

Managing the Mountains ... Conquering the Canyons...

Promoting Independence in the Grand Canyon State

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I N D E P E N D E N C E

- I Initiative to make changes
- N Never accepting barriers
- D Developing a plan to help myself

- E** Ending self-defeating thoughts & behavior
- P** Prioritizing for my own well-being
- E** Energizing myself with a positive attitude
- N** Nurturing relationships with friends
- D** Daring to take responsibility for myself
- E** Empowering myself with knowledge
- N** Noble always in deed and thought
- C** Caring for myself and others
- E** Equal in a world of inequality

By Nancy Daily
 ABIL/PAS Program Manager

TABLE OF CONTENTS

Center for Independent Living (CIL) Defined.....	3
Purpose.....	5
Introduction.....	7
Independent Living History and Philosophy	
The Movement for Independent Living	9
Ed Roberts	17
Justin Dart Jr.	21
Independent Living Values	25
When You Meet a Person with a Disability.....	27
Disability Etiquette.....	29
Wheelchair Etiquette.....	31
Consumer Control/Independent Living Service Model	
Consumer Control Principles in Independent Living	33

Developing the Independent Living Service Model - Essential Features.....	39
Core Services	
Independent Living Skills Instruction Program	42
Advocacy Program	43
Peer Mentor Volunteer Program	45
Information & Referral	47
Ancillary Programs	
Home Modification	50
Community Living Options	51
Personal Assistant Services (PAS)	52
Community Reintegration from Nursing Homes Program	53
Benefits Planning, Assistance & Outreach Program	55
Rural Programs	
Changing Attitudes: Marshall, Minnesota	57
Collaborative Transportation: Hays, Kansas	59
Initiatives to Empower People with Disabilities in Rural Minnesota: SEMCIL	61
Round Peg in a Square Hole: Independent living in Indian Country	65
Statewide Independent Living Councils	
Composition of Statewide Independent Living Councils	71
National Council on Independent Living	73
Establishing a Center for Independent Living	
Process/General Start-up Activities	75
Appendices	
A Guide to Disability Rights Laws; Websites of Interest; Readings	

Center for Independent Living

The term Center for Independent Living means a consumer-controlled, community-based, cross disability, nonresidential, private, nonprofit agency that

- (A) Is designed and operated within a local community by individuals with disabilities; and
- (B) Provides an array of independent living services.

The 1992 Reauthorization of the Rehabilitation Act of 1973

There are nearly 500 Centers for Independent Living in the United States, including five in Arizona (Phoenix, Tucson, Prescott Valley, Yuma and Tuba City).

PURPOSE

PROMOTING INDEPENDENCE IN THE GRAND CANYON STATE

is an informational manual created to assist pro-active people in grassroots efforts to establish Centers for Independent Living, (CILs) within the State of Arizona.

This manual may also be effectively utilized as a component of orientation for new employees of Centers for Independent Living. It further serves as a basic text for consumers, community service providers, and others who want to learn more about Independent Living history, philosophy and CIL services.

Resources for establishing a Center for Independent Living, as well as “A Guide to Disability Rights Laws” from the U.S. Department of Justice, are included.

INTRODUCTION By Phil Pangrazio

I am very pleased to introduce to you, “Promoting Independence in the Grand Canyon State.” We at ABIL, in collaboration with the Arizona Statewide Independent Living Council, are very excited to bring Independent Living (IL) philosophy to those desiring to learn more about our movement. We are confident that this resource guide will provide you with knowledge and understanding of the basic tenants of IL philosophy.

It is our hope that through a better understanding of IL, we will bring more people into this magnificent movement for the advancement of disability rights. Through a shared vision, we will collaboratively promote the expansion of our philosophy and programs that empower people with disabilities to be personally responsible for taking charge of their lives.

Throughout this document you will hear some recurring themes such as peer support, self-advocacy, and consumer control that are the cornerstones of IL philosophy. You will learn about the disability rights movement and how it uses consumerism as a mechanism to demand freedom and choice in “how” and “where” we live with our disabilities. You will learn about how IL philosophy differs from the traditional medical and rehabilitation models of treatment for disability. You will learn how living with a disability is about “adjustment and adaptation.” In addition, you will learn that only through the elimination of barriers can we be free to fully participate in our communities.

Importantly, by the time you finish reading this document it should be clear that IL programs do not function independently or in a vacuum. Rather, IL programs are a compilation of resources and information that interrelate across a spectrum of consumer needs. Consumers have access to, and are referred to, programs that best fit their needs, choices, and goals for independent living.

Lastly, we hope this resource guide becomes the seeds that grow and nurture independent living in your community, no matter how big or small.

THE MOVEMENT FOR INDEPENDENT LIVING: A Brief History

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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 merge 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 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 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 by 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.

REHABILITATION
PARADIGM

INDEPENDENT LIVING
PARADIGM

Definition of problem	physical or mental impairment; lack of vocational skill (in the VR system).	dependence upon professionals, family members and others; hostile attitudes, stereotypes and environments
Locus of problem	in the individual (individual needs to be “fixed” to “fit” into society).	in the environment; in the medical and/or rehabilitation process itself.
Solution to problem	professional intervention; treatment.	1) barrier removal, 2) advocacy, 3) self-help, 4) peer role models, 5) consumer control over options and services
Social role	individual with a disability is a “patient” or “client”.	individual with a disability is a “consumer,” “consumer” or “user” of services and products
Who Controls	professional	“consumer” or “citizen”
Desired outcomes	maximum self-care (or “ADL”); gainful employment in the VR system.	independence through control over ACCEPTABLE options for every day living in an integrated, community

The rehabilitation 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 the rehabilitation paradigm, 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 rehabilitation model 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.

These philosophical differences may be hard to realize when thinking about services and programs in your local area. Obviously, every community needs the rehabilitation paradigm for 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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Ed Roberts By Dick Goodwin

In the late 60's and early 70's, the University of California at Berkeley was nationally known as the home of radical politics and progressive social movements. Mario Savio and the 1964 free speech movement set the tone and developed the model for the movements that followed, particularly influencing campus anti-war movements and tactics for student involvement in ethnic and racial social movements.

Many students took note and developed progressive movements to benefit various causes. Among the students on the Berkeley campus was Ed Roberts. The university hesitated to admit Ed as he was severely disabled from polio, which he contracted as a teenager. He had virtually no functional movement and was dependent on a respirator to breath. "We've Tried Cripples Before and It Didn't Work", said the university. They reluctantly admitted Ed in 1962 and arranged for him to live in the campus medical facility, Cowell Hall. His brother, also a student, served as an on campus PA, often pushing Ed from class to class in an old manual wheelchair.

Ed was accustomed to rejection, a year earlier in 1961 the state vocational rehabilitation agency refused to serve him as he was considered too severely disabled and labeled unemployable. That decision was later overturned. One of the many ironies of Ed's life was that fourteen years later in 1975, Governor Jerry Brown appointed Ed as state Director of the same agency that deemed him too severely disabled to ever work.

The following year, 1962 John Hessler, severely disabled secondary to a spinal cord injury, began attending Berkeley and living in Cowell Hall. Others followed, and evening and late night talks evolved to developing advocacy strategies to live independently on campus and in the surrounding community with necessary supports.

Ed's leadership skills emerged and he took lessons from other campus movements to start the independent living and disability rights movements for persons with disabilities. Ed was quick to grasp that the struggle for independence was not a medical or functional issue, but rather a sociological, political, and civil rights struggle. Additionally, Ed's involvement with Gini Laurie's Toomey J. Gazette, (later named the Rehabilitation Gazette), clarified that credible information and new, innovative ways of managing life with a severe disability were best taught by peers with similar disabilities. Gini's publications were essentially forums for people with polio and various disabilities to share how they managed their lives and maintained their productivity with severe disabilities. The roots of the independent living model can clearly be traced to influences from the civil rights movement and the peer support model associated with Gini Laurie's Rehabilitation Gazette.

In the late 60's and early 70's Berkeley students with severe disabilities were organized into a group known as The Rolling Quads. Led by Ed, they began exerting pressure on the university to become more accessible and began seeking funding to develop a student organization to work for barrier removal and support services, including Personal Attendant services, for students with disabilities to live independently while attending school.

In a communication to Gini Laurie in 1970, Ed stated the following,

I have begun a consultation business for anyone needing help with problems with cripples. I've consulted with Health Education in Washington, DC, about programs for cripples in higher education, help secured \$80,000 grant for UC Berkeley program run by cripples for the education of cripples. I brought John Hessler in as director. He is doing a magnificent job. Would you like to hear more? I believe no other consulting firm like this in the country.

He continued,

I'm tired of well meaning noncripples with their stereotypes of what I can and cannot do directing my life and my future. I want cripples to direct their own programs and to be able to train other cripples to direct new programs. This is the start of something big — cripple power. -Ed

Ed Roberts was starting a self-help movement that would radicalize how people with disabilities perceived themselves. He did it for himself and then began laying the groundwork for the rest of us. Independence and rehabilitation have not been the same since, and will never return to the archaic notions which perceived people with disabilities as passive recipients of charity, unable to self direct their lives.

After establishing the campus organization, Ed and others realized the need for an off campus, community based organization. In 1972, with minimal funding, the Berkeley Center for Independent Living (CIL) was started. The core values of the Berkeley CIL, dignity, peer support, consumer control, civil rights, integration, equal access, and advocacy, remain at the heart of the independent living and disability rights movements. Today, as many as 400 CILs exist throughout the country, funded with a mix of federal, state, local, fee for service, and private money.

In the mid-70's newly elected governor Jerry Brown appointed Ed as Director of the state rehabilitation agency. In his position he was able to influence the establishment of many new CILs throughout the state. He served as director for eight years. Other states followed suit with Illinois Governor Jim Thompson appointing Jim Jeffers as Director of Rehabilitation Services, and Michael Dukakis appointing Elmer Bartels as Director of Massachusetts Rehabilitation Services.

In the early 80's Ed and others established the World Institute on Disability in Oakland, a progressive think tank focusing on independence and civil rights for people with disabilities. Ed traveled the country and the world influencing the lives of people with disabilities. He was featured on a variety of news shows, including 60 Minutes.

As is true of far too many leaders with disabilities in the independent living/disability rights movement, Ed died at a far too young an age in March 1995. He was 55 years old.

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Justin Dart Jr.

1930 – 2002

Intro by Carolan Quenneville

Abraham Lincoln, Susan B. Anthony, Mohandas K. Gandhi, Martin Luther King, Justin Dart. Justin Dart? Who? The latter is the common response I heard from those I spoke to outside the community of people with disabilities, and sadly from many within our community. Below are biographical excerpts from an article written by Fred Fay and Fred Pelka, written at Justin Dart's request. Source: Justice for All. For disability rights advocates who knew of Justin Dart's work and dream, his example, his life and passing are a call to action. For those who don't know, the following is an educational opportunity and an invitation to get on board and help make the dream real.

Justin Dart, Jr., widely recognized as “the father of the Americans with Disabilities Act”(ADA) and “the godfather of the disability rights movement,” died June 22nd at his home in Washington D.C. A leader in the disability rights movement for three decades, Dart was also an advocate for the rights of women, people of color, and gays and lesbians. The recipient of five presidential appointments and numerous honors, Dart was on the podium on the White House lawn when President George H. Bush signed the ADA into law in July 1990. Until the end, Dart remained dedicated to his vision of a “revolution of empowerment.” This would be, he said, “a revolution that confronts and eliminates obsolete thoughts and systems, that focuses the full power of science and free-enterprise democracy on the systematic empowerment of every person to live his or her God-given potential.”

Justin Dart, Jr., was born August 29, 1930, into a wealthy and prominent family. His grandfather was the founder of the Walgreen Drugstore chain, his father a successful business executive, his mother a matron of the American avant garde. Dart would later describe how he became “a super loser” as a way of establishing his own identity in this family of “super winners.” He attended seven high schools, not graduating from any of

them, and broke Humphrey Bogart's all-time record for the number of demerits earned by a student at elite Andover prep. "People didn't like me. I didn't like myself."

Dart contracted polio in 1948. With doctors saying he had less than three days to live, he was admitted into the Seventh Day Adventist Medical University in Los Angeles. "For the first time in my life I was surrounded by people who were openly expressing love for each other, and for me, even though I was hostile to them. And so I started smiling at people, and saying nice things to them. And they responded, treating me even better. It felt so good!" Three days turned into forty years, but Dart never forgot this lesson. Polio left Dart a wheelchair user, but he never grieved about this. "I count the good days in my life from the time I got polio. These beautiful people not only saved my life, they made it worth saving."

Dart attended the University of Houston from 1951 to 1954, earning his bachelor's and master's degrees in political science and history. He wanted to be a teacher, but the university withheld his teaching certificate because he was a wheelchair user. During his time in college, Dart organized his first human rights group - a pro-integration student group at what was then a whites-only institution.

Dart went into business in 1956, building several successful companies in Mexico and Japan. He started Japan Tupperware with three employees in 1963, and by 1965 it had expanded to some 25,000. Dart used his businesses to provide work for women and people with disabilities. In Japan, for example, he took severely disabled people out of institutions, gave them paying jobs within his company, and organized some of them into Japan's first wheelchair basketball team. It was during this time he met his wife, Yoshiko.

The final turning point in Dart's life came during a visit to Vietnam in 1966. Visiting a "rehabilitation center" for children with polio, Dart found squalid conditions where disabled children were left on concrete floors to starve. One child, a young girl dying there before him, took his hand and looked into his eyes. "That scene," he would later write, "is burned forever in my soul. For the first time in my life I understood the reality of evil, and that I was a part of that reality."

The Darts eventually moved to Texas in 1974, and immersed themselves in local disability activism. From 1980 to 1985, Dart was a member, and then chair, of the Texas Governor's Committee for Persons with Disabilities.

In 1981, President Ronald Reagan appointed Dart to be the vice-chair of the National Council on Disability. The Darts embarked on a nationwide tour, at their own expense, meeting with activists in every state. Dart and others on the Council drafted a national policy that called for national civil rights legislation to end the centuries old discrimination of people with disabilities - what would eventually become the Americans with Disabilities Act of 1990.

While taking pride in passage of the ADA, Dart was always quick to list all the others who shared in the struggle: Robert Silverstein and Robert Burgdorf, Patrisha Wright and Tony Coelho, Fred Fay and Judith Heumann, among many others. And Dart never wavered in his commitment to disability solidarity, insisting that all people with disabilities be protected by the law and included in the coalition to pass it - including mentally ill “psychiatric survivors” and people with HIV/AIDS. Dart called this his “politics of inclusion,” a companion to his “politics of principle, solidarity, and love.”

