelchairs to ride public buses or to enter public buildings, for example, but the steps at their entrances serve as more effective barricades than laws. That they were built in ignorance rather than malice does nothing to mitigate their effect and may actually make their removal more difficult to accomplish.
>
> Crewe, 1983

Community advocacy, sometimes called systems advocacy, acts as a catalyst in stimulating people with disabilities to address obstacles that inhibit independent living in their communities as well as overcoming problems on statewide, regional, and national levels. At the local level, community advocacy programs often work with consumer groups and strive to help persons with disabilities organize and develop appropriate strategies for accomplishing necessary changes. Key elements of community advocacy programs are:

> activities that support the efforts of persons with disabilities to reduce societal barriers to independence;
>
> an emphasis on empowering persons with disabilities to address community, state, and national problems/issues affecting people with disabilities;
>
> a process that promotes development and growth of local advocacy groups and statewide committees and improves their capacity to select and resolve common problems;
>
> efforts to increase contact among people with different disabilities; cross-

organizational activities to address specific issues influencing the lives of people with disabilities;

Organizing community service activities within an independent living center involves several interrelated steps which include the following.

Identifying Major Barriers --Independent living centers often conduct needs assessment and community surveys to determine the major barriers to independence for people with disabilities in their service locale. Ongoing impact is often acquired from center consumers and local coalitions.

Setting Targets Through Advocacy Planning --Because of resource limitations, center board members and staff have to prioritize community advocacy issues and target areas to address. Centers also have to be capable of responding to unanticipated issues as they arise. For some centers, the planning process has been formalized and culminates in an annual written advocacy plan.

Selecting Advocacy Methods and Activities --Independent living centers implement a variety of methods to gain support and visibility for their advocacy agenda. These activities range from conducting presentations to create broader disability awareness to developing coalitions around certain advocacy issues. Community advocacy activities involve the active participation of board members, staff, center consumers, and community representatives.

Providing Advocacy Training --Many centers provide advocacy training to increase the organizing, leadership, planning, and problem solving skills of board members, staff, and others that participate in carrying out the center's advocacy agenda. Training most often occurs through group situations that involve peer role modeling.

Assessing Impact --Assessing impact in the community is a complex area for independent living centers for several reasons. Center efforts are often linked to many other initiatives so that while centers may claim to have influenced a change in the community, they most often share credit for such a change with others. Also, systems change is a slow process and centers may invest time and effort over a period of years to achieve comprehensive and far reaching changes in such areas as architectural and community accessibility, housing, and transportation. Thus, on an annual basis, assessing impact often requires a sensitive and perceptive understanding of the intermediate victories that lead to the achievement of broader and long-term community advocacy goals.

Community Service Activities

Independent living centers organize and conduct a variety of activities to reduce community barriers to independence and to improve options available to people with

disabilities. These activities include community initiatives to ensure that the interests and perspectives of persons with disabilities are represented; conducting presentations and workshops; community advocacy and policy development to promote equal access to society; providing consultation and technical assistance; and, producing resources associated with public education, outreach, and systems advocacy efforts. These community service activities are described below.

Presentations: Conducting information sessions for consumer groups, service providers, and community organizations on disability or advocacy-related issues as well as services available through the center.

Workshops: Conducting training sessions for service providers and community groups focused on the specific knowledge and skills associated with independent living.

Community Initiatives: Serving on boards, developing community leaders, participating in civic organizations, and attending meetings to ensure that the interests and perspectives of persons with disabilities are represented.

Technical Assistance: Providing technical assistance or consultation related to improving community options for persons with disabilities.

Community Advocacy: Ensuring the implementation, revision or development of policies and laws, which promote equal access to society, and advocating for the removal of discriminating practices and barriers to independent living on local, state, and national levels.

Research/ Resource Development: Producing or compiling resources (fact sheets, "alerts," newsletters) to support community advocacy, outreach, and public education efforts.

