

IL NET

an ILRU/NCIL National Training and Technical Assistance Project

Expanding the Power of the Independent Living Movement

HOW IL HISTORY AND PHILOSOPHY SHAPE OUR FUTURE

A National Teleconference

Participant's Manual

August 22, 2001

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**HOW INDEPENDENT LIVING HISTORY
AND PHILOSOPHY SHAPE OUR FUTURE**
A Teleconference
August 22, 2001

AGENDA

Welcome and Introductions

Materials Galore but Not Enough Stories

Who Are We? Is a Common Philosophy Possible?

A History Worth Knowing, and Telling, and Re-Telling, and....

A Vision for the Future

Wrap-up

About the Trainer

Darrell Lynn Jones is Training Specialist for the IL NET Project at the National Council on Independent Living and has been involved in the IL movement for 24 years. She was founding Executive Director of the Rochester Center for Independent Living in Rochester, New York, and subsequently became the first director of the Association of Independent Living Centers in New York. In both positions she was a principle player in the creation of IL as a statutory program in New York State, expanding CILs from an initial nine to 34 by 1987. In various capacities Darrell has provided technical assistance to CILs for over 14 years in the areas of board training, management, resource development and strategic planning. She is also co-author with June Isaacson Kailes of **A Guide to Planning Accessible Meetings**.

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ABOUT ILRU

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

ABOUT NCIL

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL's efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation's capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.

ABOUT THE IL NET

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.
- Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.

***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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- #....."A Little History Worth Knowing," by Timothy M. Cook
- #....."The Movement for Independent Living: A Brief History," by Shreve
- #....."Language is More Than a Trivial Concern!" by Kailes

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.

D. 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.

E. 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?

- F. 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.
- G. 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.
- H. 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

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
<p>A - Independent living rehabilitation services for individuals</p> <p>B - 3 year grants to establish and operate CILs</p> <p>C - Services for older, blind adults</p> <p>D - Protection and advocacy for individual rights (PAIR)</p>	<p style="text-align: center;">Chapter 1</p> <p>A - Purpose, philosophy, definitions, structure, establishes SILCs</p> <p>B - Formula funding to states based upon state plan</p> <p>C - Ongoing funding to CILs meeting standards</p> <hr/> <p style="text-align: center;">Chapter 2</p> <p>Services for older, blind adults</p>

- 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 decisionmaking, 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 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 decisionmaking 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 (Institutional- ization)
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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. 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,"

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/resource.html>.

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 grand mother with her grand children, 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 themselves 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 mind set 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 themselves 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.
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? How can you put the principles of the independent living movement into practice?

- A. 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."
- B. 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.
- C. How organizations can pass the "reality versus rhetoric" test:
 - 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?
- D. To test your "reality," ask your trainer to take the full 76 item "reality versus rhetoric" test.

XI. 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, 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

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 Strongly
disagree 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 Strongly
disagree 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 Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree 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 Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree 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 Strongly
disagree 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 Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree 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 Strongly
disagree agree

- 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 Strongly
disagree 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 Strongly
disagree 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 Strongly
disagree 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 Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree agree

- 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 Strongly
disagree 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 Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree agree

- 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 Strongly
disagree 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
Strongly Strongly
disagree agree

- 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 Strongly
disagree 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 Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree 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 Strongly
disagree agree

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

1----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
Strongly Strongly
disagree 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 Strongly
disagree 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 Strongly
disagree 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 Strongly
disagree 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

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 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.
- _____ 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.
- _____ 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 this 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?

For more information, contact:

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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 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?

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?

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?

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 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

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 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?

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

- 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

- I. 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

- II. 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

- III. 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

- IV. 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

- V. 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
- VI. 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
- VII. Each group reports out its results from the **COULD DO** lists. Reports should be 2 minutes or less.
- 20 minutes
- VIII. 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 concept	a distinguishing trait, quality, or property 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, 1993*

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 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

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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.

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 every day 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.

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)

He had polio

He has arthritis

A person who has had a disability since
birth, a congenital disability

A person who uses a wheelchair, a
wheelchair user

She has a disability

She has cerebral palsy

A person who has a disability, people
with disabilities

A person who has a speech disability, or
is hard of hearing, or is deaf

A person who has a spinal curvature

People with disabilities, Disability
community

Seizure

Older people with disabilities

He has a mental illness. He has an
emotional disability. He has a psychiatric
disability.

People of short stature

A person without speech or a
person who has a speech impairment

A person without a disability as
compared to a person with a disability

Unacceptable

(Dehumanizing/Offensive)

He was **afflicted** with, **victim of**, **stricken** with
or **suffers** from polio

He is **arthritic**

Birth defect

**Confined to a wheelchair / wheelchair
bound**

She is **crippled**

She is **cerebral palsied, spastic**

Disabled person, disabled people

Dumb, deaf mute, dummy (Implies an
intellectual impairment occurs with a hearing
loss or a speech impairment)

A hunchback or a humpback

The Disabled

Fit

Frail

He is chronically **mentally ill, a nut, crazy,**
idiot, imbecile, moron

Midget, dwarf, little people

Mute

**Normal person, whole person, healthy
person, able-bodied person** as compared to
a disabled person

She lives with a disability
Use only when a person is actively
being seen or treated by a health care
provider
A person who has a developmental
disability or has mental retardation
Use only when a person is actually ill

Overcame her disability
Stroke **patient**, multiple sclerosis **patient**
Retard, retardate, retarded, feebleminded
Sick

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

Abnormal	Lame
Burden	Maimed
Disfigured	Misshapen
Invalid	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://www.jik.com/resource.html> and click on "Disability Awareness."

The Professional Problem

By John McKnight

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Associate Director of the Center for Urban Affairs
at Northwestern University**

**[This article was first presented at a seminar on professionalism
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***Revolutions begin when people
who are defined as problems
achieve the power to redefine the problem.
--John McKnight***

The Professional Problem By John McKnight

Revolutions begin when people who are defined as problems achieve the power to redefine the problem.

A critical point in the development of the civil rights struggle was the Black movement's capacity to declare the central issue to be the "White problem." A people, declared deficient and in need, unshackled their labels and attempted to lock them on their oppressors.

There was a revolutionary insight in that strategy. It recognized that the power to label people as deficient and declare them in need is the basic tool for control and oppression in modern industrialized societies of democratic and totalitarian persuasions. The agents with comprehensive labeling power in these societies are the helping professionals. Their badge bestows on the caring the authority to declare their fellow citizens "clients"—a class of deficient people in need.

As was the case in the Black revolution, we can now see signs of "client populations" beginning to wonder whether they are really the problem. One manifestation of this client uneasiness is the "self-help movement." This movement is peopled with many ex-clients who have understood the limits of their professional helpers or the disabling effects of their services. The angriest and most political are repeating the Black redefinition of the 1960s. They reject their clienthood and seek liberation by defining the problem as those who have defined them as the problem. To these ex-clients, the central issue is the "professional problem."

Their once lonely struggle to proclaim the "professional problem" has been aided by a growing chorus of voices. Radical social critics such as Ivan Illich have defined the iatrogenic capacities of professionals,⁶ that is, their ability to induce a problem in their clients. Peter Berger and Richard Neuhaus have described the decay of primary social structures facilitated by modern professionalism.⁷ Eli Ginzberg worries that the new class of professionals may usurp the decision-making power within our industrial structure.⁸ Jacques Barzun concludes that if our professions are to survive with their traditional freedom, a major recovery of mental and moral force will be necessary.⁹ Even Nathan Glazer is attracted by the attack on the professionals and hesitantly commends

⁶ Illich, Ivan. *Medical Nemesis*. New York: Pantheon Books, 1976.

⁷ Berger, Peter and Neuhaus, Richard. *To Empower People: The Role of Mediating Structures in Public Policy*. Washington: American Enterprise Institute for Public Policy Research, 1977.

⁸ Ginzberg, Eli. The Professionalization of the U.S. Labor Force. *Scientific American*, March 1979, pp. 48-53.

⁹ Barzun, Jacques. The Professions Under Siege. *Harpers*, October 1978, pp. 61-68.

its best spokesmen for their insight.¹⁰ And former President Jimmy Carter specifically attacked the lawyers and the doctors of America, sensing that the “professional problem” was becoming a popular political issue.

The growing critique suggests that critical issues of power and control must be at stake. Paradoxically, the two most obvious interests involved in the attack on professionals are those who oppose the growth of government and those who would increase the role of government.

The anti-government interests depend upon an automatic popular translation of “professional” into “government bureaucrat.” While significant numbers of professionals are state employees or funded by the state, there are obvious distinctions between a professional and a bureaucratic class. Nonetheless, the conservative uses of the “professional problem” are clearly focused on attacking big, bureaucratic government. The fact that this translation is so dependable suggests that both classes may have a common characteristic in the popular mind—the production of paid non-work.

The pro-government interests use the “professional problem” to defend the state and its bureaucracy by making the distinction between the professional and bureaucratic classes. They typically suggest that inflated public budgets are really caused by “greedy doctors” at the Medicare-Medicaid trough or “self-serving teachers” consuming ever more of the public wealth while school populations and standard achievement scores decrease. Carter’s attack on doctors and lawyers may be the clearest example of this particular use of the “professional problem”

Major corporations have also joined in professional-baiting. The benefits director of General Motors complains that the company’s cost of medical insurance is greater than the price of all the steel it uses to build automobiles. Corporate managers universally complain of their increasing dependence on growing cadres of lawyers. Indeed, their public rhetoric suggests that corporate leaders no longer view unions as their principal burden. Instead, they are beginning to define the “professional problem/bureaucracy” as the monkey on their backs.

Some representatives of the poor and minorities have also joined the attack on professionals. Welfare recipient organizations complain that their professional servicers now receive more money for their help than the recipients receive in cash grants. In many states, for examples, the Medicaid budget for medical service to welfare recipients is now larger than the budget for direct cash grants to the recipients. Like the corporations, many advocates of the underclass describe themselves as victims of the “professional problem”—poor people defined as deficient by those whose incomes depend upon the deficiency they define.

¹⁰ Glazer, Nathan. *The Attack on the Professions. Commentary*, November 1978, pp. 34-41.

When presidents, intellectuals, conservatives, liberals, corporations, and the poor join in common cause against a class of workers numbering 14 million Americans, it is time that we examine the causes of the “professional problem”

Three basic causes

The current analysis suggests three basic causes for the revolt against the professional “problem definers.”

The first cause is the inefficiency argument. This position suggests that the professionals are being attacked because they are doing less with more. Teachers receive much more of the Gross National product (GNP) while student achievement scores decline. The medical professions consume one-ninth of the GNP while life expectancy does not increase. The number of lawyers doubles as the popular sense of injustice multiplies. Criminal justice systems expand as the perception of personal security declines.

There is hardly a professionalized service that has not received an increasing portion of the GNP during the last decade. Nonetheless, the problems they have defined as their jurisdiction have consistently grown worse in public perceptions. In managerial terms, inputs are up and outputs are down. In investor idioms, there is no leverage. In taxpayer language, it’s a bad “proposition.”

Inefficiency is an attractive argument because it is based up American pragmatism. It explains the revolt against the professional as the simple rejection of something that isn’t working. Its proponents are not much concerned with the reasons for the non-productivity, but they are clear that they will not pay more for less. Therefore, the budget analyst, the manager, and the cost cutters are being engaged to trim the professional fat.

The arbitrary nature of this remedy for the professional problem is exemplified by Jimmy Carter and his “national health policy” that had nothing to do with health. It was really a plan to stop the inflation in medical costs by establishing an annual hospital cost inflation limit of 9 ½ percent.

The second cause of the revolt is explained by the arrogance argument. This position suggests that the nature of professions is inherently elitist and dominant. Given the professional powers to define problems, treat them, and evaluate the efficacy of the treatment, the client as a person has been a residual category in the process. As professions have become integrated into large scale specialized systems financed by public funds and insurance plans, the professional has increasingly been able to secure a guaranteed annual income. The consequence is that the client’s residual role as a volitional purchaser of service, or even as a human being in need, has disappeared, and the professional is free to use the client without pretense of humanistic service. The resulting arrogance, magnified by the modernized systems of assembly line, multi-

service “care” that institutionalize the individual professional, has evoked the consumer movements.

These reform efforts are, at the least, client efforts to develop enough counterpower to require professionals to treat clients like human beings—if not equals. Patient advocates, parent groups, and client councils are political efforts to remedy professional arrogance.

The arrogance argument is attractive because it suggests that the “professional problem” can be resolved if we reinstate the humanistic traditions of professional work. The consumer vehicle for this re-humanization is, paradoxically, advocacy and adversary, and is confrontational in its nature. It suggests that we can somehow *force* professionals to *care* again. Consumer-oriented reformers are therefore instituting new professional training curricula that attempt to *teach* professionals to *care*. The result is exemplified by a consumer group that manages to coerce a medical school to *require* all students to take courses in humanistic/holistic health *care*.

The third explanation for the “professional problem” is the iatrogenic argument. While the inefficiency argument suggests that the problem is that professionals don’t work, the iatrogenicists argue that they do work—but to our detriment. This position holds that the negative side effects of technological, specialized professionalism are so harmful to so many that the revolt is the reaction to professionally administered injury.

The injury comes in several forms that are brilliantly defined by Ivan Illich in his book, *Medical Nemesis*.¹¹ Afflicted with sick-producing medicine, stupidifying education, and criminalizing justice, the citizen reacts with an inchoate anger. Incredulous that schools could “produce” ignorance and hospitals “manufacture” malady, the citizen/client strikes out in blind rage. The professionals and their technological and intellectual allies counterattack by calling the popular outrage “know-nothingism,” “anti-intellectualism,” and “a turn to the right.”

Nonetheless, such diverse intellects as Peter Berger and Richard Neuhaus have supported the iatrogenic argument with their description of negative effects of professional dominance upon the problem solving capacities of the primary social structures of society—family, neighborhood, church, temple, ethnic group, voluntary associations, and popular political parties.¹² And Marxist historian Christopher Lasch adds his voice by describing the family as a victim of the professional serving as a capitalist vanguard making a commodity of the non-working time of Americans to insure new markets.¹³

The iatrogenic argument is the least attractive of the three causal propositions because it suggests that helpers hurt. The very idea offends the mind. Nonetheless, the disabling

¹¹ See Illich, *op. cit.*, footnote 1.

¹² See Berger, *op. cit.*, footnote 2.

¹³ Lasch, Christopher. *Haven In A Heartless World*. New York: Basic Books, 1977.

experience with professionals creates frustrations that must be expressed. For those who cannot speak the unspeakable, who cannot define the problem as those who have defined them as the problem, the alternatives include collapse into personal guilt, escape into narcissistic cults, or the numbing possibilities of licit and illicit drugs. The ultimate tragedy of each of these responses to professional iatrogenesis is that professionals feed on them. They stand ready to help again with the guilt, narcissism, or drug use. Like a hall of mirrors, the problem definer creates the treatment that creates the problem and creates the remedy....

What do we do about this?

What do we do about this increasingly inefficient, arrogant, and iatrogenic class? Jacques Barzun notes the urgency of the issue by concluding that “Without...heroic effort, we professionals shall all go down, appropriately, as non-heroes together.”¹⁴

All three explanations for the “professional problem” imply the possibility of reform by recreating an economic, democratic, and efficacious practice. Here and there, one sees serious, if fragile, efforts to reform professional practice. Its labels are eclectic: humanistic medicine, free schools, community dispute settlement, holistic health care, community-based care. Whatever the label, the common perception of the reformers is that a heroic effort can rectify professionalism and create a new class of professionals in the useful service of humanity.

It is my view that this vision is neither possible nor desirable. The hopeful future for helping work is more likely to result from the fall of the professions and the development of new definitions of good work.

Professional reform is unlikely because our current approaches to economic growth and national stability *depend* upon the development of more professionalized service of the same kind we are currently experiencing. In 1900, approximately 10 percent of the paid work force “produced” services. In 1978, 63 percent of the work force is in the service industry with 14 million people in professional service work. Daniel Bell’s projections suggest that by the year 2,000, the service work force will represent 90 percent of the employed. If his projections are correct, during the next 21 years, nearly 25 percent of America’s work will be translated from goods to service “production” jobs. This translation will provide jobs for two of the major groups that will be entering the work force during these decades—women leaving the homeforce and the graduates of higher education with expensive postgraduate education that promises them professional roles.