After passage of the ADA, Dart threw his energy into the fight for universal health care. With the defeat of universal health care, Dart was among the first to identify the coming backlash against disability rights. He resigned all his positions to become “a full-time citizen soldier in the trenches of justice.”

With the conservative Republican victory in Congress in 1994, followed by calls to amend or even repeal the ADA and the Individuals with Disabilities Education Act (IDEA), Dart, and disability rights advocates Becky Ogle and Frederick Fay, founded Justice for All, what Dart called “a SWAT team” to beat back these attacks. Both laws were saved. Dart again placed the credit with “the thousands of grassroots patriots” who wrote and e-mailed and lobbied. But there can be no doubt that without Dart’s leadership, the outcome might have been entirely different.

Today, people with disabilities across the country and around the world will grieve at the passing of Justin Dart, Jr. Keep in mind, however, that it was Justin’s wish that any service or commemoration be used by activists to celebrate our movement, and as an opportunity to recommit themselves to “the revolution of empowerment.”

*For the full text of this article and others log on to:
www.diversityworld.com/Justin%20Dart.htm*

INDEPENDENT LIVING VALUES

“ALL PEOPLE ARE CREATED EQUAL”

1. People with disabilities have common experiences in our society that can be the basis of mutual support and mutual enhancement of personal growth.
2. People with disabilities need to work together as advocates for progressive change to the institutions and systems of our society in order to increase their ability to be contributing citizens.
3. All people with disabilities deserve the opportunities and benefits of full integration with the local and global community.

4. All people with disabilities are entitled to respect without prejudice or bias regardless of type or severity of the disability.
5. People with disabilities understand best what they personally want and need to enable them to participate as equals within our society.
6. The Americans with Disabilities Act and all other civil rights legislation should be fully implemented in the American society.
7. All people with disabilities have the right to choose freely their lifestyle, profession, family composition, and level of community participation.
8. All people with disabilities have the right to determine their personal level of safety related to their lifestyle, which may or may not be consistent with the recommendations of government or medical professionals.
9. All people with disabilities are entitled to information, equipment and services that will reduce the barriers that cause them to be dependent and prevent their full integration into the community.

source unknown

WHEN YOU MEET A PERSON WITH A DISABILITY...

First of all, remember that the person with a disability is a person. He or she is like anyone else except for the special limitations of his/her disability.

A disability need not be ignored or denied between friends. But, until your relationship is that, show friendly interest in him/her as a person.

Be yourself when you meet a person with a disability.

Talk about the same things as you would with anyone else.

Help the person only when they request it. When a person with a disability falls, he/she may wish to get up by themselves, just as many persons who are visually impaired prefer to get along without assistance. So offer help, but wait for the person to request it before giving it.

Be patient. Let the person with a disability set his/her own pace in walking or talking.

Don't be afraid to laugh with him/her.

Don't stop and stare when you see a person with a disability you do not know. He/she deserves the same courtesy any person should receive.

Don't be over-protective or over-solicitous. Don't shower the person with a disability with kindness.

Don't ask embarrassing questions. If the person with a disability wants to tell you about their disability, they will bring up the subject themselves.

Don't offer pity or charity. The person with a disability wants to be treated as an equal. They want a chance to prove themselves.

Don't separate the person with a disability from his/her wheelchair or crutches unless he/she asks it. They may want them within reach.

When dining with a person with a disability, don't offer help in cutting food. They will ask you or the waiter if they need it.

Don't make up your mind ahead of time about the person with a disability. You may be surprised at how wrong you are in judging their interests and abilities.

Enjoy your friendship with the person with a disability. His/her philosophy and good humor will give you companionship.

DISABILITY ETIQUETTE

When talking about or to people with disabilities, choose words that carry non-judgmental connotations and accurate descriptions. Avoid using words such as the following:

VICTIM: say "person who has/person who experienced/person with"

CRIPPLE/CRIPPLED/THE CRIPPLED: say "person with a disability" or "individual with a disability caused by" or "the result of"

AFFLICTED BY OR WITH: say the person "has"

INVALID: (literally means "not valid"); say "a person who has a disability resulting from....."

EMPATHY: "understanding"; not the same as "sympathy"

NORMAL: what most people, including those with disabilities, think they are

PATIENT: denotes sickness and a person waiting to be served; most people with disabilities are no sicker than others.

SYMPATHY: something most individuals with disabilities would trade instantly for acceptance and respect for their talents and abilities

WHEELCHAIR BOUND/CONFINED TO A WHEELCHAIR: “say uses a wheelchair”

HOMEBOUND EMPLOYMENT: say “employed in the home”

AFFLICTED: very negative and a definite downer; person “who has” or “is affected by” is much better

POOR: Physical disabilities have nothing to do with how wealthy someone is. Love and self-esteem are priceless qualities. A person’s character determines the richness of his or her life.

SUFFERS FROM: If someone with a disability is independent and copes with life as well as most of us, then this phrase definitely does not apply.

UNFORTUNATE: What’s unfortunate is that the word is often used to describe people with physical disabilities. Don’t offend with this one!

PITIFUL, DEAF AND DUMB, CRIP, DEFORMED, BLIND AS A BAT, GIMP, AND NAY OTHER WORDS OR CLICHES THAT ARE JUDGMENTAL OR STEREOTYPING: no replacements

COURAGEOUS, BRAVE, INSPIRATIONAL: and similar words that are routinely used to describe a person with a disability; adapting to a disability does not necessarily mean acquiring these traits.

BIRTH DEFECT: say “disability from birth.”

WHEELCHAIR ETIQUETTE

1. Always ask the wheelchair user if he or she would like assistance before you help. Your help may not be needed or wanted.
2. Don’t hang or lean on a person’s wheelchair. It is part of the wheelchair user’s personal body space.
3. Speak directly to the person in the wheelchair, not to someone nearby as if the wheelchair user does not exist or has a mental impairment.
4. If the conversation lasts more than a few minutes, consider sitting down or kneeling to get yourself on the same level as the wheelchair user.

5. Don't demean or patronize the wheelchair user by patting him or her on the head or shoulder.
6. Give clear directions, including distance, weather conditions, and physical obstacles that may hinder the wheelchair user's travel.
7. Don't discourage children from asking questions about the wheelchair. Open communication helps overcome fear and misleading attitudes.
8. When a wheelchair user transfers out of the wheelchair to a chair, toilet, car, or bed, do not move the wheelchair out of reaching distance unless the person knows what you are going to do.
9. It is OK to use expressions like "running along" when speaking to the wheelchair user. It is likely the wheelchair user expresses things the same way.
10. Be aware of the wheelchair user's capabilities. Some users can walk with assistance. They use wheelchairs to conserve energy and move about more quickly.
11. Don't classify people who use wheelchairs as sick. Wheelchairs are used for a variety of disabilities.
12. Don't assume that using a wheelchair is in itself a tragedy. It provides freedom and allow the user to move about independently.

EXCERPT FROM "WHAT DO I DO WHEN I MEET A PERSON IN A WHEELCHAIR?"
(NATIONAL EASTER SEAL SOCIETY)

CONSUMER CONTROL PRINCIPLES IN INDEPENDENT LIVING

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

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

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

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

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

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

Defining "Consumer Control"

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

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

Consumer control practices apply to:

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

Consumer control is achieved and sustained by an organization that maintains the ability to be molded by its constituency. To implement consumer control principles, four

areas comprising the full range of center functions and operations need attention: policymaking; staffing; services; and community advocacy.

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

Consumer Control At The Policy Level

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

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

Consumer Control At The Staffing Level

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

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

Service delivery and support staff also constitute important links in the staffing chain. Adhering to the principles of consumer control assumes that center staff reflect disability representation and have opportunities for substantive participation and input. Staff with

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

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

Consumer Control Over Services

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

The language commonly used in centers is itself consistent with this general theme: "consumer" of services, rather than "client" is the term of choice because it assumes an active role based on equality and mutuality of experience and a participatory process.

Peer relationships are one of the key features of services organized around the principle of consumer control. In peer relationships, the two parties meet as equals. They share a common life experience with disability and have faced many of the same issues and barriers in their pursuit of independence. Services delivered by peers provide an effective avenue for dealing with a variety of issues within the context of a service relationship based on an understanding of common life experiences and barriers to independence.

Consumer control over services is, to borrow a phrase from the private sector, "a market driven economy" in which the consumer has primacy in the process.

Consumer Control Over The Advocacy Agenda

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

Summary

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

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

The practical applications of the consumer control principle must be flexible if services and advocacy efforts are to represent and respond to the varying interests and diversity among consumers in the communities served by the ILC. Across the country, independent living centers reflect wide diversity in practice while adhering to the principle of consumer control.

Shreve, Spiller, Griffen, Waldron, and Stolzman. Consumer Control in Independent Living, Chapter 2, Center for Resource Management, Inc., South Hampton, NH, 1988.

Developing The Independent Living Service Model — Essential Features

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

- Consumer control over policy and management decisions. Persons with disabilities would control decisions governing organizational policies and procedures, the provision of services, and community activities. In this sense, the term “consumer” is defined broadly to mean persons with disabilities who may be direct recipients of services as well as those who are not but who are secondary beneficiaries of advocacy efforts. Consumer control in decision-making is intended to ensure that policies, procedures, services, and activities are responsive to the needs and respectful of the rights of the disability population.
- Consumer control over service objectives and methods. This aspect of independent living services places primary responsibility for identifying service needs, setting independent living goals and objectives and making decisions about service participation with the consumer who is receiving services. This means that the service provider role shifts from that of controlling and providing the services to one that consciously seeks to promote the independence and self-sufficiency of the consumer within the context of service participation selected by the consumer.
- Cross-disability emphasis. Independent living emphasizes a responsiveness to the needs of all persons with disabilities. At the national level, this separates the independent living program from programs that emphasize services to a particular disability group.
- Community based and community responsive. Independent living centers are designed to be responsive and accessible to the disability community in their service locale, and to involve the community significantly in setting program priorities.
- Peer role modeling. The emphasis on peer role modeling in independent living reflects a belief that people with disabilities can greatly benefit from the perspectives and support of others with disabilities who have successfully struggled to lead productive and meaningful lives in their communities. Peers serve as strong role

models and facilitators to consumers in their efforts to achieve designed level of independence.

- Provision of a range of services. Because independent living is responsive to the varied dimensions of knowledge, skills, options, and support associated with achieving personal independence, a range of services is provided. These include such core services as information and referral, skills training, advocacy, and peer counseling as well as others such as attendant care services, housing services, transportation services, educational services, vocational services, equipment services, communication services, legal services, and social/recreational services.
- A community advocacy thrust. Independent living recognizes that in order for consumers to achieve independent lifestyles, environmental and social barriers in the community must be eliminated. There is thus a dual commitment to both individual services and community advocacy—activities conducted to enhance opportunities for people with disabilities to have equal access to all aspects of community life and to achieve meaningful integration into society.
- Open and ongoing access to services. Independent living is not a closure-oriented program. Services are open and available to consumers on an ongoing basis, reflecting consumers' evolving and continuing needs and interests.

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

Lachat, M.A., The Independent Living Service Model, Center for Resource Management, Inc., South Hampton, NH, 1988, p.11-13.

CORE SERVICES

The Rehabilitation Act of 1973 mandates that all Centers for Independent Living provide four core services:

(1) Independent Living Skills Education

The Independent Living, (IL), Skills Program teaches people with disabilities basic life-skills toward becoming independent, or maintaining and enhancing independence. Budgeting, using public transportation, cooking, self-advocacy, and stress management are examples of skills taught.

(2) Advocacy

Advocacy Programs offer assistance in navigating through administrative networks to obtain services such as housing and health care. Advocacy programs also operate at

the systems level to initiate, promote and protect public policy for the benefit of people with disabilities.

(3) Peer Mentoring

Peer Mentor Programs match people with similar disabilities and goals. A person who is adapting to life with a disability, transitioning to adulthood or to living more independently, may benefit from working with a mentor who has experience and knowledge to share.

(4) Information & Referral

Knowledge is power. Individuals may call when needing information on disability related issues such as housing, employment, assistive technology, legal issues, etc. CILs maintain information on disability resources and refer callers appropriately.

Service delivery methods vary among CILs depending on geographic area, population, whether urban or rural, and the availability of resources. Examples of core service programs offered in this section are as provided by The Arizona Bridge to Independent Living.

INDEPENDENT LIVING SKILLS INSTRUCTION PROGRAM

Each individual has the right to optimize his or her personal abilities. Centers for Independent Living assist motivated consumers in developing their self-determined goals to gain and retain greater independence. Independent living skills instruction includes, but is not limited to:

- Stress Management
- Use of community resources
- Transportation skills
- Self-advocacy
- Financial Management/Budgeting
- Cooking
- Household Management /Housekeeping

Consumers frequently self-refer or are referred from other ABIL programs. E.g., an ABIL consumer receiving Personal Assistance Services, (PAS), who has limited approved hours or who wishes to be less reliant on caregivers, is referred by PAS staff for independent living skills instruction. Other community service agencies also refer people to ABIL's IL Skills Instruction program.

Consumers with a new or a progressive disability may need to “relearn” certain skills or learn to do things differently. Experienced IL skills instruction staff and/ or volunteer peer mentors work individually with consumers to teach these skills and identify assistive technology or adaptive aides to get the job done.

The Independent Living Skills Instruction Program utilizes the peer aspect of service delivery in a very real, tangible way. Consumers who improve their level of independent living skills are more confident, independent and self-reliant.

ADVOCACY PROGRAM

Advocacy is...Speaking up for yourself or someone else.

There are 3 kinds of advocacy:

- **Self-advocacy**
- **Individual advocacy**
- **Systems Change or Community advocacy**

ABIL, and all other Centers for Independent Living promote and provide all three kinds of advocacy.

SELF-ADVOCACY

ABIL has programs to help people learn self-advocacy skills

- We provide monthly advocacy related workshops where people can learn together how the various systems work and self-advocacy skills. We usually provide a 3-month calendar of workshops.
-
- Individuals can work with a peer mentor volunteer to learn advocacy skills – someone who can go along with them, cheer them on and practice with them ahead of time what they want to say and do on their own behalf. The mentor might help them write letters to their legislators, or to their doctor.