Community advocacy activities are intended to have impact on a broad range of areas associated with equal access and equal opportunity. These include: architectural and community accessibility; civic and community involvement; disability awareness; educational options; employment opportunities; equipment, benefits, and services; housing; personal care and health care; recreational and social options; and, transportation. These community impact areas are described below.

Community Impact Areas

Architectural and Community Access: Reducing architectural, mobility, and communication barriers that inhibit equal access to society.

Civic and Community Involvement:	Increasing the active involvement of and leadership opportunities for persons with disabilities in civic and community affairs at local, state, regional, and national levels.
Communication:	Increasing communication accessibility for persons with disabilities through such options as TYY's/TDD's in public buildings, the institution of brailled menus, the addition of readers and interpreters to the community pool, or the establishment of policies that require interpreters on request.
Disability Awareness:	Creating meaningful community awareness of disability issues, increasing social acceptance of persons with disabilities, and reducing social barriers.
Educational Options:	Increasing the extent to which educational and vocational programs are available and accessible to persons with disabilities.
Employment Opportunities:	Increasing availability and accessibility of job and career opportunities for persons with disabilities.
Equipment, Benefits, Services:	Increasing availability of essential aids and equipment for and persons with disabilities, and assuring availability and accessibility of essential benefits and services.
Housing:	Increasing the number of accessible housing units for persons with disability and/or improving accessibility of existing units.
Personal Care and Health Care:	Improving availability and quality of personal care attendant services, as well as physical and mental health care services available to persons with disabilities.
Recreational and Social Options:	Increasing and/or improving availability and accessibility of recreational and social programs and facilities for persons with disabilities.
Transportation:	Increasing and/or improving availability and accessibility of transportation options for persons with disabilities.

The national evaluation study (Barker, et. al., 1986) confirmed that independent living centers are involved extensively in community advocacy activities, which include collaboration with a wide range of community organizations. However, independent living centers are increasingly being confronted with the conflict of balancing resources between direct service and community advocacy efforts. Centers also face challenges in setting realistic priorities for community advocacy efforts. This reflects the dilemma created by extensive needs to improve options in the community with very limited

resources and staff to initiate and sustain change efforts. Kailes (1987) recommends selecting activities with the highest potential for impact based upon an assessment and planning process that defines the primary advocacy needs of the community. Integral to this process is representative and meaningful input from the various constituencies within the disability community.

Chapter Five

THE GROWTH OF THE INDEPENDENT LIVING PROGRAM AND THE EMERGENCE OF NATIONAL STANDARDS

> Standards associated with any national program provide an important foundation on which policy, program design, resource allocation, and service delivery are based. They implicitly and explicitly reflect the core values and philosophical principles of the program and therein lies the challenge of defining standards --they must faithfully translate ephemeral things like values and philosophy into observable and measurable terms. They must accommodate the legitimate and necessary variations in structure and practice while strongly affirming essential elements. Just as standards ensure program accountability, the process through which they are developed must meet an important accountability test --it must meaningfully involve those who will be affected by their application. The extent to which these stakeholders embrace program standards as desirable depends equally on process and substance.
>
> Martha Williams, 1987

National Standards for the Independent Living Program

At the federal level, the need for increased accountability as well as for evidence that would demonstrate the results achieved through the Part B (C)- funded independent living program was reflected in the Rehabilitation Amendments of 1984,PL 98-221, Section 711 (c)(3). These amendments required independent living centers to develop an evaluation plan and to report findings on a variety of factors (A-K) (now 704 report) related to types of consumers served, services provided, outreach and collaborative efforts, and how services actually contributed to increased independence of consumers served and to improved options in the community.

The 1984 Amendments to the Rehabilitation Act also mandated the development of evaluation standards and a comprehensive national evaluation of the independent living program funded under Part B (C). These amendments echoed a growing recognition of a need for clearer definitions of the independent living program and standards that would reflect acceptable philosophical, programmatic, and organizational practices.