All of the forces in our economy are now programmed to create a geometric increase in the number of professionals while the goods production sector is designed to replace the labor of Americans with machines and foreign labor. The government must increase the GNP and “control” unemployment. There seems to be no choice but to pump up the

¹⁴ See Barzun, *op. cit.*, footnote 4.

service economy. The choice is easy because the more privileged of our society—college graduates and homeworkers entering the paid labor force—expect the prestige accorded professional work. Therefore, the development of a professionalized work force is the economic keystone of our highly educated, technologized society as long as we are committed to two propositions:

- (1) A Growing GNP is good.
- (2) The “production” of professional service adds to the GNP.

In our drive to increase professionalized service “production,” there is a popular assumption that we are intensifying the good works of society. With more professionals we will kill cancer, make the criminal justice system work, learn how to teach reading, cure deafness, and give sight to the blind.

There is, on the other hand, a contradictory popular insight that doubts that we *really* need more professionals. There are not many Americans who believe that doubling the number of lawyers will decrease either injustice or crime. There are serious doubts that we need more teachers or social workers in a population with decreasing numbers of young people. The psychological professions are feeling such popular disrepute that even *Time* magazine has noticed. And the high priests of medicine are confronted by popular doubt in the malpractice rebellion.

Obviously, Americans are ambivalent and confused about the impact of professional proliferation. In spite of this confusion, it is clear that the direction of professional growth is at the margin of perceived problems. A careful analysis of the recent areas of professional development indicates that “unmet needs” are the growth sector of the service industry. The most recent discovery of these new “needs” include “tired housewife syndrome,” “six-hour retardation” (a child who is normal for the 18 hours a day not in school), “bereavement deficit” (previously known as grief), “incipient child abuse” (the possibility that a parent might hurt a child), “litigative incapacity” (the lack of funds to sue others to secure equity), and “reclusiveness” (the desire not to associate with others).

Each of these new discoveries of unmet “needs” creates a “demand” for a new profession. At least one major university is now training graduates to meet the needs of people with “bereavement deficits” by providing a masters degree in Bereavement Counseling (MBC). The practitioners of this developing profession have organized a professional association whose first goal is to lobby for clauses in public and private life insurance policies that would guarantee their services for the kin of the deceased.

Those who are infected by “reclusiveness” have called forth a new profession in at least one major city. These professionals are tentatively called “recluse managers.” Their services include identifying recluses, maintaining inconspicuous surveillance and, at the proper moment prescribed by strict professional standards, intervening in the life of the recluse.

It is now clear that the economic pressure to professionalize requires an expanding universe of need and the magnification of deficiency. This form of marginal professional development can only intensify the ineffective, dominating, and iatrogenic nature of the professional class as they invade the remaining perimeters of personhood.

To suggest that we can “reform” bereavement counselors and recluse managers is a profound misunderstanding of the current “professional problem.” The basic issue is profession itself, dependent upon the manufacture of need and the definition of new deficiencies.

One can imagine that the modern “professional problem” will be resolved when the lives of enough people are so completely invaded by the professional need for deficiency that a popular revolt develops.

Another possibility for change

There is, however, another possibility for change that I can only verify by my personal experience. In the last few years I have spoken to numerous professional associations regarding the degrading professional “manufacture of need” and the iatrogenic effects of professionalized service. While one might expect a negative reaction to this message, the response by professionals in subsequent question periods, workshops, and discussions is almost always positive. Instead of an argument, I find professionals consistently giving me examples of their own useless and iatrogenic activities.

To my great surprise, I am not asked “How can I do a better job?” Instead, the constant question, asked especially by younger people, is “What do you think I could do that would be worth doing?”*

It is this subversive question in the minds of so many young professionals that suggests the possibility for radical change. They are not arguing that their professional work can or should be reformed. Their poignant inquiry recognizes that they know how useless, controlling, exploitative, or harmful is the central function of their work.

They are too honest to ask about reform. Their question is, “Can you tell me what good work needs to be done in America? I thought that professional training would lead me to good work, but it has led me to live off some people who don’t need me and others I can’t help.”

The politics for a new definition of legitimate work in America may grow from the confluence of citizens angered by the professional invasion of personhood and young professionals disillusioned by lives wasted in the manufacture of need.

* There is one qualification. Lawyers, social workers, psychologists, planners, social service workers, teachers, and youth workers ask this question. Most doctors do not. They are the remaining “true believers,” the professional zealots of our time.

The possibility for this politics requires an economy that can provide legitimate work for all those people who do not want to make a living by creating deficiencies in their neighbors.

What is legitimate work? What is worth doing? What is good work for America's people?

The answer to these questions takes us beyond the idea of profession. Our possibilities are incredible if we can envision a society with good work to be done that does not waste our people in the proliferation of profession.

Can you tell me what good work needs to be done in America? The answer will dissolve the "professional problem."

***The greatest discovery of my
generation is that human beings
can alter their lives by altering
their attitudes of mind.***
--William James 1842-1910

FREEDOM OF MOVEMENT

INDEPENDENT LIVING HISTORY AND PHILOSOPHY

by Steven E. Brown
Institute on Disability Culture

ILRU bookshelf series
Publications for Independent Living

**FREEDOM OF MOVEMENT
INDEPENDENT LIVING HISTORY AND PHILOSOPHY**
*by Steven E. Brown
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INTRODUCTION

Can Independent Living (IL) history be separated from IL philosophy?

When I began to write this monograph I thought I would start with the students at the University of Illinois. But as I learned more about that program I realized it may not have existed without World War II veterans who needed an education. How, I then wondered, does one distinguish the impact of World War II on disability history from Franklin Delano Roosevelt (FDR), a President who used a wheelchair and served as commander-in-chief for most of that war? So I chose to begin the history with FDR.

If someone thinks that the disability rights movement began in 1990 with the passage of the Americans with Disabilities Act or the 1970s with the first centers for independent living, how would I explain why I chose to begin with someone who predates those events by several decades. The solution seemed to be using a general explanation of IL philosophy as a preface to a beginning discussion of the history.

One of the difficulties, as well as one of the pleasures of writing this monograph, is that our history is so fragmented. I know of nowhere else where all the information in this monograph is tied together. As a historian assembling this monograph, I'm excited. But as an advocate with a disability, it is frustrating to realize how scattered our historical information remains.

Much more work needs to be done before we have even the beginnings of a coherent, let alone comprehensive, history of our movement. But as always, we must begin somewhere, and therefore I choose to begin with a description of IL philosophy I wrote several years ago that still seems appropriate.

INDEPENDENT LIVING PHILOSOPHY

Several fundamental beliefs have been combined to establish the foundation on which to construct an independent living philosophy. These premises include the notion that each individual is different and unique; that people with disabilities are the most knowledgeable experts about our own needs and issues; and that programs serving disabled people should be designed to serve all disability groups.

Just as every person is different from each other, so too are disabling conditions. This applies not only to the differences between differing disabilities, such as deafness and mental illness and paralysis, but also to individual differences within each disability category.

For example, each person with a disability who uses a wheelchair is unique. Some people using wheelchairs are paralyzed, others are not. Some use their feet, but not their arms; others their arms, but not feet. Some wheelchair users use their breath to move their chair, others their head.

The point is that just as each wheelchair must be designed to fit the individual needs of the person using that mobility aid, so too must every other adaptation be adjusted to the individual. To make this equation just a little more complicated, disabling conditions, like people, are often dynamic, not static. So the results of the disabling condition itself are often changing and, to return to the example of wheelchairs, an individual who uses a certain kind of wheelchair one year may need a different kind the next so that there is a constant adjustment to the changing conditions of the disability or, even more salient, to the changing conditions of life.

Every individual and every disability condition is different, therefore every individual with a disabling condition is unique. People who are most familiar with disabilities, that is, those who have them, are best-suited to discuss the needs and issues of people with disabilities. This is not to say that a person without a disability is incapable of knowing, understanding, or empathizing with what it is like to have a disability. But it is to say that it's much more likely for a person with a disability to possess these characteristics.

The notion of one person with a disability having some understanding of another person with a disability forms a primary underpinning of independent living philosophy, which is the concept of peer support. In independent living terms, a peer is someone with a disability who is a role model and/or support person for another person with a disability. Translated to other movements, it is the same concept that drives Alcoholics Anonymous and all the other anonymous self-help programs. It drives the concept of groups as institutionalized as the YW and MCAs and of groups as historically radical as the Black Panthers.

The ideas of peer support and people with disabilities knowing what is best for ourselves leads directly into the concept of people with disabilities running our own

programs. That is why many independent living programs require boards of directors to have at least a majority of their members be people with disabilities.

But there is another very important reason for people with disabilities managing their own programs. This is the whole issue of empowerment. For someone who is not empowered, and as a group people with disabilities are not, it is of utmost importance that power positions, such as boards of directors, can be perceived as role models.

A useful analogy is that of Women's Resource Centers. Few people would argue that men should run programs for women. Men are not women and no matter how hard we may try there are just some things that men will never be able to have in common with women. So it makes sense for women to be the primary participants in running programs designed for women. Now just plug in the phrase "people with disabilities" for women in the preceding three sentences.

Substitute "nondisabled people" for men in the same sentences. See if it makes sense. If it does, then one has just agreed with one of the basic philosophies known in independent living jargon as "consumer control," that is people with disabilities as the consumers of programs designed for them also ought to be the principal players involved in their direction and management.

The final philosophical framework of independent living programs is that they should be designed to serve all disability groups. This may be the most controversial of the independent living beliefs. Many population groups--including people with hearing impairments, visual impairments, brain injuries, mental retardation, psychiatric disabilities, and probably any other disability demographic population identified--have stated at one time or another that separate services are necessary for their specific conditions.

Proponents of the independent living philosophy known as cross-disability counter that all people with disabilities are oppressed and that there is little difference in the big picture of the discrimination against people with disabilities. To paraphrase a well-known quote: oppression is oppression is oppression.

Cross-disability advocates will agree that there may be different tools to use toward the overarching goal of independence. For example, a deaf person may need sign language for communication and a person with a head injury may need a tape recorded reminder to do a task and a person whose legs don't work well may need a wheelchair. But beyond the necessity of different tools is the common goal of an opportunity for full participation in the cultural, social, economic and political aspects of our society.

The driving beliefs of independent living philosophy are a recognition that each person with a disability, like each person, is unique; that because of this uniqueness people with disabilities are in the best position to guide, direct, and control their own programs; and that because all people with disabilities are oppressed, independent

living programs need to be designed to ensure equal social, cultural, economic, and political opportunities for all disability groups. (Brown, *Independent Living* 2-5)

In the next section, we'll look at the life of FDR to consider if he might be called a predecessor of the disability rights movement. To put it another way, could FDR have been considered, "a peer. . . someone with a disability who is a role model and/or support person for another person with a disability."

WAS HE OR WASN'T HE?

FDR grew up in a wealthy, civic-minded family in New York state. A personable and vigorous young man, he followed the path of his cousin, President Theodore Roosevelt, first in joining the Navy, then in quickly becoming a successful politician. Unlike his older cousin, FDR's first Presidential election was a losing one as the Vice-Presidential candidate of the 1920 Democratic slate.

Shortly thereafter, his political future unclear, he contracted polio. Both his legs became permanently paralyzed and he became a wheelchair-user.

FDR's wealth and contacts enabled him to pursue physical rehabilitation anywhere he chose. He selected Warm Springs, Georgia. He poured much of his energy and wealth into building a modern rehabilitation facility there.

For many years, historical accounts of FDR's polio treated it as a brief and isolated incident in his life which probably proved to his political benefit. These narratives contend that voters felt distanced from the healthy and wealthy FDR. But polio became a great equalizer. It demonstrated that even someone with FDR's breeding and riches could be brought down a notch or two and in so doing would become more appealing to the voters who would elect him. In addition, FDR turned to his wife Eleanor, whose compassion is now legendary, to keep him in touch with everyday issues and the average citizen. Finally, his long recovery enabled him to write many letters, entertain visitors, and make numerous contacts in a concerted effort to reenter the political scene. He did so with great success. FDR was elected governor of New York in the latter part of the 1920s, setting the stage for his quest to become President.

Hugh Gregory Gallagher eloquently opposes this traditional narrative in his groundbreaking study FDR's Splendid Deception. He argues that this typical portrayal of a short bout with polio contains little understanding of disability and its long-range effects.

FDR took great pains to hide the extent of his disability from the public. While the polio virus itself had disappeared and the consequent impairments did not technically make FDR "sick," that was how both he and the American public viewed disability. FDR fit the classic description of an invalid.

The word invalid describes someone who is incapable of caring for themselves. Although illness or sickness is not necessarily a permanent aspect of disability, it is an inherent concept of invalidism. Since no distinction was made between an invalid and a disabled person, that individual was considered to be sick.

FDR refused to let that mistaken perception prevent him from resuming his political career. The course he chose was to convince the American public that he was neither sick nor in-valid, and therefore not disabled in its classic sense. If he could persuade the American public that he was still healthy and vigorous, then they would

believe that FDR could fulfill the duties of public office. To fool the American public into believing that polio had only done minimal physical damage required elaborate, conscious planning, massive assistance, and--from today's vantage-- unbelievable media corroboration.

When FDR appeared in public he did not use his wheelchair. He rose from a seated position using braces and crutches. He was not stable or graceful. Aides held him up creating an illusion that FDR walked without assistance. Crowds "witnessed" FDR walking from his seat to a podium or some other device that he could stand and lean against. Rather than appearing as a sickly invalid, FDR gave the appearance of a healthy politician.

The media supported FDR's efforts to hide the extent of his disability. By conscious yet informal agreement, radio, newspaper and film correspondents simply did not discuss FDR's paralysis. Thirty-five thousand photographs were shot of FDR as President, but only two show him seated in his wheelchair, and these were never published (Hevey 102). This conspiracy of image makers extended as far as political cartoonists who would never draw FDR in his wheelchair, but always standing or walking--or running, or flying!

Although many Americans knew on some level that FDR used a wheelchair, the disguise was so successful that many other Americans professed their ignorance of his disability. As recently as the mid-1990s, this author encountered an individual working at an independent living center who yelped with astonishment upon learning that FDR had a disability. According to Gallagher, this was FDR's "splendid deception" because it enabled him to rise to the Presidency during a time in which everyone was convinced that no one with such a disability could even aspire to that position.

What did FDR's cloaking of his paralysis and wheelchair use mean for people with disabilities? The conclusions are diverse and murky. For many people with disabilities, FDR was a hero, a person who had overcome his disability and acquired the nation's most coveted office. He developed Warm Springs into an international rehabilitation facility. There he drove his car with hand controls that some credit as the first ever designed. Even some people who do not like what FDR did to gain the Presidency believe that he had no choice: given the climate of the times he was forced to hide his disability to succeed politically. Others bemoan his massive coverup, suggesting this meant that FDR, too, harbored his generation's beliefs about disability meaning illness and invalidism. He was unable to take his own personal situation and generalize it to others in similar circumstances. This, some argue, not only demonstrates FDR's acceptance of disability as illness, but it also contributed to future generations harboring those same beliefs. But, as we will see in the next section, FDR's ambivalence about disability not only affected future generations, but had a significant impact on people who might have been called his peers. (Brown *Investigating* 42-45)

THE LEAGUE OF THE PHYSICALLY HANDICAPPED

The example of the New York League of the Physically Handicapped, rediscovered by historian Paul Longmore in the late 1980s, demonstrates why many people have difficulty portraying FDR as a champion of disability rights. Like Longmore and FDR, most League members had contracted polio, though a few had cerebral palsy, tuberculosis or heart conditions. Unlike FDR, none used wheelchairs. League members came together because they believed they faced discrimination from private industry. They thought that New Deal policies, the name for the programs that FDR spearheaded to combat the Great Depression, would assist their quest for equitable employment. Instead, New Deal programs classified them as "unemployable."

Six League members went to a New York City agency in May of 1935 to discuss these discriminatory policies. When told the individual they wanted to see was out of town, some League members refused to leave. They had not planned to demonstrate, but that is what they did. Three League members remained in the building for nine days. Picketers with and without disabilities supported them outside of the building. Following three weeks of these protests, the group decided to organize formally.