INDIVIDUAL ADVOCACY

ABIL provides advocacy on behalf of people who need individual support. An ABIL staff-person or trained peer mentor volunteer might go with a consumer to their vocational rehabilitation meeting or doctor appointment. We provide this kind of support via phone and email, as much as in person.

Nothing About Us Without Us!

SYSTEMS CHANGE OR COMMUNITY ADVOCACY

ABIL, and all other Centers for Independent Living are involved in changing systems to make them more user-friendly and responsive to our needs. Independent Living & Self-Determination philosophy stresses the importance of people with disabilities being in decision-making roles about programs that are for their benefit. Here are examples of Community Advocacy:

- Inaccessible movie theaters
- Social Security rules that make it hard to go to work while still disabled
- The Department of Motor Vehicle policy of making some people provide a doctors OK before issuing a drivers license
- The need for a door opener at the bank or mall food court
- Accessible airport shuttle vans
- Service policies that do not reflect self-determination and consumer choice
- Civil rights protection from employment discrimination
- Sufficient public transit

How does the program work?

ABIL receives referrals for advocacy from individuals, other staff and community organizations. Usually we receive a call asking for information or assistance with a barrier they have encountered in the community. We either offer information through phone contact or may meet one-on-one with an individual to better understand their issue and advocacy need. When possible, we will instruct and support the individuals to advocate for themselves. When appropriate, consumers will be referred to an ABIL workshop or relevant community group that is already addressing their issue. In cases where we receive several calls or complaints regarding the same issue, we will call a meeting of all interested parties to problem solve, support the natural leader in that group to assume leadership or ask the group to choose a leader. Then ABIL will help that group develop an advocacy plan to address the issue. (i.e. inaccessible food court, theatre, post office, etc.) In some cases our staff may become members of community advocacy coalitions (i.e. Prescription drug crisis coalitions) or initiate a coalition (i.e., Medicaid Buy-in Coalition), to affect change in policy, change the law, or do whatever is necessary to remove the barrier.

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever does.” *Margaret Mead*

PEER MENTOR VOLUNTEER PROGRAM

The purpose of the Peer Mentor Volunteer Program is to be able to expand the level of peer support services offered by ABIL for its consumers. When the program began in 1990, a staff member whose job was providing independent living skills instruction was also assigned to coordinate the peer mentor volunteers. After three years it became clear that the mentoring program was effective and ABIL wanted it to continue to grow. To do this, ABIL recruited a full time, salaried, volunteer coordinator.

Since 1990, ABIL has trained 130 peer mentor volunteers. From July 2001-June 2002 (FY02), the program matched 57 mentors who work with 101 consumers (mentees).

Peer Mentor Volunteers are individuals with disabilities who are already living independently in their community and have the desire to help others do the same. Mentors help newly disabled individuals adapt to their disability, assist in finding community resources, advocate with service providers, offer friendship and encouragement, and work with consumers on achieving independent living goals. Peer Mentors are also involved in community advocacy and outreach presentations. Along with other volunteers, many peer mentors also provide technical and clerical support to ABIL programs.

Recruitment

Ongoing recruitment is essential, as volunteers come and go. ABIL staff recommends about one-third of the volunteers and peer mentors. Some people have called ABIL to inquire about volunteer opportunities. Others are recruited through ABIL's monthly newsletter, local publications and outreach activities (colleges, information fairs).

Individuals who are interested becoming a peer mentor volunteer receive a packet of information along with a peer mentor application and 3 character reference forms which are returned and reviewed by the Volunteer Coordinator. The Volunteer Coordinator schedules an initial/orientation meeting with each individual prior to the training.

Training

Peer Mentors participate in a 12-hour training course. Staff who work directly with consumers assist with the training. Peer Mentors each receive a comprehensive training manual that has been developed by ABIL. ABIL holds quarterly meetings for peer mentors to share information, brainstorm, and/or receive additional training.

Matching the Mentor and Mentee

Staff who work directly with consumers very often identify someone who would benefit from the peer support that is offered by a peer mentor volunteer. When this is the case they fill out a peer mentor request form and give it to the Volunteer Coordinator. When the Volunteer Coordinator identifies a peer mentor, the match is made. The first meeting can be conducted in several different ways: 1) by phone 2) in person 3) in person with ABIL staff.

Supervision/Evaluations

The Volunteer Coordinator is responsible for the supervision of Peer Mentor Volunteers. This is done through phone calls, quarterly meetings and evaluations. Evaluations are a shared responsibility between the Volunteer Coordinator who evaluates the mentor and the referring staff members who evaluates the mentee. Evaluations are conducted at intervals of one, three and six months; then on an annual basis or at time of exit.

Volunteer Hours and Activities

Volunteer hours and activities are tracked on a monthly basis. Team Leaders call mentors to remind them to call in their hours to the Volunteer Coordinator.

Peer Mentoring is really at the heart of the Independent Living Movement. ABIL's Peer Mentor Volunteer Program has dramatically increased our ability to offer peer support services to consumers. It has empowered people with disabilities to help each other increase their independence, improve their self-confidence and achieve independent lifestyles.

INFORMATION & REFERRAL

Information & Referral Programs bring the power of knowledge to consumers. Discovering a new resource or learning that one is eligible for a new service can make dramatic, positive changes in the lives of people with disabilities and their families.

ABIL's Information & Referral, (I&R), Program is staffed by a part-time program coordinator who responds to an average of 200 telephone calls per month. An increasing number of I&R inquiries come through e-mail.

The I&R program coordinator maintains a database of disability-related resources and offers appropriate information and referral to callers. Consumers most frequently seek information in the areas of housing, financial assistance, employment, legal assistance, transportation and assistive technology.

The program coordinator also networks within the community. Participation in community resource events provides the opportunity to exchange information with other service providers and individuals. Community networking also serves to keep ABIL's I&R database current.

Information & Referral is not a crisis line. Callers in crisis situations are referred to 911 or other specific crisis hot lines, (e.g. mental health hot lines). Occasionally, the I&R program coordinator contacts a local police department to request a safety assurance check on a caller considered to be in immediate danger.

ANCILLARY PROGRAMS

Centers for Independent Living offer a variety of services in addition to the four core services mandated by the Rehabilitation Act of 1973.

Ancillary programs often serve specific groups and may reflect local issues and needs. These programs vary in scope and method of service delivery. Funding sources differ and some programs are self-supporting or income producing.

The five examples of ancillary services presented here are operated by the Arizona Bridge to Independent Living, (ABIL):

- Home Modification
- Community Living Options
- Personal Attendant Services
- Reintegration from Nursing Homes
- Benefits Planning, Assistance and Outreach

Other examples of ancillary services include Employment Services, Social Recreation Programs, and Youth Transition Programs.

Centers may also provide support groups specifically for people with disabilities in on-going recovery from substance abuse; parents-with-disabilities support groups; gay and lesbian disability community support groups and caregiver support groups.

HOME MODIFICATION PROGRAM

Housing is the number-one issue for people with disabilities seeking an independent lifestyle. Accessible, affordable housing is scarce or non-existent. People remain on waiting lists, often for years, for existing housing. Securing integrated community housing is a common issue for people with disabilities living in both urban and rural communities.

Community Development Block Grants (CDBG) are used to provide home modification services to people with disabilities. Federal funding flows through cities and is then contracted out to Centers for Independent Living. Home modifications to improve accessibility and home safety include ramps, grab bars, handrails, widened doorways, raised toilets etc.

Project limits are established. Consumers or their family members are expected to contribute 10% of the cost of the project in dollars or in labor, materials, or other community volunteer service.

Program Delivery Example:

1. When a referral or request is made, initial information is taken to determine consumer eligibility and to explain the program guidelines and timelines.
2. If a consumer is eligible for the program, the Home Modification Coordinator will schedule an in-home assessment.
3. Residents are required to sign a form verifying their income and provide any other documents required by the City.
4. The Home Modification Coordinator provides:
 - A. Technical Consultation
 - B. Needs assessment in the home with the consumer
 - C. Coordination with licensed, bonded contractor
 - D. Follow-up after each modification to be certain the work is done properly and the consumer is satisfied.
 - E. Makes community referrals for additional services as needed.

This innovative program assists cities in meeting their plans to provide accessible housing to people with disabilities. The program meets Department of Housing and Urban Development guidelines. Individuals are provided with increased accessibility and safety in their homes. The Home Modification Program has proven to be a cost effective way to help meet accessible housing needs, utilize the IL philosophy and expertise of CIL staff, and increase community awareness of issues related to housing for people with disabilities.

COMMUNITY LIVING OPTIONS

People with developmental disabilities, i.e., those with epilepsy, autism, mental retardation or cerebral palsy receive government case management support for crisis intervention only after the age of 22. Traditional community programs generally include those supports that are sheltered, artificial, segregated and expensive.

The Community Living Options, (CLO), program developed by the Arizona Bridge to Independent Living, (ABIL), serves people over the age of 22 in the State Division of Developmental Disability (DDD) system, who are not eligible for Federal and State support services.

Consumers are referred to ABIL by DDD support coordinators, other partnering agencies and family members. Consumers participate in identifying their own needs and goals. Services requested include learning independent living, (IL), skills such as cooking, budgeting, use of public transportation, and how to live in an apartment, alone or with a roommate. Consumers may also learn self-advocacy skills, improve reading and writing, and further their education. Consumers also receive assistance in finding employment. Additionally, the CLO program provides social and recreational opportunities.

A program coordinator, student interns from universities and community colleges, and peer mentors work together to make sure consumer goals are achieved.

ABIL's CLO program, now into its fifth year, has served 600 consumers. Nearly 200 of these consumers are involved in social and recreational activities, 234 received IL skills training, 15 participated in literacy classes, 84 have moved out into the community and 6 are taking college courses. Long-term goals, e.g., learning IL skills, finding employment, or improving literacy may take from one to 12 months.

Other consumers who have been served may not be included in the above reported statistics because services were short-term. A short-term service requires less time and effort to achieve the goal. Example: The program coordinator received a call from a guardian parent on behalf of his son. His son's bicycle had been run over in a parking lot. The bike was the son's main source of transportation. The CLO program coordinator made some calls and within a week a new bike was donated to the consumer by the Mesa Police Department.

The program coordinator also works with organizations that donate computers to non-profit agencies. Forty computers have been provided to consumers over the last four years.

The Valley of the Sun United Way funds the Community Living Options Program

PERSONAL ASSISTANT SERVICES (PAS)

The ABIL Personal Assistant Services Program provides attendant care to the elderly and physically disabled who qualify for Arizona Health Cost Containment Services (AHCCCS) and are on Arizona Long Term Care Service (ALTCS). PAS is a non-medical service. Caregivers may assist with bathing, dressing, housekeeping, laundry, shopping and meal preparation.

ABIL is contracted by the ALTCS Program to recruit, train, refer, employ, and supervise caregivers that will provide service to ALTCS consumers. ABIL currently serves 950 consumers and employs 900 caregivers.

The PAS program is designed to empower the consumer to control his/her own service by participating in the recruitment, hiring, scheduling and supervising of his/her caregiver. A Consumer may select a specific prospective caregiver and refer him/her to ABIL for training, criminal background checks and pre-employment physicals, or they may interview and select a caregiver that ABIL has recruited and trained.

The ABIL Personal Assistant Training is a 40 hour class that includes instruction in personal care skills, body mechanics, wheelchair safety, disability awareness, IL philosophy, communication/conflict resolution skills, CPR/first aid, home maintenance, fire safety, universal precaution and grief and loss issues. To give students a first-hand understanding of the duties of caregivers, ABIL recruits people with disabilities to teach disability related classes.

Many people with disabilities rely on this essential service to achieve and/or maintain independence. Consumers may require Personal Assistance Services in the morning and evening, but can and do go to work, school or volunteer in the community between times of service. This program enables other consumers to remain in a familiar environment with family and friends, thus avoiding placement in care institutions.

COMMUNITY REINTEGRATION FROM NURSING HOMES PROGRAM

ABIL's Community Reintegration from Nursing Homes Program targets low to medium-income adults with disabilities, under age 65, who live in nursing homes. Many people do return to the integrated community, attain greater independence and exercise freedom of choice and control over their own lives.

Young people with disabilities are often relegated to nursing homes after the acquisition/on-set of a significant disability. Frequently this arrangement is intended to be temporary until community barriers are resolved; e.g. making modifications to the family home, obtaining funding for assistive devices, and establishing home attendant care. It is at this point that many fall through the cracks in the system. The longer people remain institutionalized the more health problems escalate, e.g. pressure sores, reduced stamina, drug dependency and chronic pain. Depression and withdrawal becomes the norm.

Young adults, in predominately geriatric institutions, who attempt to create their own activities, become labeled troublemakers by the nursing home staff. Those who exhibit frustration and anger are often documented as displaying "dysfunctional behavior". It becomes, then, a self-fulfilling prophecy that the young person is where he or she needs to be. Costly healthcare and earlier-than-natural death are certain.

Due to isolation and total reliance on non-disabled professionals for information and guidance, young adults with disabilities in nursing homes are unaware of other community options available to them.

Two Reintegration Coordinators staff this program. The coordinators work with the ombudsman program operated by the Area Agency on Aging, Maricopa County Managed Care System (MCMCS), case managers, social workers and other nursing home staff to identify young adults who may be candidates to move out into the community. Many Reintegration Program consumers self-refer or are referred by other consumers.

ABIL's program coordinators introduce consumers to the Independent Living philosophy and work with consumers to develop Independent Living Plans that address all aspects

of making a successful transition from the nursing home into the community. Plans include counseling and resource development in housing, transportation, education social/recreational activities, self-advocacy skills and family adjustment.

ABIL's experience shows that the best way to transition young adults from nursing homes is to develop outside interests and activities while still living the institution. Taking community college courses, going to restaurants and movies, and shopping with a peer mentor or family member reduce fear and provide self-confidence. Experiences outside the institution powerfully motivate young adults to leave institutions and become active, productive citizens within the integrated community.

Community Reintegration from Nursing Homes is a provably cost-effective program. Cost of care for people with disabilities residing in institutions is at least 10% higher than cost of care for people living independently with community-based supports.

A measurable benchmark of the success of a reintegration program is the dollar amount of savings per person multiplied by the number of people reintegrated into the community.

However, benefit lies not only in monetary resources saved. A greater benefit is the non-quantifiable human creativity, productivity and community participation of people with disabilities that would otherwise be lost within the walls of institutions.

