

# **Consumer Control in Independent Living**

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# Preface

For well over a decade, the independent living movement has been gaining momentum, and we continue to experience new stages in our development. As the movement expands, more seasoned activists are being joined by people new to independent living --new activists and supporters with and without disabilities. These newer participants did not experience the passion of the initial stages of the movement --the dreams, rage, hopes, fears, insecurities, and intense immediacy of the problems. The depth of these feelings generated enormous energy, spirit, and commitment, which needs to be continually rekindled if we are to succeed.

We know that to a newcomer, the passion around subtle differences is not quickly explained or easily understood. For years we have recognized the importance of capturing on paper the essence of important discussions that have clarified and enriched the movement's beliefs, ideals, philosophy, and practice.

Perhaps no issue is as fundamental to the movement as that of consumer control; it is at the very heart of the principles of full participation, equality, and self-determination. As we face changes in policy, funding, and accountability requirements, we must be clear about our core values and the history on which they were built. Our future strength depends on both leaders and followers who are grounded in a clear and sound philosophy --people who can easily articulate, negotiate for, and apply independent living tenets. And we must broaden participation in the dialogue about this and other issues.

As our movement continues to evolve, so too will our written resources. It is our hope that this monograph will be a living document that is expanded and revised as the dialogue continues. NCIL encourages you to contribute to that process by sending us your reactions, reflections, and suggestions. We hope that this monograph will be a powerful resource for the movement, and that it is the first of many editions.

June Isaacson Kailes  
NCIL Acting President  
April, 1988

# Introduction

To date, the independent living movement has produced a number of truly outstanding leaders and some profound successes. But profound success --along with the passage of time --always brings profound change. We feel that the time has come to focus on the philosophic foundations of the independent living movement... to examine our present activities in the light of those concepts and to chart courses for the future which are designed to lead us in the direction of our most deeply held beliefs."

Justin Dart (1980)

With these words, Justin Dart, former Rehabilitation Services Commissioner and spokesperson for the independent living/disability rights movement challenged independent living leaders, advocates, activists, and practitioners to begin an important re-examination of the philosophical origins of the movement, its basic tenets and values, its current practices, and future directions. Today --eight years later --Dart's "call to action" takes on new and magnified significance, given the proliferation of independent living centers (ILCs), their outreach into new disability populations, the expansion of services, and the addition of new funding sources.

As a major tenet of the independent living philosophy, the principle of consumer control provides the basic philosophical building block upon which all organizational functions, activities, and decisions are based. The principle and practice of consumer control in independent living is rooted in the history of civil rights activism for persons with disabilities and the still unfolding story of its significance and impact. Understanding the abstract principle and its relationship to current practice is critical to ensuring that the growth and expansion of the independent living model is consistent with this core philosophical principle.

This monograph is a response to the need to examine the principle and practice of consumer control in independent living center governance, administrative structures and operation, staffing, and services. It examines the origins of the principle of consumer control and explores the ways in which the principle is actualized in policy formulation; administrative structure and operations; staffing; delivery of direct services (peer

counseling, skills training, information and referral and individual advocacy); and system change efforts.

Independent living centers, like other organizations, are confronted daily with challenges to create and maintain structures that support basic values by designing activities that turn principle into reality and results. This monograph, therefore, presents practices in independent living centers that reflect the principle of consumer control based on the experience of a number of leaders in the independent living movement. Practices related to the role and responsibility of governing boards to clearly define the mission and values of their centers are specifically highlighted. Management practices for ensuring that the principle of consumer control guides the organization's pursuit of its mission are also discussed. These practices relate to administrative operations and staffing, organizing and delivering independent living services, and conducting community development and system advocacy activities.

While it is beneficial to understand practices developed by others, the reader is encouraged to recognize that the concept of consumer control is fundamentally an abstract value that becomes real when examined by board members, staff, and consumers of independent living centers --individually and collectively. Through this ongoing dialogue, the meaning of consumer control and its application to the everyday operation of the center gets defined. Though we see many legitimate variations in practice, we are convinced that consumer control can be achieved and sustained in organizations that, through intentional processes, maintain the ability to be molded by their constituencies in all areas of independent living center operation.

Mary Ann Lachat, Ed.D.  
Center for Resource Management, Inc.  
Hampton, New Hampshire  
April, 1988

# Chapter One

## CONSUMER CONTROL - THE DRIVING FORCE IN THE INDEPENDENT LIVING MOVEMENT

"Injustice anywhere is a threat to justice everywhere."  
Martin Luther King, Jr.

The principle of consumer control has been the most powerful and unifying force of the independent living movement. It emerged from a recognition by many of the movement's early leaders that the traditional service delivery system was unjust and demoralizing for people with disabilities. This service delivery system had forced many people with disabilities into dependent relationships, including the ultimate injustice of institutionalization. Thus, these early leaders of the movement espoused the basic right for control over life choices for persons with disabilities by demanding services that were community-based and over which the consumers of services would have definitive control. The legacy of this stand against traditional values and approaches was the concept of consumer control. This concept became the driving force in the formation independent living services and independent living centers as well as the philosophical cornerstone for disability rights advocacy nationwide.

### Consumer Control -The Banner of Independent Living

"Consumer control" is a phrase often expressed by people involved in the independent living movement. Nevertheless, although it is the most fundamental concept of the movement, there are scores of people with limited understanding of its meaning. Nearly fifteen years after the first independent living centers were organized, there is still a need to clarify the significance of this concept --what it means and why it is important.

Consumer control in the independent living movement means that people with disabilities decide for themselves what services they want, how they want them delivered, by whom, and in what context.

Edward V. Roberts, one of the founders of an early independent living center in Berkeley, California, describes the focus of this movement in the following way:

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 disabled persons to share fully in the responsibilities and joys of our society.

Edward V. Roberts, 1977



Within the independent living movement, consumer control became the earliest concept differentiating independent living services from rehabilitation and medical treatment. Early efforts of independent living leaders were distinguished by their demand for self-determination --that they, not the rehabilitation counselors, doctors, therapists, or nurses decide what course of action would be followed. They sought the right to design their own services --not program planners, government representatives, or policy analysts. They wanted control over their own lives rather than depending on their families or parents, institutional staff, or charitable volunteers.

The movement's early leaders grappled with the challenge of explaining what they wanted to do and how their vision was different from that of the service delivery system. The general public, much less potential funding sources, did not understand the difference between services already available and those that were implied under the concept of independent living. These early leaders conveyed their vision through their emphasis on consumer control. Within the movement, however, the leaders themselves struggled with the concept.

In the beginning, consumer control was narrowly defined. We assumed that we were consumers. Because we assumed that we were consumers, we assumed that we knew what consumers needed. As the movement evolved, we had to deal with people who had different disabilities and we began to realize that these consumers may not feel exactly as we did. This forced us to question our assumptions about definitions of consumer and consumer control.

Brenda Premo, Executive Director  
Dayle McIntosh Center, Anaheim, CA

As the independent living movement evolved, key elements of the principle of consumer control became clearer. These included:

- choice,
- significant participation in society,
- authoritative influence and a role in decision-making,
- the right to take risks,
- having personal control over life choices, services and activities,
- the exercise of power.

Consumer control is tied to the same concepts of self-reliance and self-determination that are essential for all adults in our society. Whether disabled or not, people want and need to exert control over their own lives. When individuals have a sense of personal rights, they also have the confidence to act on those rights.

Consumer Control as a Core Concept

Consumer control became an essential concept within the field of independent living

because it represented a core value that had been absent in the traditional service delivery system for people with disabilities. Translated into new organizational entities known as "centers for independent living" this value meant that consumers had control over policy, were significantly represented in staffing, and controlled services and advocacy activities. Centers that adhere to the consumer control philosophy at all levels demonstrate a responsiveness to the varying views and needs of their constituency and recognize this constituency's right to control and influence decisions that impact on their life options. These values make independent living centers unique. They represent a commitment to overcoming the sense of powerlessness felt by persons with disabilities.

Consumer control is essential to understanding how an independent living center functions and how these centers are different from traditional service providers. An independent living center is controlled by consumers (people with disabilities) by having at least a majority of people with disabilities on its Board of Directors, on its staff, and in its volunteer corps. A center's services are provided to people with disabilities only in a manner that the consumer controls. The center's community advocacy agenda must be responsive to the needs of persons with disabilities in the center's service locale.

#### The Independent Living/Disability Rights Movement

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

Gerben DeJong, 1979

Throughout our history, the life experiences of people with disabilities have been strongly influenced by attitudes and systems that segregated them from mainstream society. These attitudes and systems were so pervasive that they affected every facet of life; rights and opportunities taken for granted by non-disabled individuals were substantially denied or abridged for people with disabilities.

In the late 1970s, a new vision propelled by more humane and responsive social and political ideals became the driving force behind an effort to change existing attitudes and systems. People with disabilities and their supporters sought to redress the inequities and injustices resulting from past policies. These advocates demanded equal opportunity in law, government, health and human services, and education -in the polling place, the work place, places of learning, and in the market place.

In 1978, Gerben DeJong provided a very useful analysis of forces that had nurtured the independent living movement as it gained momentum nationally. His analysis is based on the convergence of five other movements that included: civil rights, self-help, de-medicalization, de-institutionalization and consumerism.

Civil Rights. The efforts of blacks, women and older Americans created a synergy that began to fuel an important shift in the value orientation of large segments of American society. The civil rights movement of black Americans became the model upon which other disenfranchised minorities built their hopes. The broader civil rights movement embraced the goal of assuring that all citizens enjoy the rights and opportunities afforded by our constitution, laws, and resources.

Self-Help. Self-help among people wanting human services became a popular trend in the late 1960s. Alcoholics Anonymous is considered an excellent model of the self-help approach to solving human problems. "Consciousness raising" groups among women, "rap" groups, and support groups for individuals experiencing all kinds of emotional or physical problems developed along self-help principles. Self-help was based upon the assumption that "peers" can assist with certain problems better than professionals. Aspects of the self-help movement were offshoots of the de-medicalization movement.

De-medicalization. Disability rights advocates were promoting the idea that the control many medical professionals had over their lives could be eliminated through consumer education. Care givers need not be medical professionals as long as consumers decided for themselves how they wanted assistance and from whom. The concept of consumer-controlled attendant care is a good example of an attempt to remove medical professionals from the daily lives of people with severe disabilities. Home health services provided by members of one's family or by appropriately trained personnel is another example. In addition, the move during the 1970s to emphasize the "patient's" rights in the medical treatment process supported the independent living movement philosophy. A "patient's" bill of rights includes the right to refuse treatment or to choose from alternative treatments.