Six months later, in November of 1935, they conducted a three week picket at the New York headquarters of the Works Progress Administration (WPA), one of the primary New Deal agencies for employment. They demanded that, "handicapped people receive a just share of the millions of jobs being given out by the government." As a result, the WPA hired about forty League members. Some skeptical League members believed this action was taken to squash the group, but instead it gained momentum.

In May 1936, a year after their first action, League members traveled to Washington, D.C., to meet with WPA leader Harry Hopkins. When they were informed that he was "away," they voted to stay until "Mr. Hopkins does see us."

Three days later Hopkins did meet with the group. He informed them that he didn't believe there were as many employable New Yorkers with disabilities as the League contended. He also said that he wouldn't change his mind unless he saw an analysis that disproved his belief. Then, he promised, he would take action immediately to correct these conditions.

Several months later, the League presented Hopkins with its "Thesis on Conditions of Physically Handicapped," a ten-page document that offered a comprehensive analysis of the situation. The "Thesis" described job discrimination in private and public sectors and recommended preferential civil-service hiring of disabled veterans and handicapped civilians as well. It also criticized public and private vocational rehabilitation as being underfunded and inadequate. Other employment programs the League critiqued as guilty of worse crimes: sending people to demeaning jobs, including ones as strike-breakers. The League's "Thesis" also accused New Deal programs of ignoring the problems of people with physical disabilities and categorizing people with disabilities as "unemployable."

Betraying his word, Hopkins ignored the "Thesis." The League, dissatisfied with its Washington experiences, renewed its concentration on its New York activities.

In September 1936, the League joined forces with the League for the Advancement of the Deaf to secure a promise that 7% of future WPA jobs in New York would go to deaf and handicapped individuals. As a result, 1500 people went to work. Unfortunately, more than 600 lost their jobs the next spring during nationwide lay-offs.

The League's experiences with New York's WPA was indicative of both its successes and failures. On the positive side, the League did get a number of people jobs and open the public sector to some workers with disabilities. It did not, however, as it had hoped, alter federal policies towards people with disabilities working.

In looking at the history of independent living, the League did not establish a base for future activism. But it did bring to the limelight in the 1930s some issues that would be addressed later in the 1970s and 1980s. League tactics will also seem similar to some current disability protests. Finally, and maybe most importantly, the League identified social problems plaguing people with disabilities that still remain with us.

League picket signs included ones that said, "We Don't Want Tin Cups," and "We Want Jobs." The first could be said to pre-date the current movement against telethons. The second could still be used to protest the current more than 70% unemployment rate of people with disabilities (Longmore and Goldberger 94-98; Longmore, personal communication).

WORLD WAR II VETERANS

Wars always impact disability. If nothing else, wars increase our numbers. There is also often a parallel between war and advances in medicine. An example from World War II (WWII) is that before antibiotics and treatments developed during the war to prevent decubitus ulcers, 80% of those who acquired spinal cord injuries died during the acute phase of their medical care (DeLoach 37).

In the twentieth century, wars have also accelerated disability policies. Both the Paralyzed Veterans of America and the President's Committee on Employment of the Handicapped began shortly after World War II ended. Veterans also benefited after World War II from PL 702, housing legislation passed in 1948 to provide veterans with service-connected disabilities a \$10,000 grant in addition to a \$10,000 loan to purchase, build, or modify a house (DeLoach 37-38).

Veterans, seeking social reintegration, had significant local impacts. Veterans also had a profound influence on the roots of independent living. In Los Angeles, for example, four WWII veterans began classes at UCLA in 1946 where they were assisted by CAL-VETS, a group of volunteers who carried the vets into inaccessible buildings (DeLoach 37). Our story continues with veterans in the small Midwestern towns of Kalamazoo, Michigan, and Champaign-Urbana, Illinois.

FREEDOM OF MOVEMENT

Jack Fisher was born on September 17, 1918, in Kalamazoo. He learned about the bombing of Pearl Harbor in December 1941 when he was nine months away from graduation at Harvard Law School. Unwilling to continue at Harvard after the bombing, he left school and enlisted in the army. While serving in Oklahoma, he received injuries in a jeep accident in 1943. He was sent from Tinker Field, a US Air Corp Base in the Oklahoma City area, about fifty miles southwest to Borden General Hospital in Chickasha, which housed a special orthopedic unit. Beds there were arranged head to toe so that no one breathed on someone else. The ward he stayed on was for people confined to bed. He remained there from October to February.

For more than four months he roomed with 40 non-ambulatory patients. While lying in a full body cast and traction, he leafed through the medical records of other patients to keep busy. This engrossed him during the day so he could sleep at night. At his discharge in February 1944, Fisher wore steel braces from hips to neck and walked with a pronounced limp.

While continuing to recuperate and learning to live with his residual physical problems, Fisher, at the age of twenty-five, returned to Kalamazoo. He would not return to Harvard Law School while the war waged on. He was determined to obtain a job in a defense industry. While trying to get a job, he kept getting told that with his braces and spastic right leg he could not be used, not even for the lowest possible clerkship. Companies were afraid he'd fall and puncture a lung, risking worker's compensation claims. He was even rejected at Kalamazoo's biggest defense company where he knew the personnel director.

At this point the Disabled American Veterans (DAV) contacted Fisher. The DAV informed Fisher that they needed his help. About five hundred (500) disabled veterans had submitted claims to obtain medical services, financial compensation, wheelchairs, rehabilitation and more. Their files were waiting to be processed. Fisher facilitated hundreds of claims between February 1944 and August 1944 when he finally returned to Harvard Law School.

Fisher graduated from Harvard Law School in February 1945. Large and prestigious eastern firms generally sought Harvard graduates. Fisher's experience was different. Although he had graduated in the top third of his class, he encountered two forms of discrimination. Some firms refused to hire him stating that his disabilities and braces made him a poor risk for health and additional injuries; others would not hire him because he was Jewish.

He decided to begin his own practice. From the first day, disabled veterans whom Fisher had previously assisted retained him as their attorney. He remembers his practice looked like an emergency room, with clients using crutches, wheelchairs and other adaptive equipment. These disabled veterans also brought their parents, grandparents, aunts, uncles, siblings and friends. He worked on all kinds of problems

from purchasing real estate to wills, business ventures, leases, marital concerns and more. Fisher was immersed in the lives of individuals with disabilities as fellow veterans, friends, acquaintances and clients. He learned about the problems of access, mobility, employment, the bedroom and the bathroom.

Fisher journeyed the short distance from Kalamazoo to Percy Jones Hospital in Battle Creek (the old Kellogg sanatorium featured in the movie *The Road to Wellville*) because it was the official government hospital to treat and rehabilitate amputees. A huge number of both above and below the knee amputees resided in Battle Creek. Many would travel the short distance to Kalamazoo for the bigger city's more active social life. It was not uncommon to see many people using prostheses. Unfortunately for those going downtown, Kalamazoo had quite tall curbs and people would fall on them breaking stumps and injuring themselves. Wheelchair users were simply unable to travel downtown.

In 1945, Fisher took it upon himself to get curb cuts and side-pipe rails. He petitioned the Kalamazoo city commission and testified before them. The city manager, whose adult son used a wheelchair, understood the problem firsthand. The city commission authorized the construction of cement ramps with safety rails in the central business district. Test ramps were constructed in 1945 and placed at the corners of three or four blocks.

A local DAV chapter monitored their usage. In a March 1946 letter to the mayor, Fisher stated that the "ramps were instrumental in allowing disabled veterans, disabled non-veterans, aged and infirm persons and mothers with baby carriages more freedom of movement..." and that "These cement ramps in many instances mean the difference between disabled veterans and disabled non-veterans having employment, as with the ramps a person confined to a wheelchair, on crutches or wearing an artificial limb is able to get to a place of employment unaided. The ramps thus enable many so called unemployable persons to become employable persons, and not only benefit the disabled person alone, but benefit the community at large as well."

Kalamazoo's city commission responded to the experiment by becoming the first city government known to approve a curb cut program, appropriating \$680 to install 34 additional curb cuts (Brown, "The Curb Ramps of Kalamazoo").

BUILDING PLANKS TO ROLL ON: THE GREAT EXPERIMENT AT THE UNIVERSITY OF ILLINOIS

While Jack Fisher worked to implement curb cuts in Kalamazoo, other firsts were taking place in Illinois. In the 1947-48 academic year, a former Veterans Administration Hospital in Galesburg, Illinois, was converted into a satellite campus of the University of Illinois. The University took this action to accommodate the many World War II veterans seeking to utilize the funding of the GI Bill to earn their college degrees.

A year later, however, in 1949, it was decided that the Galesburg campus would be closed. The program's director, Timothy Nugent, appealed unsuccessfully to hundreds of other universities and colleges to adopt the program. There were no takers. Unwilling to accept defeat, Nugent and the students loaded into several cars and set off for the state capitol in Springfield to request that Governor Adlai Stevenson intervene to stop the closure. They staged protests that included building temporary ramps from wooden planks to show how easy it would be to accommodate wheelchairs.

Their effort did not succeed. The campus closed. The students refused to give up. They continued their self-advocacy by seeking to move the "Rehab Program," as they called it, to Champaign-Urbana. Support for the continuation of the program at the main campus was minimal. Most administrators believed that individuals with severe physical disabilities could not possibly live "normal" lives, could not have families and could not obtain gainful employment. Why boost their hopes with a prestigious University of Illinois degree?

The experiment might have ended then except the same group of students with disabilities took their show on the road to Champaign-Urbana. Their goal in traveling to the main campus was to demonstrate that, with minimal architectural and personal assistance, they could successfully negotiate the campus and that they were more than equal to the challenge of the institution's academic programs. After a day of demonstrations, the university begrudgingly granted provisional or "experimental" status to the rehabilitation program at Champaign-Urbana. Attitudes about disability at the university were vehemently expressed. A father of a non-disabled woman dating a post-polio law student despaired that, "I suppose the University should receive some credit for trying to help these poor unfortunates, but isn't there something you can do to protect our sons and daughters from these freaks?" (Expanding Horizons, ii)

The university, wary about the program, limited the number of students that could be admitted--refusing 15 students for every one who got in. For its first eight years the program received no university funding. Nugent drummed up money from outside sources. Students continued to advocate for themselves by demonstrating their abilities through a myriad of activities, research about disability issues and athletic exhibitions ("History of the Division of Rehabilitation").

Campus buildings were not access-friendly. Quonset huts, remaining from World War II, were used as dorms for the first group of students. Campus legend says

the huts were unheated with beds in a row, just like the military. The huts were later converted to house the rehab program's administration offices. They also contained a physical therapy room for students who received credit for physical education classes by participating in PT (Breslin).

After large numbers of people with mobility impairments were admitted, the university ramped buildings and modified the World War II Quonset huts. As new dormitories were built, a limited number of rooms in each building were designed to accommodate students with disabilities. The first floor of most dorms had bathrooms with accessible shower stalls that had aluminum fold down seats and accessible toilet stalls (in the old style--with a door wide enough to face the toilet in the forward position and grab bars). Alumna and contemporary disability advocate Mary Lou Breslin recalls that these dorm rooms were identical to those on the upper floors, which could be reached by elevator in most cases, so the real access was to the first level itself (elevator or ramp) and bathrooms.

The program offered disabled students medical services, physical and occupational therapy, prosthetics, counseling, recreation and a bus service. By the mid-1950s, the Rehabilitation-Education Program (DRES) provided support services and had several lift-equipped buses that made hourly trips around the campus, town and to special university events.

In 1954, a politically savvy group of students with disabilities succeeded in getting Illinois Governor William Stratton to serve as the keynote speaker at the annual disabled students' awards banquet. Although the banquet had not previously been attended by University administrators, the Governor's appearance packed the house. That evening, Governor Stratton gave a stirring speech on the benefits of rehabilitation and the importance of the effort being developed at Illinois. From that point on, although many battles would have to be fought and won in the war for egalitarian access, the program's legitimacy was never again seriously questioned ("History").

The Illinois program expanded to include non-veterans in the 1950s and offered accessible transportation; housing to undergraduate, graduate and married students; peer counseling; specialized medical care; individually designed assistive devices and ADL training (DeLoach 41).

The folklore of the Illinois program is that it equated independence with a physically self-reliant lifestyle. No students could live in university housing if they could not move about campus or had to request help from someone else in self-care activities. Students were required to come to campus early for a week of "functional training." If students could not transfer in and out of bed, dress, bathe and toilet themselves, or maneuver, in their manual wheelchairs, up and down ramps and to the bus stops by themselves in a reasonable amount of time, they were rejected, sent home, invited to practice their skills and reapply. The memory of one student contradicts this well-known folklore. "In fact, some students who couldn't really do these things did occasionally get admitted. One I remember vividly died of complications of muscular

dystrophy. I have always thought it was because he had to struggle so to move about in the freezing weather" (Breslin). Students who successfully completed this training could still be expelled later if they were discovered receiving assistance in their living quarters or being pushed across campus (DeLoach 41-42).

By the early to mid-60s there were about 200 students, with one or two with communication disabilities. "When I was there [there were] several severely disabled students, i.e. high quads or very weak folks with MD who lived in a nearby nursing home, which was then believed to be the only appropriate way to provide personal care for such individuals. Several used power chairs, though the technology was primitive. The obvious point was nursing care was the only answer to not being able to do self care unaided. This practice ended at some point after I graduated" (Breslin).

Perhaps the most popular activities were sports--wheelchair basketball and track, judo for the blind, quadriplegic rugby. Sports, Nugent believed, boosted the athletes' self-confidence and dispelled the notion that disabled students were frail and sickly (Breslin).

Nugent also "was responsible for drafting the first ANSI standards, originally created around the dimension of Everest & Jennings standard push chairs" (Breslin).

Although not as well known in independent living circles as some other university programs, the University of Illinois claims the following firsts:

- The seminal research which led to the development of the first architectural accessibility standards that would become the American National Standards Institute Standards
- The first wheelchair accessible fixed route bus system
- The first accessible university residence halls
- The first university service fraternity and advocacy group comprised of students with disabilities (Delta Sigma Omicron)
- The first collegiate adapted sports and recreation program for students with disabilities, which also produced the first wheelchair athlete in the world to win an Olympic Gold Medal ("History")

With all these advances, why is it that disability advocates tend to recall the University of California as the trailblazer for disability programs? That is the subject of the next section.

POLIO AND THE ED ROBERTS STORY

Veterans inspired the curb cuts of Kalamazoo and the changes in the student population at the University of Illinois. Just as medicine increased the longevity and expanded the activities of veterans wounded in the military, medical progress also had enormous consequences for non-veterans. Medical breakthroughs dramatically affected the polio epidemics of the 1940s and 1950s. Unlike FDR, many of these individuals contracted polio at an early age and did not come from wealthy families.

The polio epidemics of the 1940s and 1950s left about 400 people around the country who both used respirators and were institutionalized. One hundred fifty eight of these individuals were housed at Rancho Los Amigos Medical Center near Los Angeles. The March of Dimes paid their bills, but as that organization became increasingly strapped for funds, they turned over this responsibility to Los Angeles County.

The County, in 1953, conducted a study about attendant care costs. The investigation revealed that each iron lung user would cost the county \$10 per day if they lived at home. The hospital billed the state \$37 per day for identical services. This discovery led to beginning California's In Home Support Services (IHSS) program, one of the nation's first personal assistance programs (Levy 4-5).

At his home in Burlingame, south of San Francisco, a teenager named Ed Roberts, who had contracted polio and used an iron lung, received IHSS. As he grew older he became credited with breaking the barrier against significantly disabled people attending universities. Roberts has been called the Martin Luther King Jr. of the disability rights movement, the father of independent living. Toward the end of his life, he liked to call himself the godfather. Before Roberts passed away in 1995, he conducted many interviews. Many people also viewed Roberts as one of the best public relations persons in independent living. As a result, quite a bit is known about his life. What follows is his story. It is representative of many others.

Roberts contracted polio when he was in high school. As a result of the virus he lost all but some movement of two fingers on his left hand and two toes on his left foot. The rest of his body, including his lungs, remained paralyzed, though he always retained feeling. Unable to breathe on his own for extended periods, he became a ventilator-dependent quadriplegic. He required a machine, such as an iron lung or a ventilator, to assist him with breathing.