ABIL's Community Reintegration program is funded by a grant from the Valley of the Sun United Way.

BENEFITS PLANNING, ASSISTANCE AND OUTREACH PROGRAM

Members of the Disability Community and Independent Living Movement have long recognized that most people with disabilities live in poverty that limits choices and opportunities to achieve the life they desire. Thus, even though "employment" is not a "core" IL service, removing barriers to employment has become an important goal for CILs. Even with the Americans with Disabilities Act making employment discrimination illegal and offering guidelines for accommodations, in 1999 the unemployment rate was still a dismal 70% among persons with disabilities. The Social Security Administration (SSA) noted that only 1/2 of 1% of those on SS Disability benefits left the roles because of employment. SSA has offered many work incentives over the years to assist people with disabilities to test out working and, in some cases, gradually work their way off cash benefits. However, most beneficiaries do not know about them and accurate information is difficult to obtain, even within SSA itself.

Leaders in the disability community worked with Congress to pass the Ticket to Work and Work Incentives Improvement Act of 1999 designed to remove barriers to

employment for people with disabilities and provide increased opportunities. The “Ticket” legislation included new work incentives, funding for SSA staff trained in the incentives and funding for community organizations in every state to provide Benefits Planning, Assessment and Outreach, (BPA&O).

ABIL has the statewide grant to provide outreach and services. We contract with other CILs to help us serve the entire state. Our Work Incentive Specialists are trained and certified by Virginia Commonwealth University (with whom SSA contracts for that service). Work Incentive Specialists provide trainings to consumers, family members, service providers and other members of the public to:

- Explain the variety of work incentives available through SSA
- Help people understand how employment will effect cash and medical benefits

Work Incentive Specialists also assist beneficiaries by phone and in person by providing:

- Information and referral related to SSA Work Incentives
- Advocacy and problem solving related to SSA Work Incentives
- Benefits analysis to help them discover how employment will impact their benefits and what work incentives may be available to help them achieve their employment goal
- Benefits management while they work if they are not able to do this on their own – or teach family members/circles of support how to do this

ABIL’s Program Delivery:

1. Community presentations are scheduled with other service providers. Agency presentations are scheduled and advertised locally through press releases and newsletters.
2. Referrals for work incentive related services or questions are directed to the Work Incentive Specialist who will either answer consumer questions over the phone, refer them to an upcoming presentation, or set an individual appointment. Most individual appointments are done at the CIL or at a community agency that has offered space.
3. Since Arizona has a vast rural area, ABIL’s outreach presentations and appointments are scheduled in various communities and the Specialist travels to those communities to provide the service. Usually, local service agencies will act as a host for this outreach.
4. BPA&O services primarily outreach to SSA beneficiaries on Social Security Disability Insurance and recipients of Supplemental Security Insurance who are between the ages of 18 and 64.

Changing Attitudes of Children Through Recreation Southwestern Center for Independent Living Marshall, Minnesota

People with disabilities in rural areas may face a higher level of isolation than their urban counterparts due to the sparse population and the lack of transportation. Often, a child or adult with a disability may be the only person with that disability in his or her community. This sense of isolation can be especially poignant for school children where conformity is the key to popularity and success and difference means inferiority. One way to reduce the isolation and lack of support experienced by many rural residents with disabilities is the provision of recreational services. The Southwestern Minnesota Center for Independent Living (SMCIL), which serves nine counties in Southwestern Minnesota, effectively used this approach to reach youngsters with disabilities in the community.

Many CILs, including the Southwestern Center, have provided services to assist teenagers and young adults making the transition from school to work and independence for the past several years. Although these projects have been highly successful, isolation, lack of physical activity and low self-esteem may have already become established. Many children with different disabilities are able to integrate successfully into after school recreational activities with their non-disabled peers. But others, whether due to the severity of disability, lack of access to the activity, lack of transportation, or discouragement from parents or professionals, do not participate. Transition project staff wanted to make contact with younger children in order to begin to address these issues, but limited resources made this impossible.

The Challenger baseball team was a way to reach children with disabilities not old enough for transition services. The primary impetus behind the program was a board member who had played wheelchair basketball at Southwest State University. When the program first started, center staff and volunteers, along with parents, directed the baseball team. Because the program was so successful, the Marshall Minnesota Parks and Recreation Department agreed to take the team over about five years ago. The program currently operates as part of the regular recreation program offered to the community.

When staff of the center first broached the subject of a Challenger baseball team to the Parks and Recreation Department, the response was quite disappointing. The department did not have the staff, funds or time to offer this program. They provided the team with some old equipment and use of a baseball field when it was not otherwise in use. However, this situation has radically changed. After the program had been in operation for two years, executive director Steve Thovson approached the Parks and Rec Department and explained their obligations under the Americans with Disabilities Act to offer accessible services to the community. The person who was then in charge of recreation programs had a daughter with a hearing impairment and was more sympathetic to disability issues.

The center worked with the Parks and Rec Department to remove some of the obstacles to establishing a team. Because of these cooperative efforts and significant parent advocacy, the Challenger baseball team has become a joint project of the Marshall Parks and Recreation Department and the Center. The center and the local Parks and Recreation Department approached the United Way together to solicit donations to support the team. Parks and Rec publicizes and runs the program, arranges transportation and recruits players. Center volunteers sometimes coach or support the team.

United Way has been extremely supportive of this project because of the visibility it provides to the center and the United Way. It became a pet project and the United Way has used this program to increase its own fund raising efforts. The United Way pays for transportation for out-of-town tournaments, uniforms and Parks and Recreation fees for players from low-income families. Parents assist the players and sometimes coach the team.

The Marshall team was the first team in Minnesota. A Challenger baseball team has started in Mankato based upon the success of the Marshall program. A third team is planned for another town. This provides the players with the learning and fun of out-of-town travel and some competition.

In the future, Thovson says he would like to start a wheelchair basketball team so that former Challenger players will have an accessible recreational outlet. It is in the preliminary stages of planning and must compete with other service and advocacy issues. This was a significant reason why Thovson was eager to spin the baseball team off to the Parks and Rec Department. Thovson hopes that once a wheelchair basketball team is initiated, Parks and Rec will become interested in operating it.

A major goal of the Challenger project was to reach children at an earlier age and educate them about the center and people with disabilities before they enrolled in the transition program. Challenger seems to have assisted with this goal. Approximately 160 children from ten different schools participate in the center's transition program. While it is difficult to gauge how much the Challenger program contributed to this growth, Thovson believes it has made the schools more aware of the center's services and more open to using the center as a resource.

Collaborative Transportation Developmental Services of Northwest Kansas (DSNWK) and LINK CIL Hays, Kansas

Hays is a small town with a population of about 20,000 in Ellis County in northwest Kansas. LINK is the CIL located in this area. Until recently, LINK's service area was void of public transportation, including taxi service. Some human service agencies had their own vans, but transportation was available only to clients of these particular agencies, trip purposes were limited and services were fragmented, with no coordination between the providers. Because many LINK consumers, older adults and other citizens did not drive, the lack of transportation—especially accessible transportation—was recognized as a major problem.

The Kansas Department of Transportation (KDOT), the agency that provided most of the funds for agency-based transportation, became concerned about the number of projects they were funding in Ellis County, with the plethora of vehicles and minimal and fragmented service. They looked to Developmental Services of Northwest Kansas (DSNWK), the largest recipient of funds and the provider with the most vehicles, to coordinate the transportation. At the time the transportation system began service, LINK was a division of DSNWK, but has since become a free-standing center.

LINK worked with DSNWK and other providers to help them understand the need for a comprehensive, unified transportation system that was accessible to all riders, with schedules that were responsive to consumer needs. LINK also pushed for the establishment of an advisory council composed of service recipients to guide the development of the transportation system.

Today, DSNWK operates a unified system of accessible transportation throughout 18 counties, covering 1600 miles. Participating human service providers lease their vehicles to DSNWK, which provides dispatch, drivers, and insurance. The agencies purchase transportation during certain hours and on certain days of the week for their clientele. The funds from these agencies are pooled with other contract funding, such as city, county, state and federal funds, to provide services for everyone. Riders pay \$1.00 per trip; the actual cost per trip is about \$8.00.

Transportation is available from 7:00 a.m. to 5:30 p.m. on weekdays, with extended service two nights a week until 10:30 p.m. Transportation is not available on Saturday, but is provided on Sunday from 9:00 a.m. until 4:00 p.m.

Since 1993, a route to Russell, Kansas, about 30 miles to the east, has been added to the system. An intercity bus service, which is fed by the paratransit service, links 14 of the 18 counties. The bus operates on three different routes each day, one of which is 200 miles in one direction. On July 1, a medical transportation service was initiated to serve areas not covered by the intercity bus.

Ron Straight, DSNWK's transportation manager, is planning for the future. DSNWK is looking at "intelligent transportation systems," which assist with routing, dispatching and other transit functions. These systems enable dispatchers to send written messages to the drivers to assist them in locating passengers, to inform them if a passenger is late, cancels their trip, etc. Global Positioning Systems tell the dispatcher the location of the

vehicle with an accuracy of within three feet. Some systems connect the vehicle to the maintenance department for monitoring of transmission and other maintenance issues. These systems also provide the possibility of linking providers across the state to enable passengers to travel from one service area to another. Straight is also exploring the possibility of “smart cards,” which enable riders to pay fares by credit card or pay in advance with cash.

This innovative transportation system has drastically improved the transit services available in one of the most rural areas of the country. It presents a model of cooperation that maximizes resources and staffing to improve services to consumers.

Rural Initiatives to Empower Persons with Disabilities in Rural Minnesota

The following is an outline how the Southeastern Minnesota Center for Independent Living, (SEMCIL) in Rochester, Minnesota, initiated services in their rural service area.

SEMCIL’s goal was to expand independent living services throughout the region, provide better access of services for people with disabilities through increased peer contact, provide consumers an opportunity to develop advocacy and independent living skills, and lastly, to assist individuals to take an active role in their communities economically through employment.

Project Assessment & Planning:

- Contact community organizations
- Conduct town meetings to obtain contacts and support
- Identify key community leaders to become involved
- Establish Consumer/ Provider Steering Committee to guide the needs assessment process.
- Mobilize service providers and community representatives for survey distribution.
- Analyze and compare providers and consumers survey responses.
- Steering Committee review and discuss development process based on survey results.
- Secure office space (donated if possible)

Service Development:

- Hire Independent Living Specialist
- Establish Consumer Advisory Councils to meet monthly to assist with priority of service development, and review and evaluate program performance.
- Develop marketing/ promotional materials for distribution to consumer groups and service providers.
- Presentations to community groups and create awareness of services and issues and obtain information on other services.

- Begin accepting referrals for Information and Referral, Advocacy and IL Skills Instruction services.
- Recruit and train Peer Mentors
- Begin Peer Mentor services
- Recruit and train Accessibility Technicians
- Conduct and analyze both a consumer satisfaction and a community organization/ provider survey. Discuss results with Consumer Advisory Council and CIL Governing Board to determine service implications.
- Develop ancillary programs such as Personal Assistance Services, Home Modification, Youth Transition, Americans with Disability Act Access/ Advocacy, Reintegration from Nursing Home to Community Living and Community Living Options Programs as determined by the survey results and funding availability.
- Conduct annual consumer satisfaction surveys and program evaluation.

Seven Key Strategies for Rural Initiatives and Methods for Consumer Control:

CONSUMER ADVISORY COUNCILS

Councils were established to allow for consumer control and direction to meet the specific needs of each county and community. The Council membership includes individuals with disabilities, local governmental officials, human service agency representatives, and others interested in disability related issues. Direct feedback to staff by council members is critical in developing services that fully meet the needs of consumers and the community.

EMPLOYMENT OF LOCAL PERSONS WITH DISABILITIES: PROFESSIONAL, PEER AND TECHNICAL STAFF

Each branch office has an Independent Living Specialist to deliver IL services with assistance coming from the main office. Peer Mentors are included in the service delivery and assist the IL Specialist on special projects. Contracted Access Technicians assist local businesses and governments to make proactive accessibility changes.

ACCESS/ ADVISORY COMMISSIONS

Access/ Advisory Commissions are established with consumers who are interested in making positive changes in the accessibility of buildings, transportation programs, employment, attitudes, and other disability issues at the local, state and federal levels.

CONSUMER LEADERSHIP DEVELOPMENT

Leadership skills are developed through opportunities for involvement in the Center's Consumer Advisory Councils, Access/ Advocacy Commissions, Peer Mentoring or as Access Technicians.

COLLABORATION WITH CONSUMER GROUPS AND EXISTING SERVICES

Consumers actively network among existing groups and services in each community to gather information critical to development and delivery of CIL services.

COLLABORATION WITH LOCAL GOVERNMENT AND BUSINESS

Consumers have opportunities to advocate for systems changes with local governments through the Center's Access/ Advocacy Commissions. Access Technicians provide technical assistance to local businesses to improve accessibility.

STATE, REGIONAL AND LOCAL INFORMATION AND REFERRAL SYSTEM

CILs provide a computerized Local, State, and Regional Information & Referral Network System for persons interested in accessing disability related information. Consumers are actively involved in gathering information on local services that then becomes available through the CIL's Information & Referral core service.

These initiatives empower persons with disabilities to be fully integrated into every aspect of their community. This results in effective systems changes that are desperately needed throughout rural areas of Minnesota.

Round Peg in a Square Hole: Independent Living in Indian Country

Michael H. Blatchford
Executive Director, ASSIST! to Independence

Many people, when hearing the term independent living, probably think about the movement that started in Berkeley three decades ago with the radical notion that people with disabilities had a right to make their own decisions and life choices. At that time, many people with disabilities were still institutionalized, regardless of their function or cognitive level. Out of this movement grew the philosophy that people with disabilities (now called consumers) should have control and input into programs and services that affected their lives, and equal access to the community. Independent living is the right to control and take charge of your life. It doesn't mean wanting to do everything by yourself or living in isolation. Independent living means having the same choices and control in your daily life that non-disabled friends, neighbors and family members take for granted. This includes taking risks, taking responsibility, and having the same right to succeed or fail.

In order to be considered an "Independent Living Center", at least in the eyes of the federal government, an organization must meet the following criteria: 1) have a Board of Directors that is comprised of at least 51% of people with disabilities 2) have 51% of paid employees be individuals with disabilities and 3) provide four core independent living services. The four core services are: Information and Referral, Independent Living Skills Training, Individual and Systems Advocacy, and Peer Mentoring.