The development of standards for the Part B (C) program involved a highly participatory process emphasizing broad-based input. Through this process, the recommendations of constituencies and audiences representing varying views and perspectives on the program were synthesized. A set of general standards or categories on

which there was substantial agreement was produced. After minor revisions, these standards were approved by the National Council on the Handicapped (NCH) as required by law, and they are commonly referred to as the "NCH Standards".

The development of national standards for the Part B (C) program was a significant accomplishment. These standards will have a profound influence on how the program is defined in the future and what evidence should be collected to assess its effectiveness. In this sense, the standards have great symbolic relevance for the independent living movement itself. They illustrate that certain philosophical principles are inherent to the program and must be embedded within standards that function as primary criteria for defining and evaluating the program.

Seven major topical areas are stipulated in the independent living standards: philosophy, target population, outcomes and impacts, service process, organizational management and administration, and evaluation. The NCH Standards for independent living are described below as well as the rationale underlying each standard.

PHILOSOPHY

Standard 1 The center shall promote and practice the following independent living philosophy in its programming: consumer control of direction and management of the center; consumer control of the development of own independent living service objectives and services; self-help and self-advocacy; equal access to society by individuals with disabilities; equal access to programs and physical facilities; development of peer relationships and peer role models; meeting the specific independent living needs of the local community; and, providing a range of services to all people with disabilities.

Rationale: The purpose of the philosophy standard is to ensure that the key philosophical intents of independent living are manifested and incorporated in the structure, operations, and approaches of an independent living center. This standard is particularly significant because it distinguishes independent living from other programs. It underscores the fact that persons with severe disabilities can manage their own lives and be active contributing members of society. Implicit in this philosophy is the requirement that a center's service delivery system be respectful of the rights and dignity of persons with disabilities and involve them in all levels of decision-making that influence the nature and characteristics of the services they receive. Without a philosophy standard, many traditional providers might inappropriately be included in the program.

TARGET POPULATION

Standard 2 The centers shall have a clearly defined target population that includes a range of disabilities.

Rationale: At the national level, the independent living program was funded to serve the needs of a cross-disability population and emphasized common threads of service support that should be available to all persons with disabilities. This standard separates the independent living program from other programs that emphasize services to a particular disability group.

OUTCOMES AND IMPACTS

Standard 3 The center shall increase individual consumer achievement of independent living goals, in such areas as, but not limited to the following: housing; living arrangements; income and financial management; transportation; personal care; nutrition; household management; mobility; health and health care; assistive devices; education; employment; community involvement; family life; recreation; personal growth; social skills; communication skills; self-direction; and, consumer and legal rights.

Standard 4 The center shall increase the availability and improve the quality of community options for independent living, in such areas as, but not limited to the following: housing; transportation; personal care; education; employment; communication; reduction of barriers, including architectural and social; disability awareness and social acceptance; recreation; consumer involvement in civic activities and community affairs; and, physical and mental health care.

Rationale for Standards 3 & 4: The first outcome and impact standard emphasizes that a primary purpose of the independent living program is to contribute to the actual achievement of the independent living goals of persons with disabilities. It ensures that centers are responsive to consumers' needs and successfully assist consumers to achieve desired changes and options. Under this standard, centers are accountable for supporting achievement of consumer goals in areas that directly relate to living full and productive lives in society.

The second outcome and impact standard recognizes that improving the quality of life for persons with disabilities involves changes in the environment as well as changes at the individual level. This standard ensures that centers actually contribute to creating options and reducing barriers in the community which promote equal access to society and the ability to live independently. Through this standard, centers are accountable for improving the physical, social, and economic environment of the community for persons with disabilities.

SERVICES

Standard 5 The center shall provide to persons with disabilities within the center's target population and/or their families the following independent living

services: advocacy; independent living skills training (e.g., health care, financial management, etc.); and, peer counseling. In addition to these services, the center may provide or make available other services such as, but not limited to the following: legal services; other counseling services (e.g., non-peer, group, family); housing services; equipment services; transportation services; social and recreational services; educational services; vocational services, including supported employment; reader, interpreter, and other communication services; attendant and homemaker services; and, electronic services.