The only person in his school to contract polio, Roberts resumed his education at Burlingame High School at the age of eighteen. He attended via a phone hook-up. It began with a phone connected to one room at the high school. When Ed pressed a bar on the phone he could be heard, when he released the bar he could hear, enabling him not only to listen but to communicate with his classmates.

Roberts graduated from high school, at the age of twenty, in 1959. But not without a fight. His post-polio paralysis prevented him from taking either physical education or driver's education courses. His high school counselor thought Ed should

remain in school another year. Zona, Ed's mother, was determined that her boy would be as similar to his peers as possible and was mystified by this turn of events.

Zona contacted the principal about the inequity of the situation. He supported his counselor. Zona next called a friend who also happened to be a school board member. A school representative met with Zona and Ed at their home and asked, "Ed, you wouldn't like a cheap diploma, would you?" A furious Zona contacted the superintendent of schools. She also notified some of Ed's teachers. Before they could act, the assistant superintendent of schools announced that everyone was proud of Ed and granted the diploma. Roberts later commented that he attained some of his own sense of determination from watching Zona persevere about his graduation.

Ed enrolled at the nearby community College of San Mateo. To attend classes he was placed in a corset which enabled him to sit up. A head brace emerged from the back of the corset. At first, Zona brought Ed to campus. They solicited help from passers-by to get Ed in and out of the car on campus, learning to avoid football player types who refused supervision. Ed attended class by himself, with assistance from fellow students to traverse the numerous steps. Another student was eventually hired to drive Ed.

Roberts spent three years at the College of San Mateo, finishing two years of classwork. To complete assignments, Zona wrote while Ed dictated. Ed speculated about a career as a sportswriter. Others discussed technical writing. He eventually chose political science as a major.

The most fortuitous development at the College of San Mateo occurred in Roberts' second semester when he enrolled in an English class taught by Jean Wirth. Jean, like Ed, knew about difference. She had been six feet, five inches tall from the time she was twelve years old. She became his unofficial advisor.

Jean asked Ed where he wanted to continue his education after graduating from the College of San Mateo. He responded UCLA. Roberts knew about the veterans who had attended and he thought that would make it fairly wheelchair-accessible. Jean dissuaded him from this idea because UCLA was a commuter campus. He would have to find housing, transportation, personal assistance, and friends away from the university. She suggested he apply instead to the University of California at Berkeley (UCB) where there was an outstanding political science program. Ed did just that and was accepted at UCB. The application form asked no questions that related to disability. The only hint was that Ed weighed only eighty-five or ninety pounds. Zona accurately predicted that school officials would guess Ed forgot to put a "1" before the other numerals. Ed also applied to the California Department of Rehabilitation (DR) for financial assistance. The DR counselor informed Ed that he was too severely crippled ever to work and would therefore be denied services. Zona, Jean, and Phil Morse, Ed's official advisor at the College of San Mateo, then met with DR to advocate successfully for Ed.

While this was happening, Jean, Zona, Ed and Phil visited the UCB campus prior to the commencement of the school year. UCB personnel were shocked to learn that Ed

was a post-polio ventilator-using quadriplegic and were at a loss about where he might be housed. His large iron lung wouldn't fit in a dorm room. Morse contacted the Dean of Men, who suggested they see Henry Bruyn at Cowell Hospital, the on-campus student health center.

Bruyn, a physician, had worked with polios and commented that they were becoming of college age and should be able to attend college. He thought Ed could probably live at Cowell. Successful negotiations to do just that continued throughout the summer.

During Ed's first academic year, 1962-63, the same year that the African-American James Meredith integrated the University of Mississippi, Ed was the only student with a disability at Cowell, and, as far as we know, the first student with a disability of this significance to attend an American university. An area paper ran a story about Ed headlined "Helpless Cripple Goes to School." It caught the attention of a social worker in nearby Antioch whose client, John Hessler, had broken his neck while diving. Towering above six feet tall, he was too big to be cared for by his parents and he lived in a Contra Costa hospital. He attended Contra Costa College, going back and forth by taxi. His social worker spoke with Henry Bruyn, and John joined Ed at Cowell in the 1963-64 school year.

Bruyn began to earn a reputation for this program. Several more students arrived in 1965-66. Their attendance initiated a formal program for students with disabilities. The students began identifying with one another, calling themselves the Rolling Quads. With a nursing supervisor, the Rolling Quads took over the entire third floor of the hospital. Each student lived in his or her own room. They mingled in a common room and ate together in a dining room.

Ed's DR worker in Berkeley, unlike his geographically-appointed counselor in Burlingame, supported his efforts. DR now paid for tuition, books and secretarial help. This changed again in the late 1960s when DR installed a new worker. She believed it was her responsibility to dictate behavior. She attempted to direct Ed's thesis topic, tried to instruct other students in what classes they could take, and strived to get two students evicted because she didn't approve of their educational goals or lifestyles.

The students responded to this counselor with activism. They informed the press of their frustration with her dictatorial methods and succeeded in getting her transferred. This success led to other actions. The Rolling Quads formally organized themselves into a student organization, and as such they developed and taught a university studies class called "Strategies of Independent Living," the main purpose of which was to conceive methods to live outside of Cowell. They began to talk to the Berkeley city council about building ramps in the city. The Rolling Quads got the city's attention when they went out in the middle of the night with their assistants and started taking sledgehammers to some of the curbs around campus and pouring tar on them to create makeshift ramps. Some of these still exist today. The Rolling Quads not only tested their own limits as fledgling citizens, they also began to understand their own power.

By the late 1960s, as the Rolling Quads' activism heated up, Roberts prepared to leave Berkeley. He had completed both undergraduate and graduate school, finishing all but his dissertation. Ed accepted a temporary job at the Disabled Student Services program in Riverside, near Los Angeles.

Before Ed moved, Jean Wirth called Zona from Washington to share information about a bill containing a lot of money for disadvantaged students, with ten percent of the budget earmarked for disability programs. Jean suggested Zona come to Washington for meetings about how to utilize the money, but Zona had a scheduling conflict and recommended Jean call Ed. Ed was agreeable and experienced his first airplane flight. Roberts weathered the first of many adventures traveling as an individual with a disability. First, no breathing apparatus was allowed on the plane, so Ed was forced to do exhausting frog-breathing for hours in the air. Then after landing he sat for hours while they retrieved his manual wheelchair. Jean arrived at the hotel before Ed to arrange for an iron lung to be delivered to the hotel. She learned that an iron lung would not be allowed because "they blow up you know."

Despite these hardships, Roberts loved Washington. He reveled in interacting with Senators and Secretaries, and with time's passage he realized that he made a lasting impression.

Since Ed was on his way to his temporary job in Riverside, he urged John Hessler and others to submit a proposal to the old Cabinet Department of Health Education and Welfare (HEW) for funds to institutionalize what they had learned as the Rolling Quads. Their first attempt did not get funded, but their second one did. It became the Physically Disabled Students Program (PDSP).

John Hessler became director of the program. Roberts, meanwhile, did not remain in Riverside long. His physician advised him to leave because the area was harmful to people with breathing problems. He moved to Woodside in the South San Francisco Bay area and began teaching at Nairobi College in East Palo Alto. The college attracted less traditional students than those attending UCB or nearby Stanford.

PDSP began to attract individuals with disabilities from around the San Francisco area. Many callers were not students, but there was nowhere else they could obtain the services they needed. The need to create an organization similar to PDSP for non-students became apparent.

Three people, all of whom had been Rolling Quads, began an organization they called the Center for Independent Living (CIL). A small research and development grant enabled them to rent a small apartment to begin CIL. John Hessler, a CIL board member, quickly became concerned that the much-needed CIL would fail because of a lack of leadership. He contacted Roberts, who had recently returned to Berkeley from Woodside, about his fears.

Ed and John met with their friends to discuss a CIL board take-over. Their strategy succeeded. Roberts then became CIL director because he did not have a job,

while Hessler directed PDSP. Ed expanded CIL rapidly and a national, then international, reputation quickly followed.

When Jerry Brown became governor of California in 1974, three of his former law school classmates, who also happened to be friends of Ed's, nominated Ed to become director of the Department of Rehabilitation (DR). Brown interviewed Ed and appointed him DR director in late 1975. Independent living advocates rarely tire of telling the story of Ed becoming the boss of the agency that had once told him he was "too severely crippled" ever to work. (Brown "Zona and Ed Roberts")

As chief of DR, Roberts soon had the opportunity to institute independent living throughout California. In his first year, \$500,000 from the state budget set up eleven independent living programs in the state (Kidder, 10). Shortly thereafter, in the debate over amendments to the Rehabilitation Act in 1978, Roberts was one of many who fought to implement independent living centers in the federal budget.

THE INDEPENDENT LIVING MOVEMENT

Because a comprehensive history of the disability rights and independent living movements is still to be written, the story of Ed Roberts is often discussed as the cornerstone of the independent living movement's origins. But just as Ed's story is a tale of many people, so too is that of the independent living movement. Perhaps most telling is the fact that the same year that CIL in Berkeley began operations, so too did Threshold, an independent living center in Helsinki, Finland. And like CIL, Threshold began first as a student movement. When CIL began in the early 1970s, similar organizations sprouted throughout the United States as well as other parts of the world. For example, a group in Boston began the Boston Center for Independent Living (BCIL). Unlike CIL, BCIL focused on housing issues. BCIL provided housing and attendant services to those college students housed on the fourth floor of the theological college at Boston University, and attendants were recruited from theological students (DeLoach 43). BCIL became formally established in 1974. Other groups formed in Houston, Ann Arbor and many other places across the country and around the world.

This was indeed a movement.

In Washington, D.C., Hugh Gregory Gallagher (long before he authored FDR's *Splendid Deception*) worked in a congressional office. Gallagher became extremely frustrated in trying to use the inaccessible Library of Congress. He authored the Architectural Barriers Act of 1968, which became the first federal legislation to address architectural accessibility. Unfortunately, it would be years before that kind of thinking and legislation would be enforced. But it's another example of the incipient movement.

How the disability rights movement evolved from "helpless cripples" to a political force includes all of the preceding individuals and actions. In addition, numerous policies have affected disability issues. Perhaps the most important in a history of the independent living movement is the story of Section 504 and the Vocational Rehabilitation program.

“WE WILL ACCEPT NO MORE DISCUSSION OF SEGREGATION”

SECTION 504 AND VOCATIONAL REHABILITATION

Many advocates consider Section 504 of the Rehabilitation Act of 1973 the nucleus of all ensuing progress in obtaining disability rights. Section 504 stated:

No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

This concise paragraph guaranteed disabled individuals specific civil rights for the first time in history. Vocational rehabilitation, however, began in the early twentieth century. What was its purpose? Why was Section 504 so radical? How come many disability advocates consider Section 504 the opening salvo in the battle for modern disability rights? This section provides a brief history of Vocational Rehabilitation from its beginnings until the early 1970s when the discussion shifts to the campaign to implement Section 504.

Vocational rehabilitation, like many other government programs, did not develop in a vacuum. In fact, it was a culmination of a whirlwind of societal changes.

At the end of the nineteenth century, many community leaders advocated educating all citizens to ensure that the vast numbers of new immigrants understood the civic workings of their new country. Colleges and universities increased in number at the same time. But not everyone now required to obtain an education would attend college. Teaching a manual trade to students who didn't attend college was called vocational education.

While vocational education became part of the landscape of early twentieth century models of education, new medical treatments enabled people with disabling conditions to live longer. Just as medical advances affected post World War II social movements, this earlier medical progress stimulated social change. A new discipline called 'rehabilitation' evolved to work with these individuals.

Rehabilitation's purpose was to find ways to alleviate disabling conditions by keeping people with disabilities in an appropriate social setting. Combining rehabilitation with vocational education led to vocational rehabilitation (Brown *Investigating* 39).

The first laws funding vocational rehabilitation were passed as World War I ended. Congress first passed the Smith-Hughes Law (Vocational Education Act) of 1917, establishing a Federal Board for Vocational Education (FBVE) to work with men with disabilities in hospitals and encampments. The following year Congress

unanimously ratified the Soldier's Rehabilitation Act to assist returning World War I veterans to join the labor pool (Lenihan 51; M. L. Walker 25).

Two years after the Soldier's Rehabilitation Act, President Woodrow Wilson signed the first federal act providing vocational rehabilitation services to civilians with disabilities. The program gave states a choice about participating in it. Most states chose to do so. Just four years after the 1920 passage of the Vocational Rehabilitation Act, thirty-six of the forty-eight states belonged to the program (M. L. Walker 33).

The FBVE, the umbrella agency to which vocational rehabilitation belonged, consisted of the cabinet secretaries of commerce, agriculture and labor as ex-officio members and three salaried members responsible for its operations. John Kratz, vocational rehabilitation (VR) chief in 1924, convinced the FBVE and Congress to renew VR for six years.

Early statistics maintained by VR indicated a modest expenditure of \$12,000,000 had rehabilitated 45,000 people between 1921 and 1930. This averaged out to a cost of about \$300 per person. By 1930, nine more states participated in the program. A total of 143 rehabilitation workers were employed in 44 states. VR's apparent efficiency led to its renewal in both 1930 and 1932 with increased levels of funding support. Vocational rehabilitation became a permanent program in 1935 (M. L. Walker 39, 58).

In the early thirties, VR transferred to the Office of Education in the Department of the Interior, It did not thrive in this setting. Rehabilitation workers felt their role in placing people with disabilities in the workforce differed from a narrow focus on education. They longed to be housed in another agency. It moved to the Federal Security Agency, created in 1939, along with the Office of Education, but VR continued to be dissatisfied with its place in the hierarchy (M. L. Walker 102-103).

A year later, in 1940, Congress extended vocational rehabilitation services to people with disabilities working in sheltered workshops, those who were homebound, and those in the workforce who required services to remain employed. This significant increase in responsibility set the stage for a decade of greater funding and responsibility. VR grants increased 75% in 1940 and continued to increase throughout the 1940s. In July of 1943, services were broadened to include physical restoration and people with mental illness as clients (Scotch 21; Shapiro 143; M. L. Walker 103).

Vocational Rehabilitation continued to amass larger budgets and greater prestige throughout World War II and the post-war years. Mary Switzer, a career bureaucrat, became director of the agency in 1950. A long-time advocate of vocational rehabilitation's mission, Switzer spent the next two decades zealously expanding its role and power (M. L. Walker 125-26, *passim*).

Switzer guided a comprehensive legislative package through congressional appropriations in 1954. State vocational rehabilitation grants rose to a budget of \$30,000,000. Additional monies for training medical and rehabilitation professionals

established long range agency precedents. Switzer persuaded Congress to fund research and development in medicine and rehabilitation engineering, in-service training programs, rehabilitation centers and sheltered workshops. Switzer also obtained permission to create separate vocational rehabilitation agencies outside of state education agencies (Scotch, 1984, 22).

In the following decade, rehabilitation became a soldier in President Lyndon Johnson's "War on Poverty." Funding levels continued to increase, greater numbers of individuals became eligible to receive services, and state matching fund requirements decreased (M. L. Walker 23).

Mary Switzer reluctantly retired in 1970 when she reached the then-compulsory retirement age of 70 (M L. Walker 253). Her impact has remained legendary within the rehabilitation community. But she might not recognize the evolution of disability rights that occurred after her death a year later.

During Switzer's last years directing VR, organizations like centers for independent living were in their formative stages. Activists with disabilities, like the founders of CIL, empathetic rehabilitation workers, and progressive Congressional colleagues worked together in the early 1970s to implement an agenda for the vocational rehabilitation agency that recognized disability rights. This led to the writing of Section 504.

Sociologist Richard Scotch documented the genesis of Section 504 in his book *From Goodwill to Civil Rights*. He contended that government bureaucrats developed Section 504. But the late John Hessler, who followed Ed Roberts at Cowell and went on to be a founder of PDSP and CIL, disagreed with Scotch's narrative in a letter published in the *Disability Rag*. Hessler remembered a number of activists participating in the concepts and language proposed in the Rehabilitation Act of 1972. According to Hessler's letter, Fred Collignon, a Berkeley community planner who worked with then Rehabilitation Agency Commissioner Ed Newman, actively involved many Berkeley activists in the planning of the early 1970s act. Hessler wrote that he, along with other disability advocates, worked on language that appeared in the eventual act, including the controversial Section 504 (3).