De-institutionalization. De-institutionalization was a concept first promoted by people who were mentally ill and their advocates in the 1960s. By the mid-70s, the idea of creating community-based alternatives to institutionalization was heralded by those with developmental disabilities and physical disabilities. Now, people over 65 and their advocates are pushing for increased community-based services as well.

Consumerism. The consumer movement, with Ralph Nader at its forefront, promulgated the right of the consumer to acquire quality products and services. Nader's efforts demonstrated the efficacy of consumer self-advocacy and resulted in significant changes in laws, products and grievance procedures. People with disabilities incorporated the concepts of consumer rights and self-advocacy into their efforts to guarantee accessible housing, transportation, education and other public services as well as products.

A Different Model of Service and Advocacy

Throughout the country, people with disabilities --unable to secure a decent job, relegated to dehumanizing institutions, barred from educational facilities --began to apply what had been learned from other movements to gain attention to their needs as a minority group. The movement began in small efforts in several locations but gained in strength, numbers and focus quickly. As the movement expanded, its members refined their definitions of independent living and the goal of the movement. DeJong explains this in terms of a model, or "paradigm".

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

Gerben DeJong, 1979

### Early Independent Living Centers

By the mid-1970s, organizations were being formed that put independent living concepts into operation. In Berkeley, California, students from the University of California founded the first center for independent living in 1972 as a means of creating independent living options within the Berkeley community. The Boston Center for Independent living was formed in response to student demands in the Boston area. In Houston, a variety of services emerged from the New Options Program. The state of Michigan had several centers in the mid-70s as did the state of New York.

In most of these early centers, it was people with disabilities who were demanding respect through a different form of service delivery. They were putting these organizations together and securing funding for basic human needs based upon the models of service delivery ~ wanted in order to achieve their own independent living goals. Their services and advocacy activities fit the emerging independent living paradigm and not the rehabilitation or medical model.

### Federal Laws Add Strength to the Independent Living Philosophy

At the same time that leaders of the independent living movement were articulating their core philosophical positions, they were also joining with others to achieve major changes in federal law. These leaders and disability advocates realized that fundamental revisions

were needed in the federal/state human service delivery system if independent living options were to be available at the local level. Consumer groups such as the American Coalition of Citizens with Disabilities, Paralyzed Veterans of America, the National Federation of the Blind, the American Federation of the Blind, the National Association of the Deaf, and the American Disabled for Accessible Public Transit exerted pressure on elected officials in Washington to make necessary changes.

Parent and advocacy groups such as the Association for Retarded Citizens, United Cerebral Palsy, Epilepsy Foundation, the National Mental Health Association and most recently, the Coalition of Citizens for Developmental Disabilities pushed for legislation as well. The National Council on Independent Living (NCIL) was founded in 1982. Many specific independent living principles became law in the mid-80s due, in part, to NCIL's advocacy efforts.

The result of these combined efforts is a legal system that supports many of the concepts associated with the independent living movement. A series of federal laws added the force of public policy to the movement's principles, goals, and major strategies. The most significant pieces of federal legislation guaranteeing the rights of persons with disabilities are summarized below.

- |                                  |  |
|----------------------------------|--|
| 1968 Architectural Barrier's Act | This law states that all federal buildings and programs must be architecturally barrier-free to people with disabilities.  |
| 1970 Urban Mass Transit Act      | This act requires urban mass transit systems to provide accessible transportation services to people with disabilities. The American Public Transit Association fought the enactment of this law, and the regulations regarding accessibility have been largely ignored.   |
| 1973 Rehabilitation Act          | Disability rights leaders and consumers advocated for broad civil rights language that was finally included in the Rehabilitation Act of 1973. The best known part of the Act is Section 504, which states that no otherwise qualified person with a disability can be discriminated against by any program receiving federal funding solely based upon his or her disability. Section 504 is often referred to as the civil rights act for persons with disabilities. In terms of implementation, there are still many federal agencies that have not promulgated regulations for implementing Section 504. |

1975 Developmental Disabilities of Rights Act

While making a broad declaration that people with developmental disabilities were entitled to the same freedoms, rights and responsibilities as other Americans, this bill established a system of Protection and Advocacy agencies in each state (pa's). It is the responsibility of P&A agencies to ensure that people with developmental disabilities (disabilities acquired before age 21) that are expected to be permanent and that affect a person's developmental processes) are not denied basic human rights and are provided services in the most appropriate manner.

1975 Education of All Handicapped Children Act

P.L 94-142, as it is more commonly known, mandates that all children, regardless of disability, are entitled to a free, appropriate public education. 94-142 also requires that children be placed in "the least restrictive environment", which generally means mainstreaming children with disabilities with non-disabled children.

1978 Rehabilitation Act Amendments

These amendments established parameters and funding for independent living centers under Title VII. It was the first time in the long history of the Rehabilitation Act that "independent living" was considered a legitimate service goal for persons with disabilities. While three sections established grant programs for independent living services, Part B (now Part C) was funded at levels that were shockingly below the amount authorized. Title VII Part B (C) provided funding for the establishment and operation of independent living centers.

1983 Rehabilitation Act Amendments

The Rehabilitation Act was expanded again to include provisions for independent "Client Assistance Projects", which were designed to protect the rights of individuals receiving services through the Rehabilitation Act. Funding was also appropriated for Title VII Part A (now Part B), establishing independent living services through state vocational rehabilitation agencies in much the same way as the basic vocational program operates.

1985 Mental Illness Bill of Rights Act

Protection and Advocacy agencies established for people with developmental disabilities were emulated for people who had mental illness or a history of mental illness. In many cases, the same designated agencies providing protection and advocacy services to people with developmental disabilities were expanded to serve those with mental illness.

1986 Rehabilitation Act Amendments

Title VII Part B (C), which provides grant funds for independent living centers, was refined and changed so that only organizations having a majority of persons with disabilities on their governing boards could receive funds. This major change in policy at the federal level was a direct reflection of the independent living movement's emphasis on the concept of "consumer control".

### The Importance of Title VII

As an outgrowth of the social and legal thrusts that emerged over the past two decades, the burden of accommodation began to shift away from the individual with the disability to the environment and systems that create barriers to access. The stage was thus set for establishing service models that involve consumers in governance, service delivery, and individual service planning. Title VII of the Rehabilitation Act, as amended in 1978, was key to the development of these new models since it represented a significant change in national policy and established a base of federal program support for independent living. Since 1979, Title VII Part B ( C ) has significantly increased the total number of independent living centers and independent living programs across the nation. Though still in its formative stage, the Title VII Part B ( C ) program has established itself as a viable and constructive force in facilitating the independence of persons with disabilities through a consumer-oriented service delivery system. In the February, 1984 report recommending appropriations for Title VII, the House Committee on Education and Labor wrote,

The conferees wish to strongly endorse the full implementation of the independent living concept through funding for Part A (B) of Title VII that authorizes a statewide comprehensive service delivery system... Cooperatively with the Centers funded through Part B (C) of this Title, services made available through Part A (B) would enhance, expand and stabilize the Independent Living Program. Although only five years old, Independent Living Centers have demonstrated that they are cost effective alternatives to institutional care.

U.S. House of Representatives Committee on Education and Labor, February, 1984

As Title VII funding continued and expanded, different models of independent living services emerged. Many of these programs translated consumer control principles into an array of independent living services. Others, however, were closer to the traditional rehabilitation model. Leaders of the movement became concerned that their efforts were being dissipated and undermined by programs that operated inappropriately under the banner of independent living. These leaders of consumer-controlled centers began to meet and describe what they felt were "core" principles and services for independent living centers. The National Council on Independent Living (NCIL) was an early advocate of defining core principles and services, and by 1984 the essential features of centers that operated on the basis of a consumer control philosophy emerged:

Consumer control at the policy level of a center's operations -Board of Directors comprised of a majority of persons with disabilities;

Extensive representation of persons with disabilities at the administrative and service delivery staffing level;

Emphasis on services to a cross-disability consumer population;

Emphasis on consumer control of service objectives and on peer role modeling;  
and

Provision of such core services as information and referral, peer counseling, independent living skills training, individual advocacy and community advocacy.

National leaders of the independent living movement began actively promoting these core elements as criteria for additional legislative advocacy, funding and evaluation purposes. The Rehabilitation Services Administration (RSA) was mandated by Congress to conduct an evaluation of Title VII Part B (C) grantees in 1985. This study was to be based upon "standards" developed and approved by the National Council on the Handicapped (NCH), an independent federal agency with a council membership composed of a majority of persons with disabilities. The standards were developed through a highly participatory process that was coordinated by the contractors for the study -Berkeley Planning Associates, the Center for Resource Management, and the Research and Training Center on Independent Living at the University of Kansas. NCIL played a highly active role in the process. After minor revisions, NCH approved a set of twelve standards, all of which reflected the core principles and services being promoted by NCIL and other national leaders. These standards are often referred to as the "NCH Standards" and became the basis for RSA's 1986 Evaluation Report to Congress.

#### Evaluation as a Means of Reinforcing Consumer Control

Consumer control is a principle that continues to encounter resistance and misinterpretation within the rehabilitation field and even the independent living field. Evaluation can serve as a vehicle for ensuring and reinforcing the consumer control



principle particularly at the federal level. The 1986 Evaluation Report was the first study to suggest that consumer control is a necessary feature of effective independent living centers.

Since the issuance of the Evaluation Report, the Congress has further amended the Rehabilitation Act. Through 1986 amendments, the Title VII Part B ( C ) section of the Act was amended to reflect the consumer control principle. These amendments specify that Title VII Part B ( C )funded centers must have a "governing board comprised of a majority of persons with disabilities." This change in the law represents a major victory for leaders of the disability movement who have worked long and hard to secure legal status for basic philosophical principles.

The 1986 amendments also mandated RSA to develop indicators based upon NCH-approved standards that will specify requirements associated with compliance. These indicators are being developed for implementation in FY'89. Title VII Part B ( C ) grantees will use them to report on their status, program efforts, and program results. Included among them are the requirements for consumer control at the Board of Director level.

# Chapter TWO

## CONSUMER CONTROL PRINCIPLES IN INDEPENDENT LIVING

"In matters of principle, stand like a rock..."  
Thomas Jefferson

In many organizations, the consideration of principles, values, and mission is a rare occurrence seldom connected to planning and action. In independent living centers, however, such considerations need to occur on a continual basis. These discussions are necessary for the formation of a collective consciousness that *connects* daily operations, successes, and dilemmas to the principle of consumer control. However, in developing a common understanding of the principle of consumer control, centers must also arrive at a common definition for the term "consumer".