Information & Referral provides an individual access to what services are available, and then helps explain how to get appropriate services. IL Skills Training is tailored to personal need, and may be done on an individual basis or in a group. Some examples of this type of training include managing your money, personal care, coping skills, equipment maintenance, cooking and social skills. Systems advocacy works to empower others to promote changes within their environment. An advocate is simply someone who knows the process for getting needed services, and will help you learn how to speak for yourself and gain access to those services. Peer mentoring is done through an individual with a disability who has gained a certain level of independence and community integration, and who is willing to share their experiences and knowledge with you.

In Native American culture, there typically is no word for “disability”. (Clay, 1992) A person will be described by their characteristics, such as ‘walks with a limp’ or ‘slow to learn’. As a result, most native people, when asked, will not self-identify as being a person with a disability, and will typically not seek out services identified specifically for this population. In our culture, having these types of characteristics means that we are not in harmony with the four aspects of well-being, which creates an imbalance. To be in harmony, one needs balance between the mental, physical, emotional and spiritual parts of oneself. (Joe, 1987) To be successful in providing outreach and direct services for independent living in Indian country, you need to understand the cultural concept of “wellness”. For example, in my traditional Navajo culture - health, emotional or physical problems are caused by being out of harmony or balance with nature - our spirit. Our spirituality cannot be separated from physical life, because life is considered to be holistic; one part of life cannot be separated from the whole, or the whole will suffer. When a person is experiencing ill health, emotional or physical problems, it is because the spirit is out of balance with the forces of life. Harmony can be put back in balance by an active effort, such as performing a ceremony, or any conscious activity to correct an imbalance. We believe in a spiritual life before and after our earth life. Our spirits come to earth life to learn or experience things that our spirit needs to understand. In doing so, a spirit chooses to accept the difficulties of life, including “disabilities”, in order to gain something in the spirit life. We believe that disharmony can come from three major life areas: (1) the breaking of taboos, (2) from the forces of nature, (3) from the manipulation of negative energy. (Whale, 1997) Independent living, and the independent living philosophy cannot be easily integrated into Indian Country without major adaptations which allow services to be more culturally appropriate.

In Native culture, our identity is strongly connected to our sense of place and our connection to the land. For most people with disabilities in the independent living movement, they strongly identify with being a part of the “disabled community”. The perspective for Native Americans is much different. For example, I am Indian first, a male second, and a person with a disability third. Our identity is in our cultural heritage, and the community we live in. For many people living in urban areas, or for most people of the “dominant” culture, advocacy and independence revolves around individual rights and individual decisions; in other words the person with the disability is assertive and makes all their own decisions and choices. In Native culture, decisions

are made by the family through consensus after options are presented. The choices being made do not only affect the person with a disability, but the entire family and ultimately the entire community. These are just a few of the examples of cultural differences and how they affect "independent living" for Native Americans.

ASSIST! to Independence has the unique distinction of being the only Independent Living Center and Regional Resource Center for Assistive Technology on tribal lands in the United States. Our mission is to provide culturally relevant services to a cross disability American Indian population, which will enhance quality of life and community access through maximizing independence and improving functional skills. Some major barriers to basic services on the Reservation include geographic isolation, language barriers, cultural differences, lack of resource information, lack of basic utilities, and lack of transportation. For us, the assistive technology and independent living services work hand-in-hand. The bottom line for most people is that they want to remain in their own homes and be able to continue daily activities, whether it is herding sheep, cooking or weaving. Technology has been a bridge for many people here, which allows for an alternative way for someone to continue the same activities as before. The struggle is in providing services within the community that are respectful of the culture, and at the same time abiding by the guidelines and restraints that the funding source - the Federal government - places on us.

For example, the Federal government requires that you collect demographics such as county, for those individuals you are serving. However, when providing services, we are looking at the Reservation as a whole, which for the Navajo Nation includes four states. In fact, most people are not aware of the county they reside in on the Reservation. Collecting county information for us is pretty meaningless - none of the counties provide assistance or financial support. Unless this information is going to be used to appropriate some county funds for IL services on the Reservation, what is the point of taking the extra time to get this information? Another issue is the development of a CIL plan, which states what the goals are, who is responsible for doing what, and what the time frame will be for the accomplishment of those goals. This is something that the Federal government requires offering to each individual who is receiving independent living services. A few of the younger people we work with are willing to develop a plan, but for the most part people are not interested and will instead sign a waiver to the plan. Several cultural factors contribute to this: 1) it is considered taboo to "predict" the future and 2) people tend to live in the moment. Also, many people are very wary of signing anything that is remotely connected to the Federal government. However, the Federal government feels that if you have a predominant number either of plans written, or plans waived, that something is not right and perhaps you are not offering this option to consumers. The federal guidelines also require that a Center for Independent Living offer the four core services mentioned previously: information and referral, skills training, individual & systems advocacy, and peer mentoring. Are these the main types of services that American Indians need? Most people living on the Rez are in basic survival mode, lacking transportation, telephone access, and in most cases running water and electricity. So for the majority of the individuals that we serve, the needs are very basic and grounded in very simple, everyday activities. People want to

be able to stay in their home, to get in and out of the house safely, to get to the outhouse safely, get down to check on the livestock, to be warm and have a means to haul water. Our experience in the community has shown that the majority of American Indians, at least in the areas that we serve, are pretty reserved, humble, and not very willing to openly talk about personal feelings or issues - even with a peer. Of course there are exceptions, but overall this is the case. When you are struggling for just basic survival, your needs and priorities are going to be different.

In order for "Independent Living" to truly take hold and be effective and productive in Indian Country, some changes need to occur within the funding sources that truly honor, respect and respond to the cultural differences that exist. The concept of independent living and the independent living philosophy needs to be presented in the context of wellness, not disability, and services geared toward helping an individual return to balance. Services offered should be reflective of cultural differences, and very dynamic so they can change to meet changing needs: accommodate needs which are "survival" based in nature but which allow the individual to return to a balanced state within the present moment - not looking five and ten years down the road. This could include such things as traditional healing and environmental interventions. These types of things would be more culturally appropriate core services to offer.

Many people might argue that if the federal government were to make changes and modifications in the guidelines for IL services for American Indians, then they would have to do it for every other ethnic minority in the United States. While we certainly don't see anything wrong with that, there are several things that separate American Indians from not only the general population, but from every other ethnic minority as well.

1. American Indians are the only ethnic minority that are required to carry documentation which proves they are Indian - a Certificate of Indian Blood, which states which Tribe the individual is enrolled with, and what quantum or percentage of Indian blood they carry.
2. American Indians are the only ethnic minority that have designated boundaries imposed that determine where they are able to live - the "Reservation" - and be governed by their own people.
3. Indian Nations are sovereign governments, recognized in the U.S. Constitution and hundreds of treaties with the U.S. President. American Indians are the only ethnic minority that have sovereign status; their own Tribal government which is considered a sovereign Nation; completely separate from the United States government.
4. American Indians are the only ethnic minority that have their own National Congress. The National Congress of American Indians was founded in 1944 and is the oldest and largest tribal government organization in the United States.

NCAI serves as a forum for consensus-based policy development among its membership of over 250 tribal governments from every region of the country.

5. American Indians have a higher incidence of disability, estimated at 26%, than any other group in the United States. (CDC, 1994)

Most of these differences are the results of policies imposed by the Federal Government, that do distinctly separate American Indians from other minorities. It stands to reason then, that guidelines for services under programs funded through the Federal government should also be distinctly separate and more relevant culturally. Right now, that is not the case for Independent Living Services. We are forging new ground in this area, and working hard for systems change at the funding level!

In the meantime, however, we work to provide the most culturally appropriate services we can that our community members request. We then translate these services into categories that reflect the requirements mandated by the Federal government for services and demographics for data collection. Sometimes it seems like a lot of extra work, but we have to do it until we are able to break through these barriers at the funding level. In the meantime, Walk in Beauty!

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COMPOSITION OF STATEWIDE INDEPENDENT LIVING COUNCILS

INTRODUCTION

The 1992 Amendments to the Rehabilitation Act greatly expanded the role and responsibilities of the statewide independent living councils, (SILCs), in effect making them full partners with vocational rehabilitation in the independent living process. Primary among the new responsibilities of the councils is collaborating with the state vocational rehabilitation agency to develop the state independent living plan—including determining use of independent living funds provided through Part B of the Rehab Act and monitoring, reviewing, and evaluating implementation of this state plan.

These new responsibilities (detailed in Section 705) provide councils with very significant authority in statewide independent living program administration—an authority that was lacking prior to passage of the '92 Amendments.

Therefore, it is very important that people who are appointed to the councils be not just knowledgeable about but also have a real commitment to disability rights and the independent living philosophy—and their translation into the kinds of service programs and advocacy activities that are genuinely appropriate for independent living centers.

COUNCIL MEMBERSHIP

Appointment

Members of the independent living council in each state (or territory) are appointed by the governor. (Exception: In certain states, a specific entity is authorized to make appointments instead of the governor.) The Act requires the governor (or appointing entity) to solicit recommendations from organizations representing a broad range of people with disabilities prior to selecting individuals to serve as members of the council.

Composition of the Council

The council membership must include:

—An executive director of an independent living center who has been selected by other center directors in the state to fill this role.

—A representative from the state vocational rehabilitation agency, who serves in a nonvoting ex officio role; representatives from other state agencies providing services to

people with disabilities may also be appointed as nonvoting ex officio members of the council.

Other potential council members include staff and board members of independent living centers (in addition to the center director selected by his or her peers), parents and guardians of people with disabilities, advocates of and for people with disabilities, representatives from private businesses, representatives from organizations providing services to people with disabilities, and the catch-all, "other appropriate individuals."

Consumer Control

It is important to note that the '92 Amendments require that the majority of the members of the council be comprised of people with disabilities who are not employed by a state agency or independent living center.

Membership Qualifications

Individuals selected to serve as members of the council must be knowledgeable about independent living centers and services and must represent different parts of the state as well as different disability constituencies.

National Council on Independent Living

The National Council on Independent Living (NCIL) is the oldest cross disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents over 700 organizations and individuals including: Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

NCIL was established four years after the 1978 amendments to the Rehabilitation Act of 1973. The 1978 amendments added statutory language and funding for the formation of Centers for Independent Living. The Executive Directors of the newly federally funded CILs met regularly with Rehabilitation Services Administration (RSA) to discuss issues related to the development and expansion of CILs nationwide. Believing that the views of CIL consumers and people with disabilities, as a whole, were not being heard by the federal government, the Administration or the Congress, the CIL executive directors worked to organized and establish the National Council on Independent Living - an organization governed by people with disabilities advocating for the development and expansion of a nationwide network of centers for independent living.

For the first 10 years of NCIL's existence, the organization was located in the city and state of the standing President. During those 10 years, NCIL worked diligently to increase funding in Title VII, Part B of the Rehabilitation Act of 1973 as amended, in order for more community based, consumer controlled CILs to open around the country.

NCIL's advocacy activities also included ensuring that people with disabilities who participated in various programs under the Rehabilitation Act gained greater control of the services provided to them.

In 1992 NCIL open its national office in the Washington DC area and hired its first executive director. NCIL's Governing Board is composed of 22 individuals a majority of whom have disabilities. The Governing Board meets four times each year. A seven member Executive Committee, which meets monthly via teleconference, is empowered to make policy decisions between Governing Board meetings. NCIL is a powerful voice on Capitol Hill and a national leader for disability rights.

THE PROCESS OF ESTABLISHING A CENTER FOR INDEPENDENT LIVING

GENERAL START-UP ACTIVITIES

A COLLABORATIVE PROJECT OF:

REGION V REHABILITATION CONTINUING EDUCATION PROGRAM, SOUTHERN ILLINOIS UNIVERSITY AT CARBONDALE & STATEWIDE INDEPENDENT LIVING COUNCIL OF ILLINOIS

PROCESS OF ESTABLISHING A CENTER FOR INDEPENDENT LIVING

The process of establishing a Center for Independent Living is an evolution of sorts. It doesn't just happen. It involves a variety of issues, concerns, research, and investigation. The following section looks at this process, and several key elements involved in making the establishment of a Center for Independent Living a reality. It is always important to remember the history and philosophy of Independent Living during the entire process of establishing a Center for Independent Living to ensure that you are in fact creating an advocacy and peer support entity like no other in your community.

Identifying and Developing Grassroots Activities

The first steps in the process of identifying and developing grassroots activities involves investigation. This can be looked at from several perspectives.

First, it is important to look at the idea of a Center for Independent Living in your community from a personal level. Do you personally believe in the philosophy of Independent Living and feel that there is a need for a Center for Independent Living in your community. In many instances, you will need to educate your family members,

friends, peers, and others about Independent Living and how a Center for Independent Living can benefit your community and the individuals who live there. Many individuals and groups don't know what a consumer driven Center for Independent Living is, and its commitment to cross disability. Many family members may be initially reluctant to accept Independent Living principles, and it will require continual education to help them understand this empowering concept.

A second question must also be explored: Does your community already have existing Independent Living services that meet the need? When researching these agencies and services, it is important to remember issues of consumer control and choice, and issues that are contradictory to the Independent Living philosophy. An agency may claim to be offering the services similar to a Center for Independent Living, but in reality are offering unrelated services. In a community where the benefits of a Center for Independent Living are needed, you will often find support from existing social service organizations who view a Center for Independent Living as an additional resource and not as a threat. These collaborative organizations need to be identified and working relationship should be developed. This local and regional research will also be useful when conducting a Center for Independent Living needs assessment, which is discussed later in this manual.

You may be the only one in your community interested in starting a Center for Independent Living, and will be the individual to begin organizing other interested individuals and sharing the concept of Independent Living and the benefits of a Center for Independent Living. However, it is important to ask a third question: Are any other grassroots groups with similar issues and concerns out there that you can potentially partner with? In many instances, you may start by talking to others with similar concerns and develop a grassroots group of your own. In other cases, after a little investigation, you may find an existing group or groups that share a similar belief in independent Living. Many communities have local disability coalition chapters, disability support groups, or advocacy groups that may assist in bringing together people with similar concerns.

Taking the time to investigate is important. When the process of establishing a Center for Independent Living continues in its evolution, you will find that more people will become interested in establishing a core group capable of continuing the process (Nelson, n. d.).