In the Rehabilitation Act of 1972, Hessler and his colleagues across the country thought they had devised a progressive piece of legislation. It included concepts of independent living, client advocacy programs and some prohibitions of discrimination. But President Richard Nixon vetoed the legislation. He predicted that no one had thoroughly assessed the ramifications of the legislation. His own forecast was that parts of the act, like independent living and Section 504, would be extremely costly and become an administrative nightmare.

Nixon's 1972 veto sparked demonstrations across the country. Judy Heumann, who organized disability rights protests in New York City and who had successfully fought being denied a teaching job because she used a wheelchair and who later

became the United States Department of Education Assistant Secretary of the Office of Special Education and Rehabilitative Services, recalled in a 1980 conversation that New York's Disabled in Action organized a demonstration of sixty to eighty people to go to Manhattan's federal building to protest Nixon's 1972 veto. When they arrived, they discovered the building was in an isolated section of the city. The demonstrators piled back into their vans and other vehicles, drove to Madison Avenue and stopped traffic on up to four blocks, effectively publicizing their demands (Heumann in "We Won't Go Away...")

In 1973, Congress passed another version of the Rehabilitation Act. This one contained changes Nixon approved, including eliminating independent living and client advocacy programs. But Section 504 remained in the compromise bill. President Nixon signed the Rehabilitation Act of 1973 in September. But more struggles remained (Scotch 56-57).

Section 504, still viewed by disability advocates as the linchpin of change, became bogged down in the Nixon cabinet. HEW expressed the same concerns about costs and administrative headaches that had caused Nixon to veto the earlier bill. The cabinet department simply refused to issue regulations to implement the law.

Frustrated by this federal inaction, James Cherry and the Action League for Physically Handicapped Adults sued the government in 1975 for issuance of 504 regulations. The next year, disabled leaders demonstrated in HEW Secretary David Matthews' office and threatened to picket the 1976 Republican Convention. A federal notice of intent to publish proposed rules materialized in the May 17, 1976 Federal Register. In July of the same year, the courts ruled 504 regulations should be promulgated but did not set a deadline. A second federal notice of intent to publish proposed rules was published in mid-July with little change from the earlier edition (Scotch 93-96); Brown *Investigating* 55-57).

During the 1976 presidential campaign, the Philadelphia contingent of Disabled in Action invited representatives from both major parties to a press conference. The Carter campaign emissary was so totally unaware of disability issues that DIA practically ran her out of the room. She returned to local Carter campaign headquarters and reported how tough DIA had been on her. She then educated herself and convinced the local Carter staff that this was important.

The campaign staff sent her back to talk to the group. Out of that meeting came an effort to organize nationwide for Jimmy Carter. The American Coalition of Citizens with Disabilities (ACCD), which had formed the previous year and with which DIA in Pennsylvania was associated, became the national disability focus of organizing for Carter (Pfeiffer).

Passage of 504 regulations became a battle cry of disability activists throughout the country. Two days after president Jimmy Carter's inauguration in January 1977, about fifteen people met with new HEW Secretary Joseph Califano to advocate for rapid

distribution of regulations. The administration received a deadline of April 4, 1977, to issue regulations or disability advocates would pursue an alternative course. Califano resisted for some of the same reasons that Nixon originally vetoed the entire act. He feared that both actual and administrative costs would be more far reaching than anyone imagined (Eunice Fiorito in "We Won't Go Away....", Scotch 104).

Disability advocates scheduled a series of demonstrations to follow the April 4 deadline. Ten cities across the country were targeted. The most successful action occurred in San Francisco. More than 150 people took over the federal building there and remained for twenty-eight days. Judy Heumann, who had moved to Berkeley to work at CIL in 1973, was one of the event's planners and a leader of the takeover. Ed Roberts, in his new position as director of the California Department of Rehabilitation, did not officially engage in planning the protest but left his Sacramento office to join the protest. Early in the action, Heumann, in a statement reminiscent of freedom fighters of all ages, declared, "...we will no longer allow the government to oppress disabled individuals...we will accept no more discussion of segregation" ("We Won't Go away...").

The protest in San Francisco worked because many in the community supported it. The city's mayor ordered law enforcement personnel to leave the protesters alone. The Black Panthers and the Gray Panthers brought in food donated by Safeway and assisted with personal care needs. Attendants were allowed to go back and forth from the building to bring necessities. This also enabled a communication network with those outside the building to be established (Shapiro 67-68).

Local news stations aired the story. Evan White filed the most comprehensive reports, though he was so new to the field that he did not yet have credentials to file national news stories. But White's luck was good.

Heumann left San Francisco during the occupation to lead a delegation to Washington to talk personally with Califano. He refused to meet with them. They decided to camp on his front lawn until he changed his mind. Evan White traveled from San Francisco to Washington with the group to report the story. A media strike left a void in national news stories, and uncredentialed stringers filed stories. White's coverage of the demonstrations made national news networks and both the story and his career took off (Walker, personal communication).

After twenty-five days of protests, sitting in, and having demonstrators camped on his lawn, Califano signed the 504 regulations. Victorious protesters emerged from the federal building chanting "We Shall Overcome." The siege remains the longest takeover of a federal building by any group in American history (Brown *Investigating* 57-58; Shapiro 69).

A White House Conference on Handicapped Individuals was scheduled to occur May 23-27, 1977. Some speculated one reason Califano signed the regulations was because he knew that 3,000 persons with disabilities and their supporters were on their

way to Washington. If he had not signed the regulations by the time they arrived, then many demonstrations would have occurred to the embarrassment of the Carter administration (Pfeiffer).

The successful protests to implement 504 could be considered the first battle of an ongoing war disability advocates have waged to change vocational rehabilitation. Although hardly the only program affecting disability issues, VR has for many years been perceived as one of the most important influences on disability politics.

FROM BUILDINGS TO STREETS: A GLANCE AT THE LATE 1970s

The disability rights movement accelerated phenomenally in the late 1970s. The scope of this history permits only a glimpse at the people and changes that followed the successful protests for implementation of Section 504.

1977 was the year that Houston's Independent Living Research Utilization (ILRU), the first research organization about independent living, began. ILRU was led by Lex Frieden, one of the significant leaders of that part of the country. Frieden, from northwestern Oklahoma, had been a college freshman at Oklahoma State University in Stillwater when he was involved in a car accident. He became a quadriplegic. After his accident, Frieden began to analyze the roles society had created for people with disabilities--and rebelled against them. At ILRU, Frieden and his colleagues developed a definition of independent living that is still being used: "control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities" (Frieden et al. 3).

One year after the 504 demonstrations and ILRU's founding, another kind of group emerged. ADAPT developed from a radical Denver CIL called the Atlantis Community. Atlantis began when the late Wade Blank, a white veteran of civil rights marches working at a Denver nursing home, rebelled against the oppression he witnessed in that institution. A fictionalized account of Blank's role in the disability movement was highlighted in the 1990 television movie "When You Remember Me," about the fight to remove a young boy with muscular dystrophy from a nursing home to a community-based residence. Blank's role in that action awakened in him a desire to protest the pervasive discrimination against people with disabilities.

One issue of obvious and symbolic importance was transportation. In the 1950s, blacks protested because they had to sit in the back of the bus; but in the 1970s, disabled people protested because they couldn't get on the bus. People who used wheelchairs had no way of entering a bus, even though equipment such as wheelchair lifts was available, comparatively inexpensive and fairly easy to use. A group of nineteen Denver activists organized with Blank to form a group called American Disabled for Accessible Public Transit (ADAPT).

The first ADAPT demonstrations were staged on July 5 and 6, 1978, in Denver. Soon other ADAPT chapters and similar organizations formed throughout the country. Their methods of protest included blocking buses or chaining oneself to a bus so it couldn't move. The theory was that if disabled people could not use the buses then neither could anyone else.

Police quickly arrived to arrest the protesters. But it was not such a simple process. First, police often still thought of disabled people as sick and vulnerable and were either cautious about injuring them or careless about not doing so. Second, the paddy wagons, like the buses, were frequently inaccessible, so police had no way to transfer people to jail. And if they did find a way, the jails were often inaccessible. The

protests continued and ADAPT became the first long- term United States grass roots movement of disability activists (Brown *Investigating* 58-59).

INDEPENDENCE IN THE 1980s AND 1990s

The story of independent living in the past two decades is one of growing pains and what some would term a stormy adolescence. Representative examples are used to describe the history of the past twenty years. A more detailed list of pivotal laws and activism is in Appendix A: Selected Significant Dates in Independent Living History.

During the late 1970s, the first group of federally funded independent living centers feared that in debates surrounding the next reauthorization of the Rehabilitation Act, CILs would be eliminated. Since CILs were still categorized as demonstration projects, not renewing them would be fairly simple. CIL advocates discussed their situation and decided to hold a meeting of all CILs in 1981. From this assembly developed what is now known as the National Council on Independent Living (NCIL). The national organization, first known as the National Council of Independent Living Programs, elected Max Starkloff, founder of Paraquad in St. Louis and former nursing home resident, as its first president. The association then coalesced to ensure that its members retained funding and that they adhered to the independent living philosophy as described at the beginning of this history.

Adhering to this philosophy has not come without battles. Perhaps the most famous of the period occurred in Norman, Oklahoma, when five of six staff members walked out of their CIL because of continuous confrontations with their board, including arguments over consumer control (Brown "The Walkout").

One way to put this conflict into a bigger picture is within the context of models of viewing disability. The one that has most often been called to task within independent living circles is the medical model.

Medicine, like all disciplines, has its method. A physician is trained to detect symptoms, diagnose ailments and prescribe cures. A person with a disability is not sick. A disabled person may become ill with a cold, or flu, or measles, or any other ailment a nondisabled person might acquire. But having a disability is not the same as being perpetually indisposed. There are many healthy quadriplegics. There are also sickly quadriplegics. But the quadriplegia itself is simply an inability to use all or part of four limbs. It is a disability; it is not an illness.

Medical personnel are not trained to appreciate this distinction. They are instructed to cure illnesses. When that is not possible, as in the case of disability, medical training is inadequate. Medical solutions to disability issues have been called a medical model. This model is distinguished by perpetuating the notion that someone who has a disability is broken, in disrepair, or infirm. This perception is easily integrated into medical training. If patients are broken, they can be fixed. If ill, they can be cured. There is only one viable alternative to this philosophy, and that is death. There is no room for any intermediate position. Ongoing disability does not enter into the equation.

In the medical model, if people can neither be fixed nor cured and will not die, then they are no longer of medical concern, other than easing the inevitable wait for departure from this world. The medical model validates previous perceptions of incompetence, deviance, and invalidism. Individuals with disabilities have no worth in either the medical or the social hierarchy. As one might imagine, this philosophy leads to confrontation with the notion of capable, valuable human beings with disabilities put forth by advocates with disabilities (Brown *Investigating* 52-53).

In the confrontation in Norman, the fallout from the medical model was apparent. People without disabilities felt a need to tell people with disabilities how to run their organization and, by extension, their lives. People with disabilities who were learning to rebel against models that had invalidated their own choices responded defiantly.

This led to a change in the last revision of the Rehabilitation Act in the 1980s. Known as consumer control, this change requires that more than half of the members of the board of directors in each center for independent living must be individuals with disabilities. In the 1990s this was expanded to include CIL management as well.

As independent living centers not only remained in the Rehabilitation Act but increased in numbers and funding, NCIL gained momentum throughout the 1980s. During the latter part of the decade, Marca Bristo, disability rights activist and executive director of Access Living in Chicago, who in the Clinton years has chaired the National Council on Disability, became the organization's president. She led a fight against what some observers saw as a Ronald Reagan supported backlash against progress for individuals with disabilities. Reagan unsuccessfully attempted to overturn Section 504. But Reagan is not easy to dismiss simply as an anti-disability leader. He also appointed Lex Frieden to direct the National Council on the Handicapped (now National Council on Disability) and Justin Dart as commissioner of the Rehabilitation Services Administration. Each of these individuals became pivotal in advancing our rights. While Frieden, Dart and others worked with the Reagan administration, Bristo's leadership and fiery orations guided demonstrators into opposition protest marches.

One of the most detrimental decisions of the 1980s came from the Supreme Court, which ruled in the mid-1980s that 504 applied only to the part of an institution that directly received federal funds. This meant that entire universities, for example, did not have to comply with Section 504, only that part of the school that put federal funds in its program's budget. Disability advocates fought for several years to negate this ruling, and in 1988 Congress passed, over Reagan's veto, the Civil Rights Restoration Act which ensured that "Federal anti-discrimination statutes apply to an institution in its entirety if it accepts Federal aid for as little as one program" (Levy 34).

While advocates fought to restore the intent of 504, Lex Frieden led a study at the National Council on the Handicapped about the place of people with disabilities in American society. Published in 1986 as *Toward Independence*, the monograph described discriminatory policies towards people with disabilities in housing,

employment, transportation, education and other aspects of American life. It called for the passage of a law which would bar such discrimination. This led advocates to draft legislation that eventually became the 1990 Americans with Disabilities Act (ADA).

One of the national stories that helped convince Congress to pass the ADA occurred in 1988 at Gallaudet University--the world's only university for students who are deaf and hard of hearing. In 1987, Gallaudet's president announced his resignation. Early the next year, several Gallaudet students concurred that the time was right for the university to select its first deaf president. The Gallaudet board of trustees ignored the students and chose the only hearing person of three candidates. The deaf student population rebelled with what became known as the Deaf President Now movement. Taking their issues to both the national media and to Congress, the Deaf President Now movement quickly amassed national support. In a matter of one week, the Gallaudet board agreed to the student demands, hiring popular and deaf Gallaudet dean of arts and sciences I. King Jordan as president. They also changed the composition of the board of trustees to half deaf (Shapiro 75-83).

The injustice of a hearing person trying to run a deaf university struck a chord with both the American people and Congress and helped both to understand why people with disabilities would want a law like ADA. It was one of many stories that helped achieve passage of what has been called the most important civil rights law since the Civil Rights Act of 1964.

Personal stories often embrace solutions to much larger matters. Autobiography, in fact, often plays vital roles in the passage of laws. This situation occurred with the fight to pass the Americans with Disabilities Act of 1990 (ADA).

Justin Dart, a longtime disability advocate, spent a considerable amount of time and money traveling to every state in the union in the late 1980s to collect information demonstrating the need for the ADA. He asked people to write or relate discrimination diaries, experiences that people with disabilities had in their everyday lives that led to their belief in the desirability of a such a law.

Many stories were collected. Some of the more poignant storytellers testified before Congress. One was a young woman from the state of Washington who has cerebral palsy. She testified that she tried to get into her hometown theater to see a movie, but the ticket taker would not admit her because her speech was slurred. This woman's story touched the heart of many members of Congress and President Bush, who recounted it when greeting celebrants at the ADA signing (Brown, *Investigating* 74; Shapiro 105-06, 140).

The ADA was not passed without many confrontations. ADAPT led a march on the Capitol steps in which people abandoned their wheelchairs and crawled up to the entryway to Congress. On the second anniversary of the signing of the ADA in 1992, Denver dedicated a plaque to the first ADAPT activists of the late 1970s. Wade Blank, as a nondisabled person, didn't believe his name belonged on the plaque, but he did

visit it once a week to clean it of bird droppings and other debris (Hartman, personal communication).

During the remainder of the 1990s, independent living advocates have fought to solidify their gains, expand independent living centers, retain the intent of the ADA in court decisions, get people who do not want to languish in nursing homes out into the community and fight the trend toward passage of assisted suicide legislation.

INDEPENDENT LIVING IN THE YEAR 2000

From the institutionalization of independent living centers to the current court cases that are redefining the meaning of ADA, the independent living movement has been an incredibly active part of our nation's late twentieth century history. There are now more than 600 centers in existence in every state and many countries. What can we expect at the dawn of the next millennium? Here are some highlights:

- More and more disabling conditions will be recognized as important to the independent living movement, such as people with psychiatric disabilities, mental retardation, multiple chemical sensitivities, AIDS and new conditions that arise.
- The recognition among more people with disabilities and the mainstream population that there is such a thing as Disability Culture, the movement by people with disabilities to infuse our own experiences into all aspects of everyday life, as most easily seen now in books, movies, music and other expressions of art.
- The importance of persuading the mainstream media to understand our issues from our perspective.
- The national organizing for the Spirit of ADA to celebrate our lives and victories from the last twenty-five years, culminating with events around the country on or about July 26, 2000, the tenth anniversary of the signing of the ADA.
- A comprehensive history of our movement and its importance written by one of us!