Standard 6 The center shall provide information and referral to all inquirers including those from outside the center's target population.

Standard 7 The center shall conduct activities to increase community capacity to meet needs of individuals with disabilities, such as, but not limited to the following: advocacy and technical assistance services to improve community options, remove community barriers, and create access to public programs; public information and education (e.g., presentations, press releases); outreach to consumers and service providers; and, initiatives to establish an active role in the disabled community.

Rationale for Standards 5. 6. & 7:

Although the service standards are not intended to diminish the creativity of centers in providing varied services to meet the needs of their target population, they do specify certain core services which include at a minimum, advocacy, peer counseling, skills training, and information and referral.

Also emphasized is the need to provide services and conduct activities that will achieve desired impacts in the community. Thus, the importance of directing center resources toward community change efforts is underscored.

ORGANIZATIONAL MANAGEMENT AND ADMINISTRATION

Standard 8 Qualified persons with disabilities shall be substantially involved in the policy direction, decision-making, service delivery, and management of the center, and given preference as: members of Boards of Directors (at least 51 percent qualified members with disabilities); managers and supervisors; and, staff.

Standard 9 The center shall establish clear priorities through annual and long range program and financial plans to include, but not be limited to the following: overall center goals or mission; specific objectives for numbers and disabilities of individuals to be served; service priorities and needs to be

addressed; types of services to be provided and service delivery procedures; and, budget projections.

Standard 10 The center shall use sound organizational and personnel management practices: written policies and procedures for Board and staff which specify appropriate roles and responsibilities; job descriptions for all personnel, including volunteers; clear lines of authority and supervision; personnel performance appraisal and guidance; equal opportunity and affirmative action policies and procedures; and, staff and Board training and development.

Standard 11 The center shall practice sound fiscal management: annual budget; budget monitoring system and procedures for managing cash flow; annual audit by independent public accountant; resource development activities appropriate to achievement of objectives; and, determination of costs of services and activities.

Rationale Standards 8, 9,10 and 11

A distinguishing characteristic of the independent living movement has been its emphasis upon meaningful and significant involvement by persons with disabilities. The purpose of Standard 8 is to ensure that a center is in compliance with this fundamental orientation by substantially involving persons with disabilities at the policy, management, and service delivery levels. Under this standard, "substantial involvement" at the policy level is defined as 51 percent representation of persons with disabilities on a center's board of directors.

Standard 9 creates a clear expectation that centers will engage in annual and three-year planning activities that contribute to the establishment of priorities and internal standards of accountability. A third standard in this category is intended to ensure that centers install and implement practices that will contribute to the effectiveness and efficiency of basic operations. This standard indicates that centers will operate on the basis of written policies and procedures, clear lines of authority, clear expectations about roles and responsibilities, fair hiring practices and performance review procedures, and that they will provide opportunities for board and staff training.

The fourth standard in this area is intended to ensure that a center is operating on the basis of sound fiscal procedures and is conducting activities that contribute to the financial stability and growth of the center. The standard requires that basic budgeting, accounting, and audit procedures be implemented and that the center should conduct resource development activities. Like the previous standard, it establishes minimum management requirements. Here, the focus is on fiscal responsibility and accountability.

EVALUATION

Standard 12 The grantee and the centers shall conduct annual self-evaluations and shall maintain records adequate to measure performance; documentation of the number and types of individuals served; documentation, of the types and units of services provided to individuals and the community; documentation of individual outcomes; documentation of community impact; client intake, service planning, and progress records; management records, including financial, legal, administrative, personnel, and interagency agreements; and, consumer evaluation of quality and appropriateness of the center program.

Rationale for Standard 12:

The evaluation standard ensures that centers develop capacity to demonstrate levels of service and impact. This standard also emphasizes the importance of maintaining internal records to support organizational, management, and service delivery operations.