Within the independent living field, precisely defining "consumer" and developing policies that address the role of consumers in governance, administration, staffing, service delivery, and advocacy proved to be a complex task. Early definitions focused on the participant in services, but ignored other individuals who are intended beneficiaries of independent living activities --both direct and indirect.

A broader definition of consumer has evolved and is *now* commonly used in the independent living field:

A consumer is any individual with a disability who may be a past, present, or future participant in independent living services or one who may indirectly benefit from independent living advocacy efforts.

This definition, which is reflected in this monograph, addresses the pivotal interaction of the independent living center with the larger community and the center's need to respond to a broad array of issues facing citizens with varying disabilities and ethnic, economic, and cultural differences. It addresses the need for broad-based representation of persons from cross-disability and demographic categories and lays the foundation for an organization that can serve as "a source of support and pride to [all] disabled people in the community and as a symbol of productivity and self-reliance for the broader social and economic community" (Challenge of Emerging Leadership, Mott Foundation Report, 1983). With this broader definition, organizations are charged with creating policies and establishing practices that emphasize the principle of consumer control as representing the cross-disability and social/cultural diversity that exists within their communities.

## Defining "Consumer Control"

"Consumer control" is defined as: significant representation, power, authority, and influence of individuals with varying disabilities in all aspects of an organization that provides services to enhance independence and that seeks to change the political, social, and economic environment and quality of life possible for all disabled persons.

Translating consumer control principles into consumer control practices requires the exercise of authority by consumers over the organization itself, the exercise of choice by consumers over the services they receive, and the exercise of influence by the organization in overcoming the community barriers that inhibit its consumer population.

Consumer control practices apply to:

- organizational decision-making,
- policy development,
- planning,
- staffing patterns,
- service approaches,
- volunteer involvement,
- approach to the community,
- definition of target population,
- community advocacy priorities.

Consumer control is achieved and sustained by an organization that maintains the ability to be molded by its constituency. To implement consumer control principles, four areas comprising the full range of center functions and operations need attention: policy making; staffing; services; and community advocacy.

In the remainder of this chapter, the principle of consumer control is defined in the context of major functional areas of an independent living center's operations.

### Consumer Control At The Policy Level

In non-profit corporations, the board of directors is the legal entity empowered to establish the value base of the organization, develop policies, and oversee the affairs of the corporation. The board of directors assumes an important "stewardship" function in ensuring that the mission is fulfilled and that public funds are efficiently and appropriately expended. Since independent living centers are a product of consumer self-advocacy, it follows that the board of directors is defined as a majority of individuals with disabilities who are knowledgeable about the desires and needs of consumers and who possess a critical range of other specialized knowledge and expertise relevant to governance in non-profit organizations. Indeed, the standards issued by the National Council on the Handicapped in 1985, with broad approval from leaders in the field, state that the board of directors of independent living centers should be comprised of at least 51 percent representation, by persons with disabilities.

A board of directors comprised of a majority of persons with disabilities is an important way of enacting the principle of consumer control. But it is not enough. The board must ensure that the sovereignty of consumers pervades the mission, long range goals and plans, and policies that govern staffing, financial, and service delivery decisions. More than any other group or individual, the board influences the integrity and strength of the organization's commitment to consumer control and other core values of the independent living movement.

### Consumer Control At The Staffing Level

Consumer control at the staffing level means ensuring that people with disabilities hold management and staff positions. These employment opportunities ensure significant influence by people with disabilities in administrative decision- making, service design and delivery, and community advocacy activities.

At the staffing level, consumer control can be viewed as a chain of management events and decisions. The executive director, who is a critical link in the chain, serves as the interface between the policy-making function at the board level and the implementation of policy at the staff level. The director is responsible for maintaining consistency between policy and practice and fulfilling the mission through achieving operational goals. As chief executive officer, the director is responsible for planning, staffing, resource development and allocation, and monitoring service quality. Thus, the executive director's perspective on consumer control is a critical variable in translating principles into appropriate and effective center practices.

Service delivery and support staff also constitute important links in the staffing chain. Adhering to the principles of consumer control assumes that center staff reflects disability representation and have opportunities for substantive participation and input. Staff with disabilities who are grounded in the philosophy of the movement, able to operationalize its values, and share in the experience of disability with consumers are critical to enacting principles of consumer control. By hiring people with disabilities, centers demonstrate an understanding of the need for consumer trust and acceptance and the importance of staff credibility. A unique and critically valuable feature of independent living center staffing is an emphasis on hiring persons with disabilities to provide consumer-defined services to their peers. Independent living centers committed to consumer controlled service delivery have staffing plans that build upon shared life experiences as a means of enhancing communication about life options.

It is also important to recruit and hire people with disabilities in support staff and clerical positions. This demonstrates the center's commitment to consumer representation. Finally, another means of broadening consumer control within a center is to recruit and involve people with disabilities in volunteer positions. Volunteers can perform countless functions within a center. By promoting people with disabilities in these capacities, the center can be strengthened and the individuals volunteering can increase their skills and confidence.

## Consumer Control Over Services

While there is rich diversity in service delivery methods in centers across the country, the over-riding commonality and central characteristic of the independent living service delivery model is consumer control over the design and direction of services. Consumer control over services means that it is the consumer who has the primary responsibility for identifying needs, setting goals, developing plans and strategies, and achieving independent living objectives. Consumers in this model are active participants in the service process rather than passive recipients, as in the traditional medical or rehabilitation model of service delivery. Staff function as resource identifiers, support providers, facilitators, and peer tutors.

The language commonly used in centers is itself consistent with this general theme: "consumer" of services, rather than "client" is the term of choice because it assumes an active role based on equality and mutuality of experience and a participatory process. . Peer relationships are one of the key features of services organized around the principle of consumer control. In peer relationships, the two parties meet as equals. They share a common life experience with disability and have faced many of the same issues and barriers in their pursuit of independence. Services delivered by peers provide an effective avenue for dealing with a variety of issues within the context of a service relationship based on an understanding of common life experiences and barriers to independence. Consumer control over services is, to borrow a phrase from the private sector, "a market driven economy" in which the consumer has primacy in the process.

## Consumer Control Over The Advocacy Agenda

Advocacy is an essential element in a center's programmatic design. Indeed, advocacy has been seen by many leaders in the field as the "cornerstone" of the movement in that its efforts and activities are designed to amplify the individual consumer's voice in order to change the political, social, and economic environment that prevents achieving independence and maximum quality of life. Operationalizing the principle of consumer control in advocacy requires that all key players - board, staff, and consumers - be provided with opportunities to share perspectives, knowledge, and information about needed changes in the environment and participate in activities designed to affect the desired changes. Community advocacy activities involve knowledge of the external environment, a commitment to providing opportunities to participate in the development of the advocacy agenda, and the experience and skills necessary to achieve the desired results. Through individual and collective advocacy efforts, people with disabilities acquire skills, abilities, and a greater understanding of how to affect the world in which they live. The involvement and control of people with disabilities in an independent living center's advocacy efforts is fundamental to the independent living mission of creating change and empowering people with disabilities to expand individual and community options and enhance the quality of their lives.

## Summary

Consumer control in independent living centers means having a governing body comprised of at least 51 percent of its membership with people with disabilities. It means having people with disabilities in key management roles. It means having direct service staff with disabilities who work with consumers to define their own needs, on their own terms, and with their own solutions. It means having people with disabilities in support and clerical staff positions. It means involving volunteers with disabilities in the center's daily operations. It means that stakeholders in the process --people with disabilities --play significant roles in deciding the issues and methods for advocacy efforts.

The principle of consumer control recognizes that people with disabilities should control their own destiny. It ensures their full control over the direction, composition, and operation of the organization that serves them. The principle of consumer control is translated into organizational policies by the board of directors and operationalized into practice by the management and staff of the center. This translation of consumer control principles into consistent, effective organizational practices results in the exercise of power by consumers over the center and its services, and contributes to its influence in the community it serves.

The practical applications of the consumer control principle must be flexible if services and advocacy efforts are to represent and respond to the varying interests and diversity among consumers in the communities served by the ILC. Across the country, independent living centers reflect wide diversity in practice while adhering to the principle of consumer control. In Chapters Three through Six, specific practices related to consumer control in all aspects of independent living organizations are presented:

- policy development by the governing board (Chapter 3);
- administration and staffing decisions (Chapter 4);
- defining, organizing, and delivering independent living services (Chapter 5); and
- conducting community advocacy activities (Chapter 6).

The practices and strategies presented in these chapters come from centers across the country, whose leaders have shared their thoughts and experiences with the authors.

# Chapter Three

## CONSUMER CONTROL PRACTICES RELATED TO GOVERNANCE AND POLICY DEVELOPMENT

Organizations must formalize consumer control by including standards in its mission statement, by-laws, and all written organizational policies in order for staff to know what is expected of them and for the center to have a baseline from which to evaluate its performance.

Roland Sykes, former Executive Director  
Tulsa Independent Living Center

Translating consumer control into organizational practice requires that consumers exercise authority and influence over organizational goals and operations. Empowerment through the practice of consumer control can be achieved and sustained in organizations that maintain the ability to be molded by their constituencies in the areas of governance and policy development.

Empowerment is significantly reinforced through the autonomy of the governing board and its authority for defining organizational values, mission, and priorities. Through this function, consumer controlled boards of directors communicate that persons with disabilities have not only the right, but also the ability to define direction and orchestrate initiatives in the organizations that serve them. Through the exercise of this authority, a consumer-controlled board makes an important statement to staff, consumers, volunteers, and community members that final decision-making is in the hands' of persons with disabilities. This serves to ensure that the opinions and collective experience of people with disabilities will shape policy and create an organizational agenda that is responsive to the consumer constituency.

### Creating A Consumer Controlled Board

The task of creating a consumer controlled, cross-disability board involves many practical considerations such as board composition, recruitment, selection, orientation and training, committee structure, and overall role. These are examined in the following sections of this chapter.

#### Board Composition

The practice of effective consumer control in centers requires significant authority and consistent and meaningful influence by persons with disabilities. At the governing level this is evidenced by who makes decisions and how decisions get made. A board of

directors with a majority of persons with disabilities is better able to maintain close interaction with consumers and is potentially better able to translate identified needs into policy and program directions. Thus, the power base for broad grassroots support in a center is a consumer-controlled board of individuals representing a broad disability constituency with a range of specific knowledge and expertise relating to the governance of non-profit organizations.