REFERENCES

- Berkowitz, E. D. *Disabled Policy: America's Programs for the Handicapped* New York: Twentieth Century Fund, 1987.
- Breslin, Mary Lou. Personal communication. 10 July 1999.
- Brown, S. E. "The Curb Ramps of Kalamazoo: Discovering Our Unrecorded History." *Disability Studies Quarterly*, 19 (3), (Summer 1999), 203-05.
- - -. *Independent Living: Theory and Practice*. Las Cruces, NM: Institute on Disability Culture, 1994.
- - -. *Investigating a Culture of Disability: Final Report*. Las Cruces, NM: Institute on Disability Culture, 1994.
- - -. "The Walkout." *Disability Rag* September 1985: 39-40.
- - -. "Zona and Ed Roberts: Twentieth Century Pioneers." *Disability Studies Quarterly* forthcoming.
- DeLoach, Charlene. "The Independent Living Movement." *Region V Rehabilitation Continuing Education Program ADA Train the Trainer Program*. Carbondale, IL: Southern Illinois University at Carbondale Rehabilitation Institute, 1992.
- Fisher, Jack. Letter to Mayor Henry Ford, Jr. 7 March 1946.
- Frieden, Lex, Laurel Richards, Jean Cole and David Bailey. *ILRU Source Book: Technical Assistance Manual on Independent Living*. Houston, TX: Independent Living Research Utilization, 1979.
- Gallagher, H. G. *FDR's Splendid Deception*. New York: Dodd, Mead, 1985.
- Hartman, Tari Susan. "If Heaven Isn't Accessible, God is in Trouble," *Incitement* (ADAPT Newsletter) 9.1 (Jan./Feb. 1993): 1-2, 8-9.
- Hartman, Tari Susan. Personal communication. 18 August 1999.
- Hessler, John. Letter. *Disability Rag* Sept. 1985: 3.
- Hevey, David. *The Creatures Time Forgot: Photography and Disability Imagery*. London: Routledge, 1992.
- "History of the Division of Rehabilitation-Education Services." Division of Rehabilitation Education Services, College of Applied Life Studies, University of Illinois at Champaign-Urbana. <<http://www.rehab.uiuc.edu/history.html>>
- Kidder, Lynn. "They Fought Disabilities and Won." *Antioch Daily Ledger*, 1 10-12.

- Lenihan, J. *Performance: Disabled Americans: a History*. Washington, D.C.: President's Committee on Employment of the Handicapped, 1976-77.
- Levy, C. W. *A People's History of the Independent Living Movement*. Lawrence, KS: University of Kansas Research and Training Center on Independent Living, 1988.
- Longmore, P. K. Personal communication. 14 July 1999.
- Longmore, P. K., and David Goldberger. "Political Movements of People with Disabilities: The League of the Physically Handicapped, 1945-38." *Disability Studies Quarterly* 17.2 (Spring 1997): 94-98.
- National Council on the Handicapped. Appendix. *Toward Independence: an Assessment of Federal Laws and Programs Affecting Persons with Disabilities With Legislative Recommendations*. Washington, D.C.: GPO, 1986.
- Pfeiffer, D. Personal communication. 20 July 1999.
- Rehabilitation Act of 1973. Pub. L. 93-112. 29 USC Sec. 794.
- Scotch, R. K. *From Good Will to Civil Rights: Transforming Federal Disability Policy*. Philadelphia: Temple, 1984.
- Shapiro, J. P. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Times Books, 1993.
- University of Illinois at Champaign-Urbana, Division of Rehabilitation-Education Services. *Expanding Horizons: a History of the First 50 Years of the Division of Rehabilitation-Education Services at the University of Illinois*. Champaign, IL: Roxford DT Publishing, 1998.
- Walker, M. L. *Beyond Bureaucracy: Mary Elizabeth Switzer and Rehabilitation*. Lanham, MD: University Press, 1985.
- Walker, P. Personal communication. 29 Sept. 1993.
- We Won't Go Away....* Prod. Patricia Ingram. Videocassette. 1981. Available from World Institute on Disability, 510 16th St., Oakland, CA 94612

APPENDIX A

SELECTED SIGNIFICANT DATES IN INDEPENDENT LIVING HISTORY

(for a more comprehensive list see: <http://www.sfsu.edu/~hrdpu/chron.htm>)

1918: The Smith-Sears Veterans Vocational Rehabilitation Act establishes a federal vocational rehabilitation program for disabled soldiers.

1920: The Fess-Smith Civilian Vocational Rehabilitation Act is passed, creating a vocational rehabilitation program for disabled civilians.

1921: The American Foundation for the Blind is founded.

1927: Franklin Roosevelt co-founds the Warm Springs Foundation at Warm Springs, Georgia.

The U.S. Supreme Court, in *Buck v. Bell*, rules that the forced sterilization of people with disabilities is not a violation of their constitutional rights.

1929: Seeing Eye establishes the first dog guide school for blind people in the United States.

1932: Disabled American Veterans is chartered by Congress to represent disabled veterans in their dealings with the federal government.

1933: Franklin Delano Roosevelt, the first seriously physically disabled person ever to be elected as a head of government, is sworn into office as president of the United States.

1936: Passage of the Randolph Sheppard Act establishes a federal program for employing blind vendors at stands in the lobbies of federal office buildings.

1937: Herbert A. Everest and Harry C. Jennings patent a design for a folding wheelchair with an X-frame that can be packed into a car trunk.

1940: The National Federation of the Blind is formed in Wilkes-Barre, Pennsylvania, by Jacobus tenBroek and other blind advocates.

The American Federation of the Physically Handicapped is founded by Paul Strachan as the nation's first cross-disability, national political organization.

1944: Howard Rusk is assigned to the U.S. Army Air Force Convalescent Center in Pawling, New York, where he begins a rehabilitation program for disabled airmen. First dubbed "Rusk's Folly" by the medical establishment, rehabilitation medicine becomes a new medical specialty.

1945: President Harry Truman signs a joint congressional resolution calling for the creation of an annual National Employ the Handicapped Week.

1956: Accent on Living begins publication.

1958: Gini Laurie becomes editor of the Toomeyville Gazette at the Toomey Pavilion Polio Rehabilitation Center. Eventually renamed the Rehabilitation Gazette, this grassroots publication becomes an early voice for disability rights.

1960: The first Paralympic Games, under the auspices of the International Paralympic Committee (IPC), are held in Rome, Italy.

1961: The American Council of the Blind is formally organized.

The American National Standards Institute, Inc. (ANSI) publishes American Standard Specifications for Making Buildings Accessible to, and Usable by, the Physically Handicapped.

1962: Edward V. Roberts becomes the first severely disabled student at the University of California at Berkeley.

1963: South Carolina passes the first statewide architectural access code.

1964: Robert H. Weitbrecht invents the "acoustic coupler," enabling teletypewriter messages to be sent via standard telephone lines. This invention makes possible the widespread use of teletypewriters for the deaf.

1968: The Architectural Barriers Act is passed, mandating that federally constructed buildings and facilities be accessible to people with physical disabilities. This act is generally considered to be the first ever federal disability rights legislation.

1970: Nursing home resident Max Starkloff founds Paraquad in St Louis.

Disabled in Action is founded in New York City by Judith Heumann, after her successful employment discrimination suit against the city's public school system.

The Physically Disabled Students Program (PDSP) is founded by Ed Roberts, John Hessler, Hale Zukas and others at the University of California at Berkeley.

Congress passes the Urban Mass Transportation Assistance Act, declaring it a "national policy that elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services." The law contains no provision for enforcement.

1971: The National Center for Law and the Handicapped is founded at the University of Notre Dame in South Bend, Indiana, becoming the first legal advocacy center for people with disabilities in the United States.

1972: The Center for Independent Living (CIL) is founded in Berkeley, California.

The Houston Cooperative Living Residential Project is established in Houston, Texas.

1973: The first handicap parking stickers are introduced in Washington, D.C.

The Architectural and Transportation Barriers Compliance Board is established under the Rehabilitation Act of 1973 to enforce the Architectural Barriers Act of 1968.

1974: *Halderman v. Pennhurst* is filed in Pennsylvania on behalf of the residents of the Pennhurst State School Hospital. The case, highlighting the horrific conditions at state "schools" for people with mental retardation, becomes an important precedent in the battle for deinstitutionalization, establishing a right to community services for people with developmental disabilities.

The first convention of People First is held in Salem, Oregon. People First becomes the largest U.S. organization composed of and led by people with cognitive disabilities.

North Carolina passes a statewide building code with stringent access requirements drafted by access advocate Ronald Mace. This code becomes a model for effective architectural access legislation in other states. Mace founds Barrier Free Environments to advocate for accessibility in buildings and products.

1975: Congress passes the Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds to programs serving people with developmental disabilities and outlining a series of rights for those who are institutionalized. The lack of an enforcement mechanism within the bill and subsequent court decisions will, however, render this portion of the act virtually useless to disability rights advocates.

The Education for All Handicapped Children Act (Pub. Law 94-142) is passed, establishing the right of children with disabilities to a public school education in an integrated environment. The act is a cornerstone of federal disability rights legislation. In the next two decades, millions of disabled children will be educated under its provisions, radically changing the lives of people in the disability community.

The American Coalition of Citizens with Disabilities is founded. It becomes the preeminent national cross-disability rights organization of the 1970s.

The Association of Persons with Severe Handicaps (TASH) is founded by special education professionals responding to *PARC v. Pennsylvania* (1972) and subsequent right-to-education cases. The organization will eventually call for the end of aversive behavior modification and the closing of all residential institutions for people with disabilities.

The Atlantis Community is founded in Denver as a group housing program for severely disabled adults who, until that time, had been forced to live in nursing homes.

Mainstream: Magazine of the Able-Disabled begins publication in San Diego.

Edward Roberts becomes the director of the California Department of Rehabilitation. He moves to establish nine independent living centers across that state, based on the model of the original Center for Independent Living in Berkeley. The success of these centers demonstrates that independent living can be replicated and eventually results in the founding of hundreds of independent living centers all over the world.

1976: Passage of an amendment to Higher Education Act of 1972 provides services to physically disabled students entering college.

The Disability Rights Center is founded in Washington, D.C. Sponsored by Ralph Nader's Center for the Study of Responsive Law, it specializes in consumer protection for people with disabilities.

1977: President Jimmy Carter appoints Max Cleland to head the U.S. Veterans Administration, making Cleland the first severely disabled (as well as the youngest) person to fill that position.

The White House Conference on Handicapped Individuals brings together 3,000 disabled people to discuss federal policy toward people with disabilities. This first ever gathering of its kind results in numerous recommendations and acts as a catalyst for grassroots disability rights organizing.

Passage of the Legal Services Corporation Act Amendments adds financially needy people with disabilities to the list of those eligible for publicly funded legal services.

1978: Disability rights activists in Denver stage a sit-in demonstration, blocking several Denver Regional Transit Authority buses to protest the complete inaccessibility of that city's mass transit system.

Title VII of the Rehabilitation Act Amendments of 1978 establishes the first federal funding for independent living and creates the National Council of the Handicapped under the U.S. Department of Education.

On Our Own: Patient Controlled Alternatives to the Mental Health System is published. Written by Judi Chamberlin, it becomes a standard text of the psychiatric survivor movement.

1979: Funding of the first ten independent living centers funded through the Rehabilitation Act.

The U.S. Supreme Court, in *Southeastern Community College v. Davis*, rules that, under Section 504 of the Rehabilitation Act of 1973, programs receiving federal funds must make "reasonable modifications" to enable the participation of otherwise qualified disabled individuals. This decision is the Court's first ruling on Section 504, and it establishes reasonable modification as an important principle in disability rights law.

Marilyn Hamilton, Jim Okamoto and Don Helman produce their "Quickie" lightweight folding wheelchair, revolutionizing manual wheelchair design.

The Disability Rights Education and Defense Fund (DREDF) is founded in Berkeley, California, becoming the nation's preeminent disability rights legal advocacy center and participating in much of the landmark litigation and lobbying of the 1980s and 1990s.

Self Help for Hard of Hearing People, Inc., is founded in Bethesda, Maryland, by Howard "Rocky" Stone.

1980: The first issue of the *Disability Rag* (now *Ragged Edge*) is published in Louisville, Kentucky.

Disabled Peoples' International is founded in Singapore, with the participation of advocates from Canada and the United States.

1981: The International Year of Disabled Persons begins with speeches before the United Nations General Assembly. During the year, governments are encouraged to sponsor programs bringing people with disabilities into the mainstream of their societies.

In an editorial in the *New York Times*, Evan Kemp, Jr., attacks the Jerry Lewis National Muscular Dystrophy Association Telethon, writing that "the very human desire for cures can never justify a television show that reinforces a stigma against disabled people."

1981-1984: The parents of "Baby Doe" in Bloomington, Indiana, are advised by their doctors to deny a surgical procedure to unblock their newborn's esophagus because the baby has Down syndrome. Although disability rights activists try to intervene, Baby Doe starves to death before legal action can be taken. The case prompts the Reagan administration to issue regulations calling for the creation of "Baby Doe squads" to safeguard the civil rights of disabled newborns.

The Telecommunications for the Disabled Act mandates telephone access for deaf and hard-of-hearing people at important public places, such as hospitals and police stations, and that all coin-operated phones be hearing aid-compatible by January 1985. It also calls for state subsidies for production and distribution of TDDs (telecommunications devices for the deaf), more commonly referred to as TTYs.

The National Council on Independent Living is formed to advocate on behalf of independent living centers and the independent living movement.

1983: The Disabled Children's Computer Group (DCCG) is founded in Berkeley, California.

Ed Roberts, Judy Heumann and Joan Leon found the World Institute on Disability in Oakland, California.

American Disabled for Accessible Public Transit (ADAPT) is organized at the Atlantis Community headquarters in Denver, Colorado. For the next seven years ADAPT conducts a civil disobedience campaign against the American Public Transit Association (APTA) and various local public transit authorities to protest the lack of accessible public transportation.

The United Nations expands the International Year of Disabled Persons into the International Decade of Disabled Persons, to last from 1983 to 1992.

1984: George Murray becomes the first wheelchair athlete to be featured on the Wheaties cereal box.

The Voting Accessibility for the Elderly and Handicapped Act mandates that polling places be accessible or that ways be found to enable elderly and disabled people to exercise their right to vote. Advocates find that the act is difficult, if not impossible, to enforce.

1985: Wry Crips, a radical disability theatre group, is founded in California.

The U.S. Supreme Court rules, in *City of Cleburne v. Cleburne Living Center*, that localities cannot use zoning laws to prohibit group homes for people with developmental disabilities from opening in a residential area solely because its residents are disabled.

The National Association of Psychiatric Survivors is founded.

Mental Illness Bill of Rights Act is passed.

1986: The Air Carrier Access Act is passed, prohibiting airlines from refusing to serve people simply because they are disabled and from charging them more for airfare than non-disabled travelers.

The National Council on the Handicapped issues *Toward Independence*, a report outlining the legal status of Americans with disabilities, documenting the existence of discrimination and citing the need for federal civil rights legislation (what will eventually be passed as the Americans with Disabilities Act of 1990).

Concrete Change, a grassroots organization advocating for accessible housing, is organized in Atlanta, Georgia. The Protection and Advocacy for Mentally Ill

Individuals Act is passed, setting up protection and advocacy agencies for people who are in-patients or residents of mental health facilities.

The Society for Disability Studies is founded.

The Rehabilitation Act Amendments of 1986 define supported employment as a "legitimate rehabilitation outcome."

1987: Marlee Matlin wins an Oscar for her performance in *Children of a Lesser God*.

The AXIS Dance Troupe is founded in Oakland, California.

The US. Supreme Court, in *School Board of Nassau County, Fla. v. Arline*, outlines the rights of people with contagious diseases under Title V of the Rehabilitation Act of 1973. It establishes that people with infectious diseases cannot be fired from their jobs "because of prejudiced attitude or ignorance of others."

1988: Students at Gallaudet University in Washington, D.C., organize a week-long shut-down and occupation of their campus to demand selection of a deaf president after the Gallaudet board of trustees appoints a non-deaf person as president of the university. On March 13, the Gallaudet administration announces that I. King Jordan will be the university's first deaf president.