Creating a System of Effectiveness Indicators Based on the National Standards

As mandated by Congress, the initial intent of the standards was connected to their use in the National Evaluation Study of the Part B (C) Independent Living program. Through the study, the standards were tested for their validity and practicality as a framework for defining and evaluating the program. Subsequently, 1986 amendments to the Rehabilitation Act mandated use of the standards as a basis for defining future program funding and monitoring criteria.

In keeping with the 1986 Amendments to the Rehabilitation Act, a set of minimum compliance indicators based on the national standards will be finalized during 1988, for annual reporting to RSA. For each standard, the RSA indicators will include a description of the standard, specific data elements required for annual reporting on the standard, and the minimum compliance indicator. Beginning in FY89, centers will be required to report on the data elements and on their compliance with the indicators to RSA on an annual basis.

During 1986-87, a broader set of quality and effectiveness indicators was also developed based on the national standards. Developed by the Kansas RTC/IL, in collaboration with NCIL and CRM, the system includes a wide array of specific indicators related to compliance with the national standards, organizational and programmatic effectiveness, and ability to demonstrate impact. These indicators provide very clear guidelines on how centers can achieve compliance with each of the national standards. The set of indicators can be used as a self-assessment tool to improve existing centers or to establish new ones. They can also be used as an accreditation system for examining the extent to which centers meet the requirements and intent of the national standards.

Much discussion has occurred over the possibility of creating an accreditation process for independent living based upon the NCH Standards and related effectiveness indicators. Those supporting an accreditation process feel that it will protect and support the historical intent and purposes of the program. Those who oppose accreditation express fear about diminished creativity and an over-emphasis on burdensome procedures.

The issues surrounding accreditation will not be resolved easily. However, the broad system of effectiveness indicators for independent living is a comprehensive and very useful framework that can serve many necessary and useful purposes. It is a field-based system, incorporating extensive input from representatives of independent living centers and NCIL, as well as comments and recommendations from the membership of the Council of State Administrator of Vocational Rehabilitation (CSA VR). The wide agreement on "indicators of effectiveness" among leaders and practitioners in the independent living field demonstrates that there are specific criteria associated with a commonly acceptable model. Thus, the system can be used as a self-evaluation tool to improve current centers or to establish new ones. The standards and effectiveness indicators provide centers and funding agencies with baseline requirements that indicate how to organize, operate, and manage a center's program. They also provide a way of examining growth, progress, and achievement. The system reduces ambiguity about what constitutes an effective consumer- oriented and community-based independent living center, and provides valuable guidelines for examining philosophical integrity, organizational soundness, and programmatic effectiveness.

Chapter Six

MAJOR ISSUES INFLUENCING THE DEVELOPMENT AND EXPANSION OF THE INDEPENDENT LIVING SERVICE MODEL

> If we yield to the temptation to simply place our leaders in positions of power and prestige previously held by able-bodied persons, to replace one paternalistic rehabilitation bureaucracy with another, which will set up institutionalized forms to provide housing, jobs, attendants, and transportation systems for severely disabled persons, and to hang the label "independent living" on all this, then we will betray our promise and responsibility to probe a magnificent potential, and we will have contributed not much that is profoundly new.
>
> Justin Dart, Yoshiko Dart, and Margaret Nosek, 1980

The rapid spread of independent living concepts and services has significantly contributed to the integration of persons with severe disabilities into the economic and social mainstream of community life. This community-based movement is also confronting serious issues, however, "brought on by the rapid increase in programs, rapid growth within programs, and growth in demands by the disabled community" (The Institute for Educational Leadership, 1984). Three pressing issues that have stimulated extensive discussion and concern relate to the lack of a stable and adequate funding base, conflicts over the goals and intents of independent living services, and increasing emphasis on the cross-disability mandate of serving all disability populations. These issues are discussed in this final chapter.

