

***I have the right to believe freely,
to be a slave to no man's authority.
If this be heresy so be it. It is
still the truth. To go against
conscience is neither right nor
safe. I cannot...will not...
recant. Here I stand. No man
can command my conscience.
--Martin Luther in defense of his
beliefs at the Diet of Worms 1521***

The Independent Living Movement: History and Philosophy to Implementation and Practice

Social Change for the Integration and Inclusion of All People with Disabilities Into Society

A Workshop Manual by
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THE INDEPENDENT LIVING MOVEMENT: History and Philosophy to Practice and Implementation

I. European Cultural Heritage (Judaic-Christian Tradition)

- A. Most nomadic tribes considered people with disabilities useless because they could not contribute to the wealth of the tribe. Nomads often left people with disabilities to die whenever the tribe moved to a new location.
- B. The Greeks sought rational reasons for disability. They reached such conclusions as: epilepsy was a disturbance of the mind; and people who were deaf could not learn because communication was essential to learning.
- C. Early Christianity brought a period of sympathy and pity toward people with disabilities. Churches organized services for people with disabilities within their congregations and homes. Many Christians held superior attitudes towards people with disabilities which resulted in a general loss of autonomy. To many, disability represented impurity of some kind. This impurity could be purged through worship and forgiveness of sins, including the belief that with enough prayer and rituals the disability could be eliminated.
- D. During the Middle Ages, Christians became fearful of people with disabilities as their attraction to supernaturalism increased. People with disabilities were ridiculed, such as court jester who was actually someone with a humped back. People with disabilities were not only ridiculed but persecuted as well. Disability became a manifestation of evil.
- E. The Renaissance brought the initiation of medical care and treatment for people with disabilities. The Renaissance is where the so-called "charity model" and "medical model" began. Education was available to people with disabilities for the first time in Western recorded history. An enlightened approach to social norms and dreams for a better future seemed to encourage active participation of people with disabilities in their respective communities. The "charity" model is based upon a benevolent society which provides services based upon a presumption of "what is best" for those served.

This is not to say that people with disabilities were not often institutionalized. The charity model during the Renaissance promoted institutionalization as doing what was best for people with disabilities. Periods from the Renaissance through World War II indicated that society believed people with disabilities might be educated but in "special" segregated programs or schools, often far from urban or heavily populated areas.

- F. This institutionalization led to the ultimate in abuse during the 1930s in Hitler's Germany. People with disabilities, most notably those with mental retardation

and mental illness, became the Gestapo's first guinea pigs in medical experimentation and mass execution. Before Hitler's SS began mass extermination of Jews, Gays and Lesbians and other minorities and their supporters, people with disabilities were all put to death by Hitler's concentration camp staff.

- G. Early in the formation of the United States, the first settlers of the American colonies would not admit people with disabilities because they believed such individuals would require financial support. Colonists enacted settlement laws to restrict immigration of many people, including those with disabilities. This did not, of course, prohibit people with disabilities from being born in the colonies or acquiring disabilities after they were already settled here.
- H. But by 1880, after the development of almshouses for people who were poor or in need of basic support, most states and territories had programs for people with specific types of disabilities. Most of these programs were large institutions where people who were blind, deaf, mentally retarded or otherwise physically disabled were sent for treatment, education or to spend their entire lives.
- I. The movement west, otherwise known as the American Frontier Movement, inspired a peculiarly American belief that social ills could be eradicated by local initiatives. The concept of "rugged individualism" was born in the American Frontier and still maintains a powerful hold over political debate today. In fact, the desire for independent living today carries with it the seed of many "rugged individualist" ideals. For some people with disabilities, this meant they need not be condemned because they could not earn their own living. Some community-based services began to emerge but people with disabilities were still usually segregated from society as a whole. Rural areas were the only places where people with disabilities tended to live with their families in integrated settings.
- J. Rehabilitation services on a broad scale were introduced as a federal program following World War I. The emphasis for these first rehabilitation programs was on the veteran with a disability who was returning home to the United States. The need for training or re-training created the first federally funded program for people with disabilities -- a program now known as the federal-state vocational rehabilitation system.
- K. During the 1940s, the blind community argued for separate services for people who were blind based upon the belief that people who were blind did not need rehabilitation but education. Advocates who were blind argued that rehabilitation is based upon a "medical model" where the person who is blind needs to be treated and cured rather than educated to live with blindness. The debate over what approach to use resulted in a "split" within the vocational rehabilitation program, allowing state vocational rehabilitation

agencies and agencies serving the blind to become separate entities within a state.

- L. Not until the social change movements during the 1960s were other major services for people with disabilities seriously considered by federal legislation. Although the Social Security system provided benefits to those who had earned sufficient income over a long enough time period and had become disabled (i.e., unable to work), there was no attempt to broaden the base of services for people with disabilities beyond the vocational rehabilitation approach. For the first time in U.S. history, consumers, advocates and service professionals began an intensive examination of the human service delivery system to decide what was missing. Community-based programs for people with disabilities began growing all over the nation in an attempt to fill the gaps left by these missing services. New concepts, new technology and new attitudes were beginning to make a difference in the lives of people with disabilities.

II. Attitudes and Behaviors Inherited

- A. The history of how people treated those with disabilities gives us the attitudes and behaviors of today.
- B. Attitudes of non-disabled people toward people with disabilities (and people with disabilities to people with different disabilities than their own) are generally based upon the following:
1. Projection - imagine having the disability (barrier awareness days)
 2. Ideal Body - belief that a perfect body is the norm (Playboy and Playgirl magazines)
 3. Generalization - assumption that the achievements and/or failures of one person should apply to others with the same or similar disability (super crips and TV shows with angry or self-pitying people with disabilities)
 4. Atonement - belief that disability is punishment for sin (healings)
 5. Spread - assumption that one disability includes others (waiter in restaurant speaks to non-disabled person rather than person with disability)
- C. Negative behaviors resulting from these attitudes are:
1. Abuse - verbal, visual, emotional or physical
 2. Avoidance - institutionalization, isolation, no communication or eye contact
 3. Patronization - talking down to, taking care of, assuming incapacities

III. The Start of the Independent Living Movement

- A. Beginning of IL Movement: Much of the movement results from reactions to the above attitudes and behaviors, i.e., our history. IL represents rebellion against the traditional system.
- B. First CIL in Berkeley, CA. This is the model that most generic CILs follow today.
- C. Boston, CILs in California, Massachusetts, Michigan, and Texas centers started around the same time. IL is a reaction to the traditional service delivery system and particularly the "medical model." Many early CILs had a mix of "IL philosophy" and "medical model" because of funding patterns.
- D. The "Medical Model" assumptions:
 - 1. Physician is technically competent expert.
 - 2. Medical care should be administered through a chain of authority wherein the physician is the principal decision-maker.
 - 3. The "patient" is expected to assume the "sick" role.
 - 4. The main purpose of medicine is the provision of acute/restorative care.
 - 5. Illness is muted primarily through the use of clinical procedures such as surgery, drug therapy and the "laying on of hands."
 - 6. Illness can only be diagnosed, certified, and treated by trained practitioners.
- E. The Sick Role - People with disabilities are expected to play this or the "impaired role." The sick role consists of two interrelated sets of exemptions and obligations:
 - 1. A sick person is exempted from "normal" social activities and responsibilities depending on the nature and severity of the illness.
 - 2. A sick person is exempted from any responsibility for his/her illness. He/she is not morally accountable for his/her condition and is not expected to become better by sheer will.

In exchange:

- 3. A sick person is obligated to define the state of being sick as aberrant and undesirable, and to do everything possible to facilitate his or her recovery.

4. A sick person is obligated to seek technically competent help and to cooperate with the physician in getting well.

Because disability is often an irrevocable part of a person's existence, the person with the disability begins to accept not only the condition but also the belief that his or her very own personhood is aberrant and undesirable. Moreover, he or she begins to accept the dependency prescribed under the sick role as normative for the duration of the disability.

- F. The Impaired Role - The impaired role is ascribed to an individual whose condition is not likely to improve and who is unable to meet the first requirement of the sick role, i.e., the duty to get well as soon as possible. Occupants of the impaired role have abandoned the idea of recovery altogether and have come to accept their condition and dependency as permanent. The impaired role is not a normative one or one prescribed by the medical model, but is a role a disabled person is allowed to slip into as the passage of time weakens the assumptions of the sick role. The dependency creating features of the medical model and the impaired role are most pronounced in institutional settings.

Quote: Patients are encouraged to follow instructions, rules and regulations. Compliance is highly valued, and individualistic behavior is discouraged. The "good" patient is the individual who respectfully follows instructions and does not disagree with the staff. On the other hand, the patient who constantly asks for a dime for the pay phone, a postage stamp, or a pass to leave the institution on personal business, tends to be treated as a nuisance or labeled "manipulative." Patients do not make their own appointments, keep their own medical charts, or take their own medications. Responsibility for these things is legally vested in the institution. Yet on the day of discharge, the patient is expected to suddenly assume control of his own health care and life decision-making. Corcoran, 1978.

Does this quote bring to mind other service providers (besides institutions) which create the same role for the person with the disability?

- G. Rehabilitation originates in the medical model and flows from "medical" practice. This is one reason why a medical evaluation or diagnostic is necessary for service delivery.
- H. Independent Living originates in reactions to the dehumanizing process inherent in the medical model and to the need for civil rights, equal access and equal opportunity.
- I. Centers for Independent Living represent the reality of this reaction. They also represent the convergence of five other social movements of the 1960s -- the period of U.S. history which saw great social change as mentioned above.

According to Gerben DeJong in his paper, "The Movement for Independent Living: Origins, Ideology and Implications for Disability Research," these five social movements created the necessary atmosphere for the current activities of both the disability rights movement and the development of centers for independent living. Centers still emphasize the primary principles of these other five movements in their services and advocacy approach. Starting with the Center for Independent Living (CIL) in Berkeley, California in the late 1960s, disability rights and independent living concepts merged into one operational organization. Essentially individuals with disabilities joined together to protest their exclusion from society's mainstream and to demand more humane, non-medical attention from the nation's service delivery system. By 1972, there were at least five states where CILs similar to the Berkeley model had been established. These new organizations, run by people with disabilities for people with disabilities, were trying to respond to a rising demand from the disabled community for control over their own services.

1. Much of this demand sounds like the **civil rights movement** led by African-Americans during the 1950s and 1960s. People with disabilities pointed out that -- just like other minorities -- they were being denied access to basic services and opportunities such as employment, housing, transportation, education and the like. Like Rosa Parks, people with disabilities want and need to be able to ride the bus. The only difference is that Rosa Parks as an African-American woman was not permitted to sit in the front of the bus while people with disabilities just want to get on the bus.
2. **Consumerism**, a movement led by well-known national figures such as Ralph Nader, contributed another element to the growing disability rights and independent living movement. People with disabilities were, for the first time, stressing their role as consumers first and "patients" last. In other words, individuals with disabilities wanted the right to educate themselves and decide for themselves what services and products they wished to purchase (even if a third party was paying for the service or product). As "clients" or "patients," people with disabilities were rarely given any autonomy or power over the services and products they would use.
3. **Self-help** is nothing new in the United States, but organized self-help programs are relatively new. The original non-professional, self-help program which is best known in the U.S. is Alcoholics Anonymous. Having a severe disability may not be exactly the same as having a problem with alcohol, but a strong parallel remains. Leaders of the disability rights and independent living movement believe that only persons with disabilities know best how to serve others who have the same or similar disabilities. The concept of "peer" counseling and self-help groups are the most common methods of self-help.

4. **De-medicalization** and **de-institutionalization** share certain common characteristics. De-medicalization for people with disabilities means removing the involvement of medical professionals from the daily lives of individuals with disabilities. People with disabilities are not "sick." They are disabled and not dependent upon medical professionals for every day needs. The perfect example of a "de-medicalized" service for persons with severe mobility disabilities is that of "personal assistance." Personal assistance is a consumer-directed service whereby the person with the disability recruits, hires, trains, manages and fires his or her own personal assistants. When consumers with disabilities are allowed to buy the services they need for daily survival from whomever they choose, they have "de-medicalized" the service. Unfortunately, the vast majority of services provided to people with disabilities are still rooted in the "medical model," regardless of the individual's needs and desires.

5. **De-institutionalization**, which began in response to large mental health facilities for those who are mentally ill or mentally retarded, follows the principles of de-medicalization. Most institutions are staffed by medical personnel, even if residents are not ill. Since many such individuals are only disabled by some permanent type of condition, placement in institutions is inappropriate and far more costly than providing those same residents with the support services they need to live in their chosen communities. The disability rights and independent living movement is working towards the development of those other non-medical and community-based services which would assist institutionalized persons to move back to their home towns or areas.

The disability rights and independent living movement are a compilation of all five social movements as they pertain to and are defined by people who have disabilities.

Since most traditional rehabilitation programs are built upon the "medical model" of service delivery, the disability rights and independent living movement promotes a completely different approach to service delivery. Independent living as a movement is quite unique compared to existing programs and facilities serving people with disabilities. Centers for independent living across the nation are working toward changing their communities rather than "fixing" the person with a disability. CILs were originally defined by the first CIL in Berkeley and now are commonly referred to as consumer-controlled, community-based, non-residential not-for-profit organizations providing both individualized services and systems advocacy. See the paradigms chart on the next page.

The "Independent Living Paradigm"

	MEDICAL MODEL, REHABILITATION, COMMUNITY ASSISTANCE (service delivery system), CHARITY PARADIGM	INDEPENDENT LIVING, DISABILITY RIGHTS, DISABILITY CULTURE, DISABILITY PRIDE PARADIGM
Definition of the problem	physical or mental impairment; lack of vocational skill, lack of education, lack of socio-economic status, lack of political and cultural skills	dependence upon professionals, family members and others; hostile attitudes and environments; lack of legal protection; lack of recognition of inherent worth of people with disabilities (stereotypes).
Locus of the problem	in the individual (individual is "broken" or "sick" and needs to "fixed" or "cured" to "fit" into society)	in the socio-economic, political, and cultural environment; in the physical environment; in the medical, rehabilitation, service delivery or charity processes themselves (dependency-creating).
Solution to the problem	professional interventions; treatment; "case management" or volunteer work based on pity and related attitudes	1) advocacy; 2) barrier removal; 3) consumer-control over options and services; 4) peer role models and leaders; 5) self-help -- all leading to equitable socio-economic, cultural and political options.
Social role of person	individual with a disability is a "patient," "client," or recipient of charity; in many situations, the social role is non-existent	family and community members; "consumers" or "customers," "users" of services and products -- just like anyone else.
Who controls	professional	person with the disability or his/her choice of another individual or group.
Desired outcomes	maximum self-care (or "ADL" -- activities of daily living as used in occupational therapeutic sense); gainful employment in the vocational rehabilitation system; no "social misfits" or no "manipulative clients"	independence through control over ACCEPTABLE options for living in an integrated community of choice; pride in unique talents and attributes of each individual; positive disability identity.

This paradigm was originally developed in 1978 by Gerben DeJong, now with the National Rehabilitation Hospital in Washington, D.C. It has been modified since then by Maggie Shreve, an organization development consultant working in the field of disability rights out of Chicago, and Steve Brown, a disability policy consultant and principle co-owner of the Institute for Disability Culture in Santa Fe, New Mexico.

IV. Federal Laws Supporting the Independent Living Paradigm

- 1968 **Architectural Barriers Act** (designed to eliminate architectural barriers in all federally owned or leased buildings)
- 1970 **Urban Mass Transit Act** (required that all new purchases of mass transit vehicles be lift equipped; APTA sought and won a court injunction barring implementation of the proposed regulations)
- 1973 **Rehabilitation Act** (Section 504 and related non-discrimination provisions in programs receiving federal funds)
- 1975 **Developmental Disabilities Bill of Rights Act** (Protection & Advocacy or P&A agencies in each state established)
- 1975 P.L. 94-142, **Education of All Handicapped Children Act, now titled Individuals with Disabilities Education Act** or IDEA (written to require a free, appropriate, integrated public education for children with disabilities; "mainstreaming" children with disabilities into regular classrooms)
- 1978 **Rehabilitation Act Amendments** (Title VII, Comprehensive Services for Independent Living, was created; Part B funded creation and operation of "centers")
- 1983 **Rehabilitation Act Amendments** (mandated that each state operate a Client Assistance Project or CAP; Title VII Part A funded to buy services for IL clients - a concept parallel to the basic VR program)
- 1984 **Voting Accessibility for the Elderly and Handicapped Act** (provides that all polling places must be accessible)
- 1985 **Mental Illness Bill of Rights Act** (expanded P&As to cover mental illness)
- 1986 **Rehabilitation Act Amendments** (advocates fought for and won "consumer control" for Title VII Part B center boards; supported work programs created and funded)
- 1988 **Air Carrier Access Act** (designed to provide for equal access on private airlines)
- 1988 **Civil Rights Restoration Act** (clarified that any organization or corporation receiving federal funds may not discriminate in any of their programs)
- 1988 **Fair Housing Act Amendments** (prohibits discrimination against people with disabilities in housing and creates universal design in new construction provisions)

- 1990 **Americans with Disabilities Act** (creates broad civil rights protections for people with disabilities modeled after the Civil Rights Act of 1964)
- 1991 **Civil Rights Act** (allows for punitive damages in a civil suit for discrimination on the basis of disability in employment; strengthens Title I of the ADA)
- 1992 **Rehabilitation Act** amendments (dramatically restructures Title VII to set standards for centers for independent living, to create an independent statewide independent living council responsible for statewide planning of center networks and independent living services, and establishes direct funding for centers in states where state funding for center operations is less than the federal allotment)

V. Title VII of the Rehabilitation Act – 1986 and 1992 Amendments

A. The Rehabilitation Act of 1973, as Amended in 1986, included the following parts:

1. Title VII Part A funds services for independent living rehabilitation (oxymoron) to individuals determined "eligible" for such services; parallels Title I (vocational rehabilitation program); based upon the medical/rehabilitation paradigm.
2. Title VII Part B was written to establish centers which operate with the IL philosophy, basing programs on the independent living paradigm; however, Part B grants have gone to single disability organizations, state agency operated centers, rehabilitation hospitals, and developmental disability group home operators -- none of which operate under the IL philosophy or paradigm.
3. Title VII Part C funds programs of service for older blind adults -- a contradiction of the cross disability focus of the movement.
4. Title VII Part D (un-funded until 1990) provides funds for "protection and advocacy of individual rights," but denies CILs access to these funds because they are recipients of Title VII funds -- even though consumers of CIL services are already "protected" by the mandated client assistance project (CAP) for any grievances against a specific center or center service. These funds could have been used by centers to buy "protection and advocacy" (or legal) services for CIL consumers by allowing the CIL to hire an attorney on staff or to contract with a local law firm.

B. **The Rehabilitation Act of 1992** dramatically changed the structure and flow of Title VII money to the states for centers and for services. (See chart on next page for comparison of the "old Title VII" and the new.) Included in the current draft are the following critical changes:

1. **Statewide Independent Living Councils (SILC)** -- There will be new statewide independent living councils which will have broader responsibilities and "real" authority, such as:
 - a. co-sign off authority for the state plan;
 - b. members will be appointed by the governor;

COMPARISON OF OLD AND NEW TITLE VII OF REHAB ACT

OLD	NEW
A - Independent living rehabilitation services for individuals B - 3 year grants to establish and operate CILs C - Services for older, blind adults D - Protection and advocacy for individual rights (PAIR)	Chapter 1 A - Purpose, philosophy, definitions, structure, establishes SILCs B - Formula funding to states based upon state plan C - Ongoing funding to CILs meeting standards
	Chapter 2 Services for older, blind adults

- c. one member must be the executive director of a CIL who is selected by other center directors within the state;
 - d. others on the council will include representatives of appropriate state agencies, including vocational rehabilitation and blind agencies, but they will be non-voting members;
 - e. it will be consumer controlled, with at least 51 percent of the members being people with disabilities (not counting people who work for centers or state agency representatives, even if they have disabilities); and,
 - f. at last, but my no means least, it will have staff to supervise, evaluate and assist in carrying out the SILC's duties.
2. **Systems Change** -- The new Act contains a section that is considerably different than the past Title VII Part A. It is a new Part B and will be used to demonstrate new ways to expand and improve independent living services. Money to support new and innovative approaches to service delivery may be drawn from either Title VII Part B or the new Part C under Title I ("Strategic Planning: Innovation and Expansion Grants"). The state

vocational rehabilitation agency and the statewide independent living council will jointly develop a plan for such projects. For example, these projects could include demonstrations on how independent living services can be delivered in an underserved portion of the state.