Cross-disability representation on the board of directors offers the advantage of maintaining a critical focus on the common barriers to independent living that exist in the community from the perspective of various disability groups and enables the center to present a unified advocacy front to the community as a whole by representing a broad constituency. In addition, board level representation that incorporates geographic, racial, ethnic, economic and gender diversity can act as a strong force for change in the external environment. Further, it provides a broad range of perspectives for internal design and delivery of services.

Beyond demographic considerations for board composition in independent living centers, some examples of the types of knowledge and expertise required for effective governance include: financial, legal, and human resource management skills and experience; knowledge of human service systems and service delivery; strategic planning; program evaluation; office automation technology; public speaking; and resource development skills.

### Board Recruitment

Knowing the skills and personal experience needed on the board and recruiting individuals who represent these qualities and characteristics leads to a discussion of procedures to ensure a representative governing body that is able to effectively lead the organization into its desired future. Some examples of recruitment strategies include creating a nominating committee of the board, contacting individuals and organizations that know the center and who may be interested in serving on the governing board, inviting current and former staff and consumers to identify possible board members, and seeking referrals from key stakeholders who might be interested and able to make the commitment of time, energy, and expertise.

Using a nominating committee to organize the process is an effective means of pursuing board recruitment. This committee may begin with an examination of needs relating to specific skills such as financial, planning, or fundraising expertise as well as the specific types of disabilities and geographic representation needed. From this assessment, the nominating committee develops a list of potential board members. Each person on this list is contacted directly by the nominating committee, its representative, or the executive director. The Whole Person, Inc. in Kansas City requires that persons interested in serving on the board submit a resume and letter stating the reasons for their interest. These materials are received and reviewed prior to making personal contact with potential new board members. Through personal contact and reviewing materials about



prospective board members, the nominating committee comes to an understanding of the individual's philosophy regarding independent living and his or her commitment to "rolling up their sleeves" and participating actively in the work of the board.

It is essential to provide comprehensive information to potential board members about the center, the responsibilities, role, and duties of board members, and the expected time commitment of board members. All too often, individuals agree to serve on boards without understanding the level of commitment required for the task. If there is an expectation for board members to participate in fundraising and/or make personal financial contributions to the organization, it should be stated at this time.

When recruitment activities are organized thoroughly and conducted thoughtfully, the board can feel confident that new members will meet the needs and demands of the organization. In making their final selections, current members of the board will feel confident that they have chosen individuals who match the qualities and characteristics needed; that they have chosen from among the broadest available pool of potential members; that they have chosen individuals who know enough about the organization and its requirements to be effective, committed board members; and, most importantly, that they have chosen board members who believe in the concept and philosophy of independent living and consumer control.

#### Board Selection

One of the most crucial, long-term decisions made by an independent living center is the selection of the board of directors. These decisions have tremendous impact on the positive development and growth of the center. Many center boards are comprised almost entirely of people with disabilities because centers were founded by consumers who believed that they are the best source for identifying needs and the best advocates for the disabled community. Because of their life experiences, consumer boards are truly aware of the services needed by their peers, and thus have a high degree of sensitivity to the consumers served by the center. Consumer controlled boards have a keen interest in both the quality and the scope of services offered and know from first-hand experience the deficiencies of other service delivery systems.

June Isaacson Kailes, Executive Director,  
Westside Center for Independent Living,  
Los Angeles, California

Final selection of board members in independent living centers is generally conducted through two very different methods. In centers that have a membership structure, board members are usually elected by the membership. This election often occurs on an annual basis by submitting ballots for nomination and holding an election by the membership. This process is an open-ended, democratic one in which the locus of control resides within the community through its membership. Effective organizations allocate resources

to educate its membership about current issues confronting the center and the specific needs for new board members. This can occur through workshops, presentation of issues in newsletters and mailings, and in an introduction to the voting process itself at the annual meeting. Often, candidates for board membership make speeches about how they can help the center and why they seek election to the board. An educated membership group can thus make intelligent decisions about who should be elected to represent them on the board.

If a center is not a membership organization but has a self-perpetuating board, it can disseminate board member requirements and characteristics through its by-laws and in its board recruitment policies and procedures. The entire board may vote on new members or the organization's by-laws may permit the president to cast a ballot in favor of the nominated slate of candidates as a whole.

Continuity of consumer control in both types of organizations is maintained by overlapping terms of office for members of the board. In this manner, only a percentage of members are elected each year, ensuring continuity in philosophy and consistency in procedures.

#### Board Orientation and Training

As board members, we have to be very strong in our philosophy. We can't take understanding for granted or that [new members] will buy into consumer control. We must constantly set the example.

Board President, Berkeley Center for Independent Living

Orientation to the role, responsibility, and duties of board members in independent living centers requires a structured and comprehensive training program. The content areas for board orientation suggested by a number of centers include the following:

-Information about the History of the Independent Living Movement.

This provides a clear understanding of the history of the movement, its connection to other civil rights movements, and how the center differs from traditional social service organizations. An understanding of the origins of the movement helps new members to comprehend the significance of the legacy they are being asked to carry forward within their own center.

-An Understanding of Independent Living Philosophy

This provides new board members with knowledge of the value base of the organization and an understanding of how values translate to board and administrative decisions and daily operations. Some of the issues related to philosophy that should be discussed with

new board members include: the meaning of consumer control, cross-disability representation and involvement, community-based services, civil rights and advocacy, and self-help concepts.

#### - The History of the Center

The organization's history has, to a large degree, created its current culture. New members are able to understand how its philosophy has affected growth and development and how past decisions have affected current operations and decision-making.

#### -An Update on Current Policies and Procedures

Many centers have a policies and procedures manual that can be given to new board members as part of the orientation process. Personnel, administrative, and fiscal policies and procedures should be included as well as board and staff rosters, job descriptions, program and service descriptions, and organizational charts.

#### -Information About the Board

This may include information about how the board functions, descriptions of committees, and the role and structure of the board. In addition, copies of recent board and committee meeting minutes, financial reports and the most recent audit, and a copy of the current budget with a list of funding sources should be provided to new board members.

Orientation and training of new board members is an important function of effective organizations. The center cannot simply assume that newly elected board members have a thorough grounding in philosophy and an ability to grasp complex concepts such as consumer control without facilitating a process that provides information in a setting and manner conducive to learning and sharing.

The importance of orientation and training for board members is underscored by Sharon Mistler, Executive Director of the Independence Center of Northern Virginia:

It has been my experience that if the board of directors are clear about philosophy..... they will not compromise.

Board members who understand the philosophy and always ask "what is right for the movement?" are of great value to a center. When boards understand the relevance of independent living, when they have integrated it into their knowledge and beliefs, they will use it as a basis for all decisions. These decisions represent the fundamental strength of a center. Ongoing board training and development should be part of a planned effort in a center's overall operations. To do this effectively, it is useful to assess the development needs of the board on an annual basis and draft a concrete plan to address these needs.

Centers use a range of training techniques including presentations, one or two day retreats and planning sessions, and the "buddy system", in which more experienced and knowledgeable board members are paired with new members for information sharing. Each method can be used alone or in combination with others to provide a breadth of experience in which new members develop knowledge, confidence, trust and the skills needed for effective leadership.

### Developing Committees

Committees are usually created in response to a felt need that has been identified by the full board of directors. These may be ad hoc committee structures (not permanent) created to deal with a particular issue or need, such as the development of a long-range plan. Standing committees (permanent) are a highly desirable mechanism for efficiently conducting the affairs of the organization. These may include: finance, nominating, program, personnel, administrative, and fundraising committees. While committees of the board may vary in emphasis, purpose, or duration, most appear to share the following characteristics:

- Committees are appointed and supported by the board of directors.

- Committees are allocated adequate time, space, and resources to meet their objectives.

- Committees maintain accurate notes or minutes of their activities.

- Committees report to the full board of directors and make recommendations for actions to be taken.

Membership on committees is often a mix of individuals including board members, representatives from the community, "experts" needed for the specific purpose, and interested volunteers. Committees can be an excellent way to involve consumers who have an active interest in governance and can provide a forum for mentoring and leadership development

### Role of the Board of Directors

In all non-profit organizations, the board of directors is the principal governing body of the corporation and is legally and financially responsible for its actions. The board performs a variety of governance functions necessary for effectively overseeing the organization. Typical board functions of non-profit organizations include:

- Representing the interests of consumers by establishing values, formulating policies, and executing contracts and other legally binding obligations that determine how the organization will operate;

- Hiring and evaluating the executive director or chief executive officer to ensure effective management of the operation;

Assuming financial responsibility for the corporation;

Developing long-range plans that guide the organization in the pursuit of its overall mission;

Ensuring the effectiveness of programs and services through periodic evaluation.

Across organizations, there is substantial diversity in the methods of governance employed by boards of directors. Independent living centers are not unlike other organizations in that there is no standard prescription for what the board must do to fulfill the functions cited above. Nevertheless, beyond these functions, governing boards of independent living centers are responsible for ensuring compliance with consumer control in all aspects of the organization. The overview of basic governing board functions listed above reveals the importance of the role of the board with regard to this principle. These include: defining the center's mission and purpose, developing policies, conducting long range planning, setting priorities, monitoring service quality through evaluation, and hiring and evaluating the chief executive officer. These functions are briefly discussed below. In each of these roles, the board bears a special responsibility for consistently reflecting the philosophical principles of independent living.

### Organizational Mission

Governing boards of non-profit organizations represent the interests of consumers, in part, through the exercise of their authority to define the mission of the organization. The mission of the organization is its statement of identity, purpose, and aims. It provides an overview of the philosophical and substantive underpinnings upon which decisions will be based. Statements and language relative to consumer control as the basic value and guiding philosophy are important parts of the mission statements of independent living centers. An example of a mission statement that incorporates the principle of consumer control follows:

Our mission is to provide comprehensive services that will enhance the range of acceptable options available to and improve the quality of life of persons with disabilities, and to work on behalf of the objectives of the disability rights and independent living movement. This organization maintains a commitment to providing independent living services, including advocacy, which are based on principles of cross-disability participation and consumer control.

### Hiring and Evaluating the Executive Director

In carrying out its responsibilities, the board delegates many duties to the executive director. This delegation of responsibility involves a range of tasks related to all levels of the center's operation. However, it is the board's role to clearly state what it wants done

and how it should be done. Getting it done is the domain of the executive director. Here we find the basic distinction between board and staff roles --the board is responsible for mission and policy, and the executive director is responsible for implementing policy and administration. Failure to maintain this distinction frequently results in confusion of roles, duties, and responsibilities; a lack of objectivity in decision-making; conflict over approaches; and a lack of attention to the broader and more fundamental issues of governance. A board that is overly focused on the day-to-day operation is not expending its energy in the most effective manner and is often undercutting the effectiveness of the executive director and staff.