Funding for Independent Living Services

Independent living centers have heavily relied on government funds in the form of grants and contracts from state rehabilitation agencies and federal Title VII funds provided through the state agencies. The reliance on this funding base is of serious concern to proponents of the community-based independent living center model as competition for these limited resources increases without a commensurate increase in available funding. While some centers have broadened their funding base through successful fundraising, business ventures, and expansion to new program areas and consumer populations, most centers have not developed sufficient alter-native sources of funding. Several factors influence this situation, including the competition among a variety of social service programs for limited state and local resources. In addition, local government

representatives and private funders are only beginning to develop an understanding of the contributions made by independent living centers in decreasing the dependence of persons with severe disabilities on society. Many funders believe that existing federal and state programs already provide for the needs of the disability community and view independent living as being redundant of other efforts.

While most older centers have developed a broader funding base, new centers struggle with the requirements of establishing a new organization and initiating services. Many of the new centers are already seriously under-funded which diminishes their capacity to function effectively and to undertake the resource development initiatives needed for long-term survival.

It is highly probable that the development of a stable and adequate funding base that draws upon multiple sources of support will continue to be a high priority for most independent living centers well into the next decade. It is also probable that this issue will have an inhibiting effect on some centers' capability to deliver quality services to their constituencies while other centers will be stimulated toward broader diversification and more wide-ranging effectiveness.

Issues Over the Goals and Intents of Independent Living Services

The inclusion of independent living under the federal-state rehabilitation system has created serious conflicts between rehabilitation professionals and independent living proponents.

There have been strikingly different views about the purposes of independent living services, with rehabilitation professionals initially seeing them as an alternative form of services for persons with disabilities who in their view could not be gainfully employed.

From the rehabilitation perspective, some professionals saw independent living as a competing service form that contrasted with the closure-oriented goal of gainful employment.

> From the point of view of grassroots independent living program directors, independent living encompasses employment. The goals are not competing, and employment is one of the ways an individual can achieve independence. Further, independent living is viewed by disabled leaders as a process, which may require continued provision of a particular service in order to maintain independence. The traditional rehabilitation service system, however, assumes a termination point in the provision of services, i.e., the individual is employed, and the rehabilitation goal is achieved.
>
> The Institute for Educational Leadership, 1984

Policy conflicts between vocational rehabilitation professionals and the community-based independent living movement continue around very basic issues that include state agency emphasis on standardized procedures versus the need for flexibility in meeting individual service needs. For many independent living leaders, however, a more serious political concern relates to the application of "independent living" to a wide range of program models that are not directed and managed by persons with disabilities and do not conduct community advocacy as a major program thrust. For these leaders, the fundamental issue boils down to the questionable value of federal funding if it promotes the misuse of the independent living model, creates another form of service dependency, and results in the loss of consumer control.

Achieving the Cross-Disability Mandate

The community-based and consumer-oriented approaches offered by independent living centers hold great promise for all persons with disabilities. For individuals in certain disability categories, however, independent living represents a resource that has yet to be fully realized. Increasing the availability and actual provision of independent living services to different disability groups has become a pressing and important challenge. Over the past several years, a constellation of forces --including the emergence of national standards that mandate the cross-disability thrust of the Part B (C)-funded program at the federal level --are propelling independent living centers to move beyond a historical trend of extensive service delivery to mobility impaired populations to a broader disability representation. However, this increasing focus on the cross-disability mandate is surfacing many unresolved issues and sometimes harshly varying opinions among key stakeholders and constituencies. These issues have created tensions and divisions that detract from the positive and empowering orientation of a program that has held out the hope of independence and equality for all people with disabilities; their resolution is essential to the realization of this hope. There are several key questions that merit careful consideration.

Service Needs:	How can the independent living service model effectively meet the needs and service requirements of persons representing varied disabling conditions --blindness, deafness, mental retardation, traumatic brain injury, mental illness as well as mobility impairment?
Service Philosophy:	How can the independent living program remain faithful to the basic tenet of consumer control in providing services to individuals with varying, and in some cases more limited, capacity for autonomous decision-making?
Service Delivery:	What are the common threads of service provision and what adaptations and additional services must be considered in providing independent living services to varied disability populations?