3. **Centers for Independent Living** -- One significant change in the new amendments is that organizations receiving CIL funds must meet National Council on Disability (NCD) standards, slightly revised from earlier versions. Key definitions, standards and assurances are all spelled out in the new Title VII and have been altered to fit the philosophical and experiential base the movement now has. Funding for CILs comes from the Senate version's new Title VII Part C (replacing the old Part B). Centers currently receiving Title VII Part B funds who can meet the NCD standards will continue to receive funds under the new law. As long as the centers meet standards, they will continue to receive funds. If a center does not meet standards after the first year, the Feds or states can pull their funds with only 90 days notice!
4. **Methods of Funding** -- How a center gets its money depends upon the level of state funding going into center operations. If a state contributes an amount equal to or greater than its current Title VII Part B allotment, then the state could continue to receive the federal dollars for distribution to centers. If the state is not contributing an equal amount, then funding goes directly from RSA, through regional offices, to the centers in that state. Even if a state is contributing more than the Feds, it could elect to allow the CIL funding to go directly from RSA to the CILs by not applying for the money itself.
5. **Oversight of Title VII** -- Oversight responsibility for Title VII Part B activities resides with the designated state agency and the statewide independent living council (SILC) as described in the state's plan for Title VII.

Oversight for the CILs under Title VII Part C is tricky: either it will belong to the designated state agency or it will belong to RSA, depending upon which entity contributes the most to CIL operations. In states like California, Illinois, Massachusetts and New York, the state contributes more funds to CILs than does RSA. In other states, RSA contributes more. So, whichever entity contributes more to CIL operations has oversight responsibility, including compliance reviews to ensure that CILs meet standards. Once a decision about the funding flow has been made by a state contributing more funding to center operations than the federal government, the state is expected to continue its involvement at that level. This is to protect CILs from being administered one year by their states and the next by RSA, and so on.

6. **Employability** -- Many independent living advocates wanted employment feasibility criteria removed from the Act altogether, but recognized that this

could set up the rehabilitation system as a funding source for individuals who have no intent of pursuing a vocational goal. This could have meant that people could use its funds inconsistent with the Act's basic purpose. For example, someone with a terminal illness could apply for funds to cover surgical expenses. But significant changes were made to the "employment feasibility" issue in other ways.

One significant change involves who is responsible for proving that an individual with a disability is employable or can benefit from vocational rehabilitation services. Generally referred to as "presumption of benefit," the new law places the burden to prove that an individual cannot benefit from VR services on the VR counselor. The counselor must have "clear and convincing evidence" that a person cannot benefit -- this is the highest civil standard in law. If there is confusion or doubt about eligibility because of the severity of an individual's disability, then the consumer can receive services through an extended evaluation period for up to 18 months, with an evaluation every three months to determine progress. Also, a counselor must determine eligibility in a "reasonable amount of time" but no longer than 60 days.

7. **IWRP** -- The new law requires that the "individualized written rehabilitation plan" (IWRP) be "jointly developed, agreed upon and signed" by the counselor and the consumer. An innovation here -- the IWRP must include a statement by the consumer, in his or her own words (or the words of a legal parent or guardian), describing how he or she was informed of options and how goals and objectives for the plan were selected. And there must be "consumer choice" over vocational rehabilitation options and services, including the use of vendors not previously authorized or used by the state vocational rehabilitation agency.
 8. **State Rehabilitation Advisory Councils** -- This is new. A consumer advisory council is established to be involved in the decision-making process, including helping to select impartial hearing officers. The council will be appointed by the governor and composed of a designated representative of the statewide independent living council (SILC) as well as others from public and private organizations involved in rehabilitation.
- C. The Rehabilitation Act needs radical reform if the IL paradigm is to be retained and reinforced in pursuit of equal access and equal opportunity. The Act of 1992 is a major beginning. It says, in law, that CILs must:
1. Establish themselves as private, not-for-profit organizations governed by an independent board of directors;
 2. Be community-based and community responsive;

3. Maintain a majority of people with disabilities on their boards of directors and on their staff;
4. Truly represent different disability groups; be cross-disability in approach and composition;
5. Provide services, including the "core services" of I&R, advocacy, independent living skills training, and peer counseling, which are directed by "consumers" themselves; and
6. Advocate for systems change, laws, regulations, policies and procedures which create and maintain equal access for people with disabilities who want to live independently in the communities of their choice.

VI. Standards for Independent Living Centers

The following is the current language of the standards which CILs will have to meet to continue to receive Title VII funding under the Rehabilitation Act Amendments of 1992:

SEC. 725. STANDARDS AND ASSURANCES FOR CENTERS FOR INDEPENDENT LIVING.

(a) In General. Each center for independent living that receives assistance under this part shall comply with the standards set out in subsection (b) and provide and comply with the assurances set out in subsection (c) in order to ensure that all programs and activities under this part are planned, conducted, administered, and evaluated in a manner consistent with the purposes of this chapter and the objective of providing assistance effectively and efficiently.

(b) Standards.

(1) Philosophy. The center shall promote and practice the independent living philosophy of

(A) consumer control of the center regarding decision-making, service delivery, management, and establishment of the policy and direction of the center;

(B) self-help and self-advocacy;

(C) development of peer relationships and peer role models; and

(D) equal access of individuals with severe disabilities to society and to all services, programs, activities, resources, and facilities, whether public or private and regardless of the funding source.

(2) Provision of services. The center shall provide services to individuals with a range of severe disabilities. The center shall provide services on a cross-disability

basis (for individuals with all different types of severe disabilities, including individuals with disabilities who are members of populations that are unserved or underserved by programs under this Act). Eligibility for services at any center for independent living shall not be based on the presence of any one or more specific severe disabilities.

(3) Independent living goals. The center shall facilitate the development and achievement of independent living goals selected by individuals with severe disabilities who seek such assistance by the center.

(4) Community options. The center shall work to increase the availability and improve the quality of community options for independent living in order to facilitate the development and achievement of independent living goals by individuals with severe disabilities.

(5) Independent living core services. The center shall provide independent living core services and, as appropriate, a combination of any other independent living services specified in section 7(30)(B).

(6) Activities to increase community capacity. The center shall conduct activities to increase the capacity of communities within the service area of the center to meet the needs of individuals with severe disabilities.

(7) Resource development activities. The center shall conduct resource development activities to obtain funding from sources other than this chapter.

(c) Assurances. The eligible agency shall provide at such time and in such manner as the Commissioner may require, such satisfactory assurances as the Commissioner may require, including satisfactory assurances that

(1) the applicant is an eligible agency;

(2) the center will be designed and operated within local communities by individuals with disabilities, including an assurance that the center will have a Board that is the principal governing body of the center and a majority of which shall be composed of individuals with severe disabilities;

(3) the applicant will comply with the standards set forth in subsection (b);

(4) the applicant will establish clear priorities through annual and 3-year program and financial planning objectives for the center, including overall goals or a mission for the center, a work plan for achieving the goals or mission, specific objectives, service priorities, and types of services to be provided, and a description that shall demonstrate how the proposed activities of the applicant are consistent with the most recent 3-year State plan under section 704;

(5) the applicant will use sound organizational and personnel assignment practices, including taking affirmative action to employ and advance in employment qualified

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individuals with severe disabilities on the same terms and conditions required with respect to the employment of individuals with disabilities under section 503;

(6) the applicant will ensure that the majority of the staff, and individuals in decision-making positions, of the applicant are individuals with disabilities;

(7) the applicant will practice sound fiscal management, including making arrangements for an annual independent fiscal audit;

(8) the applicant will conduct annual self-evaluations, prepare an annual report, and maintain records adequate to measure performance with respect to the standards, containing information regarding, at a minimum

(A) the extent to which the center is in compliance with the standards;

(B) the number and types of individuals with severe disabilities receiving services through the center;

(C) the types of services provided through the center and the number of individuals with severe disabilities receiving each type of service;

(D) the sources and amounts of funding for the operation of the center;

(E) the number of individuals with severe disabilities who are employed by, and the number who are in management and decision-making positions in, the center; and

(F) a comparison, when appropriate, of the activities of the center in prior years with the activities of the center in the most recent year;

(9) individuals with severe disabilities who are seeking or receiving services at the center will be notified by the center of the existence of, the availability of, and how to contact, the client assistance program;

(10) aggressive outreach regarding services provided through the center will be conducted in an effort to reach populations of individuals with severe disabilities that are unserved or underserved by programs under this title, especially minority groups and urban and rural populations;

(11) staff at centers for independent living will receive training on how to serve such unserved and underserved populations, including minority groups and urban and rural populations;

(12) the center will submit to the Statewide Independent Living Council a copy of its approved grant application and the annual report required under paragraph (8);

(13) the center will prepare and submit a report to the designated State unit or the Commissioner, as the case may be, at the end of each fiscal year that contains the

information described in paragraph (8) and information regarding the extent to which the center is in compliance with the standards set forth in subsection (b); and

(14) an independent living plan described in section 704(e) will be developed unless the individual who would receive services under the plan signs a waiver stating that such a plan is unnecessary.

A complete copy of Title VII of the Rehabilitation Act Amendments of 1992 is included in the appendices of this workbook. [Editor's Note: these are not included here because of space considerations.]

VII. Transitions Continuum or Spectrum

Some of us who were involved with centers in the late 1970s and early 1980s struggled to explain exactly what "independent living" meant in the context of a service delivery system. I came up with this spectrum to show various stages of independence based upon where one lives. It is a simple tool, really, demonstrating various residential settings a person with a disability face.

- Total Economic Independence
- Total Subsidized Independence
- Semi-Supervised Living
- Community-Based Transitional Living
- Supervised Living (Institutionalization)

Assumptions made about this spectrum include:

- A. Most models of service delivery continue to be based on what is convenient for the system rather than appropriate to the individual.
- B. Institutional biases continue to dominate in terms of cost and attitude. Remember how "patients" in institutions behave and think; people living in group homes are pressured to conform to the wishes of the professional staff; or those who have "case managers" with primary responsibility for the consumer's services and, usually, the direction of the consumer's life.
- C. Cost is key. As consumers assume more responsibility and control, costs go down. This is not necessarily true for the most severely disabled individual, but on average, costs of community-based services are much less than those of institutionalized or highly supervised services.

VIII. The Problems and Importance of Language

(see also "Language is More Than a Trivial Concern" by Kailes)¹

- A. Language paints visual portraits for everyone -- people with disabilities must be in control of what the public knows, sees, hears and understands
- B. Kailes has written that language is more than a trivial concern: she's right, but for more reasons than her current paper discusses. The movement itself is sloppy about language -- even about word choices in service delivery and advocacy.
- C. Feelings and thinking about language must be tied to our fight for equality and our identity.
- D. IL views disability as something to be proud of ... not ashamed of -- we must promote positive self-images, disability identification and disability pride.
- E. Disability is not the problem -- environment and attitudes are.
- F. Words like "case" "frail" "crippled" "patient" "wheelchair-bound" "deaf and dumb" and "retarded" paint the wrong picture of who we are.
- G. Differences with traditional rehabilitation:

¹ Much of this outline on language comes from the work of June Isaacson Kailes, Disability Policy Consultant. It has been developed into a full article, and can be ordered from: <http://www.jik.com/resources.html>.

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1. Medical model services place responsibility for service delivery on the professional while the person with a disability is treated like a "patient" or uneducated "client."
2. Independent living services place responsibility for service delivery on the person with the disability as the "consumer" and coordinator of service delivery.
3. This marks a shift in mentality from one of dependence upon professionals to dependence upon self.

H. A few of the words to avoid:

1. "**Case**" comes from both legal and service delivery systems. The typical understanding of the word case comes from "case worker," a social work term for the professional manager of service for clients. It is distancing and carries authoritarian overtones.
2. "**Client**" has the same overtones because of its heavy use within the traditional rehabilitation and medical model service delivery system. We understand that client comes from ancient Greek or Latin, meaning "to be controlled." In Webster's Seventh Collegiate Dictionary, its primary meaning is "a person under the protection of another; vassal, dependent."
3. "**Intake**" means "a taking in." In social and human service terms, it generally means that someone is taken into a program, determined eligible or "admitted." Many CIL services do not require nor should they need to "take people in."
4. "**Frail**" means "easily led into evil" or "easily broken or destroyed," "physically weak, slight, unsubstantial" -- does this word describe someone in control of his or her own destiny?
5. "**Wheelchair bound**" or "**confined to a wheelchair**" implies less value, less potency and less activity than "wheelchair user" does; also conveys a stereotype that people using wheelchairs never get up, never go anywhere, are literally tied to their chairs or their beds (as in "bed-ridden"). People use wheelchairs to increase their mobility. Some people who walk still use wheelchairs because they are faster, easier, and less tiring than walking. For many, wheelchairs mean mobility and freedom -- not imprisonment and segregation!
6. "**The disabled**," "**the handicapped**," "**cripple**," "**invalid**" (not valid????), etc. are all stereotypical and limiting in a wide variety of ways. A woman who has a disability is also a mother, wife, student, citizen, board member, gifted public speaker, etc. A man who is quadriplegic may have a severe physical disability, but he is not a "vegetable." He may be an executive

director of an agency or a marketing specialist with a major corporation. We can choose to emphasize people's similarities or differences in numerous ways. What is most important about the person you are trying to describe? The phrase, "disabled person" is just a sloppy short-cut to the sometimes more awkward, but psychologically sounder expression, "person with a disability" because the latter connotes that a person with a disability is first and foremost **a person!**

7. **"Patient"** means "an individual awaiting or under medical care and treatment." Since most people with disabilities are not actively "sick" or under constant medical care, the word patient is inappropriate when applied to someone who simply has a disability. For example, a friend's father was talking about the people he sees as a "mall walker" and he described young people, old people, a grandmother with her grandchildren, a child with a disability and a stroke patient. My friend said, "Oh! You mean the man who had the stroke was there with his doctor examining him? Isn't it kind of hard to walk and use a stethoscope at the same time?" "Patient" is only correct when a person is being actively treated by medical personnel -- just like people without disabilities describing them-selves when they talk to their doctor's office but not when mall walking!

I. The problems with these words:

1. These words set up **"superior/inferior"** relationships which embody strong value systems, expectations and key activities. Once established, these superior to inferior roles and relationships often are self-fulfilling prophecies throughout the term of the service being provided.
2. **Deficiency-oriented** language used by service providers obscures the true role of a "consumer" of service -- it inevitably harms people by undermining their sense of capacity and self-worth. Service providers must realize that their use of such words places people at risk of a reduced sense of well-being, including discrimination on the basis of social status (such as being poor) or disability or both, being segregated from community life and being generally powerless. Such language is insensitive and judgmental, implying deep-seeded attitudes towards the people being served.

QUOTE: All service providers have been exposed to discussions related to labels that generally carry heavy negative social consequences. Many people who are labeled developmentally disabled or physically disabled are never going to be "fixed" by the service professions. Nevertheless, they are frequently subjected to years of "training" to write their name or tie their shoes when these tasks will never really be accomplished in any useful, functional way. Many of the same people have many capacities that are unused and unshared while their life is surrounded by special services that will demonstrably fail to fix the deficiency, so the denial of opportunity to express capacities is a

mindset that is often reflected in service providers' language. John McKnight

EXAMPLE: People magazine (December, 1988) article about Stephen Hawking, internationally known physicist at Cambridge University, "Wrecked by Lou Gehrig's Disease, the body of the greatest cosmic thinker since Einstein huddles helplessly in a wheelchair....What's left of Stephen Hawking, the physical man, is a benign head ripped by a drooling grin and a body collapsed into a pile of wasted limbs, ravaged by ALS...."

3. At the first encounter with a person who has a disability, a service provider may find the disability the most prominent fact in his or her awareness. But its prominence in the provider's mind set may not represent any importance to the matter at hand. People need to carefully avoid giving disability more prominence than it deserves.
4. CILs can help service providers recognize this flaw by focusing on the need at hand and not on the disability itself. CILs must make a commitment to not allow service providers to hide behind the jargon and quasi-scientific vocabulary of human service that is not the precise shorthand that people espouse it to be, but a device to disguise service provider policy confusion and ignorance. This commitment allows people with disabilities who are requesting services to understand what is available almost immediately and to relate to it personally, to own it and to advocate for it. See chart of example on next page.
5. The Americans with Disabilities Act of 1990 is radically changing the way in which employers, government and places of public accommodation **CAN** treat people with disabilities -- since they cannot ask questions about disability, stereotype or make false assumptions about negative characteristics, why should the service delivery system???? We must be the best at putting forth the right vocabulary. We must be the role model!

EXAMPLES OF MODEL LANGUAGE FROM THE INDEPENDENT LIVING MOVEMENT
(from a draft by June Isaacson Kailes)

Traditional Services (Dehumanizing, offensive, paternalistic, unacceptable)	CIL Services (Acceptable)
CLIENT	Person with a disability, "consumer," "citizen," (colleague, brother, sister, husband, wife, friend)
CASE	Individual with a disability, "consumer"
CASE MANAGEMENT	Service coordination, getting the right people and the right services to show up at the right time
TERMINATED CLIENT	Inactive consumer
MENTAL STATUS	Judgment
CLIENT NEEDS ASSESSMENT	Understanding the needs of the individual
INFORMAL SUPPORT NETWORKS	Friends and relatives
QUALITY ASSURANCE	Making sure the people helping the individual know what they are doing
HOME MAKER, HOME HEALTH NURSE, CARE-GIVER	Personal assistant
FRAIL; DISABLED PERSON	Elderly; a person with a disability

J. .Euphemisms

1. Some people with disabilities -- frustrated and dissatisfied with the common negative terms used to describe disability -- have coined such new terms as:
 - a. Able-disabled
 - b. Differently-abled
 - c. Handicapper
 - d. Handi-capable and handi-capper
 - e. Inconvenienced
 - f. Physically challenged (or mentally challenged)
 - g. Exceptionality or "special" (used mainly in special education)
2. "Consumer," a word which has substantial power within the "consumer movement" defined by Ralph Nader and other consumer advocates, has become euphemistic within the disability service delivery system. "**Consumer**" means "one who consumes." But within the disability service system, many people with disabilities are not free to decide what they will and will not "consume." Therefore, the word consumer presents new problems. Many rehabilitation agencies and service providers are using the word consumer but not changing their attitudes or behaviors toward their "clients." McKnight likes the word "citizen." Code-switching may be the answer to this current dilemma.
3. Euphemisms simply lessen the impact of what we truly want: **power!** Power over our daily lives and power within the democratic system of government and society as a whole.

K. Code-switching

1. Just as Negro became African American and Indian became Native American (depending on what tribe you encounter -- some tribes prefer American Indian), so must people with disabilities speak in unison about what we choose to call ourselves. We need a vision of who we are. People with disabilities must stop thinking of them-selves in an apologetic way and be proud that they are strong enough to demand their rights instead of begging for whatever they need to live independently and with dignity.

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2. Code-switching means that we use correct terminology, i.e., "people with disabilities" when speaking outside our culture, but we can use our own labels within our culture, i.e., "consumers."
 3. African Americans are most adept at code-switching. On the job, they use English. Back home, they use black English or "street language" which has its own idioms and syntax.
 4. People who are deaf do the same thing, using signed English in the college classroom but switching back to ASL in the dorm with other students who are deaf.
 5. People with disabilities may use "gimp" or "crip" when and where it is safe to do so -- among ourselves -- but not when we are presenting ourselves to others outside the culture. Right now the disability rights movement has rooted its culture in CILs and a few other disability-specific and grass-roots organizations.
- L. As a movement, we haven't been able to agree on what to call ourselves. Some people who are blind use "blink" in a joking way, others do not. Some people who are deaf are using a capital D in deaf as a matter of pride, such as culturally Deaf.
- M. Terms used to describe us have been imposed from the outside for the most part. We are still struggling to choose our words ourselves, but consensus seems to be developing.
1. Social services have called us handicapped.
 2. Medical models and insurance companies call us disabled.
 3. There was even a contest sponsored by the Cristina Foundation to come up with a positive word or phrase to describe people with disabilities. The winner, a special education teacher who has a disability but who does not identify himself as an individual with a disability, received \$50,000 for his suggestion of "differently able." Do you think any other minority group would tolerate a contest with a cash prize for the best name for themselves? Why do we as people with disabilities tolerate this type of activity?
- N. Culture and language
1. Generally, language is the root of a culture. ASL is the root of deaf culture; Spanish is the root of Hispanic cultures; Russian is the root of Russian culture, various languages distinguish one Indian tribe from another, etc.