### Long Range Planning

Translating the mission and philosophy into operational reality in part occurs as a result of long range planning processes that involve setting goals, objectives, and priorities that define the organization's desired future. In effective consumer controlled organizations, this process is directed by governing boards and provides opportunities for staff and consumers with disabilities to participate and influence the planning process. Ensuring broad input and influence in long range planning by staff and consumers legitimizes organizational plans and priorities, provides opportunities for job enrichment and leadership development, and ensures effective team building while underscoring the principle of consumer control.

### Internal Evaluation

It has become common practice for centers to collect information through internal evaluation systems that document the level and extent of services provided, consumers served, and the impact of services in response to consumer-defined goals. In part, this practice has been motivated by external influences and the need to provide accountability to funders on the use and impact of public resources. However, consumer controlled centers moved to the forefront of this issue by participating in the design and development of evaluation systems that are consistent with philosophy, principle, and practice in their centers.

By utilizing internal evaluation information, consumer controlled centers extend their accountability to their primary stakeholders --consumers. Boards of directors can be integrally involved in the implementation of internal evaluation systems and the use of information in their centers. Monitoring data produced by an internal evaluation system provides the board of directors with critically important information regarding consumer services, program effectiveness, and community activities. Internal evaluation systems that document consumer goal achievement help to ensure accountability to funders and ensure consumer control over service delivery. Information generated by internal evaluation systems is also useful in long range planning, staff supervision, and performance appraisal based on results in all areas of independent living activity. Boards of directors in some centers have also used information from internal evaluation systems as a basis for determining annual salary increases for staff and for identifying annual management goals and objectives for the organization and its staff.

## Summary

The role of the governing board in maintaining consumer control is carried out through its responsibility for defining the organization's values and mission, developing long term plans, conducting program evaluation, and creating the desired image within the community. Oversight responsibilities of the board include managing the legal, ethical and financial aspects of the organization and assuming responsibility for evaluating the performance of the executive director.

The board maintains its ability to carry out these responsibilities through active and ongoing board member recruitment; careful and thoughtful selection procedures for new members; thorough orientation and training for new members; developing committees for efficiently conducting its business; and by clearly delegating authority and responsibility to an executive director.

It is essential that the board adopt and use an effective performance appraisal system for annually evaluating the executive director. Through this means, the board ensures that the executive director is representing and operationalizing its values and philosophies with regard to the treatment of staff and consumers.

Utilizing an evaluation system for internal monitoring is an invaluable method for acquiring the necessary information about center operations, effectiveness, and impact. Such systems should produce data about consumers served, types and levels of services provided, referral relationships, service and advocacy impact, consumer satisfaction, and community agency satisfaction. The data from such a system is a valuable resource for identifying consumer needs and priorities and areas for improvement or expansion.

# Chapter Four

## CONSUMER CONTROL AT THE ORGANIZATIONAL LEVEL: ADMINISTRATION AND STAFFING

The presence of staff with disabilities in administrative, management, direct service, and support positions is a powerful indication that the independent living center is representing the interests, opinions, attitudes, and needs of people with disabilities and is operationalizing consumer control at the organizational level. Operationalizing the concept of consumer control in staffing is central to demonstrating the center's philosophical integrity to its participants, others with disabilities, and the community-at-large. In addition, staff with disabilities contribute unique and necessary perspectives to planning and decision-making and are able to address issues and barriers to independent living from the perspective of personal life experience.

Those who say that they cannot find qualified people with disabilities to serve on their board or staff are not viewing this as a developmental process. You must build consumer groups. You must identify people with potential and groom them. Entry level positions must be given to people with disabilities. The big question is what are we doing to create qualified people and to involve them in our movement and in our organizations.

June Isaacson Kailes, former Executive Director of the Westside Center for Independent Living in Los Angeles, California offered these comments on operationalizing the principle of consumer involvement in centers. Kailes' perspective and experience emphasize a critical need in the field --to create opportunities for individuals with disabilities to develop the skills, knowledge, and professional experience that overcome extrinsic barriers and strengthen the leadership of the movement.

Independent living centers committed to the consumer control principle at the organizational level engage in affirmative action and provide reasonable accommodation in recruitment, interviewing, hiring and promoting staff.

### Affirmative Action and Reasonable Accommodation Policies

In independent living centers, affirmative action policies are vital to recruiting people with disabilities --as well as minorities and women --for administrative, management, and staff positions. Affirmative action mandates require that organizations that receive federal funding of \$25,000 or more demonstrate that they have made sincere efforts to recruit and hire individuals from groups such as ethnic and racial minorities, and women. People over the age of forty-five and individuals with disabilities are also included in



instructions for affirmative action programs, which are monitored by the U.S. Department of Labor. The intent of the law is to eliminate discrimination against otherwise qualified individuals by using particular methods for seeking new employees and promoting current employees.

#### Effective Affirmative Action and Reasonable Accommodation Practices

In addition to establishing organizational policies about hiring and promoting minorities, women, and people with disabilities, it is also important to develop an Affirmative Action Plan that includes a statement of practices to be followed by staff. There are several basic affirmative action practices, including:

In all employment advertising, clearly state that your center is an "Equal Opportunity/Affirmative Action Employer" and that people with disabilities are encouraged to apply.

Include the criterion of "personal experience with a disability" in job announcements and position descriptions. Qualifications should allow for substituting work or volunteer experience for advanced education, as many people with disabilities have been denied both basic and advanced educational opportunities.

Give serious consideration to all applicants with disabilities when reviewing resumes and conducting interviews. One of the clear tenets in *Affirmative Action* law is to hire the qualified individual who most fits the Affirmative Action categories and who appears to have adequate skills and abilities for the position. Minorities and women should also be given careful consideration.

Ensure that people with disabilities are not discriminated against in interviewing and hiring. The principle of reasonable accommodation extends to the interview phase of employment recruitment and hiring practices. This accommodation takes many forms, such as utilizing barrier-free office space, making skilled interpreters available for the deaf and hearing impaired, providing reader service or taped materials, and making parking spaces accessible.

Reasonable accommodation to the work site may include such things as a computer with adaptations for the employee's use and other technical aids or equipment. Whatever can be done to make the job accessible to the qualified individual with a disability is a possible "reasonable accommodation". The term "reasonable" usually refers to the financial burden on the employer to make the accommodation, but even in cases where costs are extreme, there are federal and state programs to assist employers. Vocational rehabilitation agencies are among the best resources for this type of information and support.

An example of an effective method of ensuring adherence to Affirmative Action and reasonable accommodation is to establish an ongoing committee comprised of members of the board and staff with responsibility for monitoring and reviewing recruitment, hiring, and promotion practices against the criteria imposed by law and the center's own policies.

### Staff Recruitment Activities

The most critical challenge facing any manager is that of recruiting qualified staff who have the requisite knowledge, skills, and abilities and who can make a commitment to the organization's philosophy, policies, principles and service priorities. It is essential to use every avenue available in announcing staff vacancies to the public. Centers have used a variety of methods to accomplish this, including radio advertising, posting openings in community newsletters and publications of other organizations, newsletters aimed at a single disability group, other centers, vocational rehabilitation offices, the Governor's Committee on Employment of the Handicapped, rehabilitation facilities, sheltered workshops, ethnic and minority publications, national organizations such as NCIL and the Research and Training Centers on Independent Living, and schools and universities. It is important to extend notification as far and as wide as possible to recruit people with disabilities for all positions. Such efforts will increase the chances of finding appropriate, qualified, and talented staff who also have disabilities.

When job openings are advertised outside of a center's state, it is helpful not only to describe the job itself but the service available in the area. Many potential applicants need to know if there is accessible housing, transportation, and personal assistance available before they make an application. A person living in one state might like the job description but does not know what life is like in another state, so it is important that the center provide information about the lifestyle a person can expect in the center's locale.

### Staff Orientation and Training

A center's service delivery approach, staffing practices, use of volunteers, interactions with the disability community, and relationships with other agencies and organizations are all grounded in the independent living philosophy. Employees come to an understanding of this philosophy and how it is reflected in all aspects of the organization through systematic and organized staff orientation and training programs. Orientation for new staff should include:

- History and philosophy of the independent living movement;
- History of the center;
- Independent living legislation and funding;
- Cross-disability representation and consumer control approaches; .
- Self-help concepts and practices;
- Civil rights and disability law and their impact on advocacy issues;
- Descriptions of community-based services and options for independent living for consumers.

Knowledge of the history of the independent living movement and the center's history, origins, and philosophy provide a convincing focus for staff activities and performance. These elements communicate much about the uniqueness of the center. Without this background, it would be reasonable for an employee to perceive his or her work as no different from that of other service providers. Training in these areas provides a critical consciousness and perspective for one's work and the relationship of the center to the independent living/disability rights movement.

Written materials and audio or videotapes are a helpful and efficient way to conduct training. A training manual can be developed including most of the material contained in the board training manual plus all policies and procedures directly affecting the employee. In addition, office procedures, forms and reports that are routinely used by the center should be explained and demonstrated. Evaluation system forms, reports, and procedures for documenting service activities and impact should also be explained and demonstrated in training sessions for new staff.

Mentor programs provide a successful staff training vehicle in some centers. In a mentor program, a new employee is assigned to an experienced employee for training and orientation. The mentor is available to answer any questions and to explore issues as he or she begins to understand the center's philosophy and operations.

#### Staff Development

As advocates and people with disabilities, we need to be sure that centers are developing people.....

In this comment, Barbara Bernhart, former Executive Director of the Space Coast Association for the Physically Handicapped in Satellite Beach, Florida, captured an important aspect of the work of centers regarding affirmative action, reasonable accommodation, mentoring, and leadership development of persons with disabilities in the independent living movement. The "challenge of emerging leadership", according to the 1983 Mott Foundation report, identifies staff development as a critical need area "because in the youth of [independent living] programs, disabled staff have not had access to the many alternate forms of specialized training and experience which allow for development and maturation of leadership skills. More formal training programs need to be developed which can assure programs of a cadre of capable staff to carry out the broad range of responsibilities at the program level....".

Consistent staff development is of particular importance in a center to sustain understanding and practice of consumer control and peer role modeling concepts. This is particularly true for new staff who have not been involved in the movement's history and evolution. Staff development opportunities can take such forms as in-house training via group discussions and workshops on various topics by qualified staff members, bringing in external trainers, attending regional and national conferences on independent living, or attending outside training workshops.