Staffing:	What changes in the staffing and hiring patterns of independent living organizations are required in order to provide services to a broader cross-disability population?
Funding:	Is adequate funding available to support the effective delivery of expanded services to new disability populations?
Inter-agency Relationships:	What types of networking activities and referral relationships are needed to support service delivery to particular populations?

Currently lacking is a knowledge base that describes existing models of independent living service delivery to multiple disability populations and to specific populations, including traumatic brain injury, blind, deaf, mentally retarded, mentally impaired, and learning disabled. No systematic examination has been made of the experience of independent living centers currently serving multiple as well as specific disability populations, or of the approaches of other organizations that have provided effective services to particular disability groups. Without this knowledge base, effective practices cannot be identified and shared. The current lack of research related to cross-disability service delivery in the independent living field is a serious void at a time when the program is seeking to expand its services to disability populations that have been historically underserved by the program.

Independent Living --A Vision For All People

In striving for a full and satisfying life, all of us hope that we are able to retain control over our daily life activities, to exercise choice, and to feel accepted and a part of the community around us. The fact, however, that we live in a society that does not recognize the essentialness of these basic human needs for populations with disabilities or populations who have experienced hardships, underscores the fact that the philosophical principles of independent living have yet to be broadly known and understood. This gap in cultural values diminishes all of us, as we increasingly experience our own sense of vulnerability and mortality.

> Regardless of whether we join activist groups, support those who do, or seek in other ways to change the social, political, and economic structure of America, we must at least examine ourselves. If morality or justice do not provide sufficient motivating force, perhaps personal survival will. All of us must contend with our vulnerability. Increased life-expectancies may yet make independent living services necessary for everyone. Not to recognize this can only leave us unprepared for the exigencies of life. As medicine enables us to survive, sick or disabled, for ever-longer periods of time, we will experience a triple sense of powerlessness. First, we will 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, in the realization of what we have done to those who have aged before us, we will feel that we have lost our right to protest.
>
> Zola, 1983

The independent living movement and resulting service model is in its infancy when compared to other social programs. As described in this manual, it represents far more than a program of services. It has great potential for shaping general societal values and creating more promising opportunities for people with disabilities.

For the independent living movement, yesterday's efforts and today's accomplishments are only milestones on a very long journey. The broad societal change that is an explicit aspect of the independent living agenda depends upon a critical mass of people in all arenas possessing the beliefs, attitudes, and understanding that is necessary to ensure equality of opportunity for all. This challenge may create the greatest dilemma faced yet by the movement's leaders --the resource allocation dilemma. All resources are finite, and all are woefully inadequate for meeting the legitimate goals of our pluralistic society. Those in positions of authority must listen to many voices and accommodate multiple and conflicting priorities.

> The IL movement is fighting an uphill battle. Compared with the nuclear arms race, the bankruptcy of gigantic corporations, environmental pollution, and unemployment, its plight commands little public attention. What will be the consequences if it is defeated? by inertia, the budget squeezers, fragmentation, the aesthetic sensibilities of the beautiful people, or by a refusal of the powerful to release the underprivileged minority beneath them?
>
> Nancy Crewe, 1983

It will be up to those who fight to establish the importance of equal rights and opportunities to also deal with the challenge of balancing competing priorities and allocating resource reasonably and equitably among them. Complicating the dilemma, or set of dilemmas, is that the competition for resources occurs not only between disability areas and others, but within the many sub-groups of the disability rights movement -- from unborn infants to the elderly; from mild to severe; from physical to mental and emotional.

In the next decade, independent living faces two great challenges. One is to continue to advance the cause against the tide of a complacent if not resistant mainstream. The other is to take the movement to a higher plateau that transcends divisions across the field and creates a vision of the future that is clearer to all and can be shared by all.

REFERENCES CITED

Barker, L., Collignon, F., Lachat, M.A., Budde, J., Comprehensive Evaluation of the Title VII. Part B Centers for Independent Living Program Final Report. Berkeley, CA: Berkeley Planning Associates, 1986.