2. Every major ethnic, racial or religious minority group in the United States has some language or "code" at the core of its cultural identity. People with disabilities do not have this cultural tie, except for people who are deaf.
- O. We are creating language to reflect the culture we are trying to create -- once we have language and reach consensus on the value of that language, disability pride, disability rights, and the movement for independent living will blossom.

IX. What Next? Passing the "reality versus rhetoric" test

How can you put the principles of the independent living movement into practice?

- P. CILs must meet federal definitions, assurances and standards
1. "Consumer controlled", meaning run by people with disabilities (not parents or professionals);
 2. "Market-driven" where the primary market is people with disabilities;
 3. Community based, meaning located in the community it serves and non-institutional;
 4. Non-residential, meaning the center does not provide residential programming unless it is of 8 weeks or less and only for the sole purpose of independent living skills training such as many rural areas use;
 5. Cross-disability in governance, approach, marketing and promotional efforts, advocacy and service delivery, ensuring that no one disability group is heavily favored over another and that all center services are accessible to all persons, regardless of disability type;
 6. Combining service delivery ("converting" or persuading those with disabilities to the independent living philosophy) and systems advocacy (using service information and community feedback to organize for community and social change);
 7. Resisting evaluation systems which are heavily bureaucratic, viewed as "paternalistic" or "product-driven" (i.e., bean-counting);
 8. Viewing disability issues in terms of "civil rights" rather than "special services."
- Q. The Americans with Disabilities Act (ADA) is key to the future. Work on its implementation through technical assistance and education as well as through alternative dispute resolution or the filing of complaints.
- R. How organizations can pass the "reality versus rhetoric" test:

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1. Is the person with the disability in charge of service selection and direction? Is the person with the disability expected to accept responsibility for selecting or directing support services?
 2. Are people with disabilities the majority of the decision making body (board, staff, volunteers)?
 3. Is advocacy to change society (i.e., eliminate architectural, communication, social and related barriers) a top priority? Are services to individuals tied to this same advocacy thrust?
 4. Is non-discriminatory language used daily? Are people with disabilities referred to as "they" or "them?" If the words "person with a disability" are exchanged with "person who is African American," do the words become racist or patronizing?
- S. To test your "reality," ask your trainer to take the full 76 item "reality versus rhetoric" test.

X. Bibliography about the Independent Living and Disability Rights Movement

Books

No Pity, Joe Shapiro, 1993

Monographs and Articles

"Challenges of Emerging Leadership: Community Based Independent Living Programs and The Disability Rights Movement," The Institute for Educational Leadership, publisher, funded by a grant from the Mott Foundation (#81-332), a report of a "leadership conference" held in August, 1982. Addresses unavailable, but suggests contacting Mott Foundation in Lansing, Michigan.

"Consumer Control in Independent Living," M. Shreve, P. Spiller, E. Griffin, N. Waldron and L. Stolzman, Center for Resource Management, Route 150 at Highland Road, South Hampton, NH 03847. The monograph, "The Independent Living Service Model" is also available from CRM.

"Independent Living: Preparing for the 21st Century," report of a national conference held in Oakland, CA, October, 1991; published by CIL, Berkeley, 2539 Telegraph Avenue, Berkeley, CA 94704, 1992.

"A People's History of Independent Living," Chava Willig Levy, Research & Training Center on Independent Living, University of Kansas, 66045

"Toward Independence: An Assessment of Federal Laws and Program Affecting Persons with Disabilities - With Legislative Recommendations," February, 1986,

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National Council on the Handicapped [now the National Council on Disability]. Can be obtained through the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402, Stock Number 052-003-01022-4. **AND**

"On the Threshold of Independence: A Report to the President and the Congress of the United States," January, 1988, National Council on the Handicapped [now the National Council on Disability]. Can be obtained from NCD, 800 Independence Avenue, S.W., Suite 814, Washington, D.C. 20591 (202/267-3846).

"Environmental Accessibility and Independent Living Outcomes: Directions for Disability Policy and Research," Gerben DeJong, June, 1981, published in collaboration with the University Center for International Rehabilitation, Michigan State University, East Lansing, MI

"Physical Disability and Public Policy," Gerben DeJong, Scientific American, June, 1983, Vol. 248, No. 6, pp. 40 - 49

"The Movement for Independent Living: Origins, Ideology and Implications for Disability Research" Gerben DeJong, March, 1979, may be available from the University Center for International Rehabilitation cited above.

Periodicals

The Disability Rag, a bi-monthly publication reflecting ideas and discussions in the disability rights movement, available at \$12 for a one year subscription. Write to: Subscriptions, The Disability Rag, Box 6453, Syracuse, NY 13217

This Brain Has a Mouth, another bi-monthly publication started by a head injury survivors group and published out of Rochester, NY. Write to: This Brain Has A Mouth, Inc., 61 Brighton Street, Rochester, NY 14607

Attitudes About and Values Toward Disability: A Self-Assessment

Each statement below makes an assumption or assumptions about people with a wide variety of disabilities. You are asked if you agree or disagree with the assumptions implied by each statement. After you have completed this tool, you will be discussing your responses with others in a small group. Your small group discussion will analyze the assumptions made by each statement and whether or not these assumptions are valid or have been proven in fact.

Assess your attitudes and values about disability by circling the number in each scale that reflects your feelings and thinking. Small group results will help us decide which values are critical to developing an independent living philosophy statement. **BE HONEST!** Make notes or write your questions on the right hand side of each page.

Notes for Discussion

1. Most people with significant disabilities cannot live independently.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

2. Most people with disabilities have low self-esteem.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

3. People with disabilities are a blessing or a gift from God who show us how to cope with life's difficulties here on earth.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

4. People with disabilities deserve as much sympathy, empathy and support as society can give.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

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5. If someone with a significant disability chooses suicide because he/she has no autonomy and cannot live a quality life, we should support him or her.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

6. Families with disabled members face far more physical, mental, emotional, and financial strains than families without disabled members.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

7. Parents of newborn babies with significant medical problems or disabilities have the right to withhold medical treatment from their infants, letting nature take its course.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

8. People with disabilities have the same aspirations, dreams, desires and needs as anyone else.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

9. One of the worst problems facing people with disabilities is the attitudes of others about disability.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

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10. People with disabilities deserve support, but not at the expense of the American taxpayer.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

11. Compliance with the Americans with Disabilities Act is costly and generally unreasonable, given the few people with disabilities in the total population.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

12. Most people with disabilities get their specific disability-related needs met through medically-oriented services and programs.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

13. Being 75% or more disabled means that you cannot work.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

14. Sheltered workshops are necessary because they help people with very severe disabilities learn about work.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

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15. Supported employment programs are great because they provide people with disabilities with special job coaches; without job coaches, these individuals would not be able to work in a competitive setting.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

16. People with disabilities should be expected to take risks, make mistakes, and compete with others...just like everyone else.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

17. Reasonable accommodations for a qualified employee with a disability are generally a minor expense in relation to the quality and productivity received from the worker.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

18. I would hire someone with a disability who was qualified for a job, even if I had to make reasonable accommodations for the individual.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

19. It would be difficult to fire someone with a disability from a job.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

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20. People with disabilities should not have sex or procreate (have children); they could have children with disabilities or, at the very least, their children with have a difficult childhood.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

21. It is truly inspiring to see how some people with disabilities overcome their disabilities to achieve major goals.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

22. People with disabilities need love and attention from family members and others.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

23. Some people with disabilities get awards, recognition, or jobs only because they have disabilities.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

24. People with disabilities have been treated like second class citizens for too long now.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

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25. All social service and advocacy programs, including social security and related benefits, should focus their attention on making this an accessible society in which to live, work, and play.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

26. People with disabilities are a distinct and diverse minority group which are creating a disability culture and politic.

1 2 3 4 5 6 7

27. People with disabilities can do almost anything that non-disabled people do (unless it is a specific task specifically related to their disability such as, blind people cannot drive) -- they just do it differently.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

28. People with disabilities often need the advice and guidance of specialized professionals to help them live a quality life.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

29. People with disabilities are more comfortable around their own kind.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

30. Housing which is affordable and accessible to people with disabilities is best located in one building where all necessary non-medical services and personal needs can be met easily and cost-efficiently.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

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31. Special education helps children with disabilities learn alongside non-disabled children in public education settings.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

32. People with disabilities face enormous personal struggles to overcome negative attitudes and compete with others for work.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

33. Most people with disabilities who are filing suit under the Americans with Disabilities Act (ADA) are people with back injuries who are trying to get more than their fair share of workers' compensation benefits.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

34. People who are blind have nothing in common with people who are deaf, physically or cognitively disabled.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

35. If people with disabilities could gain access to assistive technology, they would live higher quality lives.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

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36. People with disabilities generally are not skilled enough to work competitively.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

37. If we allow people with disabilities full access to health care and medical insurance, especially long-term care, our nation's medical costs will greatly increase.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

38. Many people with disabilities abuse accessible parking laws by allowing non-disabled people to drive their vehicles or use their placards to park in reserved, accessible spaces.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

39. People with disabilities are always asking for more and more special favors.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

40. If a person with a disability needed help with anything, he or she should be able to get what they need from a special organization set up to help people with his or her specific type of disability.

1 2 3 4 5 6 7

Strongly
Disagree

Strongly
agree

Myths and Misconceptions About Independent Living Philosophy

Mark each statement with a T for true if you think the statement is true or a F for false if you think the statement is false. If you cannot decide whether the statement is true or false OR if you think it is both true and false, then mark the statement with an *. Think carefully and deeply about each statement before you respond. Make any notes or questions you have about a statement on the right hand side of each page.

Your Notes:

- _____ 1. Independent living is a service delivery system designed to enable someone with a severe disability to live as independently as possible.
- _____ 2. The independent living philosophy is a collection of key values, principles, attitudes and behaviors related to how services should be provided so that people with disabilities live independent, integrated, and full lives.
- _____ 3. One of the primary principles of the independent living philosophy is "consumer control."
- _____ 4. Independent living would not be possible without federal funding support from Title VII of the Rehabilitation Act.
- _____ 5. In order to be eligible for independent living services, a person must be able to prove that s/he has a severe disability which limits her/his ability to function independently in the family or community or to gain, maintain or advance in employment.
- _____ 6. Independent living services were created by the Rehabilitation Act of 1973, as amended in 1978, to help people whose disabilities are so severe that they could not benefit from the basic vocational rehabilitation program.
- _____ 7. If an organization is "consumer-controlled," a majority of its board of directors and a majority of its staff are people with disabilities.
- _____ 8. Centers for independent living were created with funds from the federal Rehabilitation Act for the sole purpose of providing services to people with severe disabilities.
- _____ 9. Centers for independent living develop policies and procedures based upon the ideals of the independent

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living philosophy which was built upon the principles of the civil rights movement, self-help, and peer role models, "consumerism" (as practiced by consumer advocates like Ralph Nader), deinstitutionalization and de-medicalization.

- _____ 10. Centers do not use medical model, social work or professional service provider practices in their work with people who have disabilities.
- _____ 11. The primary activity and focus of a center practicing independent living philosophy is systems or social change.
- _____ 12. The mission and purpose of a center practicing independent living philosophy is to eliminate attitudinal, architectural and communication barriers to full integration of people with disabilities.
- _____ 13. The independent living philosophy is rooted in "consumer choice" which means that centers and service providers must assist and support the choices individuals with disabilities -- even if it means moving into a nursing home.
- _____ 14. Independent living means having control over your own life and being able to make decisions about life, work and play in the same ways that people without disabilities do.
- _____ 15. As funded by the Rehabilitation Act, one of the most important features of independent living services is the development of an individual's independent living plan.
- _____ 16. According to the Rehab Act, Independent living services always include an intake, assessment, determine of eligibility, independent living plan, maintenance of the consumer's service record, and evaluation based upon goals set and goals achieved.
- _____ 17. If a center receives Title VII Part C funding through the Rehab Act and center staff are unsure about a particular individual's disability and its effects on daily living, they secure a release of information from the consumer and obtains copies of medical records, diagnostics, and/or social history files from agencies serving that consumer.

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- _____18. If an individual with a disability doesn't cooperate with center or service provider staff on a signed independent living plan, then services may be discontinued and that consumer's case may be closed as "uncooperative."
- _____19. Center and service provider staff must document their work in consumer case files in the event that a federal or state program audit is conducted.
- _____20. In keeping with independent living philosophy and according to the Rehab Act, consumers of independent living services must be notified of and told how they may contact the state's client assistance program (CAP) if they are dissatisfied with services, service decisions, or policies of providers.
- _____21. The independent living philosophy is built upon commonly understood definitions of civil rights, social justice and equality of opportunity and participation in society.
- _____22. Independent living philosophy is difficult to practice because of traditional and long-held views and attitudes towards people with disabilities.
- _____23. A "systems or social change" approach means that the problems associated with disabilities are presumed to be located in the environments, systems or society that already exist...not in the person with a disability.
- _____24. To be true to the independent living philosophy in practice, one would never treat a person with a disability any differently than someone without a disability.
- _____25. If the independent living movement has struggled or failed to make its philosophy known and understood, it may be because centers, leaders and advocates have not known how to educate others about it.
- _____26. Independent living services are different from traditional medical, rehabilitation, or charitable social services only because they are provided by people with disabilities.
- _____27. The truest measure of success for people with disabilities living independently is how much control they have over their lives and how satisfied they are with the quality of their lives.

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- _____28. If all centers and service providers practiced the independent living philosophy, people with disabilities would have more control over their lives and over the organizations, programs, and services in which they have a stake.
- _____29. On a personal level, practicing the independent living philosophy means being assertive about what you want and advocating for systems and social change so that negative, medical model, and charitable attitudes about disabilities are eliminated.
- _____30. Consumer control means that you, the "consumer" of services or products, have complete freedom and control over living in the community and style of your choice.

Myths and Misconceptions About Independent Living Philosophy
Maggie Shreve's Opinions and Answers

- F 1. Independent living is a service delivery system designed to enable someone with a severe disability to live as independently as possible.

Independent living is a way of thinking about life which may involve services but which may not. It is being able to control your life, advocating for yourself, or knowing how to get support from others to do what you want and/or need to do. Many people with significant disabilities live independently without on-going support services.

- T 2. The independent living philosophy is a collection of key values, principles, attitudes and behaviors necessary for people with disabilities to live independent, integrated, and full lives.

Any philosophy is a collection of key values, principles, attitudes and behaviors, including the independent living philosophy. The problem associated with independent living philosophy across centers and the nation's human service delivery system is that it is not understood and, therefore, is not practiced.

- T 3 .One of the primary principles of the independent living philosophy is "consumer control."

"Consumer control" is at the heart of independent living in every way. The individual with a disability MUST have control over his or her life and all decision-making.

- F 4 .Independent living would not be possible without federal funding support under Title VII of the Rehabilitation Act.

Independent living is a way of life. When considering funding for "independent living" concepts, there were several centers for independent living before federal funds were funneled into Title VII of the Rehabilitation Act. There have been people with significant disabilities living independently long before there were centers. Federal funds were designed to make living independently easier through better support mechanisms, but even this is questionable given the practice of many centers and service providers across the nation today.

- F 5 .In order to be eligible for independent living services, a person must be able to prove that s/he has a severe disability which limits her/his ability to function independently in the family or community or to gain, maintain or advance in employment.

When talking about programs and services under Title VII of the Rehabilitation Act Amendments of 1992, many believe that people with disabilities must prove they are eligible. Yet, centers are expected to serve anyone and everyone with information and referral services (I&R). The other three core services (advocacy -- both

individual and systems, independent living skills training, and peer counseling) may be provided to individuals who meet the federal definition of someone with a "significant disability." But this too, can be easily handled by asking the individual with the disability to make a determination of whether or not they meet the federal definition.

- F 6. Independent living services were created by the Rehabilitation Act of 1973, as amended in 1978, to help people whose disabilities are so severe that they could not benefit from the basic vocational rehabilitation program.

The original intent of the Title VII amendments to the Rehabilitation Act in 1978 were to initiate centers and to provide services. Regulation and practice created the notion that a person determined "too severely disabled" for the vocational rehabilitation program under Title I would be eligible for services under Title VII. As of the amendments made in 1992, these distinctions have been totally removed from the Rehab Act.

- T 7. If an organization is "consumer-controlled," a majority of its board of directors and a majority of its staff are people with disabilities.

The above is true, but consumer control should go beyond mere numbers. Consumer control should be a way of working, a way of thinking, a way of advocating for broad community and systems change. There are many organizations which have a majority of people with disabilities on their board of directors and hired as staff who do not practice consumer control in their programs or services.

- F 8. Centers for independent living were created with funds from the federal Rehabilitation Act for the sole purpose of providing services to people with severe disabilities.

Like number 6 above, the 1978 amendments to the Rehabilitation Act were written to fund the establishment and operation of centers for independent living, but not for the sole purpose of providing services to individuals with disabilities. They were also created to act as catalysts for social and systems change.

- T 9. Centers for independent living develop policies and procedures based upon the ideals of the independent living philosophy which was built upon the principles of the civil rights movement, self-help, and peer role models, "consumerism" (as practiced by consumer advocates like Ralph Nader), deinstitutionalization and demedicalization.

If centers are practicing the independent living philosophy, they have policies and procedures which support the principles of these five earlier social movements. The independent living movement is patterned after civil rights, self-help, consumerism, deinstitutionalization and demedicalization movements of the 1960s and 1970s.

- F 10. Centers do not use medical model, social work or professional service provider practices in their work with people who have disabilities.

Centers often fall into the trap of "professionalizing" their staff, copying medical model, social work or charitable role models. While having degrees in medical fields, social work or other specialties are not, in and of themselves, barriers to working for a center for independent living, they should NOT be criteria FOR working at a center.

- T 11. The primary activity and focus of a center practicing independent living philosophy is systems or social change.

An exemplary center -- one that practices the independent living philosophy daily and is known within the disability communities it serves as a leader in practicing the independent living philosophy -- would have systems and social change as its primary focus. Providing services to individuals with disabilities is simply a method for spreading the word about what this philosophy means and how it can change attitudes and values about living with disability.

- T 12. The mission and purpose of a center practicing independent living philosophy is to eliminate attitudinal, architectural and communication barriers to full integration of people with disabilities.

These should be the foundations of a center for independent living. Like number 11 above, centers which practice the independent living philosophy and root their work in civil rights, consumerism, self-help, demedicalization and deinstitutionalization are working on the removal of barriers and promotion of full integration.

- F 13. The independent living philosophy is rooted in "consumer choice" which means that centers and service providers must assist and support the choices individuals with disabilities make -- even if it means moving into a nursing home.

Centers advocate choice for individuals with disabilities OVER ACCEPTABLE OPTIONS. The problem with living with a disability in America today is that the options available are not acceptable. Whenever a person with a disability "chooses" to live in an environment where s/he has LESS CONTROL, this is not independent living. Centers should be highly visible agents of social change which do not accept institutionalization based upon the presence of a disability. If someone chooses to live in a nursing home, that may be fine for him or her but it is not appropriate for a center to help in making that move. There are hundreds, possibly thousands, of social service agencies which help people move to more dependent living arrangements.

- T 14. Independent living means having control over your own life and being able to make decisions about life, work and play in the same ways that people without disabilities do.

This is exactly what "independent living" means.

- F 15. As funded by the Rehabilitation Act, one of the most important features of independent living services is the development of an individual's independent living plan.

The 1992 amendments to the Rehabilitation Act make it perfectly clear that an independent living plan is not necessary if the individual with a disability believes it to be unnecessary. The independent living plan is not pivotal to the provision of independent living services.

- F 16. According to the Rehab Act, Independent living services always include an intake, assessment, determination of eligibility, independent living plan, maintenance of the consumer's service record, and evaluation based upon goals set and goals achieved.

Completing "intakes," "assessments," "determinations of eligibility," "independent living plans," and the like are copies of the traditional medical model or social work method of case management. These are inappropriate for centers for independent living because they do not vest control in the individual with the disability. The center is responsible for documenting work done with individuals, but it is not responsible for using the same methods as all the service providers use. Centers were created to be different from service providers -- not the same.

- F 17. If a center receives Title VII Part C funding through the Rehab Act and center staff are unsure about a particular individual's disability and its effects on daily living, they secure a release of information from the consumer and obtains copies of medical records, diagnostics, and/or social history files from agencies serving that consumer.