## Staff Supervision and Performance Appraisal

Supervisory management focuses primarily on the "people side of the enterprise". Although every supervisor is responsible for managing numerous resources, the most important of these is the management of staff. Supervisors commonly ask, "What can I do to be a more effective manager of staff?" In independent living centers, this question challenges supervisors to confront the complex set of factors that reflect the uniqueness of centers. While finding and developing people is an overriding challenge in any organization, its challenge is more complex in the independent living environment, where it is not enough to hire the most qualified individual for the job, but the one who fits most closely to the ideals and characteristics embodied by the philosophy of the movement. While a candidate with a disability may not have a "string of credentials", he or she may very well be the person who should be selected for the position based on life experience with a disability and externally imposed barriers. In these situations, the quality of the center's orientation, training, staff development and supervision becomes a critical factor in the success of the new employee. Management literature abounds with theory and practice on approaches to staff supervision that result in increased self-confidence, motivation, skills, and performance. Staff supervision practices that develop skills and abilities, provide opportunities for growth and development through work, and lead to increased confidence, self-reliance, and economic independence are all aspects of empowerment for staff with disabilities. The future strength and success of the independent living movement will, in large measure, depend on what today's managers in independent living centers do to provide opportunities for developing people through orientation, training, staff development, and supervision.

### Use of Volunteers

An often overlooked method for broadening consumer control within an independent living center is the recruitment and placement of volunteers with disabilities. By placing people with disabilities in volunteer positions in the center, the organization is strengthened and the volunteers acquire new skills and confidence in their abilities. Today's volunteers may be the independent living leaders of tomorrow if the center ensures that they are treated as a vital part of the organization, feel good about their experience, are effectively oriented and trained, and receive support and supervision. The volunteer pool is the place where opportunities may exist to develop individuals whom later become salaried staff. To achieve this, centers need to ensure that volunteers have the opportunity to develop skills and abilities through training and enrichment activities.

### The Role of Non-Disabled Persons in IL Centers

Throughout the evolution of the independent living movement, there has been a consistently intense, and sometimes heated debate about the role of non-disabled persons in independent living centers. To date, this issue remains unresolved in practice. It is closely tied to the principle of consumer control. At one end of the continuum are those

who believe that consumer control precludes the meaningful participation of non-disabled individuals; at the other end are those who interpret consumer control to mean "significant involvement" of persons with disabilities but not the exclusion of the non-disabled. The continuing debate focuses on whether independent living centers can effectively pursue a leadership mission in the disability community if they are not directed and controlled by persons with disabilities.

In 1983, the Mott Foundation report entitled The Challenge of Emerging Leadership, which grew out of a conference of independent living leaders, posed the issue of the role of non-disabled persons in independent living centers in this manner:

A major issue that has become a focus of great concern and debate over the last few years is the role of the non-disabled person in the independent living/disability rights movement. It is similar to the tensions that existed in the civil rights movement on behalf of racial minorities and women.

It is an important issue in disability because of the history and numbers of traditional professions and programs that were dedicated to care for, help, and protect disabled people. These programs traditionally molded the life options and directed decision-making for the disabled person in education, rehabilitation; and related social services; employment and training opportunities; medical care; and recreation/leisure. Each program area fostered dependency, segregation, sheltered care, and stereotyped job options. The charities fostered attitudes of pity and helplessness in order to raise funds for disabled people. In each area, the decision-makers and providers have been and continue to be predominantly non-disabled.

Both the independent living and disability rights movement focus upon disabled people assuming control over their own lives and their increased involvement in the decision-making process. The role of non-disabled persons will continue to create controversy within the movement and with non-disabled professionals in rehabilitation programs and related policy areas. and in the broader civil rights policy arena.

The Conference participants believe the issue must be addressed both within the local community programs and in the broader movement. The participants recognize an increasing tendency to hire non-disabled persons for leadership and management positions, thus weakening the leadership development role of the programs. This tendency is becoming more apparent as the Center's are pressured by federal and state agencies to become more oriented toward traditional social services and less oriented toward advocacy. The long-term result of this pattern is the loss of the ability to serve as catalyst for community change and change in the lives of individual disabled people in the community.

For both the independent living and disability rights movement this is a major concern. The loss of leadership at the local level and the loss of mechanisms to develop new

leaders weaken the movement's ability to achieve its goal of integration. Thus, the participants recognize that the issue must be addressed and must be confronted in a manner that is not merely separatist, but recognizes the necessity of working with and within the professional system to affect necessary change, and support and foster the ability of disabled people to direct their own lives and achieve increasing involvement in the decision-making and policy-setting arenas.

Persons who do not have a direct life experience of living with a disability cannot know it, feel it, or receive acceptance from peers in ways comparable to their counterparts with disabilities. In the context of direct services, many independent living leaders hold that it is the commonality of experience that serves as the bonding agent between peers.

Other independent living leaders have assumed a different posture, asserting that there is a role within centers for non-disabled persons. They believe that the primary question is the nature and purpose of the role. Non-disabled staff who hold less visible, less influential positions in the center are more acceptable to proponents of this position who are comfortable with non-disabled persons in support roles, such as providers of interpreter and transportation services, readers and personal attendants. This position further asserts that when non-disabled persons attain greater authority and professional responsibility in centers, their positions should be considered "temporary". This temporary status is given with the clear caveat that the staff person hired has skills and abilities not currently available to the center. In this model, the onus of responsibility is on the center to make every effort to pass these skills on to other staff and/or volunteers with disabilities.

The executive director position is especially sensitive to both leadership and experiential requirements, and a consumer control emphasis has underscored the importance of having a person with a disability in this position. Whether an executive director of an independent living center must always be a person with a disability has caused intense debate. Below are two perspectives, which support disability representation at the director level.

The issue of whether or not the executive director of a center needs to be a person with a disability in order to ensure consumer control is both a question of credibility and accountability. In terms of credibility, the issue is one of consistency between the practice and the preaching of a center. From an image perspective it's the difference between doing it ourselves or, in the more traditional sense, having it done for us. In terms of accountability, the issue is a matter of being positively anchored in the common experience among people with disabilities along with some good old-fashioned peer pressure, which, at times can label an executive director as either Uncle Tom or Sweet Aunt Patsy, and at other times as a role model and outstanding advocate.

Eric Griffin, former Executive Director  
Independence Associates, Massachusetts

Another important ideal is that the executive director of the ILC be an individual with a disability. In such a situation, the executive director serves as a role model to all individuals with disabilities with whom (s)he comes in contact. He or she also sends an organizational message to society around the ILC that an individual with a disability can be an executive, can take a position of leadership, can be a spokesperson for disability issues, and does have the support of his or her constituency. This is a very symbolic message.

Elmer Bartels, Commissioner  
Massachusetts Rehabilitation Commission

One of the key problems associated with hiring non-disabled persons in executive positions is the image portrayed to the disability community and the community-at-large. Executive directors often play a critical role in the community, representing the center in speeches, fundraising events, coalitions and networks, and with the media. In some independent living centers, it has become practice for the non-disabled executive director to assume the administrative and managerial roles and defer the public relations role to a board or staff member with a disability.

#### Summary

Concepts and practices of affirmative action and reasonable accommodation are complementary to consumer control in independent living centers. These concepts and practices acknowledge and attempt to correct the fact that there has been limited opportunity for persons with disabilities in employment. For centers whose philosophy is based on consumer control concepts, adherence to affirmative action and reasonable accommodation policy and practice is a must.

The ability of an employee to respond to external and internal pressures that can mitigate against the exercise of philosophical values begins with a clear and comprehensive orientation process. This enables the employee to have an understanding of how his or her job relates to philosophical principles. For example, the principle of consumer control has significant impact on how services are organized and delivered to consumers. In orienting staff, it is important to discuss these implications thoroughly and to clearly identify how the development of peer-conducted processes are at the root of the independent living/disability rights movement and the center's service approach.

An effective program of staff development, supervision, and performance appraisal are key to operationalizing consumer control concepts at the organizational level. Effective management of staff results in creating the "stars" of today and independent living leaders of the future.

While the debate on the role of non-disabled persons in independent living centers continues, it is essential that centers make a major commitment to developing the skills of

persons with disabilities through leadership development programs, mentor programs, and apprentice programs in order to groom and support new leaders for the movement. Development activities must include complete and thorough grounding in the philosophy and history of the movement. Training for board and staff members is critical to individual and collective understanding of the historical forces from which the independent living philosophy emerged. Resources need to be identified to support training and mentoring opportunities for individuals who desire leadership positions but have been denied access to experiential learning in the work place. Affirmative action and reasonable accommodation policies and practices need to be developed by governing boards and rigorously adhered to by management staff. The philosophy of consumer control should be intentionally and consistently discussed within centers so that all key players understand the connection between this core philosophical principle and daily practice.



# Chapter Five

## CONSUMER CONTROL OVER SERVICES

The ultimate goal of any independent living program should be the acceptance by each individual of primary responsibility for making a total, rational effort to maximize quality of life for the self and for everyone. By taking action on this responsibility, the individual will necessarily fulfill his or her present potential to attain desirable aspects of psychological, physical and socio-economic independence; he or she will become, in a very real sense, independent.

Justin Dart, Yoshiko Dart, and Margaret Nosek,  
1980

The focus of consumer control over services is the consumer's expression of needs and desired services and consumer definition of independent living goals and the ways of achieving them.

.In the effective practice of consumer control over services, the locus of control by consumers is evident both in the types of services provided and in the methods and processes used to help consumers identify needs, explore options, and expand their horizons about personal independence and quality of life.

### The Independent Living Service Process

In order to have equal access to society and achieve as full and as independent a lifestyle as possible, individuals with disabilities need to have economic, housing, transportation, and personal care options that allow them to live as fully participating members of the community. In addition, specialized support services and other community resources available from a number of organizations are critical. These needs underscore the various responsibilities and roles performed by independent living service staff in organizing and providing services to consumers. Their efforts include the provision of core services which are described later in this chapter as well as outreach and networking with other agencies, organizations, and consumer groups; and, service coordination and joint planning with other agencies on behalf of consumers. In working with consumers, independent living staff play a number of roles as activists, role models, coordinators, coaches, managers, counselors, advocates, and planners.