Barker, L., Altman, M., Youngdahl, A., Dimensions in Peer Counseling: Observations from the National Evaluation of Independent Living Centers. Berkeley, CA: Berkeley Planning Associates, 1987.

Crewe, N .M., "Freedom for Disabled People: The Right to Choose". In N. Crew, I. Zola and Associates, Independent Living for Physically Disabled People. San Francisco, CA: Jossey-Bass Publishers, 1983.

DeJong, G., The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research. Boston, MA: Medical Rehabilitation Institute Tufts-New England Medical Center, 1978.

DeJong, G., The Movement for Independent Living: Origins, Ideology and Implications for Disability Research. East Lansing, MI: University Centers for International Rehabilitation, USN Michigan State University, 1979.

DeJong, G., "Defining and Implementing the Independent Living Concept". In N. Crew, I. Zola and Associates, Independent Living for Physically Disabled People. San Francisco, CA: Jossey-Bass Publishers, 1983.

Frieden, L., Richards, L., Cole, J., Bailey, D., ILRU Source Book. Houston, TX: The Institute for Rehabilitation and Research, 1979.

Frieden, L., "Understanding Alternative Program Models". In N. Crew, I. Zola and Associates, Independent Living for Physically Disabled People. San Francisco, CA: Jossey-Bass Publishers, 1983.

Funk, R., "Self-Advocates Push Beyond Civil Rights". Independent Living Forum, vol. 4, no. 1. Winter, 1986.

Kailes, J.M., Weil, M., "People with Physical Disabilities and the Independent Living Model". In M. Weil, J. Karls, Case Management in Human Service Practice San Francisco, CA: Jossey-Bass Publishers, 1985.

Kailes, J .M., "Establishing an Effective Advocacy Program". Playa Del Rey, CA: 1987.

Lachat, M.A., "Independent Living Consumer Goal Index". In M.A. Lachat, M. Williams, The Evaluation and Management Information System for Independent Living. Hampton, NH: 1987.

National Council on the Handicapped, Toward Independence. Washington, D.C.: U.S. Government Printing Office, 1986.

National Council on the Handicapped, On the Thresho1d of Independence. Washington, D.C.: U.S. Government Printing Office, 1988.

Nosek, P., Dart, J., Dart, Y., Independent Living Programs: A Management Perspective. Austin, TX: 1981.

Pflueger, *S.S.*, Emerging Issues in Rehahi1itation- Washington, D.C.: Institute for Research Utilization, 1977.

Roberts, E. V., Foreword to Emerging Issues in Rehahi1itation by *S.S.* Pflueger. Washington, D.C.: Institute for Research Utilization, 1977.

Report from the Study Group on Peer Counse1ing as a Rehabilitation Resource. By Joseph Pankowski, Chairman. Hot Springs, AK: Arkansas Rehabilitation Research and Training Center, 1981.

The Institute for Educational Leadership, Inc., Challenges of Emerging Leadership: Community Based Independent Living Programs and the Disability Rights Movement. Washington, D.C., 1984.

Varela, R.A, "Changing Social Attitudes and Legislation Regarding Disability". In N.Crew, I.Zola and Associates, Independent Living for Physically Disab1ed People. San Francisco, CA: Jossey-Bass Publishers, 1983.

Zola, I.K., "Developing New Self-Images and Interdependence". In N.Crew, I.Zola and Associates, Independent Living for Physica11y Disabled People. San Francisco, CA: Jossey-Bass Publishers, 1983.

THE NATIONAL COUNCIL ON INDEPENDENT LIVING (NCIL)

The National Council on Independent Living (N CIL) is a membership association of consumer controlled independent living centers. Incorporated in 1982 when leaders across the country saw a need to examine national and regional issues, NCIL has become an effective national organization in a short period of time. Information about NCIL membership can be obtained by phone or mail at the address below:

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