If someone with a disability comes to a center, declares that s/he meets the federal definition of someone with a significant disability and wants independent living services, this should be sufficient for center staff. Only if the person will not identify what her/his disability is should any additional information be needed. In the event that the person will not reveal this information or does not know this information, the center staff can assist the person to get information from other providers...but the information should go back to the consumer, not to the center. Centers have no need for such material in a consumer's service record, but perhaps the consumer her/himself would benefit from knowing what exists elsewhere.

- F 18. If an individual with a disability doesn't cooperate with center or service provider staff on a signed independent living plan, then services may be discontinued and that consumer's case may be closed as "uncooperative."

Center staff should seriously question why any individual consumer is not involved in following through with a plan s/he developed for her/himself. It makes me wonder if,

in fact, the plan was the consumer's in the first place -- perhaps it was the staff member's? But if a consumer is no longer interested in pursuing her/his own plan, then the center can simply move that person's name from one statistical list to another. Centers do not need to "close" files at all.

- F 19. Center and service provider staff must document their work in consumer case files in the event that a federal or state program audit is conducted.

Centers do not maintain "case files." They keep consumer service records to prove that they provided services to specific individuals. A federal or state audit would examine these records, so they must be kept. Centers should not, however, think of them as "case files" or staff may fall into the trap of thinking of themselves as "case managers."

- T 20. In keeping with independent living philosophy and according to the Rehab Act, consumers of independent living services must be notified of and told how they may contact the state's client assistance program (CAP) if they are dissatisfied with services, service decisions, or policies of providers.

Anyone receiving services from funding through the Rehabilitation Act must be informed about and how to contact their state's client assistance program. This is in keeping with the "consumer control" principle of independent living philosophy. An informed "consumer" makes the best choices for him/herself. An informed "consumer" should be involved in a center's operations, plans, and structure in capacities other than that of "a consumer."

- T 21. The independent living philosophy is built upon commonly understood definitions of civil rights, social justice, personal responsibility, and equality of opportunity and participation in society.

Like earlier statements on philosophy, independent living is a campaign cry for equal rights and integration. Combined with the group call for justice is a demand for personal responsibility on the part of individuals with disabilities. After all, it is individuals with disabilities and their advocates who are responsible for enforcement of all federal civil rights laws providing protection from discrimination. While these principles are commonly understood in racial, minority, gender and age discrimination cases, they are not well understood among people with disabilities. One of the most critical roles of a center is to promote that understanding among people with disabilities and the public.

- T 22. Independent living philosophy is difficult to practice because of traditional and long-held views and attitudes towards people with disabilities.

Attitudes about and values toward people with disabilities have developed over thousands of years of recorded history. Changing the negative ones is the principle

job of the independent living movement. This will not happen overnight, but it will happen more quickly if centers practice independent living philosophy well.

T 23. A "systems or social change" approach means that the problems associated with disabilities are presumed to be located in the environments, systems or society that already exist...not in the person with a disability.

True. Centers should take a "systems-wide" approach to resolving disability-related problems rather than a "fix the person" approach. The "fix the person approach" stems from the medical model and is pervasive within the entire field of human services for people with disabilities. Centers should be different.

T 24. To be true to the independent living philosophy in practice, "customer satisfaction" behavior has to be understood and practiced (i.e. one would never treat a "customer" with a disability any differently than a "customer" without a disability or any differently than you personally would want to be treated).

Most people who work in centers would never complete all the paperwork required if their own lives were in question. Centers must examine everything they do -- from how the telephone is answered to how people are treated when the necessary paperwork is being done -- to determine if they are treating people with dignity, honor, and respect. Centers which think of themselves as professional service providers are generally not treating people with disabilities the way non-disabled people would be treated.

T 25. If the independent living movement has struggled or failed to make its philosophy known and understood, it may be because centers, leaders and advocates have not known how to educate others about it.

My own personal observation about the lack of understanding of philosophy is rooted in the problem of how to educate and train others in something which is just evolving now. Frankly, many people may have some good ideas but they may not be able to effectively educate others about them because they do not yet have these educational skills. This should be a primary task of our movement's leaders -- learn how to train others effectively, train your own staff and board members, train people with disabilities, and then work on how to educate the rest of the community.

F 26. Independent living services are different from traditional medical, rehabilitation, or charitable social services only because they are provided by people with disabilities.

Unfortunately, too many centers are providing traditional medical model, rehabilitation or charitable social services -- even though the staff are people with disabilities. When I ask center staff "How are you different?," this is the most typical answer I receive. Just having people with disabilities in staff and board positions is

no guarantee that independent living philosophy will be believed or practiced. Centers must go further. They must provide their services differently, act differently, be different in attitude and approach. Only then, will people with disabilities who are still oppressed and living in dependent situations begin to understand their personal and collective power to change.

T 27. The truest measure of success for people with disabilities living independently is how much control they have over their lives and how satisfied they are with the quality of their lives.

If centers are truly making a difference in their communities and in the lives of the people they serve, then success would be that people with disabilities have control over their lives and are happy with the way they are living those lives. So far, I have not seen one center which measures its own success based upon these criteria. I think it is because we don't know how -- which is fine -- but the time has come to work on figuring that out and putting it in place in all of our centers.

T 28. If all centers and service providers practiced the independent living philosophy, people with disabilities would have more control over their lives and over the organizations, programs, and services in which they have a stake.

If everyone understood independent living philosophy, then people with disabilities would be taking on stronger and stronger roles. They would be on boards of directors, running for public office, joining the PTA, advocating for accessible polling places, becoming staff or directors of programs and services, etc. Too many people are afraid of what consumer control means. Too many "professionals" think that people with disabilities do not know what is really best "for them." When people with disabilities assume the role of assertive consumer and ask professionals or specialists for the information or help they need when they decide they need it, they still run into defensive and hostile attitudes from many professionals. Only through self-help and peer support will people with disabilities be able to change this reaction and, ultimately, change the very nature of the organizations established to serve people with disabilities.

T 29. On a personal level, practicing the independent living philosophy means being assertive about what you want and advocating for systems and social change so that negative, medical model, and charitable attitudes about disabilities are eliminated.

As friend and fellow disability rights advocate/consultant June Isaacson Kailes puts it, an assertive person who seeks systems and social change is the real "disability hero." If each of us worried less about controlling others and worried only about being assertive in our own lives, the world would be a saner place. People with disabilities have been told what to do, how to do it, when to do it and where to do it for so long that becoming assertive seems next to impossible. Center staff should be totally supportive of all assertive behavior, encouraging its expression at all times.

Being assertive and not caring about what others think is what will eventually change the negative attitudes and values we have inherited.

T 30. Consumer control means that you, the "consumer" of services or products, have complete freedom and control over living in the community and style of your choice.

True again. If people with disabilities have true control over their lives, then they can go where they want, when they want and with whom they want at any time. The world would be an accessible place for everyone. Anyone who can breathe and move one digit, as Lou Brown (academic advocate for people with developmental disabilities at the University of Wisconsin-Madison) would say, would be working at competitive wage jobs. And there would be adequate support services, such as personal assistance and assistive technology, available at low cost or no cost depending upon the income level of the individual with the disability. If these things were in place, everyone would have freedom to live where they want and in the lifestyle they want...the ultimate goal of the independent living movement.

Independent Living Philosophy: Stop Action Skit

The following script is for a skit to be performed as part of training on independent living philosophy. If you are not participating in a training where the skit can be produced for the entire group, you can still benefit from reading through it. As you read the skit, decide for yourself where independent living philosophy is being violated.

How is independent living philosophy being violated?

What is happening in the skit?

How does the behavior of the center staff make you feel?

What have you learned from the interactions in the skit?

What implications does the skit have for your center in terms of its policies, procedures, practices, and philosophy?

What values must center staff have to practice the independent living philosophy effectively?

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Independent Living Philosophy: Stop Action Skit

This skit requires three different actors. The skit can be stopped at the end of each scene OR at any time by any member of the audience who thinks that an issue related to the practice of independent living philosophy has been demonstrated. When the skit is stopped, the facilitator asks any of a series of questions to generate discussion about that portion of the skit witnessed so far.

The roles required are:

- LEE** A staff member of a center for independent living who provides services to individuals with significant disabilities.
- KIM** A person with a significant disability who is seeking some assistance from the center to move from parents' home to own home.
- SAL** Lee's supervisor at the center for independent living.
- Setting:** The entire skit takes place within a center for independent living's offices over a two month period. Some scenes are in Lee's office and some are in Sal's office. The time period will be marked each time the skit moves forward in time.

Scene 1

- Facilitator:** It is a nice day in March, 1993. We are watching Lee and Kim meeting each other for the first time in Lee's office.
- Lee** Hello, Kim. It is nice to meet you. I'm glad that you could come to the office today to complete this intake I have to do. Please ... make yourself comfortable.
- Kim** I'm not really sure what you mean by an intake. I hope I have all the information you need.
- Lee** Well, don't worry. Any information we don't gather today, I'm sure we can get it soon. Let me explain our intake process to you, OK?
- Kim** OK.
- Lee** When you come to a center for independent living -- which is what we are here -- you must be determined eligible for the services we provide according to federal law. We receive funding from the federal government and

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it has strict requirements for who can be served. So, to make sure that you are eligible for what we offer, we complete an "intake" form. It's sort of like an application. It answers all the questions we need to have on file in case a federal employee comes to audit our program. Is that clear?

Kim Sure, I guess.

Lee OK. Let's get started. What is your full name?

Kim Kim H. Wallace. I have no middle name, just an initial.

Lee And where do you live?

Kim [Give your own address...or] 1523 West Edgewater, here in Chicago. The zipcode is 60660.

Lee What is your telephone number?

Kim 312/989-4385 [or give your own].

Lee Now I need your social security number and Medicaid or Medicare numbers if you have them.

Kim 123-45-6789 [or give your own]. I don't know my Medicaid number off the top of my head. Why do you need these numbers?

Lee The federal government requires that we get these numbers. I'm not sure why.

Kim Well, maybe we ought to talk a little bit more about what kind of service you provide before we go any further. This is getting a little too personal for me.

Lee Oh, I'm sorry. I usually explain our services before I do the intake. Sure. Let me explain how we work. We are a center for independent living, which means we help people with disabilities become independent. When you come to us for service, we find out what you want to do with your life -- what your goals for independence are -- and then we help you achieve them. The paperwork we have to do is really just to support the nature of our service relationship. After the intake is complete, then you and I will talk about your independent living goals. When we think we have established reasonable goals for you, then I write them up into an "independent living

plan." If you are satisfied with this plan, then it becomes the basis for our work together. Is that clear?

Kim I guess so. But what do you **do, exactly**? I mean I want to move out of my parents' home and I need help to do that. Do you help me find a place and get enough money to live on my own? A vocational rehabilitation counselor told me that you provide rehabilitation services for people who don't have vocational goals. Is that right?

Lee Well, sort of. Many people with severe disabilities haven't been eligible for the vocational rehabilitation program because their disabilities were so severe. But the independent living program helps them through centers like ours, whether they have a vocational goal or not. Some of the people who come here have vocational goals and some don't. Many of our clients are pretty severely disabled and probably would have a difficult time getting a job in the competitive world. So, in some ways, your voc. rehab. counselor is right. Are you getting services from the state voc. rehab. agency now?

Kim I'm not sure. I have seen this one counselor, but only once. He did an "intake" too and said he wasn't sure they could help me. I thought that is why he referred me to you.

Lee That's OK. We can check on that later. What's important is that you have an independent living goal. It sounds like you do if you want to move out of your parents' home, right?

Kim Yes. But what do YOU do for me?

Lee What I do is show you how to do things for yourself. We have independent living skills training classes here at the center where you can learn to do many things for yourself. We also have peer counselors who can work with you when you want to discuss emotional issues like coping with your disability and stuff like that. You can call here at any time during our business hours for what we call information and referral. That means that you call with a question and we answer the question with information from our library or we refer you to someone else who may be able to answer the question. And we do advocacy, meaning that if you need our help as an organization to resolve a problem -- like let's say a

landlord refuses to rent you an apartment that you can afford and you think it is because you have a disability -- then we would help you file a complaint with the U.S. Department of Housing and Urban Development ... if you wanted to do that.

Kim Well, it all sounds good, but I'm still confused about how you do things.

Lee Maybe it would be easier if you just thought of me as your case manager. You have had a case manager before, haven't you?

Kim Yes, I had one when I was in school and I have one at the recreation program I attend.

Lee OK...just think of me like you think of them. I help you find the resources you need to do the things you want to do. Sometimes I will make calls for you and sometimes I will simply show you how to make a call for yourself. We can meet whenever and wherever you want ... within reason of course!

Kim OK. I think I get it now.

Lee Good. Now, let's get back to that intake.

Scene 2

Facilitator: It is now a week later and Lee is meeting with Sal in Sal's office.

Sal So let's go over your intakes from last month. Anything interesting or unusual?

Lee Well, I had a few referrals from VR who didn't know why they were coming to see us -- AGAIN! You know, I'm getting really tired of this. The VR staff knows what we do, don't they? I feel like I waste a lot of time just explaining what our services are to new clients when I think they should already know what we do if they were referred by another professional.

Sal Hmmmm. Maybe we need to increase our outreach efforts. Let's be sure and talk about this at the next full

services staff meeting. So how many ILPs did you complete?

Lee For the whole month, I had 40 ILPs. Of course, I haven't seen many of them but once or twice. You know I'm up to 100 on my caseload now and it's getting tougher and tougher to write out those plans. Isn't there some way we could ease up on some of the paperwork?

Sal Not that I can see. Even with the new Rehab Act, the feds seem to want a lot and so does the state. I think the Executive Director is working on that through the state association. But I'm glad you brought that up. I'll talk with the Executive Director about it shortly and get back to you when there is some news. So, anything else on your mind these days?

Lee Actually, yes. I had new client last week, Kim Wallace. Kim seemed pretty naive -- like a lot of those VR referrals. What struck me about Kim that was kind of different from most others I see is that she/he was reluctant to give out personal information like social security number and stuff like that. She/he didn't want to sign the independent living plan either until I told her/him that we couldn't provide services until that was done.

Sal It could be that Kim has had some problems elsewhere. Did you explain how we were different from other service agencies because of the independent living philosophy?

Lee I tried to, but I don't think she/he got it. Maybe Kim is retarded too and we just don't know it.

Sal Well, then why don't you ask for her/his records from some other agencies. You did get information about where else Kim has been, didn't you?

Lee Sure. I simply forgot to ask Kim for a release. I'll do it when I see her/him next time. Thanks. I really don't have any other news. Anything new on the salary increases?

Sal Nope. I guess the Finance Committee is still working on the budget with the Executive Director. Believe me, if anything changes, I'll let you know.

Scene 3

Facilitator: We are back in Lee's office now. Lee is asking Kim to sign a release of information so that the center can gain copies of Kim's files from other agencies.

Kim I just don't understand why you need this information. I signed the independent living plan. We have agreed on the goals I'm trying to achieve. What does other agency information matter?

Lee It's a matter of professional protocol, if nothing else. How can I help you if I don't know what you've been through with other agencies? Maybe you have disabilities we haven't discussed and those will affect how successful you can be. I know that additional information will help me work with you more effectively.

Kim I can tell you right now that I didn't like those other agencies. I always felt like I was being patronized.

Lee Patronized? That's a mighty accusation. You think the staff of these agencies were treating you like a child? Is that what you mean?

Kim Yes. That is exactly what I mean. [Getting more emotional...] I may be disabled, but I'm not stupid. I want to live my life like other people do, but if I have to keep going to these "special" agencies, I don't think I'll ever get there.

Lee Whoa, now! Don't get all worked up about this. We can work something out. Let me think for a moment. [Pausing, thinking] How about if YOU request a copy of your records and then we can go over them together here in the office?

Kim [Pausing, thinking this offer over first...] Ummm. Maybe I would like to see what those records say. Yes, maybe that will be all right.

Lee You know some case file information may be too confidential for you to see. I know there are certain service agencies who withhold information from their clients because the information can be harmful to the client or the client's progress. So, don't assume we will get everything we want.

- Kim** What could possibly be harmful to me?
- Lee** Oh, you know. Stuff like psychological exam results or diagnostic reports. Sometimes they are hard to read if they are about you.
- Kim** But shouldn't I know what's in those files about me. It's my life, isn't it?
- Lee** Sure it is. Let's just complete this release form and have them send what they will to you, care of the center's address. Then I'll call you when they come in and we can go over them together. OK?
- Kim** I guess.

Scene 4

- Facilitator:** It is now six weeks later. Certain file contents about Kim have come into the office and Lee is reviewing them with Sal.
- Lee** Look here. It says that Kim is unmanageable and manipulative. The psychologist thinks there may even be some pathology to Kim's behavior but the family wouldn't let him do any more testing. What do you suppose that means?
- Sal** It could mean lots of things. It's hard to say without more detailed notes. But you can confirm the unmanageable description, can't you? Maybe Kim isn't ready for independent living. It almost sounds like she/he has a big chip on the shoulder. Maybe moving to an apartment is biting off more than Kim can chew right now. How well do you think Kim gets along with other people? Have you watched her/him interact in a skills training class or in a support group?
- Lee** Kim does seem awfully defensive with other people. Kind of angry all the time. I'm not sure where it is coming from, but Kim is not real friendly.
- Sal** Well, then, maybe you should look at some social skills development. Maybe you should meet with the voc rehab counselor to see what the status is there and talk with

him or her about the skills training Kim needs. You know ... as of April 1st, VR is paying us \$60 per hour for skills training if it is written into the client's IWRP. Kim might be a likely candidate for such fees if you can convince the VR counselor that Kim needs it.

Lee Good idea. I think I'll call Alex over at the local VR office. What should I do with the rest of these copies from Kim's files?

Sal Well, I'm not sure Kim needs to see most of this. Why don't you simply remove those pages which seem to indicate problem areas and leave in the information which is pretty neutral. Share the neutral information with Kim and file away the rest of it.

Lee OK. I hope Kim doesn't ask about it, though. I will feel pretty badly if I'm forced to lie about what came in to us.

Sal Don't worry about it. Kim will be anxious to read the stuff you do share.

Lee OK, Sal, thanks.

Scene 5

Facilitator: We are back in Lee's office again. Kim has just reviewed the copied material that had been sent to the center and that Lee has decided to share. Kim is looking upset.

Lee You don't look happy, Kim. What is it?

Kim There's not much here, is there? And why was this opened? Wasn't it addressed to me in care of the center?

Lee Oh, I think it came to the center in both our names. That probably was a clerical screw up. I'm sorry. Did you want to see it first?

Kim Well, I would have thought that something addressed to me should be opened by me, wouldn't you?

Lee Yeah. I guess you're right. I'm sorry.

Kim That's really not what's bothering me, though. I got a call from Alex Conrad, my VR counselor. He told me that you had recommended that I take skills training classes in social adjustment, pre-vocational skills, and other subjects. He said that if I would take these classes, he would finish up the eligibility requirements so I could enter the voc. rehab. program. Frankly, I don't think I need those classes and I can't understand why you would tell him I needed them without talking to me first. What happened to the goals in my independent living plan? Where are we going on that?

Lee Listen, Kim, sometimes we see things that people need that doesn't go into their written plan. This was one of those things. I was talking to Alex about your case and suggested some skills training would be helpful. That's all. We offer them here, you know. You don't have to go anywhere else for these classes.

Kim I don't care where the classes are! That's not the point! The point is that Alex is making me take these classes so that I can enter the voc rehab program. I have some ideas about employment I want to work on, but I don't like being told I have to do one thing before I get to do something else. It feels like I'm being held hostage to you two.

Lee Oh come on now. It isn't that bad! How can a few classes hurt you? Why wouldn't you assume that they would help you? I know for a fact that the people who go through our classes are far more ready for independent living than those who just try to wing it. I think the VR counselors are beginning to realize the value of our classes too. Frankly, I'm flattered that Alex thought enough of our program that he recommended you take it before you begin working on an IWRP.

Kim [Really mad now.] That's it! I've had it! You are just like all the others. All you care about is your program and if I fit into it. You don't care about me. You care about your funding and your professional status. I'll find my own apartment and get my own job! You and VR can go take a flying leap! [Kim leaves Lee's office in a huff.]

Lee Oh shoot! Another "uncooperative" closure! [Lee looks at the audience in frustration and walks off].