As noted, the consumer who defines and expresses his holds the locus of control in services provided by independent living centers or her own needs, desires, and goals. Effective service processes support and enhance consumer choice, self-direction, self management and empowerment. In this model, the consumer defines the direction of the service, which is in sharp contrast to the attitudes and practices of more traditional programs based on the "medical model". In traditional programs, the role of the person with a disability reflects the "patient" or "client" stance of a passive recipient of services. The danger in these models is that the individual becomes an object to be "fixed" rather than an active participant in a service process designed to meet his or her individual needs (Roessler, 1982). John Chappell, Deputy Commissioner of the Massachusetts Rehabilitation Commission and former Executive Director of a center in Virginia, offered these words of reminder in the preface to "Charting the Future of Independent Living" (1985): "People with disabilities are the solution, not the problem; people with disabilities have a right to live as independently as possible; people with disabilities have a right to try --and sometimes fail, as others do."

The options available to individuals with disabilities in the more traditional service settings are often limited by the attitudes and decisions of professional providers of services. Harry Boyte notes in his book, Community is Possible that the issue of power and control by "supposedly apolitical ideologies of the helping professions in fact mask operations of well developed industries with a vested interest in expansion of their control" over the lives of those who seek their services or counsel. In contrast, the independent living philosophy and service approach have politicized service delivery in support of control by and empowerment of consumers through their rejection of the stereotypical roles of "helper" and "client". Consumer control as a basis for independent living services and practices emphasizes responsibility for one's own life. Centers carry out this emphasis through peer role modeling and service activities that increase consumer ability to attain self-sufficiency.

### Types of Independent Living Services

The basic premises of the independent living service model are evidenced in a common set of core services offered by centers across the country. These services include: information and referral, peer counseling, independent living skills training, and individual advocacy. Each is discussed below.

#### Information and Referral (I & R)

I&R is provided to persons with disabilities, their families and friends, other service providers, educators, students, and the community-at-large. The I&R system is designed first and foremost to be responsive to the information and referral needs of a center's consumer population. Generally, however, I & R responses are provided to family members of consumers, other service providers, and the community at large. A good I & R system will provide information on a wide range of disability-related topics including: architectural accessibility; civil rights; disability law; independent living and

other programs and services; aids, benefits, and equipment; housing; transportation; health care; personal assistance; education and employment options; interpreters and readers; and recreation and social opportunities.

Information and referral services reflect the principles of consumer control and self management in that consumers take the initiative for requesting information about options for independent living services, supports, and resources in the community. Centers often maintain a library of resource materials to guide staff in providing up-to-date information. I&R is an important link to the process of achieving independence. It provides necessary information to consumers who desire to make changes in their personal living situation, education, employment or other areas related to independent living.

The dialogue that occurs between the consumer and the center staff member through I&R is a significant one. It is characterized by respectful probing on the part of the staff person to determine the consumer's specific situation and possible need for services beyond the information request. I&R often leads to a consumer deciding to consider participation in specific center services. Consumer-oriented I&R is characterized by focused attention to the consumer's needs and situation and helping the consumer develop a clear awareness of options.

### Peer Counseling

Peer counseling is a service that facilitates problem-solving and decision-making through mutual sharing of disability-related experiences and role modeling. It stresses empathy and mutuality and is supportive of the consumer's choice. A peer counselor is a person with a disability with experiential knowledge of disability issues, and effective coping and communication skills. In peer relationships, the two parties meet as equals who share similar life experiences and face similar barriers in pursuit of their independence.

### Effectiveness of the Peer Model

Although sound information on the extent of peer counseling in independent living is limited, some recent studies indicate that most centers offer some form of peer relationship-based services (Barker, Youngdahl, Altman, 1988). This most often occurs through staff and volunteer peer programs that offer support, assistance in problem-solving, and role modeling.

The literature in social services provides strong evidence of the effectiveness of peer counseling as a service method. This effectiveness is evidenced in the consumer's ability to transfer techniques learned through decision-making and problem-solving to other life problems. The national evaluation study of the Part B ( C ) funded independent living program examined the influence of peer counseling on the lives of consumers and found that consumers who received peer counseling services were more likely to report more

positive personal and social changes, increases in knowledge and skills, and increased independence overall than consumers who did not receive peer counseling (Barker, Altman, Youngdahl, 1988).

### The Peer Counseling Process

The process of peer counseling involves building and maintaining a relationship based on trust and respect; using effective communication skills such as active listening, communicating understanding and sensitivity to the issues and problems presented by the consumer; effectively exploring the needs, problems, concerns and issues of the consumer; identifying and prioritizing needs; defining goals; and working effectively with consumers towards goal attainment.

The peer counselor often also serves as a role model, providing concrete evidence of what is possible in achieving personal, social, and economic independence.

### Characteristics of Peer Counselors

In addition to sharing a life experience with disability, peer counselors must also have a thorough grounding in independent living philosophy, an understanding of the differences between the traditional medical/rehabilitation model of service delivery and the independent living service model, and knowledge about how consumer control and self-management is structured in the service relationship. Peer counseling also requires skills in interpersonal relationships and effective communication, maintaining confidentiality, understanding personal and organizational limits, distinguishing between support and assistance versus acting as a "rescuer", and respect for the various value systems of consumers. (Rehab Brief, Vol. VII, No.2, 1984).

### Independent Living Skills Training

Independent living skills training focuses on consumer skill development as a way of achieving independent living options. Skills training can occur on a one-to-one basis, in group settings in educational environments and residential settings, and in consumers' homes.

Maintaining consumer control over this service requires that center staff involve consumers in defining the skill areas that will help them achieve more independence. Methods for providing skills training should take into account the approaches that best support personal growth, decision-making, problem-solving, and self-advocacy, reduce dependence on the center, and foster autonomy and independence.

As in peer counseling, skills training involves an interpersonal process that is enhanced by effective communication skills, empathic understanding, and the ability to convey understanding and sensitivity. In addition, skills trainers need to be well-grounded in

basic teaching skills (such as organizing and presenting material, sensitivity to the consumer's developing skills and abilities and readiness to learn, and assessing needs); service planning; and, facilitating goal attainment by consumers.

### Individual Advocacy

Individual advocacy is a service process aimed at self-help and building consumer's confidence to act on their own behalf. It is a process of empowering the individual to manage his or her own affairs. Freedom of choice and personal control over one's life is fostered through individual advocacy services.

This service demands, by its nature, a belief in people and their ability to understand and change the situations that restrict them. When appropriate, a staff member may act on the consumer's behalf in confronting a situation, but the primary emphasis is on self-reliance.

The process of individual advocacy begins with the consumer identifying situational barriers. Strategies are developed with the consumer to resolve the identified barriers, and the consumer participates to the maximum extent possible in pursuing these strategies. As in other independent living services, individual advocacy is structured to promote greater autonomy and independence on the part of the consumer in confronting his/her environment.

### Beyond Core Services

Other services that centers provide beyond the core services are organized in response to consumer needs in the center's service locale. The scope of services provided is limited to available resources, however. Services often relate to housing, transportation, equipment, personal assistance, communication, legal assistance, and recreation. In examining potential new services, some independent living advocates and leaders caution that if the center provides services that should be provided by others in the community, it is more difficult to advocate for lasting change in their communities. In addition, new funding sources and service methods will require the ultimate "litmus test" in independent living - the examination of the principle of consumer control against potential obligations imposed by funders.

### Consumer Control at Each Step of the Service Delivery Process.

In each service area, the essential ingredient is consumer control over the direction and process. Services are freely chosen; consumers define service objectives with the assistance and support of staff. Consumers and staff meet in an atmosphere of equality to share problems and identify solutions that are consistent with the individual's abilities, desires, and goals. The consumer defines success and determines when services will be terminated.

In effective independent living centers, all aspects of the service process are based on the principle of consumer control. For example:

Application/intake and assessment procedures are not invasive and are designed to provide easy access to independent living services. Assessment practices collect only information related to the services desired by the consumer in order to inform the service planning process.

Eligibility criteria are clearly written and communicated and eligibility decisions are communicated to consumers in a timely fashion. Service planning consists of a dialogue between staff and consumer about current needs, goals, options, and opportunities available to enhance quality of life and independent living in the community. The process is guided by the consumer's assessment of his or her own needs and desire for change. Interactions with consumers are focused and purposeful, emphasizing specific concerns such as health, personal assistance, housing, transportation, benefits, equipment, etc. Probing questions are used to help the consumer identify relevant life problems in specific areas.

Goals and objectives emerge from a dialogue based on mutual respect, equality, and understanding. Goals and objectives are consistent with consumer choice and reflect consumer need, desires, and characteristics. Goals and objectives relate to the problem to be solved, the skill needed to enhance independent living, or the situation to be changed.

The Independent Living Plan results from an open-ended dialogue with the consumer about needs and priorities and the identification of specific goals. The plan incorporates the specific responsibilities of each party, identifies the anticipated target dates for completion or accomplishment, and identifies the specific tasks to be accomplished. These components are stated in clear terms and progress reviews are agreed upon. The consumer actively participates in developing the plan and approves it.

While principles of consumer control assume that the consumer is the best judge of his or her needs, the process of identifying and prioritizing goals is facilitated by independent living services staff who are knowledgeable about the resources in their communities that support independence. This facilitating function requires that staff, in a delicate balancing act, remain in the role of "guide" rather than "manager" of the process. It requires an understanding and commitment to the principle of consumer control, understanding and awareness of the consumer's ability, and sensitivity and attention to the consumer's own needs and desires and the developing service relationship. This challenge is further intensified for staff who work with new independent living consumers who may have limited capacity for self-direction or cognitive, behavioral, linguistic, and emotional impairments' resulting from head injury, stroke, mental retardation, or mental illness. In addition, there may be pressure from other service providers, advocates, parents, guardians and others to "manage" the consumer's life. Consumer choice and self-direction in providing services to individuals in these circumstances presents a significant challenge

to staff as they implement the independent living model and its philosophical principle of consumer control and self-direction.

Goal achievement and progress towards achieving the goals identified in the Independent Living Plan are reviewed through periodic discussions with the consumer that elicit perceptions of progress or barriers to achievement.

The goals identified by consumers generally fall into the following categories: Attendant Care, Civil Rights/Law, Communication, Education, Employment, Equipment, Finances/Benefits, Health Care/Medical, Housing, Self-Care/Daily living, Self-Help/Personal Growth, Social/Recreation, and Transportation. The achievement of independent living goals includes: increased knowledge of independent living options acquisition and application of independent living skills that enable persons with disabilities to live independently and have more control over their lives; acquisition of aids, benefits, and services related to acquiring the necessary goods and services that enable persons with disabilities to participate fully in contemporary society; improvements in educational, employment, housing, and transportation situations; and, increased personal confidence and the acquisition of social skills that enable full participation in the community.