The Technology-Related Assistance Act for Individuals with Disabilities is passed, authorizing federal funding to state projects designed to facilitate access to assistive technology.

The Fair Housing Amendments Act adds people with disabilities to those groups protected by federal fair housing legislation and establishes minimum standards of adaptability for newly constructed multiple-dwelling housing.

Congress overturns President Ronald Reagan's veto of the Civil Rights Restoration Act of 1987. The act undoes the Supreme Court decision in *Grove City v. Bell* and other decisions limiting the scope of federal civil rights law, including Section 504 of the Rehabilitation Act of 1973.

1989: The Center for Universal Design (originally the Center for Accessible Housing) is founded by Ronald Mace in Raleigh, North Carolina.

Mouth: The Voice of Disability Rights begins publication in Rochester, New York.

1990: The Americans with Disabilities Act is signed by President George Bush on July 26 in a ceremony on the White House lawn witnessed by thousands of disability rights activists. The law is the most sweeping disability rights legislation in history, for the first time bringing full legal citizenship to Americans with disabilities. It mandates that local, state, and federal governments and programs be accessible, that businesses with more than 15 employees make "reasonable accommodations" for disabled workers, that public accommodations such as restaurants and stores make "reasonable modifications" to ensure access for

disabled members of the public. The act also mandates access in public transportation, communication and other areas of public life.

The Ryan White Comprehensive AIDS Resources Emergency Act is passed to help localities cope with the burgeoning HIV/AIDS epidemic.

With passage of the Americans with Disabilities Act, American Disabled for Accessible Public Transit (ADAPT) changes its focus to advocating for personal assistance services and changes its name to American Disabled for Attendant Programs Today.

The Education for All Handicapped Children Act is amended and renamed the Individuals with Disabilities Education Act (IDEA).

1991: Jerry's Orphans stages its first annual picket of the Jerry Lewis Muscular Dystrophy Association Telethon.

1993: Robert Williams becomes commissioner of the Administration on Developmental Disabilities, the first developmentally disabled person to hold that post.

1995: Justice for All is founded in Washington, D.C.

When Billy Broke His Head... and Other Tale of Wonder premieres on PBS. The film is, for many, an introduction to the concept of disability rights and the disability rights movement.

The American Association of People with Disabilities is founded in Washington, D.C.

The U.S. Court of Appeals for the Third Circuit, in *Helen L. v. Snider*, rules that the continued publicly funded institutionalization of a disabled Pennsylvania woman in a nursing home, when not medically necessary and where the state of Pennsylvania could offer her the option of home care, is a violation of her rights under the Americans with Disabilities Act of 1990.

Sandra Jensen, a member of People First, is denied a heart-lung transplant by the Stanford University School of Medicine because she has Down syndrome. After pressure from disability rights activists, administrators there reverse their decision, and, in January 1996, Jensen becomes the first person with Down syndrome to receive a heart-lung transplant.

1996: Not Dead Yet is formed by disabled advocates to oppose Jack Kevorkian and the proponents of assisted suicide for people with disabilities.

Sen. Robert Dole becomes the first person with a visible disability since Franklin Roosevelt to run for president of the United States. Unlike Roosevelt, he publicly acknowledges the extent of his disability. He is defeated by incumbent Bill Clinton.

Disabled Persons' Independence Movement--Oral History of the Berkeley Movement is funded by the National Institute on Disability Research and Rehabilitation.

1999: Jack Kevorkian is sentenced for murder. He has been a proponent for and a practitioner of what is called "physician-assisted suicide."

About 50 disability advocates gathered in Louisville, KY, to discuss methods to bring disability issues more effectively to the media at the 1999 May Media Meeting.

Very Special Arts changes its name to VSA Arts.

Groups from all over the United States are planning Spirit of ADA, to celebrate the 10th anniversary of the signing of the ADA, 25th anniversary of IDEA, 25th anniversary of the American Coalition of Citizens with Disabilities (ACCD) and the 50th anniversary of Arc.

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History of Independent Living

**by Gina McDonald
and Mike Oxford**

History of Independent Living by Gina McDonald and Mike Oxford

This account of the history of independent living stems from a philosophy which states that people with disabilities should have the same civil rights, options, and control over choices in their own lives as do people without disabilities.

The history of independent living is closely tied to the civil rights struggles of the 1950s and 1960s among African Americans. Basic issues--disgraceful treatment based on bigotry and erroneous stereotypes in housing, education, transportation, and employment --and the strategies and tactics are very similar. This history and its driving philosophy also have much in common with other political and social movements of the country in the late 1960s and early 1970s. There were at least five movements that influenced the disability rights movement.

Social Movements

The first social movement was deinstitutionalization, an attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities. This movement was led by providers and parents of people with developmental disabilities and was based on the principle of "normalization" developed by Wolf Wolfensberger, a sociologist from Canada. His theory was that people with developmental disabilities should live in the most "normal" setting possible if they were to be expected to behave "normally." Other changes occurred in nursing homes where young people with many types of disabilities were warehoused for lack of "better" alternatives (Wolfensberger, 1972).

The next movement to influence disability rights was the civil rights movement. Although people with disabilities were not included as a protected class under the Civil Rights Act, it was a reality that people could achieve rights, at least in law, as a class. Watching the courage of Rosa Parks as she defiantly rode in the front of a public bus, people with disabilities realized the more immediate challenge of even getting on the bus.

The "self-help" movement, which really began in the 1950s with the founding of Alcoholics Anonymous, came into its own in the 1970s. Many self-help books were published and support groups flourished. Self-help and peer support are recognized as key points in independent living philosophy. According to this tenet, people with similar disabilities are believed to be more likely to assist and to understand each other than individuals who do not share experience with similar disability.

Demedicalization was a movement that began to look at more holistic approaches to health care. There was a move toward "demystification" of the medical community. Thus, another cornerstone of independent living philosophy became the shift away from

the authoritarian medical model to a paradigm of individual empowerment and responsibility for defining and meeting one's own needs.

Consumerism, the last movement to be described here, was one in which consumers began to question product reliability and price. Ralph Nader was the most outspoken advocate for this movement, and his staff and followers came to be known as "Nader's Raiders." Perhaps most fundamental to independent living philosophy today is the idea of control by consumers of goods and services over the choices and options available to them.

The independent living paradigm, developed by Gerben DeJong in the late 1970s (DeJong, 1979), proposed a shift from the medical model to the independent living model. As with the movements described above, this theory located problems or "deficiencies" in the society, not the individual. People with disabilities no longer saw themselves as broken or sick, certainly not in need of repair. Issues such as social and attitudinal barriers were the real problems facing people with disabilities. The answers were to be found in changing and "fixing" society, not people with disabilities. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional.

Using these principles, people began to view themselves as powerful and self-directed as opposed to passive victims, objects of charity, cripples, or not-whole. Disability began to be seen as a natural, not uncommon, experience in life, not a tragedy.

ADAPT

Wade Blank began his lifelong struggle in civil rights activism with Dr. Martin Luther King, Jr. in Selma, Alabama. It was during this period that he learned about the stark oppression which occurred against people considered to be outside the "mainstream" of our "civilized" society. By 1971, Wade was working in a nursing facility, Heritage House, trying to improve the quality of life of some of the younger residents. These efforts, including taking some of the residents to a Grateful Dead concert, ultimately failed. Institutional services and living arrangements were at odds with the pursuit of personal liberties and life with dignity.

In 1974, Wade founded the Atlantis Community, a model for community-based, consumer-controlled, independent living. The Atlantis Community provided personal assistance services primarily under the control of the consumer within a community setting. The first consumers of the Atlantis Community were some of the young residents "freed" from Heritage House by Wade (after he had been fired). Initially, Wade provided personal assistance services to nine people by himself for no pay so that these individuals could integrate into society and live lives of liberty and dignity. In 1978, Wade and Atlantis realized that access to public transportation was a necessity if people with disabilities were to live independently in the community. This

was the year that American Disabled for Accessible Public Transit (ADAPT) was founded.

On July 5-6, 1978, Wade and nineteen disabled activists held a public transit bus "hostage" on the corner of Broadway and Colfax in Denver, Colorado. ADAPT eventually mushroomed into the nation's first grassroots, disability rights, activist organization.

In the spring of 1990, the Secretary of Transportation, Sam Skinner, finally issued regulations mandating lifts on buses. These regulations implemented a law passed in 1970-the Urban Mass Transit Act-which required lifts on new buses. The transit industry had successfully blocked implementation of this part of the law for twenty years, until ADAPT changed their minds and the minds of the nation. In 1990, after passage of the Americans With Disabilities Act (ADA), ADAPT shifted its vision toward a national system of community-based personal assistance services and the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The acronym ADAPT became "American Disabled for Attendant Programs Today." The fight for a national policy of attendant services and the end of institutionalization continues to this day.

Wade Blank died on February 15, 1993, while unsuccessfully attempting to rescue his son from drowning in the ocean. Wade and Ed Roberts live on in many hearts and in the continuing struggle for the rights of people with disabilities.

These lives of these two leaders in the disability rights movement, Ed Roberts and Wade Blank, provide poignant examples of the modern history, philosophy, and evolution of independent living in the United States. To complete this rough sketch of the history of independent living, a look must be taken at the various pieces of legislation concerning the rights of people with disabilities, with a particular emphasis on the original "bible" of civil rights for people with disabilities, the Rehabilitation Act of 1973.

Civil Rights Laws

Before turning to the Rehabilitation Act, a chronological listing and brief description of important federal civil rights laws affecting people with disabilities is in order.

- 1964 Civil Rights Act: prohibits discrimination on the basis of race, religion, ethnicity, national origin, and creed -- later, gender was added as a protected class.
- 1968 Architectural Barriers Act: prohibits architectural barriers in all federally owned or leased buildings.
- 1970 Urban Mass Transit Act: requires that all new mass transit vehicles be equipped with wheelchair lifts. As mentioned earlier, it was twenty years, primarily because of machinations of the American Public Transit Association (APTA), before the part of the law requiring wheelchair lifts was implemented.
- 1973 Rehabilitation Act: particularly Title V, Sections 501, 503, and 504, prohibits discrimination in federal programs and services and all other programs or services receiving federal funding.
- 1975 Developmental Disabilities Bill of Rights Act: among other things, establishes Protection and Advocacy services (P & A).
- 1975 Education of All Handicapped Children Act (PL 94-142): requires free, appropriate public education in the least restrictive environment possible for children with disabilities. This law is now called the Individuals with Disabilities Education Act (IDEA).
- 1978 Amendments to the Rehabilitation Act: provides for consumer-controlled centers for independent living.
- 1983 Amendments to the Rehabilitation Act: provides for the Client Assistance Program (CAP), an advocacy program for consumers of rehabilitation and independent living services.
- 1985 Mental Illness Bill of Rights Act: requires protection and advocacy services (P & A) for people with mental illness.
- 1988 Civil Rights Restoration Act: counteracts bad case law by clarifying Congress' original intention that under the Rehabilitation Act, discrimination in AN-Y program or service that is a part of an entity receiving federal funding --not just the part which actually and directly receives the funding --is illegal.
- 1988 Air Carrier Access Act: prohibits discrimination on the basis of disability in air travel and provides for equal access to air transportation services.

- 1988 Fair Housing Amendments Act: prohibits discrimination in housing against people with disabilities and families with children. Also provides for architectural accessibility of certain new housing units, renovation of existing units, and accessibility modifications at the renter's expense.
- 1990 Americans with Disabilities Act: provides comprehensive civil rights protection for people with disabilities; closely modeled after the Civil Rights Act and the Section 504 of Title V of the Rehabilitation Act and its regulations.

The modern history of civil rights for people with disabilities is three decades old. A key piece of this decades-long process is the story of how the Rehabilitation Act of 1973 was finally passed and then implemented. It is the story of the first organized disability rights protest.

The Rehabilitation Act of 1973

In 1972, Congress passed a rehabilitation bill that independent living activists cheered. President Richard Nixon's veto prevented this bill from becoming law. During the era of political activity at the end of the Vietnam War, Nixon's veto was not taken lying down by disability activists who launched fierce protests across the country. In New York City early leader for disability fights, Judy Heumann, staged a sit-in on Madison Avenue with eighty other activists.

Traffic was stopped. After a flood of angry letters and protests, in September 1973, Congress overrode Nixon's veto and the Rehabilitation Act of 1973 finally became law. Passage of this pivotal law was the beginning of the ongoing fight for implementation and revision of the law according to the vision of independent living advocates and disability rights activists. Key language in the Rehabilitation Act, found in Section 504 of Title V, states that:

No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Advocates realized that this new law would need regulations in order to be implemented and enforced. By 1977, Presidents Nixon and Ford had come and gone. Jimmy Carter had-become president and had appointed Joseph Califano his Secretary of Health, Education and Welfare (HEW). Califano refused to issue regulations and was given an ultimatum and deadline of April 4, 1977. April 4 went by with no regulations and no word from Califano.

On April 5, demonstrations by people with disabilities took place in ten cities across the country. By the end of the day, demonstrations in nine cities were over. In one city, San Francisco, protesters refused to disband.

Demonstrators, more than 150 people with disabilities, had taken over the federal office building and refused to leave. They stayed until May 1. Califano had issued regulations by April 28, but the protesters stayed until they had reviewed the regulations and approved of them.

The lesson is a fairly simple one. As Martin Luther King said,

It is an historical fact that the privileged groups seldom give up their privileges voluntarily. Individuals may see the moral light and voluntarily give up their unjust posture, but, as we are reminded, groups tend to be more immoral than individuals. We know, through painful experience that freedom is never voluntarily given by the oppressor, it must be demanded by the oppressed.

Leaders in the Independent Living Movement

The history of the independent living movement is not complete without mention of some other leaders who continue to make substantial contributions to the movement and to the rights and empowerment of people with disabilities.

Max Starkloff, Charlie Carr, and Marca Bristo founded the National Council on Independent Living (NCEL) in 1980. NCEL is one of the only national organizations that is consumer-controlled and promotes the rights and empowerment of people with disabilities.

Justin Dart played a prominent role in the fight for passage of the Americans with Disabilities Act, and is seen by many as the spiritual leader of the movement today.

Lex Frieden is co-founder of ELRU Program. As director of the National Council on Disability, he directed preparation of the original ADA legislation and its introduction in Congress.

Liz Savage and Pat Wright are considered to be the "mothers of the ADA." They led the consumer fight for the passage of the ADA.

There are countless other people who have and continue to make substantial contributions to the independent living movement.

REFERENCES

DeJong, Gerben. "Independent Living: From Social Movement to Analytic Paradigm,"
Archives of Physical Medicine and Rehabilitation 60, October 1979.

Wolfensberger, Wolf. The Principle of Normalization in Human Services. Toronto:
National Institute on Mental Retardation, 1972.

***Disability is not a “brave struggle” or
“courage in the face of adversity”...
disability is an art. It’s an ingenious
way to live.—Neil Marcus, 1993***

The New Paradigm of Disability

A Bibliography

September 30, 2000

This bibliography was developed by an *ad hoc* task group of the President's Committee on the Employment of People with Disabilities, Subcommittee on Communications.

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The New Paradigm of Disability

A Bibliography

It has been thirty years since the beginning of the contemporary Independent Living Movement. It was a time when the previously separate groups of people with disabilities began to collectively fight for the respect, and demand the civil rights, enjoyed by mainstream America. There are now the first generation of laws protecting the rights of disabled people. Access to employment, Transportation, education, and public accommodations is now mandated by Federal law for disabled people. More than ever people with disabilities are participating in American life. But, the mainstream media barely recognizes that disability is an inherent, integral, and inevitable component of the human experience. Nor do newspapers, television, and movies portray the role that society plays in marginalizing and stereotyping disabled people. More often the antiquated myths and stereotypes about people with disabilities are the norm. From disabled activists using civil disobedience for social justice to university professors with disabilities researching and teaching disability studies, a new, clearly articulated analysis of the disability paradigm has emerged and is taking root throughout the nation and around the world. This new perspective on the human condition needs to be integrated into mainstream media. Following on the successful Disability Messenger project of the President's Committee on Employment of People with Disabilities this bibliography is intended as a catalyst to further articulate, amplify, and promote this new perspective of disability to allies, potential allies, academics, and policy makers and the media. This bibliography is further demonstration of the power of a community defining itself and articulating its members own collective and individual identity.