Independent Living Philosophy: Reality Versus Rhetoric Test

[Editor's Note: This section originally contained a document co-authored by Maggie Shreve and June Isaacson Kailes which reflected their personal view of how the philosophy should be practiced. It was a self-analysis of how well a center for independent living practices independent living philosophy. Subsequently, the document was revised and updated in 1999 by Kailes and can be ordered from her at 6201 Ocean Front Walk, Suite 2, Playa del Rey, California 90293, or online at <http://www.jik.com/resource.html> and click on "Independent Living."]

Case Studies In Independent Living Philosophy

The Age-Old Temptation

You are a member of the board of a small, rural independent living center. The state health and welfare agency has asked your center to submit an application in response to a "request for bids" to serve people with HIV infection. The total value of the service contract is \$150,000.

People with HIV or AIDs are under-served in your service area. The board decided to target outreach to people with HIV or AIDS as part of its last long-term planning process.

The purpose of the program funding is to provide support services for people with HIV infections or full blown AIDS so that they can remain in the community. Your board feels strongly that the center can fulfill the intentions of this program. It wants to serve people with HIV/AIDS. And, the center can certainly use the funding.

The request for bids contains a number of key requirements that your center will have to meet to qualify for funding. These include:

1. A qualified, certified social worker with a minimum of a master's degree must coordinate the program.
2. A registered nurse must be on staff full-time to deal with medical needs of people who are HIV or who have AIDS.
3. At least two full-time case managers must be employed to do outreach, counseling, case management and provide related support services to people with HIV/AIDS.

These requirements do not fit your current personnel policies, job descriptions, organizational chart or hiring patterns. The center has never required medical degrees or professional certifications for its positions because of independent living philosophy or because such certifications may discriminate against qualified people with disabilities.

- As a board member, what issues should be raised in the debate about whether or not to seek this funding?
- What is your opinion?
- What will the board finally decide?

CASE STUDIES IN INDEPENDENT LIVING PHILOSOPHY

Changes in Direction

Your center has an effective, working housing committee, composed mostly of consumers with disabilities. This committee's purpose is to work with staff to secure adequate, accessible, affordable housing in integrated settings in the community for people with various types of disabilities. The committee has conducted two highly successful projects thus far:

- It conducted a survey of all residential complexes with eight apartment units or more for accessibility and then compiled this data into a computer data base for the center's information and referral service.
- It also sponsored a series of workshops for local builders, developers, construction companies, lawyers and architects on the Fair Housing Amendments Act and the Americans with Disabilities Act. These workshops resulted in at least one developer making a commitment to build all his new rental housing with at least 10% of the units meeting ANSI or ADAAG standards for architectural accessibility.

Representatives of five different social service organizations joined the center's housing committee in the last few months. At first, everyone was delighted. No one would have suspected a problem. But after three meetings, it became evident that the social service agency representatives were advocating for the center to build a HUD 202 high-rise apartment building just for people with disabilities. The consumers on the committee were silent at first -- just listening to the suggestions and ideas of the professional social service providers. More recently, however, they began to support the idea of building a HUD 202 project. After all, they reasoned, it would be easier to house everyone with a disability in one place and would cut back on the work of the committee for searching for accessible housing options.

The executive director has brought this information to you after hearing about it from the committee's staff liaison. The housing committee chair is a wonderful person, but he is not very assertive. You, as board president, are concerned that this committee may be getting "off track."

- What should you do?
- Who should you talk to?
- Should the committee continue working on a HUD 202 project or not?

Case Studies In Independent Living Philosophy

Working it Out with VR

You are the executive director of a well-established center in a small, urban area. You have been receiving federal Title VII Part C funding for the last ten years. You also receive state grant funds and are starting a private fund raising effort. Your total budget is \$300,000.

The state vocational rehabilitation agency has been conducting a Title VII Part B (and old Title VII Part A) program of independent living services for the last five years through its own counseling staff. The new independent living unit manager wants to transfer the Part B program to independent living centers across the state. She also wants to combine the Part B services program with a new push to use 110 (basic VR program under Title I of the Rehabilitation Act) dollars to buy independent living services for a wide variety of people with disabilities. She has instructed each regional VR office director to work out a contract with its local center on what services would be provided and how they would be funded -- out of Title VII Part B, 110 (Title I) or both.

You have met with the regional VR director three times in the last month to discuss the service contract and amount. The VR director has been insisting that:

1. VR counselors will "certify" every person you serve through this proposed contract as "eligible" for services;
2. to be "eligible," a medical evaluation and assessment of ability to live independently will be conducted by a well-established vendor who has been used by the state agency for many years (and the money for these evaluations and assessments will be taken out of the contract amount); and
3. each "eligible" client will have an individualized written independent living rehabilitation plan (IWILRP) written by the center's staff but approved by a VR counselor.

You have suggested that these steps are unnecessary, not required by the Rehabilitation Act Amendments of 1992 and will create more bureaucratic red tape. You suggest that every person referred by a VR counselor could be certified as eligible before your center provides services under Title VII Part B. You have explained the independent living philosophy and how the center conducts its services. Yet the regional VR director does not seem to be interested in your suggestions.

- What should you do?
- Who should you talk to?
- How do you think the board will react?
- What do you think the final result of your efforts will be?

1 -- Determining Eligibility

You are the services manager of a small center for independent living in a rural state. Since the Rehabilitation Act was reauthorized in 1992, you have completely restructured your management information system and how your staff documents services provided. Everyone on staff was thrilled when the Rehabilitation Act set standards for centers and no longer required a written independent living plan for people with significant disabilities who did not want them. You and your staff believe that the changes in the law will allow you to practice the independent living principles of consumer control and self-help more honestly.

You now have one "application for services" form where new consumers give basic information about themselves, such as name, address, telephone number, TT/TDD/TTY number, gender, disability type, and, optionally, racial or ethnic group. The form states the federal definition of an "individual with a significant disability" and asks the consumer to self-identify as meeting this definition. It also has a "waiver" paragraph which explains that the center is interested in assisting consumer with the development and achievement of independent living goals, but that a written plan is not necessary for the provision of service. If a consumer does not want to develop a plan, he or she may sign the waiver clause.

A regional Rehabilitation Services Administration (RSA) employee is visiting all the centers in her region. She stopped by to meet your center's staff and discuss changes in the Rehabilitation Act this morning. You were so pleased to show her how you had changed your documentation system, you were shocked when she said, "You mean to tell me that you are not collecting medical documentation proving that an individual has a severe disability? You must have this or how can you determine that someone is eligible for independent living services. The language of the law may have changed slightly, but you have the same obligation you always had -- prove that someone has a disability so severe that they cannot live independently or work without your services. I can see that we may need to do some regional training on this subject."

- What do you say?
- This is a case study about compliance with standard 1 -- promoting and practicing the independent living philosophy. Why?

**The Independent Living Movement: History and Philosophy to
Implementation and Practice by Maggie Shreve**

1 -- Determining Eligibility

Guidelines for Discussion

1. How has the law changed which allowed the services manager to change his/her documentation system?
2. Why would one simple application for services form be a good idea?
3. Why is self-identifying as an individual with a significant disability consistent with independent living philosophy?
4. Why is it important that an individual with a disability be able to waive the development of an independent living plan?
5. Why would the RSA official assume the center was gathering medical documentation to prove the presence of a severe disability?
6. What is the role of RSA in providing training to centers about the Rehabilitation Act Amendments of 1992?
7. Why might a center director change documentation systems to comply with what the RSA official has said?
8. How well do you think the RSA official understands the independent living philosophy?

**The Independent Living Movement: History and Philosophy to
Implementation and Practice by Maggie Shreve**

1 -- Determining Eligibility

Learning Objectives

1. To understand how few statistics and other documentation are required under the new Title VII Part C requirements.
2. To understand how an individual can be determined "eligible" for services of a center based upon the definition of "significant disability."
3. To understand how a center can serve an individual who self-identifies as meeting the federal definition.
4. To understand how a center can serve an individual with a significant disability without developing an independent living plan.
5. To understand how government officials may interpret laws differently than advocates.
6. To be able to respond when government officials tell you, as a center director, to do something a particular way -- whether or not the instruction is a correct legal interpretation of law (or regulation).
7. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to actual service delivery within a center.
8. To be able to think and act differently when first encountering people with disabilities as they come to a center for independent living as opposed to how they are treated by a service provider.

2 -- But We Need This Information to Effectively Serve Joan

You are the executive director of a new, small center for independent living in a town of about 100,000 people. You recently hired a new peer counselor named Manuel. Manuel has his degree in rehabilitation counseling and had been a volunteer for your center before you hired him. His first six months on the job were a breeze and you thought he was on his way to becoming a top notch peer counselor, capable of moving up to a management position within the center as the center grows.

As part of your management plan, you review consumer service records every six months by pulling ten file folders at random from your centralized filing system. You look at five files and begin to see a pattern emerging from Manuel's consumer service records. He appears to ask each consumer for a blanket release of information and then requests medical documentation, psychological evaluations, service notes, and other data from agencies providing services to his consumers. You take one file, Joan's, and go to Manuel's office to talk with him.

You put Joan's file on Manuel's desk and ask, "Why are you collecting all of this information about Joan from agencies providing services to her?"

Manuel responds, "I need this information to provide professional services to Joan. I must know how other agencies see her and her problems to be an effective advocate for her. Joan gave me permission."

You say, "But why do WE have this information. Does Joan need it and if so, what for? I can't imagine why we need to collect this information."

Manuel says, "But we need this information to effectively serve Joan. This is one of the most basic lessons I learned in college. I must be comprehensive in my approach to understanding my consumers, their services and their needs."

- What do you do?
- This is a case study about compliance with standard 1 -- promoting and practicing the independent living philosophy. Why?

2 -- But We Need This Information to Effectively Serve Joan

Guidelines for Discussion

1. Why was Manuel securing a blanket release of information from his consumers?
2. Why would a blanket release of information violate independent living philosophy?
3. Why would a center need copies of medical, psychological or service provider records about a consumer of its services?
4. Could Manuel's behavior create dependencies on the center for his consumer? If so, how? If not, how do you know?
5. What kinds of ideas do you have for how to retrain Manuel on this issue?
6. What kinds of training are provided to center staff now on independent living philosophy?
7. How are employees of centers evaluated in terms of their practice of independent living philosophy?
8. What kind of behavior do you want from Manuel which would promote the independent living philosophy?

2 -- But We Need This Information to Effectively Serve Joan

Learning Objectives

1. To understand how educational training can affect one's ability to practice independent living philosophy.
2. To understand how intrusive it can be to collect information about people with disabilities for center purposes.
3. To understand how to distinguish what the consumer wants from a center as opposed to what a staff member wants.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to actual service delivery within a center.
5. To be able to practice independent living philosophy when it comes to ensuring that the "consumer" has control over his/her life, including such things as records of service providers.
6. To understand the difficulty of supervising someone who has been trained to behave in one way.
7. To be able to conceptualize and then provide training on independent living philosophy to employees of centers.

3 -- All I Need is a Chain Saw

You are a volunteer peer counselor at a rural center. Your main role as a peer counselor is to support the consumers with whom you work, no matter what. You encourage people to develop and achieve their own independent living goals, but you do not make judgments about their choices. Once someone sets a goal, you work with them in whatever way you and the consumer are comfortable to achieve the goal -- even if failure seems likely.

You just met Eugene, a new consumer. He is the son of a small family farmer who lost an arm in a tractor accident when he was 16. He is graduating from high school and plans to continue working on the family farm. Your supervisor met Eugene at a "transitions support group meeting" and suggested he call for an appointment with a peer counselor. Since you are an amputee, your supervisor referred Eugene to you.

It is clear that Eugene wants to continue farming. While he has done well helping his family members, he wants some adapted farm equipment to be more independent as a farmer. He is highly motivated and interested in pursuing all his options, but he needs financial assistance to obtain new equipment. You suggested that he contact the local office of vocational rehabilitation to request funding for such equipment. You explained to him that the vocational rehabilitation program often funds training, support services, or equipment purchases for people with disabilities who have vocational goals. So Eugene made an appointment with and met a vocational rehabilitation counselor. He says that he explained what he wanted and needed to continue living on the family farm, but the counselor told him that he did not have a clear vocational goal.

"All I need is something like a chain saw to chop wood...simple farm equipment that we could modify for a one-armed person...I know I could learn to use equipment independently if I could get some help," Eugene reports what he said. "The counselor told me that he could fund some independent living rehabilitation services, but that I did not have a significant disability and that the state doesn't have enough money for everybody. In fact, he told me to ask the center for funding to do this."

- What do you say to Eugene?
- How can you assist Eugene to meet his goal?
- This is a case study about standard 1 -- promoting and practicing the independent living philosophy. Why?

3 -- All I Need is a Chain Saw

Guidelines for Discussion

1. What is most noticeable about Eugene?
2. What is the role of the peer counselor?
3. How does the peer counselor promote and practice independent living philosophy in his/her work with Eugene?
4. Why might the vocational rehabilitation counselor believe that Eugene does not have a clear vocational goal?
5. Why might the vocational rehabilitation counselor have referred Eugene back to the center for funding?
6. What do you think Eugene will do without center support?
7. What do you think Eugene will do with center support?
8. What do you think the eventual outcome of this situation will be?

3 -- All I Need is a Chain Saw

Learning Objectives

1. To understand the difficulty of pursuing a real goal through the current rehabilitation system.
2. To understand how a state agency employee may misinterpret "independent living" and "significant disability."
3. To understand the role of a peer counselor in promoting and practicing the independent living philosophy.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to actual service delivery within a center.
5. To be able to think through how to support someone like Eugene in securing needed services and funding through the vocational rehabilitation program.
6. To understand how to use an appeals process or the Client Assistance Project.

4 -- Where is Stella?

You are a transition specialist working with an urban center for independent living. Your job is to work with young people on issues of making the transition from school to independence or school to work. Your center uses the peer counseling model and approach to transition services, treating youth with disabilities just like you approach adults with significant disabilities.

Your center has many written policies which explain how board, staff and volunteers practice the independent living philosophy. One of your center's policies concerns consumer control. "No volunteer or staff person will participate in any meeting concerning any consumer of the center's services unless the consumer is present at the meeting or if the consumer asks the center's representative to attend in his or her place."

Stella is one of your consumers. She is a 14 year old with cerebral palsy. She uses a wheelchair and her speech is affected by her cerebral palsy. She is bright, witty, fairly self-confident for a 14 year old, and highly motivated. She has been exploring different careers with you and her school vocational counselor. You have helped her work through some exercises in the book, What Color Is Your Parachute? It seems that Stella's strengths are with analysis and human interaction. Stella is excited about the prospect of going to college and has told her vocational counselor that she wants to go to the local university.

Her new individualized education plan (IEP) is being developed and a meeting has been scheduled to review the draft. Stella asked you to attend the meeting with her.

You enter the meeting room to find Stella's teachers, her mother, the vocational counselor, the general guidance counselor, the special education administrator, and the school system's occupational therapist and speech therapist. Stella is not there. You turn to Stella's mother and ask, "Where is Stella?"

Stella's mother said, "Her vocational counselor is very concerned that Stella's expectations are too high and asked that we not bring her to this meeting. He wants to talk honestly about Stella's capabilities and skills and doesn't want to hurt her feelings, so I said OK."

- What do you say? What do you do?
- This is a case study about standard 1 -- promoting and practicing independent living philosophy. Why?

4 -- Where is Stella?

Guidelines for Discussion

1. Why does the center have a policy which states that staff should not attend meetings without their consumers present?
2. What is unique about Stella as a consumer?
3. Why are there so many people attending Stella's IEP meeting?
4. Why do you think Stella's vocational counselor did not want her present at her own IEP meeting?
5. Why do you think Stella's mother agreed not to bring Stella to the meeting?
6. How difficult will it be to confront the group at the meeting about why Stella is not there?
7. Would it be possible to go and get Stella and bring her into the meeting?
8. What is your or Stella's legal recourse to stop this meeting?
9. Do you think Stella's mother would sign the IEP, even though Stella was not there and had not seen it?
10. How would your staying at the meeting without Stella be beneficial?

**The Independent Living Movement: History and Philosophy to
Implementation and Practice by Maggie Shreve**

4 -- Where is Stella?

Learning Objectives

1. To understand the difficulty of supporting an individual with a disability in the special education system.
2. To understand the pressures placed on children in special education by professionals and family members.
3. To understand the role of a center's transition specialist in promoting and practicing the independent living philosophy.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to actual service delivery within a center.
5. To distinguish between the role of being an advocate and the role of being a support person for an individual with a disability who can speak for her/himself.
6. To understand the critical importance of asking professionals and others to not meet or to cease a meeting when the individual being discussed is not present.
7. To be able to stop such a meeting from taking place.
8. To understand that attending the meeting without Stella present violates independent living philosophy and practice.

5 -- You Can't Do That...It's Reverse Discrimination

You are a self-employed trainer and consultant who is working with centers for independent living on compliance with the new standards for centers in the Rehabilitation Act Amendments of 1992. You have ten years of experience working in and with centers and are known to be a skilled and interesting trainer.

You have covered independent living history and philosophy with the board of directors and staff of a newly funded Title VII Part C center. Most of this information is brand new to the group, even though they wrote a successful grant application and were funded through the Rehabilitation Service Administration's peer review process.

You are now discussing the definition of a CIL, the assurances it must make, and the standards it must meet. Using overheads and flip charts, you point out how consumer control is measured in centers --

- the majority of the board of directors must be people with significant disabilities;
- the majority of the staff must be persons with disabilities;
- the majority of the decision-making staff must be persons with disabilities; and
- the center must report the number of persons with significant disabilities on staff.

In addition, you explain that a center must take affirmative action, under Section 503 of the Rehabilitation Act, to recruit, hire, train and advance in employment persons with disabilities.

The services manager of the new center raises her hand and asks, "Isn't this reverse discrimination? I'm not disabled and I think this is reverse discrimination. Why should I hire people with disabilities when there are many people without disabilities who are more qualified for some of the jobs we have?"

- What do you say?
- This is a case study about standard 1 -- promoting and practicing the independent living philosophy. Why?

5 -- You Can't Do That...It's Reverse Discrimination

Guidelines for Discussion

1. Why are these standards of majority control written into the Rehabilitation Act Amendments of 1992?
2. How do you define the word "qualified?"
3. How are qualifications for jobs within your center determined?
4. How are candidates for jobs in your center measured against such qualifications?
5. Does having a disability mean that someone understands and practices the principles of independent living philosophy (consumer control, barrier removal, equal access to society, and advocacy)?
6. Why might a center hire a non-disabled services director?
7. Are there potential job performance problems with the services manager in this case? How would you handle them?
8. How, as a trainer, do you educate people about issues such as consumer control? How do you reach people whose beliefs, values, and attitudes may not support independent living philosophy? How do you change their beliefs, values and attitudes?

5 -- You Can't Do That...It's Reverse Discrimination

Learning Objectives

1. To understand how the principles of "consumer control" are practiced in governance and staffing of a center for independent living.
2. To understand the basic requirements of centers which are included in definition, assurances and standards of Title VII.
3. To understand how some individuals might react to majority control by people with disabilities within a center.
4. To think about why majority control by people with disabilities might be upsetting to some people.
5. To be able to explain to someone why having the majority control of a center for independent living is important.
6. To understand how the independent living philosophy of consumer control applies to actual staffing within a center.
7. To think about how the word "qualified" could be used to support principles of independent living and consumer control (and reversely, how the word "qualified" has been used to discriminate against people with disabilities in the past).

6 -- Sorry. Nobody Here Knows Sign Language

You are the only independent living skills trainer in the office. The center's new receptionist/secretary comes into your office, looking flustered. "There is someone in the lobby who must be deaf. He keeps signing to me and I can't understand his speech. What do I do?" You tell her you'll take care of this.

You go to the lobby and wave to the man. You write out a note, saying "Sorry. Nobody here knows sign language" and pass it to the man.

He looks at you, shrugs, and then writes back, "Need help now. Wife sick. We new to city. No doctor. Boss said you help."

You look at him and write back, "I'm really sorry, but I don't sign and neither does any other staff member. If you want to make an appointment, we will find an interpreter. We usually refer the deaf to the Speech and Hearing Center where qualified interpreters provide a wide range of services. Let me get their number for you." You look up and watch his reaction as he reads. He looks like he is getting really mad.

You rush off to get that phone number and when you return, he has gone. The receptionist/secretary says, "He just left, slamming the door behind him. I guess he won't be back soon."

You think for a moment. Have you done something wrong?