Accountability to stakeholders in consumer controlled centers can be enhanced when independent living goals are formalized into a written document and signed by the consumer. This provides valid evidence that the consumer has actively participated in the service delivery process. Progress is reviewed and documented by the staff member and consumer to ensure that goals remain relevant, are consistent with need and personal objectives, and are achievable.

## Summary

Designing a range of services and employing approaches that support consumer control is one of the most critical challenges to staff in independent living. It is here that the pressure to actualize philosophy is most keenly felt on a daily basis. Effective independent living services based on consumer control reject the traditional exercise of staff authority over the consumer. An example of this is the use of the term "peer", which emphasizes equality and mutuality rather than passivity, dependence, authority and control.

Independent living service staff must continually assess their own behavior and activities to determine if these are consistent with principles of consumer control and self-direction. This self-assessment is particularly critical with regard to service planning and reviewing consumer progress. Service staff need to have opportunities to develop the skills necessary for effective service delivery, including interpersonal and communication skills, collaboratively assessing need with the consumer, setting priorities, and developing goals and objectives related to independent living.

Developing independent living plans and reviewing consumer progress towards goal

attainment is a central characteristic of the independent living service model. These are the most effective vehicles for ensuring consumer control and self- management. Reviewing consumer progress should become a routine activity in the center, and one that involves the consumer in identifying progress and success.

An effective community-based, consumer controlled independent living center is one that provides more than services --it communicates a pervasive sense of opportunity, empowerment, and self-determination in every aspect of its organization.



# Chapter Six

## CONSUMER CONTROL OVER THE ADVOCACY AGENDA

The environment around individuals with disabilities and the independent living center dictate the results to be achieved by individual, and thus the center. If architectural barriers have been eliminated, if interpreter services are available, if housing and transportation are accessible, if employment practices are non-discriminatory, if social and vocational services are adequate and sufficient, if the public has a positive perception of its citizens with disabilities, then and only then, will individuals with disabilities have the equivalent options and rights of their non-disabled counterparts.

Justin Dart, Yoshiko Dart, and Margaret Nosek, 1980

Community advocacy sets independent living centers apart from organizations that view themselves only as service providers. Centers accept direct responsibility for a diverse set of advocacy issues and broad responsibility for the societal changes needed to achieve social, economic, and political justice for millions of individuals with disabilities across this country. Without major attitudinal shifts, changes in all areas of social policy, and significant environmental modifications, real independence is not possible.

There are many critical issues facing people with disabilities today. Centers play a leading part in the effort to empower individuals with disabilities and to concentrate their efforts into a collective strength that can reduce barriers and change discriminatory policies. The necessity for consumer involvement in system change was very well stated by Justin Dart, one of the most respected leaders in the movement:

History has repeatedly demonstrated that independence and equality cannot be given by paternalistic methods. The significant decisions of all cultures are made through systems of individual and organizational self-advocacy. No disadvantaged minority ever attained true equality without first becoming fully active in the advocacy and decision-making processes of their society.

The challenge facing independent living centers is to define a broad advocacy agenda, set advocacy priorities, conduct advocacy activities that amplify the individual consumer's voice for change, enhance the advocacy skills and abilities of constituents, provide leadership opportunities for consumers and others, and develop broad coalitions of support within the community in order to liberate persons with disabilities from the societal binds that imprison them --all within the context of consumer control principles.

## Developing the Advocacy Agenda

In developing its advocacy agenda; centers need to plan opportunities for broad representation and input into the identification and definition of issues to be addressed. This may take the form of consumer surveys on priority need areas; surveys of community agencies, organizations, and individuals; or, input from staff and board members. Other issues to be addressed in the advocacy plan include the center's available resources, staffing patterns, any legal or funding constraints on use of public resources for community advocacy; and/or the identification of new resources.

A committee structure can be an efficient means of acquiring input from various segments of the center and the larger community. The committee can be charged with responsibility for reviewing information on advocacy needs and making recommendations to the board of directors and executive director about advocacy priorities.

## Setting Advocacy Priorities

The board of directors and the executive director are usually the final decision-makers in defining the advocacy agenda and setting priority issues for action. This decision-making function should be considered a critical part of the center board's annual planning process. However, even with the best planning, new issues may emerge during the year. June Isaacson Kailes, former executive director of the Westside Center for Independent Living in Los Angeles, calls these unanticipated advocacy needs "crop-up issues" and offers this advice for dealing with new issues in the midst of a strategic advocacy plan:

When committee members present crop-up issues, the list of questions below should be addressed:

- Is the issue related to an already stated primary advocacy goal?
- How will the issue affect consumers?
- Who else is working on this issue?
- Are they able to deal with the issue adequately?
- Do they have sufficient expertise and a solid philosophical orientation?
- Does the group need assistance?
- How much of the center's resources will be involved?
- Who in the center can take primary responsibility for coordinating and monitoring advocacy activity?

If the board can answer all questions to its satisfaction, then perhaps the center should become involved in the issue. Kailes also provides this example of how the Westside board and staff effectively dealt with one crop-up issue:

Due to pressure from the construction industry and land developers, the state legislature was considering a bill to reduce the number of architecturally barrier free units required in new construction of developments of twenty units or more.

This issue came as a total surprise as the state had a fairly good law requiring that 5% of all such units had to be constructed according to ANSI standards for accessibility.

The proposed legislation was brought to a meeting of the subcommittee on access at the center. A quick assessment was conducted by the subcommittee, which determined that 20% of the center's consumers would be adversely affected by this legislation and that 10% of the state's population would be hurt by the proposed change. The subcommittee contacted a number of their allies to seek their support through a letter writing campaign. With support from the Paralyzed Veteran's of America and the Governor's Committee on Employment of the Handicapped, the subcommittee felt ready to 'tackle' the proposed legislation.

The subcommittee on access informed the board of directors of its wishes to oppose the bill and stated its plan to ask volunteers to testify against the bill in the state capitol and the need for travel expenses and staff time. Staff would be required to draft testimony and prepare handouts for elected officials. Financial resources would be required to support travel costs for eight people to go to the state capitol on two separate occasions. The board reviewed the plan and proposed budget and decided to take an official position in opposition to the proposed bill and authorized the access subcommittee to move ahead with its plans.

This is an example of how a center can mobilize itself to handle an advocacy issue. While it represented an unanticipated situation, the center had established internal mechanisms that allowed it to respond effectively.

#### Advocacy Training and Leadership Development

In effective consumer controlled independent living centers, all key players have an opportunity to define and develop the advocacy agenda and participate in advocacy activities. A critical area of organizational activity, then, is to create opportunities to develop the advocacy and leadership skills of constituents through a planned program that may include formal and informal training, development of self-advocacy groups, participation in community advocacy through public speaking, representation on committees and task forces, and mentoring experiences with more experienced members. Advocates and agents for change need to acquire skills in order to effectively represent the needs, rights, and opinions of persons with disabilities. Effective public speaking; small and large group communication skills; effective letter writing; understanding disability law, benefit structures, fair employment and housing practices; and, information regarding the legislative process at the state and federal level are some suggested topic areas in advocacy training for board, staff, volunteers, and consumers.

## Advocacy Activities

Typical barriers to independent living that are encountered by large numbers of people with disabilities cover a wide range of issues, including: architectural, programmatic, attitudinal, educational, employment, housing, personal assistance and medical care, transportation, and recreation. There are as many ways to conduct system advocacy as there are advocacy issues. Some of the activities employed by independent living centers include: letter writing campaigns, giving public testimony, engaging in public demonstrations, 'civil disobedience, legal action, and drafting position papers on proposed legislation affecting people with disabilities for distribution to government and elected officials. Some independent living centers prefer to place their board, staff, and volunteers in key positions on community boards such as regional transit authorities, housing authorities, and regional planning commissions to ensure constant and vigilant attention to legislation, policy, and administrative procedures. A consumer-controlled center with adequate internal and external involvement and adequately trained staff, board, consumers and volunteers has access to many different avenues and strategies for action.

## Competing Pressures

David Gil (Toward Social and Economic Justice, 1985) reminds social service practitioners of the competing pressures on their organizations to provide direct service and politicize need through advocacy efforts. He reminds us that administrative and service staff are routinely confronted with the need to prioritize the needs and demands made upon them and their organizations. The external environment and limited internal resources force us to "Choose. Choose between long-range and short-range goals. Choose between revolution and reform. Choose between technical advancements in service delivery and raising popular consciousness about social responsibility. Choose to help those in need or to advocate structural changes that would alter the sources of need. Choose".

Independent living centers are confronted with these choices in their financial decisions, deployment of staff, and allocation of time to competing responsibilities and needs. These competing forces for advocacy and direct services often create tensions and complex pressures on the organization in relation to its philosophy and resources. The choices are not always clear. This issue --the balance between advocacy and services --is a critical issue: today's choices will affect communities and individuals tomorrow.

If we as disabled consumers are serious about controlling and directing our lives, we must assume the role of initiators and 'watchdogs' when it comes to the programs and policies that affect our lives. The challenge is there. It is up to us to meet it."

Doris Brennan, former Executive Director  
Services for Independent Living, Euclid, Ohio

## Summary

Central to the design of independent living centers are advocacy efforts that reflect and amplify the individual consumer's voice for change in the social, political, physical, and economic environment. The consumer's voice is amplified through significant participation and input in the identification and definition of issues to be addressed by the independent living center, by other advocacy groups, and by organizations that establish policies and agendas for change.

Within the independent living center, committees may be an efficient means of acquiring input from consumers and various other segments of the larger community. The committee can review information on advocacy needs and center resources and make recommendations to the board of directors and executive director about advocacy priorities. The advocacy committee is also an effective method for addressing unanticipated advocacy issues in the midst of implementing a well-defined advocacy plan.

Advocates and agents for change need to acquire skills in order to effectively represent the needs, rights, and opinions of persons with disabilities. It is important that opportunities be provided for board, staff, consumers, and volunteers to develop advocacy skills through well planned training programs, self-advocacy groups, public speaking opportunities, participation on committees and task forces, and mentoring experiences with more experienced members.

Because of the wide range of barriers that limit independence, the list of potential advocacy issues warranting attention is long. The energies and other resources of the independent living center need to be focused on priority areas developed through a careful analysis of impact and potential for change. A consumer-controlled center has potential access to many different avenues and strategies for action that can be matched to the issues being addressed.

Finally, creating a reasonable balance between advocacy and services in independent living centers requires an ongoing commitment to community change and the conscious attention of boards, administrators, staff, and consumers in planning for this balance.



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## THE NATIONAL COUNCIL ON INDEPENDENT LIVING (NCIL)

The National Council on Independent Living (NCIL) 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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