Once a semi-formal core group is formed, one of the most important issues you must decide is whether the group is willing to take the steps necessary to become a Center for Independent Living. Establishing a Center for Independent Living takes many months and often many years. Often many years! Does the core group believe in the Independent Living philosophy and in the need for a Center for Independent Living in the community or region? During the process, some people will stay involved, while some may lose interest. Some people may leave and return as the group becomes more cohesive and recognized in the community.

Many groups interested in developing a Center for Independent Living have conducted grassroots training to help educate the community about Centers for Independent Living and to garner further support from interested individuals. Existing Centers for Independent Living and Statewide Independent Living Councils (SILC's) are good sources to discuss the core group's ideas and concerns, gather literature, arrange for guest speakers, and receive additional support for your grassroots efforts. It is important to note that all training should be made available to all people regardless of their particular disability and be held in a location that meets the Americans with Disabilities Act (ADA) accessibility requirements. This includes the need to have a certified sign language interpreter available, and materials that are available in Braille and large print or other alternative formats (SILC of Illinois, 1998). If you do not attempt to accommodate all persons with disabilities, you may be disregarding the cross disability philosophy of Independent Living.

The grassroots training creates public awareness, attracts like-minded individuals, and provides an opportunity to outreach to the community and region at large. These like-minded individuals are often willing to assist with the process, and to share your core group's plan with other social service providers. It is important to develop and utilize the vast resources of existing Centers for Independent Living, your Statewide Independent Living Council and your state association of Centers for Independent Living. These groups will be valuable partners with your core group throughout the entire process of developing a Center for Independent Living.

The process of developing a Center for Independent Living takes a significant amount of time and requires the commitment, dedication, and patience of everyone involved in the process. Thus, you may determine to remain as a grassroots organization and perhaps work on the development of a Center for Independent Living in the future. This is an important consideration to make, because it takes the commitment of long hours and extensive paperwork to make the transition from a grassroots core group into a Center for Independent Living steering board. Therefore, the most important issue is whether your group is committed to taking the next steps in developing a cross disability, consumer driven, advocacy organization that views Independent Living as a civil right for all persons with disabilities.

Establishing a Steering Committee

The next step in the evolution of a Center for Independent Living involves the transition from a core grassroots group of like-minded individuals who believe in the concepts of Independent Living into a more structured steering committee whose ultimate goal is the establishment of a Center for Independent Living in their community or region.

Some steering committees have been formed at the completion of community or regional grassroots training where the excitement level is high and you can take advantage of the momentum garnered. A follow up meeting could be scheduled at the

local public library or city hall and should be open to any individuals interested in establishing a Center for Independent Living. This first meeting provides the opportunity for individuals to demonstrate their willingness to serve on the steering committee or to assist the steering committee in the specific tasks identified to make the eventual transition from a steering committee to a board of directors. You may want to ask for the assistance of a representative from a Center for Independent Living or Statewide Independent Living Council to assist at the first meetings before publicized elections can take place (Curtis, 1980). However, it should be stressed that the steering committee not become too dependent on the assistance that may be available, and take the initiative to develop on your own without the influence of other organizations. In addition, it is important that the steering committee elect its officers early, and that sub-committees are formed to accomplish the tasks necessary to move forward. At all times, the steering committee should include individuals of all disability types, with at least 51% of its membership being individuals with severe disabilities. In addition, it should be representative of the community's cultural diversity and geographic regions. This is inclusive of the time when officers may change, as your steering committee takes the step to becoming a governing board of directors.

How are officers chosen? They must be elected by a vote; either by a written ballot form or an oral vote. It should be publicized that elections will be taking place for all interested individuals to participate. The steering committee officers should include a chair, vice, chair, treasurer, and secretary/librarian. While the chair will run the meetings and is the chief officer, a key office in the initial development of a Center for Independent Living is that of the secretary. A written record of the meetings needs to be kept for historical reasons and for future reporting requirements. In addition, the secretary may serve as the steering committee's librarian; gathering and filing informational materials from Centers for Independent Living, Statewide Independent Living Councils, state and federal regulations, and other documents that will be required of a not-for-profit organization.

The first action the steering committee, once formed, should be to develop and adopt by-laws for the Center for Independent Living. The by-laws are the structure upon which the Center for Independent Living is built, and must be in place before incorporation and tax exempt status can be sought, or funding proposal submitted. Sample by-laws can be obtained from other Centers for Independent Living to provide guidance in developing your steering committee's own by-laws.

Specific sub-committees will be determined by the steering committee. They may include outreach and community awareness, researching not-for-profit status, and others that are identified as necessary by the steering committee during the initial planning stages. It should be noted that some individuals may be interested in becoming involved with the steering committee as a means of finding employment if a Center for Independent Living were to be opened in the community. At all times it should be clear that, while employment opportunities will become available, individuals serving on the steering committee should not be viewed as having an "inside track" on any potential employment opportunities. This is not to say that assisting with the

steering committee would not give an individual the opportunity to learn about what it takes to operate a Center for Independent Living and what some of the essential staff functions may be. In some instances, people serve on a board of directors for a period of time and eventually become employed after gaining experience and a better understanding of a particular staff function (R. F. Kilbury, Personal communication, July 16, 1998). However, it should be understood throughout the entire process of establishing a Center for Independent Living that staff positions would be filled by its executive director who is the only person chosen and supervised by the eventual board of directors.

It is important to visit the Centers for Independent Living nearest to your community to gather information, collect brochures, and to discuss issues related to developing a Center for Independent Living with staff and board members. Gathering training materials, borrowing and viewing Independent Living focused videos, and attending workshops and conferences will also be helpful as the steering committee continues its development.

Conducting a Needs Assessment

While you have been informally gathering information throughout the entire process of establishing a Center for Independent Living thus far, a formal needs assessment (Curtis, 1980) provides you with the hard data that you will need to determine if your community or region can benefit from the services of a Center for Independent Living. A needs assessment is a formal tool to take to your legislators, possible funding sources, and others in the community to demonstrate that you have done the research necessary to successfully “argue” for the establishment of a new not-for-profit, which will benefit the community and region, and does not duplicate the services of an existing agency or organization. Frankly, if you cannot convince the legislators, funding sources, and your community, all of your efforts will be for naught.

Several steps need to be taken during your information gathering stage. A good place to start is to contact your Statewide Independent Living Council (SILC) and ask for a copy of the State Plan for Independent Living. Each state is required by the Rehabilitation Act to submit a three-year plan that includes information about where in your state are areas in need of a Center for Independent Living. A SILC can also assist with gathering other information, but the steering committee should develop the habit of gathering its own data and not become too dependent on others. Many states have an association of Centers for Independent Living that can assist your steering committee in its needs assessment, and in many other aspects of developing your Center for Independent Living. This may include providing technical assistance with writing a grant proposal. Letters of support that indicate the need for such a service and how the community or region will benefit should be solicited from persons with disabilities, community leaders, local legislators, other Centers for Independent Living, and area service providers. Additional outreach needs to be made to share your intentions with the community, which may take the form of conducting smaller grassroots training and focus groups to garner measurable support for your efforts.

A final question must be revisited upon completion of a needs assessment: Does the steering committee want to help develop a Center for Independent Living? If you are able to prove a need and have weighed the positives and negatives, it is time to begin looking at state and federal indicators and reporting requirements and what it takes to become a not-for-profit corporation.

Organizing a Not-for-Profit Corporation

The first step in organizing a not-for-profit corporation involves filing Articles of Incorporation with the Secretary of State. What are the Articles of Incorporation? They are legal document through which a corporation is formed. It is often referred to as an organization's "charter." A typical Articles of Incorporation contains the following items and is submitted in duplicate with one copy bearing the original signatures. It should be noted that the following is an example from one state and other state's requirements may vary somewhat. You can obtain information on your state's requirements from the office of your Secretary of State.

Articles of Incorporation

- I. Corporate Name: (full name of organization);
 - II. Registered Agent: (e.g., board of director officer);
 - III. Purpose Statement: (must be specific about the organization);
 - IV. Office Address: (initially, a board of director officers address. May not be post office box);
 - V. Duration of Incorporation: (usually perpetual);
 - VI. Tax-Exempt Status: (see section below);
 - VII. Board of Directors names: (most states require three minimum);
 - VIII. Incorporator: (may be more than one group);
 - IX. Other Provisions: (consider tax-exempt status, restrictions, federal/state/local regulations);
 - X. Date of annual meeting
 - XI. Fiscal Year: (e.g., calendar, state, federal);
 - XII. By-laws;
- (Illinois Secretary of State, 1996).

The second step is applying for your Federal Tax-Exempt Status. After receiving your submitted Articles of Incorporation back from the Secretary of State, you may be required to file them with the Recorder of Deeds of the county in which the corporation has (or will have) its office. Following are additional state and federal requirements for applying for tax-exempt status. Again, it should be noted that requirements may vary from state to state and may change over time.

Applying for Tax-Exempt Status

- I. Obtain a federal Employee Identification Number (EIN): An “SS4 Form” is available from and is returned to the Internal Revenue Service;
- II. Obtain required tax audit forms: An “AG 990 Form” is available from and returned to the Attorney General;
- III. Obtain a state payroll application: An “NUC1 Form” is to create a new business account number. It is available from and returned to the department of employment security;
- IV. Obtain unemployment liability forms
- V. Obtain Internal Revenue Service tax-exempt status application: a “1023 Form” is the application to receive “501[c] (3)” not-for-profit status. It is available from and returned to the Internal Revenue Service (IRS).

Operations, Policies and Procedures

Clearly the one of most important aspects of running a successful Center for Independent Living is to have an understanding of the operations, policies and procedures, and fiscal issues (Nosek & Smith, 1982). It should be noted that the following section offers only a basic overview of personnel, insurance, and fiscal concerns. This basic overview will assist Individuals to better comprehend the complexities of operating a Center for Independent Living. Ultimately, operations will be the function of the executive director and his or her staff on a day-to-day basis. A comprehensive manual must be developed to ensure that your Center for Independent Living’s policies and procedures are collected in one place.

Personnel

Following is a sample of specific topics that may be included in policies and procedures for personnel.

- I. Employee Job Descriptions;
- II. Wages & Benefits, Salary Schedules;
- III. Performance Appraisal Evaluations;
- IV. Hiring procedures;
- V. Discipline and Termination Procedures;
- VI. Personnel Management Procedures;
- VII. Drug Free Workplace Policy;
- VIII. Sexual Harassment Policy.

Insurance & Risk Management

Centers for Independent Living are responsible for providing insurance coverage including that which is required by law to protect the Center for Independent Living, its employees and visitors, and that which constitutes fringe benefits for employees (Ann Ford, personal communication, November 12, 1998)

Following is a sample of specific types of insurance that a Center for Independent Living may be purchasing:

Required

- I. Worker's Compensation: (provides coverage for employees for work related injuries or illnesses);
- II. Unemployment Insurance: (required by the state; paid in the form of a tax. Some larger Centers for Independent Living may also be required to pay federal unemployment tax);
- III. General Liability & Casualty: (protects Center for Independent Living against loss related to fire or theft, as well as against liability claims in the instance where a visitor is injured on the Center for Independent Living's property);
- IV. Professional Liability: (protects Center for Independent Living staff in the event of lawsuits by consumers).

Fringe Benefits

Fringe benefits include Health, Life and Dental Insurance. These policies can be purchased as group policies and provided as a benefit package to employees. Other types of policies may include retirement plans and deferred compensation options (Nosek & Smith, 1980).

Fiscal Reporting Requirements

Following is a basic overview of some of the fiscal reporting requirements of a Center for Independent Living. Extensive grant research to identify Center for Independent Living funding streams will be required. A projected budget should be developed and anticipated start-up costs must be identified. For example, you will need funds to apply for not-for-profit status, to conduct grassroots training, or to pay for a board of director member's accommodation.

Nosek and Smith (1982) stress that "sound financial and accounting systems are of paramount importance" (p.23). This is particularly important for new entities, which will be "under pressure to demonstrate their effectiveness to federal, state, and other funding agencies" (p.23).

Establishing an accounting system is essential in tracking a Center for Independent Living's activities. Many Centers for Independent Living utilize the services of a Certified Public Accountant with assistance in their bookkeeping activities and to prepare for independent audits. Following are several identifiers of sound record keeping:

- I. To identify sources of receipts;
- II. To comply with government reporting requirements;

- III. To prepare financial statements for the board of directors;
- IV. To prepare budgets and projections for the future;
- V. To determine depreciation of assets.
(Nosek & Smith 1982)

A chart of accounts will track a Center for Independent Living's Assets, Liabilities, Income, and Expenses (MAS 90,1994).

Following are the office of Management and Budget (OMB) management document circulars that directly apply to Centers for Independent Living:

The **OMB circular "A-110" is:** The Uniform Administrative Requirements for Grants and Agreements with Institutions of Higher Education, Hospitals, and Other Non-Profit organizations (revised, 11/19/1993). The **A-110** circular established uniform administrative requirements for Federal grants to non-profit organizations. In addition, it established pre-award requirements, standards on financial and program management, property standards on financial and program management, property standards, procurement standards, financial and program reporting requirements, and enforcement.

The **OMB circular "A-133" is:** The Audits of Institutions of Higher Education and Other Non-Profit Institutions (revised, 4/22/1996). The **A-133** circular established standards for consistency and uniformity for the audit of non-profit organizations expending federal awards. In addition, it established audit requirements, the scope of the audit, audit reporting, and audit findings.

In conjunction with the **OMB** circulars, an additional reporting requirement tool is the EDGAR (U.S. Education Department General Administrative Regulations; 3/6/1997). For example, the EDGAR looks at grant administration, lobbying restrictions, and drug-free policies at Centers for Independent Living.

Public Relations Activities

Public relations are an ongoing process that begins with the initial planning process. You will be establishing relationships with legislators, local and state service organizations, the community at large, and future consumers for your Center for Independent Living. You will also be recruiting for the board of directors. Developing a public relations plan identifies your target audiences and the short-and long-term priorities necessary to execute the plan effectively. In addition, a time line for the execution of the plan may prove useful (Crimando & Riggan, 1988).

When developing materials for your public relations efforts, it is important to remember your responsibility to educate your target audiences about the Independent Living philosophy and how the community or region benefits from a Center for Independent Living. At all times, when designing your public relations materials, you must provide

alternative formats: including Braille, cassette, large print, or computer disk (SILC of Illinois, 1998).