- Do you tell your supervisor about this incident?
- This case study violates standard 1 -- practicing and promoting the independent living philosophy. How?
- This is a case study about standard 2 primarily -- serving individuals with a range of significant disabilities. Why?

6 -- Sorry. Nobody Here Knows Sign Language

Guidelines for Discussion

1. Why doesn't this center have someone on staff or available to interpret for this potential consumer?
2. How can this consumer's needs be met?
3. What are the forms of accessibility that a center must provide in order to provide services to and welcome any potential consumer, regardless of disability type?
4. Should centers have available lists of physicians for referral? If not, how would you handle this potential consumer's request?
5. What would your supervisor say if you told him/her about the incident?
6. What is your center's policy on communication access?
7. How does your center handle other types of accessibility issues, such as providing materials in alternative formats?

6 -- Sorry. Nobody Here Knows Sign Language

Learning Objectives

1. To understand how accessibility applies to people who are deaf.
2. To understand the necessity of providing interpreter services to be accessible to the deaf community.
3. To understand that referral to other agencies is not appropriate for a center for independent living which is mandated to provide its services to a cross-disability population.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to actual service delivery within a center.
5. To understand that a person's first impression of a center is the most important form of public relations conducted.
6. To know how to be able to respond quickly to the needs of a "drop-in" potential consumer.

7 -- How Can You Determine What Cross Disability Means?

You are a peer reviewer for new Title VII Part C grants. You are a member of a panel of three peer reviewers meeting in Washington to analyze and recommend for funding grant applications to establish new centers. Your panel has been given 9 proposals -- 5 from one state and 4 from another.

You just finished your first grant review and are meeting with your peer review panel to discuss your scores and assessments. You are very concerned that this first grant applicant does not indicate a cross-disability approach. The organization had been told that it was a center for independent living by its blind state agency and it has been state-supported for three years, but it only served people who were blind. The applicant says that they will serve all disability groups once fully funded and that it has served people who are blind and have other disabilities in the past.

You are not convinced. You see no clear evidence that the organization is ready or understands how centers for independent living incorporate cross-disability philosophy into everything they do, including advocacy and provision of services. The applicant even included a percentage breakdown of disability population in its proposed service area, but did not indicate the numbers of different disability types it proposed serving. You don't think this center meets standard 2.

Your fellow peer reviewers think this organization has an excellent track record and should be funded. They also don't want to make waves with the blind community. You do not think the applicant should be funded and say to your panel that you don't care what single disability group has been served, a center must be cross-disability to meet federal standards.

- How do you resolve this issue within your peer review panel?
- What recommendations do you make in your peer review comments?
- This is a case study about standard 2 -- serving people with a range of significant disabilities. Why?

7 -- How Can You Determine What Cross Disability Means?

Guidelines for Discussion

1. Why do you think this blind service agency applied for a Title VII Part C grant?
2. Why should this blind service agency be funded?
3. Why shouldn't this blind service agency be funded?
4. Why do you think the blind service agency did not set targets for the cross-disability approach it promised to take?
5. What are some of the issues the peer review panel should take into consideration before it makes a final decision about whether funding should be recommended or not?
6. If you cannot convince the other two reviewers that the applicant should not be funded, what can you do as a single peer reviewer?

7 -- How Can You Determine What Cross Disability Means?

Learning Objectives

1. To understand how critical cross-disability service delivery is to meeting federal standards.
2. To understand something about how a federal grant application for Title VII Part C funds might be reviewed.
3. To understand the difficulty of reaching agreement when one out of three reviewers does not agree on a funding decision.
4. To understand how peer review comments are made when a federal grant application is being reviewed.
5. To understand how cross-disability relates to practice of independent living philosophy.
6. To be able to respond to single disability group pressure when a cross disability approach is clearly mandated.

8 -- I Don't Know...What's an Independent Living Goal?

You are a new peer counselor at a small town center for independent living. You have a few years of college in a social work program and you have been a client of many social service agencies and the vocational rehabilitation program. You have been through an orientation with your supervisor, a training on independent living history and philosophy, and some peer training from other peer counselors on how to complete the documentation and paperwork required for serving people as a peer counselor.

The paperwork makes you dizzy, there's so much of it. There is an application for services, an intake form, an independent living assessment form (one short form and one long form), a written independent living plan form, case notes, consumer time record, and a consumer evaluation survey. You do not clearly understand why there is so much documentation required, but you have been told that the center won't get its funding if it is not done thoroughly.

After your first two weeks of orientation, you get your first referral. A new consumer, Sandy, has come to the center at the suggestion of her vocational rehabilitation counselor. She is not clear about why she has come, but her vocational rehabilitation counselor apparently told her that the center could help her.

You talk with Sandy for about fifteen minutes, trying to understand what she wants to accomplish with her life. You have told her a little about the center and asked her to complete the application for services. She completes the application form but tells you that she doesn't know what she wants. When you ask her what her goals are, she says, "I don't know...what is an independent living goal?"

You explain that she can live independently in spite of her disability and that you can show her how, but it is up to her to decide if she wants to do this and what life style she would like to have. Sandy seems confused about what is possible, so you ask her for another appointment when you can discuss these things more fully. She says OK and you set a date for next week.

After Sandy leaves, you try to fill out all the paperwork. Your peers have told you that Sandy must have an independent living goal if you are to serve her. So, you complete a short independent living assessment form, giving her a goal of "exploring career options," and "finding accessible housing." But you are unsure about what to do with the intake form and the long assessment.

- Why might these forms or their use violate independent living philosophy?
- This is a case study about standard 3 -- facilitation of the development and achievement of independent living goals. Why?

8 -- I Don't Know...What's an Independent Living Goal?

Guidelines for Discussion

1. Why does this center have so much paperwork?
2. What is the value of the various forms this peer counselor is expected to complete?
3. Why is the peer counselor writing down two goals for Sandy when Sandy has not expressed any goal?
4. How does the new Rehabilitation Act Amendments of 1992 affect a center's documentation system?
5. Should centers "take in" ("intake form") potential consumers? Should a center assess a potential consumer? How might such language or practice violate independent living philosophy?
6. How can a center's staff facilitate the development of a person's independent living goals without doing intakes and assessments?
7. How can a center's staff facilitate the achievement of a person's independent living goals without violating the independent living philosophy principle of "consumer control?"

8 -- I Don't Know...What's an Independent Living Goal?

Learning Objectives

1. To understand a typical reaction of a potential consumer.
2. To understand the reason behind the newly legislated "waiver" of an independent living plan for consumers of center services.
3. To understand the flexibility given to center staff in how they work with consumers under the new Rehabilitation Act Amendments of 1992.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to actual service delivery within a center.
5. To understand the problems of using traditional service delivery documentation methods in center services.
6. To understand how some demands for paperwork can facilitate staff violation of independent living philosophy, such as the principle of consumer control.
7. To be able to question the need for specific types of documentation and/or forms used by centers in their services programs.
8. To be able to confront one's own center policies and procedures related to documentation and management information systems in terms of how they may violate independent living philosophy or lead staff (paid or unpaid) to violate independent living philosophy.

9 -- But the Board Doesn't Think We Should Do Advocacy

You are an executive director of a small center in a suburban, primarily middle and upper class area. You have a board of 11, 8 of whom are people with significant disabilities and most of whom work for other social service agencies in your service area.

Now that the Rehabilitation Act has changed, you can use the law to promote a stronger advocacy agenda. You have always feared that your image in the community is only that of a service provider and that you could do much more if your center engaged in systems change activities. Knowing that many board members work for social service agencies and these individuals are heavily influenced by their professional status in the community, you bring in an outside consultant to facilitate the development of an advocacy plan.

The consultant has planned a one day retreat of board and staff to map out the center's advocacy vision, identify obstacles to that vision, develop strategic directions to remove the identified obstacles and get individuals involved in teams which follow through on planned action steps. The consultant is well-known in the independent living community, so you feel confident that problems with social service agency board members can be overcome during the retreat.

After the consultant does some warm-up exercises, he asks the group to identify the pieces of its systems change vision. To your dismay, several of the social service agency representatives tell the consultant that the center is not permitted to do lobbying or systems change activities. They explain to the consultant that the center can do individual advocacy, but that most professionals treat each other with respect in this community and do not advocate against each other or each other's agencies. The consultant tries to explain that the new standards for centers mandate systems change activities and suggests that centers can lobby legislatures as long as they keep their "financial house in order." Several members of the board argue with the consultant and it looks as if the day's plans are quickly going down the drain.

*What do you say and do?

*This is a case study about standards 4/6 -- increasing the availability of and improving the quality of community options/increasing community capacity. Why?

9 -- But the Board Doesn't Think We Should Do Advocacy

Guidelines for Discussion

1. What types of systems advocacy can a center do?
2. What is a center prohibited from doing if it receives Title VII Part C funding?
3. Does a center have to be a 501(c)(3) tax exempt organization in order to receive a Title VII Part C grant?
4. Why are these social service agency personnel on the center's board? How could they be helpful? How could they be harmful?
5. How can systems change activities occur if everyone in the community agrees to not advocate against each other?
6. If you say something at this juncture in the facilitated retreat, will it help or hurt your ultimate cause?
7. How can the consultant handle this situation?

9 -- But the Board Doesn't Think We Should Do Advocacy

Learning Objectives

1. To understand the importance of systems change advocacy work within a center's mandate.
2. To understand how individual board members, based upon their own biases or perceptions, can influence center policy.
3. To understand potential "conflicts of interest" or "self-dealing" with board members who work for other disability organizations.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to center standards 4 and 6.
5. To be able to plan for systems change advocacy activities for your center.
6. To be able to confront board members who do not know or understand issues consistent with law and/or regulations (in this case, the Rehabilitation Act Amendments of 1992 and the Internal Revenue Code).
7. To understand the language of standards 4 and 6 -- to increase the availability of and improve the quality of community options and to increase the community's capacity.

10 -- We Have Provided Public Education to More Than 1,000 People

You are the executive director of a center in a state where there are ten other centers. You meet with your fellow executive directors about every other month to discuss issues of mutual concern and interest. Now that the indicators have been published for compliance with the federal standards, you all plan to discuss how you will report your indicators.

There is one center about which you have always had some grave concerns. As far as you can tell, the center never engages in any systemic advocacy. The center has had several directors in the seven years you have been in the state. The directors rarely participate in any legislative activity in the capitol, even though they seem to be supportive of such advocacy during meetings and discussions of the group. You are particularly curious about how this center director will respond to the indicators for standards 4 and 6 -- the systemic change standards.

After everyone settles down and shares some personal news, you ask if each director would share some of their personal ideas about how they will respond to the indicators. The first two directors talk about their current advocacy plans which cover such issues as: interpreters at public meetings and in hospitals; elimination of curbs; increased use by vocational rehabilitation counselors of supported employment, personal assistance services, and on-the-job training services for their clients; and a push to get the governor to appoint more CIL representatives to the statewide independent living council (SILC).

The director about which you are curious has the next turn. "We have provided public education to more than 1,000 people. We issue our newsletter to 500 people every two months. We provide technical assistance to about 20 agencies each year, and we are trying to start an ADA education program...but we haven't had much success with that one yet. I think our greatest strength is our individual advocacy program where our staff served over 200 clients last year alone. Overall, I'm pleased with our advocacy activities to date."

- What do you say?
- What do you think your fellow directors will say?
- This is a case study about standards 4/6 -- increasing the availability of and improving the quality of community options/increasing the community's capacity. Why?

10 -- We Have Provided Public Education to More Than 1,000 People

Guidelines for Discussion

1. Should all centers address the same issues within their state?
2. If you believed that a center in your state did not meet federal standards for a center, what would you do?
3. How could state CIL directors discuss their differences openly? What has to happen for center directors to be able to discuss their differences?
4. Do you have a center association in your state? Who are members? How is the association organized? How deeply do centers discuss their differences within the association?
5. Do you think the center which is providing public education, newsletters, technical assistance and disability sensitivity training, is meeting standards 4 and 6? Why? Why not?
6. Can CILs advocate for change at the state government level? Does this violate lobbying rules of the federal funding received under Title VII Part C?
7. Does a center have to be a 501(c)(3) tax exempt organization in order to receive a Title VII Part C grant?
8. Does CIL advocacy at the state government level violate anti-lobbying rules of the Internal Revenue Code?
9. How can a center engage in systemic advocacy, grass roots lobbying, and direct lobbying of elected officials?

10 -- We Have Provided Public Education to More Than 1,000 People

Learning Objectives

1. To understand that public education is not necessarily systemic advocacy.
2. To understand that centers must assess their communities to determine which options meet the independent living needs of the disabled community and which do not.
3. To understand that centers must assess their communities to determine the capacities of these same communities to support people with disabilities trying to or living independently.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to center standards 4 and 6.
5. To understand how difficult it is to discuss some issues with your peers.
6. To understand how difficult it might be to agree on reporting methods for all the centers within a state.
7. To be able to disagree with fellow directors and still work together on issues of common concern.
8. To be able to report your center's compliance with standards regardless of what other centers in your state do and how they do it.
9. To understand that there do not need to be identical reporting and evaluation systems within each center.

11 -- Advocacy is Not Always Individual Advocacy

You are a new board member of a small center in a rural area. You have not been very involved with the center until now and you are just beginning to learn about the independent living philosophy. Your own personal career has been rather shaky. You went to a special, segregated high school and enrolled in the regional community college. You found the community college not very friendly and not very accessible. You were always late to class because it took so much longer for you to wheel from building to building than it took those who walk. You asked professors to change classrooms for you, but they were usually hostile and nothing ever seemed to happen. You live at home with your mother and father and two younger brothers. You dropped out of the community college when your father offered to help you set up a baseball card swap shop at the local mall. You are not sure why you were asked to join the board -- it is probably because you are now a business owner and they needed someone with a disability who worked in the community.

You are attending your first board training and the issue of advocacy has just come up for discussion. The executive director is explaining that the center takes a two-pronged approach to advocacy -- assistance for individuals who request support for an individual advocacy problem and systems change activities to eliminate discriminating policies, remove barriers, increase or improve service delivery systems or secure "consumer control" over a support service. Each board member is being asked to volunteer for one systems change advocacy effort this year...and it is your turn to speak.

"I had real trouble at the community college. They never removed the snow and the curb cuts were really bad. I couldn't make it to class on time. I tried real hard, but I could never make it on time. And the paratransit service was so unreliable. I don't know what kind of advocacy project I could do, but I know I needed help with the community college." The executive director suggests that your issues may be an individual advocacy example rather than systems advocacy. She asks you to explain further how the college was or was not in compliance with section 504 of the Rehabilitation Act or the Americans with Disabilities Act.

- What do you say?
- What do you think the other board members will say?
- This is a case study about standards 4/6 -- increasing the availability of and improving the quality of community options/increasing the community's capacity. Why?

11 -- Advocacy is Not Always Individual Advocacy

Guidelines for Discussion

1. Why do you think this new board member dropped out of the community college?
2. Do you think this new board member is aware of his/her individual rights as a person with a disability?
3. Does this new board member need training? If so, what type of training does s/he need and what should s/he be expected to know or be able to do as a result of the training?
4. Why should board members be involved in systemic advocacy planning and implementation?
5. Why might this new board member be fearful of pursuing his/her own advocacy goal with the community college?
6. Why might this new board member be fearful of joining a team working on increasing accessibility at public education programs?
7. How does your center distinguish between individual and systems advocacy?
8. What kinds of systemic change advocacy does your center conduct?

11 -- Advocacy is Not Always Individual Advocacy

Learning Objectives

1. To understand the difference between individual advocacy, such as 504 or ADA compliance for a person, and systems advocacy, such as working with a college to increase its accessibility and policies guiding reasonable accommodation.
2. To understand how difficult it is for many individuals with disabilities to distinguish between their personal needs and the systems which have discriminated against them.
3. To understand how difficult it might be to educate individuals with disabilities in preparation for engaging in systems advocacy activities.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to center standards 4 and 6.
5. To be able to determine broad systemic advocacy goals from the experiences of individuals with disabilities in the community.
6. To understand the importance of board participation in systems advocacy planning and implementation.

12 -- Consumer Satisfaction Must Exceed 80% of Surveys Returned

You are the executive director of a center for independent living in a state where federal Title VII Part C funds flow through your state vocational rehabilitation agency. The state agency wants to work out an agreement with all centers about what information will be gathered from centers, including those requirements of the federal government and how the state might measure consumer satisfaction for everyone in the state.

A program evaluator who has worked with the state vocational rehabilitation agency for 25 years has been assigned to work with the state's center directors on a customer satisfaction survey form and to develop a schedule for how often centers will survey their consumers on issues of satisfaction.

You are meeting with the program evaluation person and your fellow executive directors. The program evaluator has designed a survey form that looks much like the state agency's annual "needs assessment" form. You raise some serious questions about how the form can measure consumer satisfaction based upon the services that were provided or the advocacy that was conducted. The program evaluator says, "Oh, that is not as important as learning what service needs are still unmet. We won't rest until we get consumer satisfaction rates of 80% or higher on all surveys returned. And...we want a 70% return rate of the surveys.

This will give us invaluable data for future planning and I know the SILC would like to have this information as a part of its monitoring role over the state's plan."

You ask how this draft form will address consumer satisfaction with the way the center practices independent living philosophy or how it will measure staff attitudes and approaches. The program evaluator tells the group that the new Rehabilitation Act seeks consumer satisfaction to determine whether or not centers are providing adequate independent living services, not how the consumer "feels about philosophy or attitudes. Centers are established to meet consumers needs and so, if a center is not meeting those needs, it must reconfigure what it is doing."

- What do you say?
- What do you do?
- This is a case study about standard 5 -- provision of core services. Why?

12 -- Consumer Satisfaction Must Exceed 80% of Surveys Returned

Guidelines for Discussion

1. What should a customer satisfaction survey address?
2. How do you address your consumers' degree of control over their own lives now?
3. How do you address your consumers' degree of satisfaction with your center's staff and approach?
4. How do you think the state agency's program evaluator reached the conclusion that 80% of consumers' returned surveys should indicate satisfaction with center services?
5. How do you think the state agency's program evaluator reached the conclusion that 70% is a reasonable return rate of consumer satisfaction surveys?
6. What is the primary purpose of a customer satisfaction survey?
7. What might be an appropriate tool for measuring consumers' needs?
8. How does independent living philosophy apply to the development and implementation of a consumer satisfaction survey?

12 -- Consumer Satisfaction Must Exceed 80% of Surveys Returned

Learning Objectives

1. To understand the meaning of "consumer satisfaction" within the context of the Rehabilitation Act Amendments of 1992 and the independent living philosophy.
2. To understand how the state vocational rehabilitation agency might look at the issue of "consumer satisfaction."
3. To understand the impact of independent living philosophy on what services a center might provide.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to the provision of core services (advocacy -- individual and systems, information & referral, independent living skills training, and peer counseling).
5. To understand the purpose of "consumer control" and its relationship to evaluating "consumer satisfaction."
6. To understand the pressures placed upon centers to satisfy all the needs of individuals with disabilities rather than advocate for systems changes so that people with disabilities get the services they need from appropriate, existing service providers.
7. To be able to resist consumer satisfaction surveys which only address surface level issues of services provided.
8. To be able to develop a customer satisfaction mechanism which is rooted in independent living philosophy and consumer control.

13 -- And How Many People Have You Prepared and Referred to VR?

Your center is funded through Title VII Part C which is passed through your state agency. As executive director, you have worked with the board to develop policies which support the independent living philosophy throughout the center. While your funding comes through the state vocational rehabilitation agency, you have made it clear to staff that referrals to or from the state agency are not to be treated any differently than any other referrals. The center only takes referrals from people with disabilities themselves, not from professionals or staff of service providers.

When the state's new reporting form arrives, you are surprised to see a category labeled:

_____ Number of cases referred to VR

_____ Number of cases referred from VR

You immediately call the independent living program liaison at the state VR central office to check on this form. She tells you that the federal government wants to ensure that centers are working cooperatively with state agencies, particularly the vocational rehabilitation agency. The VR staff felt it was critical to get a monthly, quarterly and annual count of the number of VR referrals -- both to and from -- to check on how well centers were cooperating with the state VR agency. She points out that no other center director has called her about this, but knowing you as she does, she fully expected to hear from you about this. "Why don't you just learn to cooperate? You know you don't have to play the role of advocate on EVERY issue. Is it really that difficult to record this data when you know how helpful it will be to us?"