Description

This is an annotated bibliography of books organized by categories: Community/Culture, Disability Studies, Family, Children, & Sexuality, History, Identity, Policy/Civil Rights, Children/Young Adults, and separate categories for Radio, Movies, WWW (Internet), Publications and Videos. The list is a compilation of recommendations from a diverse group of disability scholars and activists and other bibliographies. All of the entries illustrate an authentic view of disability using the new paradigm. Included is disability experience, identity, pride, passion, intellect, and community as we define it. The focus is on disability in the United States, but it also includes international perspectives. Far too many of the books are no longer in print. Larger university libraries have many of these books in their collections. Also, you can use inter-library loan through most libraries to borrow them. Bibliofind.com and other on-line sources for used books are possibilities, as well. This bibliography is updated regularly. It will be formally updated on a semi-annual basis. The next formal version will be posted by July 1, 2001.

Community/Culture

ABC Clio Companion to the Disability Rights Movement (ABC-Clio Companions to Key Issues in American History and Life) (1997) Pelka, Fred Short entries on everything to do with the Disability Rights Movement.

What Psychotherapists Should Know About Disability (1999) Olkin, Rhoda A useful overview of disability that is valuable for anyone involved with disability issues.

Disability Studies

Claiming Disability: Knowledge and Identity (Cultural Front Series) (1998) Linton, Simi, A strong overview of the "construction" of disability and the resulting ramifications.

Disability Is Not Measles: New Research Paradigms in Disability (1994) Rioux, Marcia H. & Bach, Michael A collection of essays on disability and statistical analysis that reveals how false stereotypes pollute much disability research.

Missing Pieces: A Chronicle of Living with a Disability (1982) Zola, I. K., A wonderful combination of personal disability discovery and sociological analysis. Considered by many disabled people as a key to understanding the personal and the political. (Out of print)

Pride Against Prejudice: Transforming Attitudes to Disability (1991) Morris, Jenny An accessible and pioneering study of the way that people are disabled by society. Includes discussion of the role of cultural representation and social barriers, and the problems with feminist research on community care. (out of print)

Family, Children, & Sexuality

Enabling Romance : A Guide to Love, Sex, and Relationships for the Disabled and the People Who Care About Them (1992) Kroll, Ken One of the few books on sexuality and disability. (out of print)

Past Due: A Story of Disability, Pregnancy, and Birth (1990) Finger, Anne Well-written exploration of disability, pregnancy, and reproductive rights.

Question of David: A Disabled Mother's Journey Through Adoption, Family, and Life, The (1999) Jacobson, Denise Sherer An intimate, honest portrayal of a woman with a significant disability as she grapples with the lifelong issues of self-worth, sexuality, family value, relationships, and motherhood.

History

Beyond Affliction (1998) Block, Laurie A detailed, fascinating, radio documentary on the history of disability in the United States. (Available on tape and excerpts on RealAudio at www.npr.org/programs/disability)

By Trust Betrayed: Patients, Physicians and the License to Kill in the Third Reich (1990) Gallagher, Hugh Gallagher documents the history of the German T-4 project which killed 200,000 disabled people in the name of eugenics during the Third Reich.

Disabled State, The (1984) Stone, D. A. Valuable for its historical perspective on the formation of disability social construct and its affect on US government policy.

FDR's Splendid Deception, FDR Memorial Edition (1998) Gallagher, H. How FDR was changed by disability, the lengths he used to conceal it, and the legacy of the "cured cripple." Gallagher argues that FDR's social consciousness is a direct result of his disability experiences.

History of Disability (Corporealities) (1982) Stiker, Henri-Jacques & Sayers, William (Translator) The welcome English translation of this European perspective on the historical basis for disability.

Last Civil Rights Movement: Disabled Peoples' International, The (1989) Driedger, D. One of the first books on disability rights and self-determination. Has a strong international and Canadian perspective. (out of print)

New Disability History: American Perspectives, forthcoming, Umansky, Lauri & Longmore, Paul K. This much anticipated historical view of disability in the US is edited by one of the foremost disability scholars, Paul Longmore.

No Pity: People with Disabilities Forging a New Civil Rights Movement (1993) Shapiro, Joseph P. Probably the most accessible accounting of the contemporary disability rights movement, although from a "great men" perspective.

When The Mind Hears: A History of the Deaf (1984) Lane, Harlan. The key text on the Deaf and their history.

Identity

Body, Remember: a Memoir (1997) Fries, Kenny. The intertwining identities of being Jewish, disabled, and gay are the subject of this memoir.

Count Us In: Growing Up with Down Syndrome (1994) Kingsley, Jason And Mitchell Levitz. First person account of exceeding society's expectations by two friends.

Don't Worry, He Won't Get Far On Foot: The Autobiography of a Dangerous Man (1989) Callahan, J. Dark humor about spinal cord injury and addiction. The final three chapters outline the difficulties and frustrations of living on government disability support.

Moving Violations: War Zones, Wheelchairs, and Declarations of Independence (1995) Hockenberry, John. Another first-person account of life from a wheelchair. Hockenberry's insight, humor, candor, and fascinating career raise this text to the next level.

Nobody Nowhere: The Extraordinary Autobiography of an Autistic (1992) Williams, Donna. First person account of autism that has helped change how we regard people with autism.

Planet of the Blind (1998) Kuusisto, Stephen. Kuusisto writes about his struggle to deny his disability and his eventual understanding and accommodation to it.

Seeing Voices; A Journey Into the World of the Deaf (1990), Sacks, Oliver. An exploration of the culture, politics, and neurology of American Sign Language and its place in the Deaf community.

Staring Back: The Disability Experience from the Inside Out (1998) Fries, Kenny. Valuable compilation of contemporary disability writings.

Waist High in the World: A Life Among the Nondisabled (1998) Mairs, Nancy, Essays on living with a disability in an illogical world.

Policy/Civil Rights

Disability Politics: Understanding Our Past, Changing Our Future (1996) Campbell, Jane & Oliver, Michael. An accessible account, drawing on the perspectives of British disabled activists on the rise of the civil rights movement in UK, summarizing the history and the issues.

Exploring Disability Policy (1999) Barnes, Colin; Mercer, Geof; & Shakespeare, Tom, An undergraduate text reviewing the sociology of disability, which will be of interest to a general audience. Clear, comprehensive and the best place for any academic or student to start reading.

Nothing About Us Without Us: Disability Oppression and Empowerment (1998) Charlton, James. First American text to document and synthesize the growth of the disability rights movement.

People with Disabilities Explain It All For You: Your Guide to the Public Accommodations Requirements of the Americans With Disabilities Act (1992) Johnson, Mary & the Editors of the Disability Rag. An insider's view of the Americans with Disabilities Act, capturing the spirit and intent of the law. (out of print)

Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of The Disability Rag, Shaw, Barrett. The Disability Rag has been the voice for the politicized disability community. All of the key issues of the past fifteen years are debated in these pages.

Unexpected Minority, Handicapped Children in America, The (1980) Gliedman, J. & Roth, W. A significant turning point in disability studies that still has powerful insights about the disability experience. (out of print)

Children & Young Adults

Thank you to Chris Saad of Chris' Corner: Books for Kids & Teens in Philadelphia, PA for her recommendations.

ABC for You and Me, Ginnis, Meg (2000) preschool
Alex, the Kid with AIDS, Girard (1993) primary
The Crazy Horse Electric Game, Crutcher, Chris (1991) high school
Deenie, Blume, Judy (1983) middle school
Extraordinary Friends, Rogers, Fred (2000) primary
From Anna, Little, Jean (1991) upper elementary
Invincible Summer, Ferris, Jean (1991) high school
Izzy, Willy-Nilly, Voigt, Cynthia (1995) high school
Kathy's Hats, Krishner, Trudy (1992) primary
The Seeing Stick, Yolen, Jane (1977) upper elementary (out of print)
Someone Special Just Like You, Brown, Tricia (1984) preschool
Summer of the Swans, Byars, Betsy (1997) upper elementary

Radio

Disability Radio Worldwide, Parker, Jean. A truly international perspective on disability. International on short-wave frequencies 6975, 15050 and 21460, Mondays at 19:00 UTC, Fridays at 17:00 UTC and Saturdays at 22:00 UTC, each with a second broadcast eight hours later. (www.independentliving.org/radio/index2.html)

On a Roll Radio, Smith, Greg, Contemporary issues in disability that does not shy away from the controversial or un-hip. (Available on RealAudio at www.onarollradio.com)

Movies

Color of Paradise, Rang-e khoda (1999) Majidi, Majid. An insider's view of a blind, Iranian boy's life including a residential school for the blind. (English sub-titles)

Coming Home (1978) Ashby, Hal. Still controversial twenty years later for its portrayal of the effects of the Viet Nam conflict on veterans, their families, and society. A good insider view of rehabilitation and living as a wheelchair user. (VHS-closed captioned)

Freaks (1932) Browning, Tod. Pauline Kael, the New Yorker's long time critic, described the actors as "creatures" who used their "physical deformity for ...horror" but this movie's portrayal of disability community and reaction to exploitation is remarkably powerful and affirming.

Gaby, A True Story (1987) Mandoki, Luis. A remarkably straight forward look at coming of age for a young woman with CP in Mexico. Gaby's loves, flirtations, and crushes are artfully explored.

Genghis Blues (1999) Belic, Roko A documentary of San Francisco bluesman, Paul Pena's search for fellow throat singers in China. Pena's blindness is central to the beginning of the story, but ultimately is peripheral.

My Left Foot (1989) Sheridan, Jim. Daniel Day Lewis brings Christie Brown's autobiography to life with a savage intensity fueled by Day Lewis experience of staying in character throughout the course of filming. (DVD & VHS-closed captioned, & VHS Spanish captioned)

Pelswick (2000) Callahan, John. Disabled, acerbic, non-PC, cartoonist John Callahan's amusing depiction of a wheelchair-using eight grader is over-the-top, but somehow realistic. Nickelodeon, Saturdays 6 P.M. (ET) & 7:30 A.M. (ET).

Waterdance, The (1992) Jimenez, Neal & Steinberg, Michael. An accurate portrayal of the grief, shock, and loss that often comes with a new spinal cord injury while in a rehab hospital. (VHS-closed captioned)

World Wide Web & Internet

Art, Disability & Expression Exhibit of VSA arts (1999) Moore, Stephanie & Jeffries, Chris. This on-line exhibit shows some of the best examples of the vital artistic, political, and cultural expression of the disability community. Caution, there are many high definition images on the site, so downloads might be lengthy. (<http://www.vsarts.org/gallery/exhibits/disability/index.html>)

Beyond Affliction (1998) Block, Laurie, The companion web site to the four hour disability history radio program on NPR. The site contains excellent primary source material. (www.npr.org/programs/disability)

Assistive Technology (2001) Williams, John W. Pragmatic and realistic about the advantages and disadvantages of technology for disabled people, William's columns highlights computers and other electronic devices. Go to Business Weeks Technology page and look under Assistive Technology. Archived at the National Organization on Disability at <http://www.nod.org/jwarchive.html>.

Disability Policy, Mazrui, Jamal and Pierce, Kelly, DIMENET A moderated list that provides members with policy, government, and legal documents and articles on emerging issues in the disability community. Subscribe by sending to:

Majordomo@trip.tripil.com the following command in the body of your e-mail message:
subscribe dpolicy Archives are at: <http://www.dimenet.com/dpolicy>

Disability-Research Discussion List, Priestly, Mark, University of Leeds Based in the United Kingdom with a world wide focus this list focuses on disability research, both theoretical and practical from a social model perspective. To join e-mail to: JISCmail@JISCmail.ac.uk: with the following message: join disability-research your name Past messages are available in a searchable archive at <http://www.leeds.ac.uk/disability-studies/>

Disability Social History, Dias, Steve & Chadwick, Pat, A window into the untold disability history. (www.disabilityhistory.org)

Disability World Duncan, Barbara & Berman-Bieler, Rosangela. A bimonthly web zine in English and Spanish focusing on an international perspective of independent living and disability. It has a strong arts and culture section plus international politics with a distinct point of view. (<http://www.disabilityworld.org/>)

DS-HUM Listproc, Holmes, Martha Stoddard, Georgetown University A list-serv discussing disability in the humanities. To subscribe to DS-HUM, send a message in the following format to listproc@listproc.georgetown.edu
subscribe ds-hum Yourfirstname Yourlastname More information is available at: <http://www.georgetown.edu/crossroads/interests/ds-hum/index.html>

Interdisciplinary Bibliography on Disability in the Humanities, Doug Baynton Works within the humanities (rather than social sciences) that explore disability. (<http://www.georgetown.edu/crossroads/interests/ds-hum/ds-bib.html>)

JFA E-mail Network, Fay, Fred, Justice for All. An electronic newsletter with the latest news, legislative alerts, and current problems in the disability community. To subscribe send a message to: majordomo@jfanow.org with the following in the body of the message: subscribe justice Archives are available at: <http://www.jfanow.org/cgi/getin.pl?1R>

Manifesto, Brown, Steven E., Institute on Disability Culture. An electronic newsletter of thoughts, news, and information on disability. To subscribe send a message to: majordomo@tripil.com the following command in the body of your e-mail message: subscribe disculture Searchable archives are at: <http://www.acils.com/disculture/>

Publications

The Mouth, Voice of the Disability Nation, Gwin, Lucy Ed. Mixing news, humor, and attitude, The Mouth covers the struggles for disability identity and freedom. (<http://www.mouthmag.com/subform.htm>)

New Mobility, Disability Culture and Lifestyle, Corbet, Barry Ed. This glossy, lifestyle magazine has equipment reviews, sex and relationship advice, profiles, and the arts. P.O. Box 220, Horsham, PA 19044 (<http://www.newmobility.com/>)

Ragged Edge, Johnson, Mary Ed., This magazine (formerly the Disability Rag) has been where the disability rights community has found its news, argued its policies, and celebrated its successes. Avocado Press PO Box 145 Louisville, KY 40201. (<http://www.ragged-edge-mag.com/>)

Videos

Able to Laugh (1993) Dougan, Michael J., Fanlight Productions, Six disabled comics are featured interpreting the disability experience.

Breathing Lessons: The Life and Times of Mark O'Brien (1996) Yu, Jessica, Fanlight Productions. The Academy Award winning documentary of the late disability poet and author Mark O'Brien. Mark's passionate and incisive poems are highlighted. (Open captioned)

Disability Culture Rap: Disability Identity and Culture (2000) Wade, Cheryl Marie & Smith, Jerry, Tools for Change Wade's expanded version of her ground-breaking and celebratory "Disability Culture Rap" paired with images from disability history and the disability rights movement. Includes facilitator's manual. (Closed captioned)

If I Can't Do It... (1998) Brock, Walter, Fanlight Productions. This is an unflinching portrait of a complex and cantankerous disabled man, Arthur Campbell, as he pushes for independence and an equal slice of the American pie.

King Gimp (2000) Hadary, Susan Hannah, HBO. An extensive look at the commitment, passion, and struggles of a disabled artist. An Academy Award winner.

My Country: The Civil Rights Movement That Created the Americans with Disabilities Act, Ward & Associates, Program Development Associates. A powerful video on the parallels between the Disability Rights Movement and the African American civil rights struggle of the 1960s.

Storm Reading (1996) Marcus, Neil, Access Theater Written and performed by Neil Marcus, this one man show (with two aides) shows the expressiveness of his atypical body and intellect.

Tell Them I'm a Mermaid (1983) Daley, E., & Kaplan, C., Embassy Telecommunications, 1901 Avenue of the Stars, Los Angeles, CA 90067
A documentary of Victoria Lewis' ground breaking theatrical troupe exploring disabled and women's identity.

Twitch and Shout, a New Day film, Chiten, Lauren, Fanlight Productions
Humor and gritty reality highlight this documentary on people living with Tourette's.

Vital Signs: Crip Culture Talks Back (1995) Mitchell, David T. and Snyder, Sharon L., Fanlight Productions Disability culture is highlighted by some its prime exponents. Theater, monologues, humor, and stories help to illustrate disability pride and culture. (Open captioned)

When Billy Broke His Head...and Other Tales of Wonder (1994) Golfus, Billy and Simpson, David E., Fanlight Productions One man's search for his new disability identity. Many of the leading disability activists are profiled. (Closed or open captioned)