Following are some examples of types of materials and activities that could be included in your public relations efforts:

- I. Introductory letters to legislators, service organizations, and other interested groups or individuals;
- II. Brochures (e.g., about Independent Living, about Centers for Independent Living, advocacy issues);
- III. Public Service Announcements (PSA);
 - a) Press Releases.
 - b) Print Media Coverage.
 - c) Television Coverage.
 - d) Radio Coverage
- IV. Position Papers;
- V. Community Awareness (e.g., booths, fairs).

Centers for Independent Living Requirements

Gathering information on and understanding state and federal compliance indicators and reporting requirements is the next step in developing a Center for Independent Living in your community or region. These requirements and indicators will help guide the steering committee to develop its level of sophistication and understanding of the numerous requirements of operating a Center for Independent Living.

Following are the Rehabilitation Services Administration **Evaluation Standards and Compliance Indicators** that all Centers for Independent Living must follow (U.S. Department of Education, 1995):

The Center for Independent Living shall promote and practice the IL philosophy of:

- I. Consumer control
Document: Most recent annual performance report. Indicator: More than 51% of governing board is individuals with significant disabilities; and more than 51% of employees in decision-making and staff positions are individuals with disabilities.
- II. Self-help and self-advocacy
Document: Most recent annual performance report. Indicator: Evidence that it promotes self-help and self-advocacy among individuals with significant disabilities.
- III. Development of peer relationships and peer role models
Document: Most recent annual performance report. Indicator: Evidence

that it promotes the development of peer relationships and peer role models among individuals with significant disabilities.

IV. Equal access

Document: Most recent annual performance report. Indicator: Evidence that the Center for Independent Living ensures equal access of individuals with significant disabilities, including communication and physical access, to a Center for Independent Living's services, programs and activities, resources and facilities, whether public ally or privately funded. Equal access means the same access provided to any individual with a significant disability regardless of the individual's type of significant disability.

V. Alternative formats

Document: Most recent annual performance report. Indicator: A Center for Independent Living shall make available in alternative formats, appropriate, of all its written policies, materials and IL services.

Compliance indicator #2: Provisions of services on a cross-disability basis:

Document: Most recent annual performance report. Indicator: Provides IL services to eligible individuals or groups of individuals without restrictions based on the particular type or types of significant disability.

- a) The Center for Independent Living shall provide IL services to individuals with a range of significant disabilities.
- b) The Center for Independent Living shall provide IL services on a cross-disability basis (i.e., for individuals with all different types of significant disabilities, including individuals with significant disabilities who are members of populations that are unserved or underserved by programs under Title VII of the Rehabilitation Act).
- c) The Center for Independent Living shall determine eligibility for IL services. The Center for Independent Living may not base eligibility on the presence of any one significant disability.

Compliance Indicator #3: Independent living goals: The Center for Independent Living shall facilitate the development and achievement of IL goals selected by individuals with significant disabilities who seek assistance in the development and achievement of IL goals from the Center for Independent Living.

Compliance Indicator #4: Community Options: The Center for Independent Living shall conduct activities to increase the availability and improve the quality of community options for IL to facilitate the development and achievement of IL goals by individuals with significant disabilities.

Compliance Indicator #5: Independent living core services: The Center for Independent Living shall provide IL core services and, as appropriate, a combination of any other IL services specified in section 7(30) (B) of the Act.

Compliance Indicator #6: Activities to increase community capacity: The Center for Independent Living shall conduct activities to increase the capacity of communities within the service area of the Center for Independent Living to meet the needs of individuals with significant disabilities.

Compliance Indicator #7: Resource development activities: The Center for Independent Living shall conduct resource development activities to obtain funding from sources other than Chapter 1 of Title VII.

Other Program Reporting Requirements

The U.S. Department of Education; Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration (RSA), requires that Centers for Independent Living file "704 Reports"; including a 704 Quarterly performance report, and a 704 Annual performance report (sample of both reports are included in the appendix). The reports are used to measure the number and types individuals with significant disabilities receiving services, and other specific guidelines necessary to operate a Center for Independent Living.

704 Quarterly Performance Report to RSA:

The following items must be included in or with the 704 Quarterly Performance Report. Reporting is done for the quarter and year to date:

- I. The age category of individuals served;
- II. The gender of individuals served;
- III. The race/ethnicity of individuals served;
- IV. The individuals disability category;
- V. Types and numbers of community services provided;
- VI. Types and numbers of individuals services provided.

704 Annual Performance Report to RSA:

The following items must be included in or with the 704 annual performance report:

- I. The number of employees in decision-making and staff positions.
- II. Ensure that financial resources in Subpart IID are added correctly.
- III. Make sure that the total consumers served is consistent with the demographic totals in Subpart IIF, section VI, VFII, VIII, and IX.
- IV. Ensure that all direct service data is unduplicated.
- V. Ensure that the total number of information and referrals in the Community Services section in subpart IIG is documented.

- VI. The goals and objectives, and status updates of the reporting year must be completed and included.
- VII. Include the county chart of consumers served by county (if applicable).
- VIII. Include the service area population demographics.
- IX. Include an updated board list, the number of persons with disabilities and types of disability.

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Appendices

U.S. Department of Justice, Civil Rights Division, Disability Rights Section
A GUIDE TO DISABILITY RIGHTS LAWS
August 2001

TABLE OF CONTENTS

Americans with Disabilities Act	1
Telecommunications Act	8
Fair Housing Act	9
Air Carrier Access Act	11
Voting Accessibility for the Elderly and Handicapped Act	12
National Voter Registration Act	13
Civil Rights of Institutionalized Persons Act	14
Individuals with Disabilities Education Act	15
Rehabilitation Act	16
Architectural Barriers Act	19
Other Sources of Disability Rights Information	19
Statute Citations	20

For persons with disabilities, this document is available in large print, Braille, audio tape, and computer disk.

Reproduction of this document is encouraged.

Americans with Disabilities Act (ADA)

The ADA prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.

ADA Title I: Employment

Title I requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others. For example, it prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment. It restricts questions that can be asked about an applicant's disability before a job offer is made, and it requires that employers make reasonable accommodation to the known physical or mental limitations of otherwise qualified individuals with disabilities, unless it results in undue hardship. Religious entities with 15 or more employees are covered under title I.

Title I complaints must be filed with the U. S. Equal Employment Opportunity Commission (EEOC) within 180 days of the date of discrimination, or 300 days if the charge is filed with a designated State or local fair employment practice agency. Individuals may file a lawsuit in Federal court only after they receive a "right-to-sue" letter from the EEOC.

Charges of employment discrimination on the basis of disability may be filed at any U.S. Equal Employment Opportunity Commission field office. Field offices are located in 50 cities throughout the U.S. and are listed in most telephone

directories under “U.S. Government.” For the appropriate EEOC field office in your geographic area, contact:

(800) 669-4000 (voice)

(800) 669-6820 (TTY)

www.eeoc.gov

Publications and information on EEOC-enforced laws may be obtained by calling:

(800) 669-3362 (voice)

(800) 800-3302 (TTY)

For information on how to accommodate a specific individual with a disability, contact the Job Accommodation Network at:

(800) 526-7234

(voice/TTY)

www.jan.wvu.edu

ADA Title 11: State and Local Government Activities

Title 11 covers all activities of State and local governments regardless of the government entity’s size or receipt of Federal funding. Title II requires that State and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

State and local governments are required to follow specific architectural standards in the new construction and alteration of their buildings. They also must relocate programs or otherwise provide access in inaccessible older buildings, and communicate effectively with people who have hearing, vision, or speech disabilities. Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and

procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided.

Complaints of title II violations may be filed with the Department of Justice within 180 days of the date of discrimination. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department may bring a lawsuit where it has investigated a matter and has been unable to resolve violations. For more information, contact:

Disability Rights Section Civil
Rights Division
U.S. Department of Justice P.O. Box
66738 Washington, D.C. 20035-6738

www.usdoj.gov/crt/ada/adahoml.htm

(800) 514-0301 (voice) (800)
514-0383 (TTY)

Title II may also be enforced through private lawsuits in Federal court. It is not necessary to file a complaint with the Department of Justice (DOJ) or any other Federal agency, or to receive a “right to-sue” letter, before going to court.

ADA Title 11: Public Transportation

The transportation provisions of title 11 cover public transportation services, such as city buses and public rail transit (e.g. subways, commuter rails, Amtrak). Public transportation authorities may not discriminate against people with disabilities in the provision of their services. They must comply with requirements for accessibility in newly purchased vehicles, make good faith efforts to purchase or lease accessible used buses, remanufacture buses in an accessible manner, and, unless it would result in an undue burden, provide paratransit where they operate fixed-route bus or rail systems. Paratransit is a service where individuals who are unable to use the regular transit system independently (because of a physical or mental impairment) are picked up and dropped off at their destinations. Questions and complaints about public transportation should be directed to:

Office of Civil Rights
Federal Transit Administration U.S. Department of Transportation
400 Seventh Street, S.W., Room 9102 Washington, D.C. 20590

www.fla.dot.gov/office/civ.htm

(888) 446-4511 (voice/relay)

(202) 366-2285 (voice)

(202) 366-0153 (TTY)

ADA Title III: Public Accommodations

Title III covers businesses and nonprofit service providers that are public accommodations, privately operated entities offering certain types of courses and examinations, privately operated transportation, and commercial facilities. Public accommodations are private entities who own, lease, lease to, or operate facilities such as restaurants, retail stores, hotels, movie theaters, private schools, convention centers, doctors' offices, homeless shelters, transportation depots, zoos, funeral homes, day care centers, and recreation facilities including sports stadiums and fitness clubs. Transportation services provided by private entities are also covered by title III.

Public accommodations must comply with basic nondiscrimination requirements that prohibit exclusion, segregation, and unequal treatment. They also must comply with specific requirements related to architectural standards for new and altered buildings; reasonable modifications to policies, practices, and procedures; effective communication with people with hearing, vision, or speech disabilities; and other access requirements. Additionally, public accommodations must remove barriers in existing buildings where it is easy to do so without much difficulty or expense, given the public accommodation's resources.

Courses and examinations related to professional, educational, or trade-related applications, licensing, certifications, or credentialing must be provided in a place and manner accessible to people with disabilities, or alternative accessible arrangements must be offered.

Commercial facilities, such as factories and warehouses, must comply with the ADA's architectural standards for new construction and alterations.

Complaints of title III violations may be filed with the Department of Justice. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department is authorized to bring a lawsuit where there is a pattern or practice of discrimination in violation of title III, or where an act of discrimination raises an issue of general public importance. Title III may also be enforced through private lawsuits. It is not necessary to file a complaint with the Department of Justice (or any Federal agency), or to receive a "right-to-sue" letter, before going to court. For more information, contact:

Disability Rights Section
Civil Rights Division
U.S. Department of Justice P.O. Box 66738
Washington, D.C. 20035-6738

www.usdoj.gov/crt/ada/adahoml.htm

(800) 514-0301 (voice)
(800) 514-0383 (TTY)

ADA Title IV: Telecommunications Relay Services

Title IV addresses telephone and television access for people with hearing and speech disabilities. It requires common carriers (telephone companies) to establish interstate and intrastate telecommunications relay services (TRS) 24 hours a day, 7 days a week. TRS enables callers with hearing and speech disabilities who use telecommunications devices for the deaf (TDDs), which are also known as teletypewriters (TTYs), and callers who use voice telephones to communicate with each other through a third party communications assistant. The Federal Communications Commission (FCC) has set minimum standards for TRS services. Title IV also requires closed captioning of Federally funded public service announcements. For more information about TRS, contact the FCC at:

Federal Communications Commission 445 12th
Street, S.W.
Washington, D.C. 20554

www.fcc.gov/cib/dro

(888) 225-5322 (Voice)
(888) 835-5322 (TTY)

Telecommunications Act

Section 255 and Section 251(a)(2) of the Communications Act of 1934, as amended by the Telecommunications Act of 1996, require manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible to and usable by persons with disabilities, if readily achievable. These amendments ensure that people with disabilities will have access to a broad range of products and services such as telephones, cell phones, pagers, call-waiting, and operator services, that were often inaccessible to many users with disabilities. For more information, contact:

Federal Communications Commission 445 12th
Street, S.W.
Washington, D.C. 20554

www.fcc.gov/cib/dro

(888) 225-5322 (Voice)
(888) 835-5322 (TTY)

Fair Housing Act

The Fair Housing Act, as amended in 1988, prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and national origin. Its coverage includes private housing, housing that receives Federal financial assistance, and State and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the disability of that individual, an individual associated with the buyer or renter, or an individual who intends to live in the residence. Other covered

activities include, for example, financing, zoning practices, new construction design, and advertising.

The Fair Housing Act requires owners of housing facilities to make reasonable exceptions in their policies and operations to afford people with disabilities equal housing opportunities. For example, a landlord with a “no pets” policy may be required to grant an exception to this rule and allow an individual who is blind to keep a guide dog in the residence. The Fair Housing Act also requires landlords to allow tenants with disabilities to make reasonable access-related modifications to their private living space, as well as to common use spaces. (The landlord is not required to pay for the changes.) The Act further requires that new multifamily housing with four or more units be designed and built to allow access for persons with disabilities. This includes accessible common use areas, doors that are wide enough for wheelchairs, kitchens and bathrooms that allow a person using a wheelchair to maneuver, and other adaptable features within the units.

Complaints of Fair Housing Act violations may be filed with the U.S. Department of Housing and Urban Development. For more information or to file a complaint, contact:

Office of Program Compliance and Disability Rights Office
of Fair Housing and Equal Opportunity
U.S. Department of Housing and Urban Development
451 7th Street, S.W., Room 5242
Washington, D.C. 20140

www.hud.gov/offices/fheo/index.cfm

(800) 669-9777 (voice)

(800) 927-9275 (TTY)

For questions about the Fair Housing Act, you may call the Office of Fair Housing and Equal Opportunity at:

(202) 708-2333 (voice)

(202) 401-1247 (TTY)

For publications, you may call the Housing and Urban Development Customer Service Center at:

(800) 767-7468 (voice)

(800) 877-8339 (TTY)

Additionally, the Department of Justice can file cases involving a pattern or practice of discrimination. The Fair Housing Act may also be enforced through private lawsuits.