- What do you say to her? What do you say to your fellow center directors?
- What do you do with your own staff? Board?
- This is a case study about standard 5 -- provision of core services (information & referral, advocacy -- individual and systems, independent living skills training and peer counseling). Why?

13 -- And How Many People Have You Prepared and Referred to VR?

Guidelines for Discussion

1. Why does the state agency need to know the number of referrals made to or from your center? Can this information be gathered by the state agency itself?
2. Why does the state agency use the word "cases?"
3. What does the state agency mean by "working cooperatively?"
4. What do you think "working cooperatively" means?
5. Does "working cooperatively" strengthen the relationship between agencies and centers over the relationship between centers and consumers? How so or how not?
6. Why might a center resist collection of this information?
7. What would your board and staff say to this request from the state agency?
8. What would your fellow directors say to this request from the state agency?

13 -- And How Many People Have You Prepared and Referred to VR?

Learning Objectives

1. To understand how independent living philosophy impacts the practice of documentation and data collection within a center.
2. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to the provision of core services (advocacy -- individual and systems, information & referral, independent living skills training, and peer counseling).
3. To understand the difference between "working cooperatively" with a state agency and tracking where referrals for center services come from, directly or indirectly.
4. To understand how a funding source can interpret federal law differently than a center might.
5. To understand a center's obligations for reporting under the Rehabilitation Act Amendments of 1992 in relationship to what a state can request of a center.
6. To be able to respond to a state agency's request for data which your center thinks is unreasonable or unnecessary.

14 -- I Have So Many Advocacy Commitments

You are an independent living specialist with a center in an urban area. One of the most frequently mentioned problems facing your consumers who use wheelchairs is the lack of curb cuts. In fact, in the last two or three years, the numbers of angry consumers who are ready to do something drastic about the curb cut problem seems to be growing by leaps and bounds.

You bring this issue up at your next meeting of services staff, suggesting several alternative approaches to getting consumers organized to take some advocacy action.

The executive director is chair of the Mayor's Committee on Disability Issues, an advisor to the state's assistive technology project, a member of the UCP/ARC housing committee, and the local transit authority's paratransit advisory board. He is also under consideration for a seat on the Statewide Independent Living Council (SILC). When you bring up your ideas for developing a grass roots group to file complaints and take other advocacy actions against the city, the executive director starts to grind his teeth.

He says, "I have so many advocacy commitments now, I don't think it is a good time to take on a new issue. Besides we have our five year plan in place...we're making headway on the plan...and curb cuts were not a part of the plan."

- What do you do?
- This is a case study about compliance with standard 6 -- increasing the community's capacity. Why?

14 -- I Have So Many Advocacy Commitments

Guidelines for Discussion

1. Why is the executive director resisting formation of a new advocacy group or activity?
2. How can staff of a center facilitate formation of advocacy groups without support from upper management?
3. What is the role of the board of directors in a situation like this?
4. Does your center have a grievance procedure for staff who disagree with a policy determination by management? If so, how does it work?
5. How can you secure support from upper management to form new advocacy groups?
6. How did the executive director get involved in so many other agencies' activities? How do you think these are affecting his/her performance as center director? Do you think the board of directors know about the director's involvement in these other groups? If not, why?
7. Would your staff be supportive of facilitating new advocacy groups? How do you know?

14 -- I Have So Many Advocacy Commitments

Learning Objectives

1. To understand the importance of systems advocacy within a center.
2. To understand the difficulty of conducting systemic advocacy when there are conflicting personal or organizational goals in place.
3. To understand the power of bringing together people who recognize the same problem and are willing to do something to resolve it.
4. To understand how the independent living philosophy of consumer control, barrier removal, equal access to society, and advocacy applies to center standard 6, increasing the community's capacity to support people with disabilities who desire or need to maintain independent living.
5. To understand the difficulty of confronting the executive director who is unwilling or unable to support your or other staff advocacy issues.
6. To be able to facilitate the formation of community-based advocacy groups based upon issues identified by people with disabilities as needing resolution.

15 -- The Money You Raise Must be Subtracted From Your Grant

You are the board president of an urban/suburban center for independent living. Your center is 15 years old and is doing well financially and programmatically. You and others affiliated with your center were active in making changes to the Rehabilitation Act when it was reauthorized in 1992. And, you were delighted when standard 7 was added to the law, mandating that centers raise funds from sources other than Title VII.

Your center had developed a five year funding plan in 1991. It called for the hiring of a development director by 1993. The plan's primary goal is to increase its private funds from less than 5% of the center's total budget to at least 15% by 1995. Once the new Title VII was law, the center revised its budget so that the development director could be hired with Title VII money. This allowed the center one full-time position for resource development.

Your development director was hired in May, 1993. During the 1993 calendar year, she was able to generate \$25,000 in private funds. She is moving now toward a \$50,000 goal for 1994. The board is excited and actively involved in fund raising for the first time. The executive director is thrilled to see such action. And consumers are supporting the center's fund raising activities in ways that had not been imagined.

Your center director just called to tell you that he had received a call from the regional Rehabilitation Services Administration (RSA) office about the annual financial report submitted in December, 1993. This report covered the time period of October, 1992 through September, 1993, and included the \$25,000 raised. The RSA employee told the executive director that a portion of this money would have to be returned to RSA since it was raised by staff funded with Title VII money or it could be subtracted from the 1994 grant total. Your director argued with the regional RSA person to no avail. The RSA staff member even said that Title VII was supposed to be spent on services, not on fund raising. He called the Washington, D.C. office to check on this interpretation but had no success thus far. He is very upset and is calling you for support.

- What do you do?
- This is a case study about standard 7 -- develop resources from sources other than Title VII. Why?

15 -- The Money You Raise Must be Subtracted From Your Grant

Guidelines for Discussion

1. Where in the law or regulation does a problem with fund raising using Title VII Part C funding exist?
2. Does the regional RSA staff person have final authority over how Title VII Part C and EDGAR rules are interpreted? If not, who does?
3. How can you work with your regional office staff to resolve a difference in interpretation of law and regulation?
4. How can your board president assist in securing an interpretation favorable to your center?
5. Why do you think there is room for interpretation over an issue like the one in this case study?
6. If the regional office's interpretation is declared the official final interpretation, what more can be done to enable the center to keep the money it raises?

15 -- The Money You Raise Must be Subtracted From Your Grant

Learning Objectives

1. To understand why standard 7 was included in the Rehabilitation Act Amendments of 1992.
2. To understand the difficulty of changing the law when a conflict with existing regulations may exist (in this case, the conflict is within the Education Department Guidelines and Administrative Rules or EDGAR).
3. To understand how Title VII funding can be used to support the salaries of individuals conducting fund raising from other sources.
4. To understand the importance of board support on critical questions of concern to center staff.
5. To understand the power of the board president to inquire, on behalf of the center's voluntary board of directors, why a certain interpretation of law has been given which may have an adverse effect on the center.
6. To be able to support center staff as a volunteer member of the board of directors.
7. To be able to research and understand federal and state laws, regulations, and rules for the benefit of your center.

16 -- Charging Fees for Services

Your center initiated a fee-for-service program a few years ago to generate new funds and to hire additional staff with disabilities. You are now receiving:

- private insurance dollars for individuals recently injured who need technical assistance to return to the community;
- state and federal money through the developmental disabilities department for independent living skills training;
- local, community mental health funds for peer counseling; and
- state funding from the new head injury program for management facilitation of personal assistance services.

As the center's fiscal manager, you are pleased with how well the fee-for-service program is working. It is netting more dollars than you anticipated and enabled you to add several additional staff.

Rehabilitation Services Administration administers your federal Title VII Part C grant. After reviewing your annual report, an RSA employee calls to discuss your "program income." You understood that dollars earned with Title VII funds could be saved for future development and expansion of the center's programs. You had, therefore, used some Title VII Part C money (about 40%) to support some of these staff.

The RSA staff implied, but was not terribly clear, that program income must be returned to RSA unless there have been pre-grant award arrangements made for the use of this money. Even if such arrangements have been made, the RSA representative says that program income must be spent within the next fiscal year.

You are confused and concerned. You approach the executive director to discuss what should be done.

- What do you decide to do? Who do you talk with to make your decision?
- How do you continue your fee-for-service program -- with or without Title VII support?
- This is a case study about standard 7 -- developing resources from sources other than Title VII. Why?

16 -- Charging Fees for Services

Guidelines for Discussion

1. How has the center distributed its Title VII Part C funding to staff positions?
2. Do you think staff supported by Title VII Part C funding charged fees for all the people they served?
3. Why might RSA believe that fees generated by grant supported staff are "program income?" Why might they be incorrect?
4. Where within law or regulation would you find a definition of "program income" for Title VII Part C funding?
5. What kinds of difficulties can you run into when implementing a fee-for-service program?
6. Could your center initiate a fee-for-service program? How would you do it?
7. Could fees-for-services compromise your center to violate independent living philosophy? How?
8. How do you think this issue of "program income" will be resolved ultimately?

16 -- Charging Fees for Services

Learning Objectives

1. To understand the value and potential problems of fee-for-service funding mechanisms.
2. To understand the relationship between fees-for-services and grant funds under Title VII Part C.
3. To understand how a combination of fees generated by service provision and grant funds can support individual job positions within a center.
4. To understand how to safeguard income generated by fees-for-services when staff providing services are funded by both grant and fee sources.
5. To understand how differently federal officials may interpret law and regulation.
6. To understand how difficult it might be to secure an interpretation of law and regulation supportive of your own.
7. To understand how to work through such problems within the center's staff and board of directors.
8. To be able to research and understand federal and state laws, regulations, and rules for the benefit of your center.

Organizational Blasphemies: Clarifying Values²

Goals:

1. To provide an opportunity for the participants to be creatively open about aspects of their organization.
2. To identify and compare the organizational values of group members.
3. To provide an opportunity to explore the match between the goals or values of the participants and those of the organization.

Group Size:

Three or more participants who work in the same organization, department or temporary system.

Time Required:

One to one and one-half hours.

Materials:

- Three sheets of blank paper and writing instrument for each participant
- Newsprint and felt-tipped markers
- Masking tape

Physical Setting:

A writing surface or floor space for each participant.

Process:

1. The facilitator introduces the activity by stating that it is useful for the members of an organization (or group) to think from time to time about the organization's objectives and whether they, as individuals, are working toward those objectives.
2. The facilitator distributes three sheets of blank paper and a writing instrument to each participant and explains that each participant is to write an organizational blasphemy³ -- a phrase or slogan so alien to what the group represents that the members will squirm in their seats when they

² Modified from "Organizational Blasphemies: Clarifying Values," by Tony McNulty, *The 1983 Annual for Facilitators, Trainers, and Consultants*, Goodstein and Pfeiffer, eds., Pfeiffer & Company, San Diego

³ The idea of an organizational blasphemy was suggested in *Corporate Man* by Anthony Jay, Penguin Books, Ltd., 1975

hear it. The facilitator then gives examples of blasphemies for other organizations:

University Associates: "You can't teach an old dog new tricks."

A four-star restaurant: "If we run out of veal, use lean pork; no one will notice."

A center for independent living: "People with disabilities should be supervised and directed by qualified medical personnel." (5 minutes)

3. Participants are told that they will have 5 minutes in which to invent their own blasphemies and are instructed to write them on one of their sheets of blank paper.(5 minutes)
4. The facilitator calls time, collects the blasphemies, and reads them aloud while a member of the group posts them on newsprint.(10 minutes or more)
5. The group discusses (use large group if 10 or less, otherwise break into smaller groups for discussion) the activity so far. Questions which may facilitate discussion can include:
 - How did it feel to consider and write down ideas of this nature?
 - Why did members select these particular blasphemies?
 - Is there a common theme running through the blasphemies? What might this mean in terms of the way members perceive the organization [or independent living philosophy]?
 - What blind spots or biases in the organization might these blasphemies indicate?
 - What taboos are there within the group that appear clearly in the list of blasphemies?
 - What does this imply about the goals or values of the organization? What does this imply about how the organization works or doesn't work?
 - Does any group member's blasphemy differ significantly from the rest? What might be the reason?
 - What implications do the results of this activity have for the way the organization functions now? For the future design of the organization? For individual members of the organization? For the fit among all three? (30 minutes or more)
6. The facilitator states that blasphemies often highlight beliefs or aspects of behavior that have been "socialized out" of the group members by the organization's processes. The participants are then invited to contribute their own examples of how this process of socialization has operated, if at all, within the group.(10 minutes)
7. The facilitator states that groups are often cultures within other cultures and that the values of these cultures can differ to a great extent. The facilitator then posts a diagram of three overlapping circles (similar to the

five overlapping circles symbolizing the Olympic games, but using only three). One circle represents “the values of the organization for which all members work OR the values of an outside organization/group to which the individual belongs.” Another circle represents “the values of this group.” And the third circle represents “personal values of the individual.” The overlapping area is shaded and this represents “overlapping values.”

The facilitator explains that the larger the shaded area, the more “comfortable” individuals are likely to feel in the organization or group. If the shaded area is large, the individual is confronted by less value conflict. The facilitator says that tension can be present whenever the individual perceives a clash between the values of one culture and the values of another culture to which he or she is connected (e.g., personal and work or department or organization or professional training). These values may conflict more than one often realizes.

(5 minutes)

8. The facilitator asks participants to think of two departments or groups to which they belong. Ideally, these would be groups that are related to the organization for which this activity is being used or related to the jobs of the people within the group conducting the activity. The participants then are directed to think about themselves in relation to these groups and, using the diagram of the three circles as a model, to draw the circles (of approximately the same size) to represent their own values in relation to their two chosen groups, departments, organizations or professional associations, and to list these values in each circle. (10 minutes)
9. The facilitator divides the group into dyads and directs the members of each pair to discuss their respective drawings. Each individual is to explain to his or her partner the rationale behind his or her drawing.(10 minutes)
10. The facilitator reassembles the entire group and leads a discussion of this experience, focusing in particular on:
 - The shaded areas on the drawings and what these indicate about the match between the individual and the work area.
 - What values are seen as common (shaded area)? What values outside the common areas are shaded by individuals in the group?
 - Is there a common theme running through the blasphemies? What might this mean in terms of the way the members perceive the organization?
 - How can blasphemies be turned around and stated in terms of agreed-upon goals or values?(15 minutes)

Variations:

- I. The facilitator can ask for the group members' perceptions of what their individual bosses [or the independent living movement's "leaders"] would give as blasphemies [or what would be "politically correct" in independent living movement language]. These blasphemies can be compared with the participants' own blasphemies. The group can discuss whether issues highlighted by the bosses' or others' blasphemies differ significantly from those of present in the group.

- II. The activity can be made less sophisticated by ending after step 5.

To Create Design Ideas:

This exercise could be followed by individual thinking, then small group discussions of two questions leading to independent living philosophy design ideas. Given our understanding of what constitutes "blasphemies" related to independent living philosophy....

1. What COULD you do in your job to demonstrate commitment to independent living philosophy and values?

2. What COULD your organization do to teach, support and nurture behaviors which demonstrate commitment to independent living philosophy and values?

Small groups could post their answers on "T-formatted" flip chart sheets for report outs of 3 minutes or less.

Creating Organizing Principles Based Upon Independent Living Philosophy and Values

1. Pass out “The Independent Living Paradigm,” “The 10 Key Elements of Independent Living Philosophy” and “Definitions of Key Action Words” to each participant. Review this information thoroughly. 20 minutes
2. Organize people into small groups and assign one of the 10 key elements to each small group. If there are insufficient numbers of people to create 10 small groups, assign two elements to some or all of the groups assembled. 10 minutes
3. Ask individuals to privately record two things in response to these questions:
 - A. What are you, personally, doing now to demonstrate your personal belief in this element or these elements of independent living philosophy?
 - B. What is the organization is doing now to demonstrate its commitment to this element or these elements of independent living philosophy? 15 minutes
4. In small groups, individuals share their thinking for group discussion and record results on flip charts divided into two columns: PERSONALLY DOING NOW and ORGANIZATION IS DOING NOW. 30 minutes

BREAK

5. Moving back to individual thinking, ask everyone to jot down their thinking/responses to these two questions:
 - A. What could you do to demonstrate to others your personal belief in this element of these elements of independent living philosophy?
 - B. What could the organization do to demonstrate its commitment to this element or these elements of independent living philosophy? 15 minutes
6. In small groups, individuals share their thinking for group discussion and record results on flip charts divided into two columns: COULD DO PERSONALLY and COULD DO ORGANIZATIONALLY 30 minutes
7. Each group reports out it results from the COULD DO lists. Reports should be 2 minutes or less. 20 minutes
8. Large group calls out design ideas emerging from COULD DO lists and master list is created for future consideration. 20 minutes

Independent Living Philosophy Design Work

Agenda

- 9:00 - 9:15 Introductions and Overview of FCFP Process
- 9:15 - 9:35 Pass out new handouts and review information included
- 9:35 - 9:45 Organize group into small groups and assign one key element (or two) to each group
- 9:45 - 10:00 Individuals record their private thoughts about DOING NOW
- 10:00 - 10:30 Groups discuss and record their answers to DOING NOW questions
- BREAK (10:30 - 10:50)
- 10:50 - 11:05 Individuals record their private thoughts about COULD BE DOING
- 11:05 - 11:35 Groups discuss and record their answers to COULD BE DOING questions
- 11:35 - 11:55 Each group reports out its "COULD BE DOING" lists
- 11:55 - 12:15 Large group creates master list of design ideas supporting independent living philosophy

Philosophy⁴

1. The inquiry into the most comprehensive principles of reality in general or of some sector of it, as human knowledge or human values.
2. The love of wisdom and the search for it.
3. A philosophical systems; also, a treatise on such a system.
4. The general laws that furnish the rational explanation of anything; the philosophy of “_____.”
5. Practical wisdom, fortitude.

⁴ From *Funk & Wagnalls Dictionary*, 1975

The "Independent Living Paradigm"

	MEDICAL MODEL, REHABILITATION, COMMUNITY ASSISTANCE (service delivery system), CHARITY PARADIGM	INDEPENDENT LIVING, DISABILITY RIGHTS, DISABILITY CULTURE, DISABILITY PRIDE PARADIGM
Definition of the problem	physical or mental impairment; lack of vocational skill, lack of education, lack of socio-economic status, lack of political and cultural skills	dependence upon professionals, family members and others; hostile attitudes and environments; lack of legal protection; lack of recognition of inherent worth of people with disabilities (stereotypes).
Locus of the problem	in the individual (individual is "broken" or "sick" and needs to "fixed" or "cured" to "fit" into society)	in the socio-economic, political, and cultural environment; in the physical environment; in the medical, rehabilitation, service delivery or charity processes themselves (dependency-creating).
Solution to the problem	professional interventions; treatment; "case management" or volunteer work based on pity and related attitudes	1) advocacy; 2) barrier removal; 3) consumer-control over options and services; 4) peer role models and leaders; 5) self-help -- all leading to equitable socio-economic, cultural and political options.
Social role of person	individual with a disability is a "patient," "client," or recipient of charity; in many situations, the social role is non-existent	family and community members; "consumers" or "customers," "users" of services and products -- just like anyone else.
Who controls	professional	person with the disability or his/her choice of another individual or group.
Desired outcomes	maximum self-care (or "ADL" -- activities of daily living as used in occupational therapeutic sense); gainful employment in the vocational rehabilitation system; no "social misfits" or no "manipulative clients"	independence through control over ACCEPTABLE options for living in an integrated community of choice; pride in unique talents and attributes of each individual; positive disability identity.

This paradigm was originally developed in 1978 by Gerben DeJong, now with the National Rehabilitation Hospital in Washington, D.C. It has been modified since then by Maggie Shreve, an organization development consultant working in the field of disability rights out of Chicago, and Steve Brown, a disability policy consultant and principle co-owner of the Institute for Disability Culture in Santa Fe, New Mexico.

The 10 Key Elements of Independent Living Philosophy

1. Civil rights -- equal rights and opportunities for all; no segregation by disability type or stereotype.
2. Consumerism -- a person ("consumer" or "customer") using or buying a service or product decides what is best for him/herself.
3. De-institutionalization -- no person should be institutionalized (formally by a building, a program, or by family life) on the basis of a disability.
4. De-medicalization -- individuals with disabilities are not "sick," as prescribed by the assumptions of the medical model and do not require help from certified medical professionals for daily living activities.
5. Self-help -- people learn and grow by discussing their needs, concerns, and issues with people who have had similar experiences; "professionals" are not the source of the help provided.
6. Advocacy -- systemic, systematic, long-term, and community-wide change activities are needed to ensure that people with disabilities benefit from all that society has to offer.
7. Barrier-removal -- in order for civil rights, consumerism, de-institutionalization, de-medicalization, and self-help to occur, architectural, communication and attitudinal barriers must be removed.
8. Consumer control -- the organizations best suited to support and assist individuals with disabilities are governed, managed, staffed and operated by individuals with disabilities.
9. Cross-disability -- activities conducted by organizations supporting independent living philosophy must be cross-disability in approach, meaning work is carried out by people with different types of disabilities for the benefit of all persons with disabilities.
10. Inclusion -- after barriers are removed and legal rights instituted, society in its broadest sense appreciates and includes people with disabilities in all its forms, including institutions of education, employment, housing, recreation, transportation and all other forms of public and private group activity.

Definitions of Key Action Words⁵

assumption	a fact or statement (as a proposition, axiom, postulate, or notion) taken for granted
attitude	a mental position with regard to a fact or state; a feeling or emotion toward a fact or state
behavior	the manner of conducting oneself; anything that an organism does involving action and response to stimulation; the response of an individual, group, or species to its environment.
belief	a state or habit of mind in which trust or confidence is placed in some person or thing; a tenet or body of tenets held by a group; conviction of the truth of some statement or the reality of some being or phenomenon, especially when based on examination of evidence.
characteristic	a distinguishing trait, quality, or property
concept	something conceived in the mind (thought, notion); an abstract or generic idea generalized from particular instances
policy	prudence or wisdom in the management of affairs; a definite course or method of action selected from among alternatives and in light of given conditions to guide and determine present and future decisions; a high-level overall plan embracing the general goals and acceptable procedures, especially of a governmental body.
premise	a proposition antecedently supposed or proved as a basis of argument or inference
principle	a comprehensive and fundamental law, doctrine, or assumption; a rule or code of conduct
value (n)	relative worth, utility or importance; something (as a principle or quality) intrinsically desirable

⁵ *Merriam Webster's Collegiate Dictionary*, Tenth Edition, 1983

A Little History Worth Knowing

By Timothy Cook

The Alabama legislature declared them a "menace to the happiness...of the community." A Mississippi statute called them "unfit for citizenship." A Texas law mandated segregation to relieve society of "the heavy economic and moral losses arising from the existence at large of these unfortunate persons."

***Ancient penal statutes for convicted felons? No.
Racist epithets from the Jim Crow era? Not quite,
though these declarations did arise in that period.***

Such was the treatment accorded disabled persons, especially those of us with severe disabilities, by democratically elected state legislatures, in this century.

Nor was the government-mandated regime of segregation, exclusion, and degradation of people with disabilities limited to the South. In every state, in inexorable fashion, the policy was to keep us out of polite society.

In Pennsylvania, disabled people officially were termed "anti-social beings;" in Washington, "unfitted for companionship with other children;" in Vermont, a "blight on mankind;" in Wisconsin, a "danger to the race;" and in Kansas, "a misfortune both to themselves and to the public."

In Indiana, we were required to be "segregated from the world;" a Utah government report said that a "defect...wounds our citizenry a thousand times more than any plague;" and, in South Dakota, we simply did not have the "rights and liberties of normal people."

State officials actively inculcated fear of disabled persons, especially retarded persons, directed their identification and removal from the community, and coerced the assistance of physicians, health workers, social workers, and a variety of others to do so.

The United States Supreme Court, in an opinion by Justice Oliver Wendell Holmes upholding the constitutionality of a Virginia law authorizing the involuntary sterilization of disabled persons, ratified the view of disabled persons as "a menace." Justice Holmes juxtaposed the country's "best citizens" (non-disabled persons) with those who "sap the strength of the state" (disabled people), and, to avoid "being swamped with incompetence," ruled "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind."

So, the next time someone tries to explain to you that handicappism is a more "benign" form of discrimination, tell them how the segregation and exclusion of

**The Independent Living Movement: History and Philosophy to
Implementation and Practice by Maggie Shreve**

people with disabilities all began. Tell them how, historically, a lot of important decision-makers passed laws sending us away.

Now, of course, Congress has enacted the Rehabilitation Act, the Education of the Handicapped Act [Individuals with Disabilities Education Act or IDEA], the Architectural and Transportation Barriers Act, the Americans with Disabilities Act, and a number of other laws in an attempt to reverse this historic legacy. Laws requiring integration.

The Movement For Independent Living: A Brief History

December 31, 1994

By Maggie Shreve, Consultant
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ATTITUDES STARTED IT ALL

A brief look at the history of how people with disabilities have been treated by various Western cultures can help us see how the movement for independent living began in this country. From nomadic tribes to social change in the 1960s, people with disabilities have played various roles in their societies. What is occurring now is the horizon of a new age for people with disabilities.

Most **nomadic tribes** considered people with disabilities useless because they could not contribute to the wealth of the tribe. Nomads often left people with disabilities to die whenever the tribe moved to a new location.

The **Greeks** sought rational reasons for disability. They reached such conclusions as: epilepsy was a disturbance of the mind; and people who were deaf could not learn because communication was essential to learning.

Early Christianity brought a period of sympathy and pity toward people with disabilities. Churches organized services for people with disabilities within their congregations and homes. Many Christians held superior attitudes towards people with disabilities which resulted in a general loss of autonomy. To many, disability represented impurity of some kind. This impurity could be purged through worship and forgiveness of sins, including the belief that with enough prayer and rituals the disability could be eliminated.

During the **Middle Ages**, Christians became fearful of people with disabilities as their attraction to supernaturalism increased. People with disabilities were ridiculed, such as court jester who was actually someone with a humped back. People with disabilities were not only ridiculed but persecuted as well. Disability became a manifestation of evil.

The Renaissance brought the initiation of medical care and treatment for people with disabilities. Education was available to people with disabilities for the first time in Western recorded history. An enlightened approach to social norms and dreams for a better future seemed to encourage active participation of people with disabilities in their respective communities.

This is not to say that people with disabilities were not often institutionalized. Periods from the Renaissance through World War II indicated that society believed people with disabilities might be educated, but usually in "special" segregated programs or schools, often far from urban or heavily populated areas.

This institutionalization led to the ultimate in abuse during the 1930s in **Hitler's Germany**. People with disabilities, most notably those with mental retardation and mental illness, became the Gestapo's first guinea pigs in medical experimentation and mass execution. Before the Hitler's SS began mass extermination of Jews, Gays and Lesbians and other minorities and their supporters, people with disabilities were all put to death by Hitler's concentration camp staff.

Early in the formation of the United States, the first settlers of the **American colonies** would not admit people with disabilities because they believed such individuals would require financial support. Colonists enacted settlement laws to restrict immigration of many people, including those with disabilities. This did not, of course, prohibit people with disabilities from being born in the colonies or acquiring disabilities after they were already settled here.

But **by 1880**, after the development of almshouses for people who were poor or in need of basic support, most states and territories had programs for people with specific types of disabilities. Most of these programs were large institutions where people who were blind, deaf, mentally retarded or otherwise physically disabled were sent for treatment, education or to spend their entire lives.

The movement west, otherwise known as the **American Frontier Movement**, inspired a peculiarly American belief that social ills could be eradicated by local initiatives. The concept of "rugged individualism" was born in the American Frontier and still maintains a powerful hold over political debate today. In fact, the desire for independent living today carries with it the seed of many "rugged individualist" ideals. For some people with disabilities, this meant they need not be condemned because they could not earn their own living. Some community-based services began to emerge but people with disabilities were still usually segregated from society as a whole. Rural areas were the only places where people with disabilities tended to live with their families in integrated settings.

Rehabilitation services on a broad scale were introduced as a federal program following World War I. The emphasis for these first rehabilitation programs was on the veteran with a disability who was returning home to the United States. The need for training or re-training created the first federally funded program for people with disabilities -- a program now known as the federal-state vocational rehabilitation system.

During the 1940s, **the blind community** argued for separate services for people who were blind based upon the belief that people who were blind did not need rehabilitation but education. Advocates who were blind argued that rehabilitation is based upon a "medical model" where the person who is blind needs to be treated

and cured rather than educated to live with blindness. The debate over what approach to use resulted in a "split" within the vocational rehabilitation program, allowing state vocational rehabilitation agencies and agencies serving the blind to become separate entities within a state.

Not until the **social change movements** during the 1960s were other major services for people with disabilities seriously considered by federal legislation. Although the Social Security system provided benefits to those who had earned sufficient income over a long enough time period and had become disabled (i.e., unable to work), there was no attempt to broaden the base of services for people with disabilities beyond the vocational rehabilitation approach. For the first time in U.S. history, consumers, advocates and service professionals began an intensive examination of the human service delivery system to decide what was missing. Community-based programs for people with disabilities began growing all over the nation in an attempt to fill the gaps left by these missing services. New concepts, new technology and new attitudes were beginning to make a difference in the lives of people with disabilities.

THE IMPACT OF OTHER SOCIAL MOVEMENTS

Five other social movements of the 1960s and 70s contributed to the evolving movement for independent living for people with disabilities. These were:

- Civil rights movement
- Consumerism
- Self-help
- De-medicalization
- De-institutionalization

According to Gerben DeJong in his paper, "The Movement for Independent Living: Origins, Ideology and Implications for Disability Research," these five social movements created the necessary atmosphere for the current activities of both the disability rights movement and the development of centers for independent living. Centers still emphasize the primary principles of these other five movements in their services and advocacy approach.

Starting with the Center for Independent Living (CIL) in Berkeley, California in the late 1960s, disability rights and independent living concepts merged into one operational organization. Essentially individuals with disabilities joined together to protest their exclusion from society's mainstream and to demand more humane, non-medical attention from the nation's service delivery system. By 1972, there were at least five states where CILs similar to the Berkeley model had been established. These new organizations, run by people with disabilities for people with disabilities, were trying to respond to a rising demand from the disabled community for control over their own services.

Much of this demand sounds like the civil rights movement led by African-Americans during the 1950s and 1960s. People with disabilities pointed out that -- just like other minorities -- they were being denied access to basic services and opportunities such as employment, housing, transportation, education and the like. Like Rosa Parks, people with disabilities want and need to be able to ride the bus. The only difference is that Rosa Parks as an African-American woman was not permitted to sit in the front of the bus while people with disabilities just want to get on the bus.

Consumerism, a movement led by well-known national figures such as Ralph Nader, contributed another element to the growing disability rights and independent living movement. People with disabilities were, for the first time, stressing their role as consumers first and "patients" last. In other words, individuals with disabilities wanted the right to educate themselves and decide for themselves what services and products they wished to purchase (even if a third party was paying for the service or product). As "clients" or "patients," people with disabilities were rarely given any autonomy or power over the services and products they would use.

Self-help is nothing new in the United States, but organized self-help programs are relatively new. The original non-professional, self-help program which is best known in the U.S. is Alcoholics Anonymous. Having a severe disability may not be exactly the same as have a problem with alcohol, but a strong parallel remains. Leaders of the disability rights and independent living movement believe that only persons with disabilities know best how to serve others who have the same or similar disabilities. The concept of "peer" counseling and self-help groups are the most common methods for addressing this parallel.

De-medicalization and **de-institutionalization** share certain common characteristics. De-medicalization for people with disabilities means removing the involvement of medical professionals from the daily lives of individuals with disabilities. People with disabilities are not "sick." They are disabled and not dependent upon medical professionals for every day needs. The perfect example of a "de-medicalized" service for persons with severe mobility disabilities is that of "personal assistance." Personal assistance is a consumer-directed service whereby the person with the disability recruits, hires, trains, manages and fires his or her own personal assistants. When consumers with disabilities are allowed to buy the services they need for daily survival from whomever they choose, they have "de-medicalized" the service. Unfortunately, the vast majority of services provided to people with disabilities are still rooted in the "medical model," regardless of the individual's needs and desires.

De-institutionalization, which began in response to large mental health facilities for those who are mentally ill or mentally retarded, follows the principles of de-medicalization. Most institutions are staffed by medical personnel, even if residents are not ill. Since many such individuals are only disabled by some permanent type of condition, placement in institutions is inappropriate and are be far more costly than providing those same residents with the support services they need to live in their chosen communities. The disability rights and independent living movement is

working towards the development of those other non-medical and community-based services which would assist institutionalized persons to move back to their home towns or areas.

INDEPENDENT LIVING AND TRADITIONAL REHABILITATION

Since most traditional rehabilitation programs are built upon the "medical model" of service delivery, the disability rights and independent living movement promotes a completely different approach to service delivery. Independent living as a movement is quite unique compared to existing programs and facilities serving people with disabilities. Centers for independent living across the nation are working toward changing their communities rather than "fixing" the person with a disability. CILs were originally defined by the first CIL in Berkeley and now are commonly referred to as consumer-controlled, community-based, non-residential not-for-profit organizations providing both individualized services and systems advocacy.

Referring again to Gerben DeJong, traditional rehabilitation and independent living programs see the problems associated with disability from two different perspectives. The paradigms below have evolved from DeJong's work in 1978 and now include the thinking of many disability rights advocates, most notably Steve Brown of the Institute on Disability Culture in Sante Fe, New Mexico:

The "Independent Living Paradigm"

	MEDICAL MODEL, REHABILITATION, COMMUNITY ASSISTANCE (service delivery system), CHARITY PARADIGM	INDEPENDENT LIVING, DISABILITY RIGHTS, DISABILITY CULTURE, DISABILITY PRIDE PARADIGM
Definition of the problem	physical or mental impairment; lack of vocational skill, lack of education, lack of socio-economic status, lack of political and cultural skills	dependence upon professionals, family members and others; hostile attitudes and environments; lack of legal protection; lack of recognition of inherent worth of people with disabilities (stereotypes).
Locus of the problem	in the individual (individual is "broken" or "sick" and needs to "fixed" or "cured" to "fit" into society)	in the socio-economic, political, and cultural environment; in the physical environment; in the medical, rehabilitation, service delivery or charity processes themselves (dependency-creating).
Solution to the problem	professional interventions; treatment; "case management" or volunteer work based on pity and related attitudes	1) advocacy; 2) barrier removal; 3) consumer-control over options and services; 4) peer role models and leaders; 5) self-help -- all leading to equitable socio-economic, cultural and political options.
Social role of person	individual with a disability is a "patient," "client," or recipient of charity; in many situations, the social role is non-existent	family and community members; "consumers" or "customers," "users" of services and products -- just like anyone else.
Who controls	professional	person with the disability or his/her choice of another individual or group.
Desired outcomes	maximum self-care (or "ADL" -- activities of daily living as used in occupational therapeutic sense); gainful employment in the vocational rehabilitation system; no "social misfits" or no "manipulative clients"	independence through control over ACCEPTABLE options for living in an integrated community of choice; pride in unique talents and attributes of each individual; positive disability identity.

This paradigm was originally developed in 1978 by Gerben DeJong, now with the National Rehabilitation Hospital in Washington, D.C. It has been modified since then by Maggie Shreve, an organization development consultant working in the field of disability rights out of Chicago, and Steve Brown, a disability policy consultant and principle co-owner of the Institute for Disability Culture in Santa Fe, New Mexico.

The traditional paradigm defines the problem with disability as the actual physical or mental impairment whereas independent living defines the problem as the dependence upon professionals and others. Under this model, the person in control of service is the professional. Under independent living, the person in control is the person with a disability, i.e., the consumer. In the traditional paradigm, the desired outcome of service delivery is maximum physical or mental functioning (or, as in vocational rehabilitation, gainful employment). Desired outcomes in independent living are tied to having control over one's daily life. Control does not necessarily mean having the physical or mental capacity to do everyday tasks for one's self. For some disability groups, complete control may not be possible, but the independent living movement continues to work toward complete consumer control wherever and whenever possible. What may be even more critical is that a person with a disability identifies him or herself as a "normal" person and has pride in self, including the disability.

These philosophical differences may be hard to realize when thinking about services and programs in your local area. Obviously, every community needs the some traditional services such as education and rehabilitation or the provision of quality medical-based services. But, more importantly, each community needs an equal amount of advocacy, support services, and attention from the independent living paradigm. Currently, 99% of all public dollars go into the rehabilitation paradigm while less than 1% goes into independent living.

Picture a town where every curb has a curb cut and ramp!

- where children with disabilities are fully integrated into all schools and all grades with non-disabled children
- where there are no institutions or "state schools" but many scattered small group homes for those with disabilities so severe that they are not capable of controlling their everyday lives
- where buses are equipped to pick up any type of passenger, including those who use wheelchairs or have other mobility impairments
- where closed or open captioning is available on every TV station and for every program
- where in-home services are available at any time and for any person, regardless of type of disability or level of income.
- where individuals with disabilities go to the college, training, or vocational schools of their choice and find job opportunities following their skills training.

Such a picture is possible. Based upon historical developments such as those cited above, upon the numerous federal, state and local laws currently in place (and those yet

to come), and upon the pure energy, dedication and drive of people with disabilities in this country, a new vision of the United States is becoming a reality.

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Now, with the passage of the Americans with Disabilities Act of 1990 (ADA), we have full recognition of the harm done by discriminating against people with disabilities. The ADA will assist the movement in completing the picture--a picture of equal opportunity and access for all. A picture shared by people involved in both the traditional rehabilitation system and the newer, younger disability rights and independent living movement.

The even more recent passage of The Rehabilitation Act Amendments of 1992 will go a long way to resolving attitudinal problems within the traditional rehabilitation service delivery system. The new Rehab Act gives centers greater autonomy at the local level and institutes statewide independent living councils with real power and authority over how independent living programs will be implemented within the state. It emphasizes increased "consumer control" and "consumer choice" throughout the act. And the new Title I (basic state vocational rehabilitation program) is based upon a philosophy that **ALL** individuals with disabilities should be presumed to benefit from vocational rehabilitation services. While there is still considerable room for reform within the Rehabilitation Act and the service delivery system driven by it, the 1992 amendments indicate clear and steady progress towards a more integrated approach to resolving disability-related problems in America.

Some material about the history of the role of people with disabilities in various societies was drawn from an unpublished paper titled "Attitudes Toward the Disabled: An Historical Perspective," by J.K. Hannah and M.L. Jones (1982) at the Research and Training Center on Independent Living at the University of Kansas. Their work used information from Frank Bowe in his book, *Handicapping America*.

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Language Is More Than A Trivial Concern

[Excerpt]

By June Isaacson Kailes
Disability Policy Consultant
Los Angeles, California

EXAMPLES OF DISABILITY-RELATED PREFERRED TERMS

Acceptable (Subject to change and continuing debate)	Unacceptable (Dehumanizing/Offensive)
He had polio	He was afflicted with, victim of, stricken with or suffers from polio
He has arthritis	He is arthritic
A person who has had a disability since birth, a congenital disability	Birth defect
A person who uses a wheelchair, a wheelchair user	Confined to a wheelchair / wheelchair bound
She has a disability	She is crippled
She has cerebral palsy	She is cerebral palsied, spastic
A person who has a disability, people with disabilities	Disabled person, disabled people
A person who has a speech disability, or is hard of hearing, or is deaf	Dumb, deaf mute, dummy (Implies an intellectual impairment occurs with a hearing loss or a speech impairment)
A person who has a spinal curvature	A hunchback or a humpback
People with disabilities, Disability community	The Disabled
Seizure	Fit
Older people with disabilities	Frail
He has a mental illness. He has an emotional disability. He has a psychiatric disability.	He is chronically mentally ill, a nut, crazy, idiot, imbecile, moron
People of short stature	Midget, dwarf, little people
A person without speech or a person who has a speech impairment	Mute
A person without a disability as compared to a person with a disability	Normal person, whole person, healthy person, able-bodied person as compared to a disabled person
She lives with a disability	Overcame her disability
Use only when a person is actively being seen or treated by a health care provider	Stroke patient , multiple sclerosis patient
A person who has a developmental disability or has mental retardation	Retard, retardate, retarded, feeble-minded
Use only when a person is actually ill	Sick

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Other words which should be avoided because they are negative, reinforce stereotypes and evoke pity include:

- Abnormal
- Burden
- Disfigured
- Invalid
- Lame
- Maimed
- Misshapen
- Spaz
- Unfortunate

Excerpted from: Language is More Than a Trivial Concern, by June Isaacson Kailes, Disability Policy Consultant, 1999, Self-published by Kailes, 6201 Ocean Front Walk, Suite 2, Playa del Rey, California 90293. For information regarding ordering a full copy of this article visit: <http://jik.com/resource.html> and click on “Disability Awareness.”