Air Carrier Access Act

The Air Carrier Access Act prohibits discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements address a wide range of issues including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities. People may enforce rights under the Air Carrier Access Act by filing a complaint with the U.S. Department of Transportation, or by bringing a lawsuit in Federal court. For more information or to file a complaint, contact:

Aviation Consumer Protection Division U.S.
Department of Transportation 400 Seventh
Street, S.W.
Room 4107, C-75 Washington,
D.C. 20590

www.dot.gov/airconsumer

(202) 366-2220 (voice)

(202) 755-7687 (TTY)

Voting Accessibility for the Elderly and Handicapped Act

The Voting Accessibility for the Elderly and Handicapped Act of 1984 generally requires polling places across the United States to be physically accessible to people with disabilities for federal elections. Where no accessible location is available to serve as a polling place, a political subdivision must provide an alternate means of casting a ballot on the day of the election. This law also requires states to make available registration and voting aids for disabled and elderly voters, including information by telecommunications devices for the deaf (TDDs) which are also known as teletypewriters (TTYs). For more information, contact:

Voting Section Civil Rights Division U.S.
Department of Justice
P.O. Box 66128
Washington, D.C. 20035-6128

(800) 253-3931 (voice/TTY)

National Voter Registration Act

The National Voter Registration Act of 1993, also known as the “Motor Voter Act,” makes it easier for all Americans to exercise their fundamental right to vote. One of the basic purposes of the Act is to increase the historically low registration rates of minorities and persons with disabilities that have resulted from discrimination. The Motor Voter Act requires all offices of State-funded programs that are primarily engaged in providing services to persons with disabilities to provide all program applicants with voter registration forms, to assist them in completing the forms, and to transmit completed forms to the appropriate State official. For more information, contact:

Voting Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66128
Washington, D.C. 20035-6128

www.usdoj.gov/crt/voting

(800) 253-3931 (voice/TTY)

Civil Rights of Institutionalized Persons Act

The Civil Rights of Institutionalized Persons Act (CRIPA) authorizes the U.S. Attorney General to investigate conditions of confinement at State and local government institutions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, publicly operated nursing homes, and institutions for people with psychiatric or developmental disabilities. Its purpose is to allow the Attorney General to uncover and correct widespread deficiencies that seriously jeopardize the health and safety of residents of institutions. The Attorney General does not have authority under CRIPA to investigate isolated incidents or to represent individual institutionalized persons.

The Attorney General may initiate civil law suits where there is reasonable cause to believe that conditions are “egregious or flagrant,” that they are subjecting residents to “grievous harm,” and that they are part of a “pattern or practice” of resistance to residents’ full enjoyment of constitutional or Federal rights, including title II of the ADA and section 504 of the Rehabilitation Act. For more information or to bring a matter to the Department of Justice’s attention, contact:

Special Litigation Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66400
Washington, D.C. 20035-6400

www.usdoj.gov/crt/split

(202) 514-6255 (voice/TTY)

Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs.

IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student.

IDEA also mandates that particular procedures be followed in the development of the IEP. Each student's IEP must be developed by a team of knowledgeable persons and must be at least reviewed annually. The team includes the child's teacher; the parents, subject to certain limited exceptions; the child, if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents' or agency's discretion.

If parents disagree with the proposed IEP, they can request a due process hearing and a review from the State educational agency if applicable in that state. They also can appeal the State agency's decision to State or Federal court. For more information, contact:

Office of Special Education Programs
U.S. Department of Education
330 C Street, S.W., Room 3086
Washington, D.C. 20202

www.ed.gov/offices/OSERS/OSEP

(202) 205-5507 (voice/TTY)

Rehabilitation Act

The Rehabilitation Act prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in title I of the Americans with Disabilities Act.

Section 501

Section 501 requires affirmative action and nondiscrimination in employment by Federal agencies of the executive branch. To obtain more information or to file a complaint, employees should contact their agency's Equal Employment Opportunity Office.

Section 503

Section 503 requires affirmative action and prohibits employment discrimination by Federal government contractors and subcontractors with contracts of more than \$10,000. For more information on section 503, contact:

Office of Federal Contract Compliance Programs
U.S. Department of Labor
200 Constitution Avenue, N.W., Room C-3325
Washington, D.C. 20210

www.dol.gov/dol/esa/public/ofcp_prg.htm

(202) 693-0106 (voice/relay)

Section 504

Section 504 states that “no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under” any program or activity that either receives Federal financial assistance or is conducted by any Executive agency or the United States Postal Service.

Each Federal agency has its own set of section 504 regulations that apply to its own programs. Agencies that provide Federal financial assistance also have section 504 regulations covering entities that receive Federal aid. Requirements common to these regulations include reasonable accommodation for employees with disabilities; program accessibility; effective communication with people who have hearing or vision disabilities; and accessible new construction and alterations. Each agency is responsible for enforcing its own regulations. Section 504 may also be enforced through private lawsuits. It is not necessary to file a complaint with a Federal agency or to receive a “right-to-sue” letter before going to court.

For information on how to file 504 complaints with the appropriate agency, contact:

Disability Rights Section Civil
Rights Division
U.S. Department of Justice
P.O. Box 66738
Washington, D.C. 20035-6738

www.usdoj.gov/crt/ada/adahoml.htm

(800) 514-0301 (voice)
(800) 514-0383 (TTY)

Section 508

Section 508 establishes requirements for electronic and information technology developed, maintained, procured, or used by the Federal government. Section 508 requires Federal electronic and information technology to be accessible to people with disabilities, including employees and members of the public.

An accessible information technology system is one that can be operated in a variety of ways and does not rely on a single sense or ability of the user. For example, a system that provides output only in visual format may not be accessible to people with visual impairments and a system that provides output only in audio format may not be accessible to people

who are deaf or hard of hearing. Some individuals with disabilities may need accessibility-related software or peripheral devices in order to use systems that comply with Section 508. For more information on section 508, contact:

U.S. General Services Administration
Center for IT Accommodation (CITA)
1800 F Street, N.W.
Room 1234, MC:MKC
Washington, DC 20405-0001

<http://www.itpolicy.gsa.gov/cita>

(202) 501-4906 (voice)
(202) 501-2010 (TTY)

U.S. Architectural and Transportation
Barriers Compliance Board
1331 F Street, N.W. Suite 1000
Washington, DC 20004-1111

<http://www.access-board.gov>

800-872-2253 (voice)
800-993-2822 (TTY)

Architectural Barriers Act

The Architectural Barriers Act (ABA) requires that buildings and facilities that are designed, constructed, or altered with Federal funds, or leased by a Federal agency, comply with Federal standards for physical accessibility. ABA requirements are limited to architectural standards in new and altered buildings and in newly leased facilities. They do not address the activities conducted in those buildings and facilities. Facilities of the U.S. Postal Service are covered by the ABA. For more information or to file a complaint, contact:

U.S. Architectural and Transportation
Barriers Compliance Board
1331 F Street, N.W., Suite 1000
Washington, D.C. 20004-1111

www.access-board.gov

(800) 872-2253 (voice)

(800) 993-2822 (TTY)

General Sources of Disability Rights Information

ADA Information Line

(800) 514-0301 (voice)

(800) 514-0383 (TTY)

www.usdoj.gov/crt/ada/adahoml.htm

Regional Disability and Business

Technical Assistance Centers

(800) 949-4232 (voice/TTY)

www.adata.org

Statute Citations

Air Carrier Access Act of 1986

49 U.S.C. § 41705

Implementing Regulation:

14 CFR Part 382

Americans with Disabilities Act of 1990

42 U.S.C. §§ 12101 et seq.

Implementing Regulations:

29 CFR Parts 1630, 1602 (Title I, EEOC)

28 CFR Part 35 (Title II, Department of Justice)

49 CFR Parts 27, 37, 38 (Title II, III, Department of Transportation)

28 CFR Part 36 (Title III, Department of Justice)

47 CFR § § 64.601 et seq. (Title IV, FCC)

Architectural Barriers Act of 1968

42 U.S.C. §§ 4151 et seq. Implementing Regulations:
41 CFR Subpart 101-19.6

Civil Rights of Institutionalized Persons Act

42 U.S.C. §§ 1997 et seq.

Fair Housing Amendments Act of 1988

42 U.S.C. §§ 3601 et seq.
Implementing Regulation:
24 CFR Parts 100 et seq.

Individuals with Disabilities Education Act

20 U.S.C. §§ 1400 et seq.
Implementing Regulation:
34 CFR Part 300

National Voter Registration Act of 1993

42 U.S.C. §§ 1973gg et seq.

Section 501 of the Rehabilitation Act of 1973, as amended

29 U.S.C. § 791
Implementing Regulation: 29 CFR § 1614.203

Section 503 of the Rehabilitation Act of 1973, as amended

29 U.S.C. § 793
Implementing Regulation: 41 CFR Part 60-741

Section 504 of the Rehabilitation Act of 1973, as amended

29 U.S.C. § 794

Over 20 Implementing Regulations for federally assisted programs, including:
34 CFR Part 104 (Department of Education)
45 CFR Part 84 (Department of Health and Human Services)
28 CFR §§ 42.501 et seq.

Over 95 Implementing Regulations for federally conducted programs, including:
28 CFR Part 39 (Department of Justice)

Section 508 of the Rehabilitation Act of 1973, as amended
29 U.S.C. § 794d

Telecommunications Act of 1996
47 U.S.C. §§ 255, 251(a)(2)

Voting Accessibility for the Elderly and Handicapped Act of 1984,
42 U.S.C. §§ 1973ee et seq.

*U.S. Government Printing Office: 1998- 417-737174258

WEBSITES OF INTEREST

National Council on Independent Living (NCIL)
www.ncil.org

Directories to Centers in All States

Virtual CIL
Listing of Independent Living Centers in the United States

www.virtualcil.net/cils

ILRU
The ILRU (Independent Living Research Utilization) program is a national center for information, training, research, and technical assistance in independent living.

www.ilru.org

ILRU's listing of Independent Living Centers in the Country.

<http://www.ilru.org/jump1.htm>

Other Disability-Related Links

Office of Personnel Management
Site offers information in clear and understandable language on federal job opportunities, accommodation issues, benefits and telecommuting. Also contains an E-

learning training module for managers on reasonable accommodation, as well as information on laws and executive orders on disability employment.

www.opm.gov/disability

Acces-able

Travel options available to people with disabilities

www.access-able.com

ADA BookStore/Library Initiative

22 pages of books are available during this 10th anniversary celebration

<http://adr-service.com/>

ADA Home page

Department of Justice ADA information.

www.usdoj.gov/crt/ada/adahom1.htm

American Indian Rehabilitation Research and Training Center

The mission of AIRRTC is to improve the quality of life for American Indians and Alaska Natives with disabilities. Affiliated with Northern Arizona University.

www4.nau.edu/ihd/airrtc/

Blind Net

General information about blindness and links to member organizations.

www.blind.net

Center for Accessible Society (CAS)

Acts as a communications clearinghouse dedicated to expanding media coverage of critical disability-related issues. CAS is funded by a five-year grant from the National Institute on Disability and Rehabilitation Research.

www.accessiblesociety.org

Children with Disabilities

This site, part of a joint effort by several Federal agencies to promote a national agenda for children and foster positive youth development, will provide information on learning disabilities, debilitating conditions and physical disabilities.

www.childrenwithdisabilities.ncjrs.org

Concrete Change

Promotes "An international effort to make all homes Visitable! Provides detailed construction guidelines and cost estimates for barrier free design in new homes. Suggests ways to encourage wheelchair accessible construction in all homes.

<http://concretechange.home.mindspring.com>

CyberCil of Arizona

The mission of CyberCil of Arizona is to provide innovative, meaningful assistance in accordance with the principles and philosophy of independent living to, and on behalf of, Arizonans with disabilities so that they may attain or continue an independent lifestyle.

www.cybercil.com

David Carey

David Carey's personal story with links and resources.

www.onesplitsecond.com

Deafness Cross Reference Links

Links to member organizations and information relating to deaf culture.

www.deafworldweb.org/pub/d/deafness.html

Disability Link Barn

Over 1,100 links to magazines, sports information and more.

www.accessunlimited.com/links.html

Disability News Groups

Links to news groups for just about any disability.

www.ability.org.uk/newsgrou.html

Know-the-ADA in Arizona

Arizona Office for Americans with Disabilities Home Page.

www.know-the-ada.com

Managed Care Center

National Clearinghouse for information regarding managed care and people with disabilities.

www.mcare.net

MCS Referral & Resources

Professional outreach, patient support, and public advocacy devoted to the diagnosis, treatment, accommodation, and prevention of Multiple Chemical Sensitivity Disorders.

www.mcsrr.org

Mobility International USA

Facilitates multicultural exchanges among people with disabilities.

www.miusa.org

National Alliance for the Mentally Ill (NAMI)

Education, Support, Advocacy, Outreach and Research. Dedicated to improving the lives of people affected by serious mental illness.

www.nami.org

On A Roll Radio

Talk Radio about life and disability.

www.onarollradio.com

PACER Center

Non-profit organization for families of children and adults with disabilities. The site includes newsletters, articles and legislative information.

www.pacer.org

Pacific Disability Business Technical Assistance Center

ADA questions answered and materials distributed.

www.pacdbtac.org

Parents with a Disability

Forum for parents with a disability to meet and exchange experiences.

<http://rainforest.parentsplace.com/dialog/get/disability.html>

Southwest Institute for Families & Children and Special Needs

The Southwest Institute has administered projects funded by the U.S. HRSA/Maternal and Child Health Bureau (MCHB), the U.S. Department of Education/ Office of Special Education Programs (OSEP), and the American Academy of Pediatrics.

www.ppmhome.com

World Institute on Disability

Conducts international research and develops policy for cutting-edge disability issues and tries to overcome obstacles to independent living.

www.wid.org

WRITTEN PROOF YOU ARE NOT ALONE

We sometimes need proof that we are not alone in experiencing a disability. There are many books, journals and magazines that tell our stories, and have updates on current issues and resources. The following is a small sampling of periodicals that can introduce you to ideas and resources.

ACCENT ON LIVING

Like a "Readers Digest." Personal stories, resources and humor. Gillum Rd. and High Dr., P.O. Box 700, Bloomington, IL 61702

DISABILITY INTERNATIONAL

Get a wider view, learn what people with disabilities are doing all over the world. Quarterly. 101-7 Evergreen Place, Winnipeg, MB Canada R3L 2T3

SPORTS 'N SPOKES

By-monthly magazine published by the Paralyzed Veterans of America, focusing on adapted sports for persons with disabilities. 2111 East Highland Ave., Suite 180, Phoenix, AZ 85016-4702

DISABILITY TODAY

Advanced equity & opportunity for people with a disability. Quarterly. P.O. Box 2659 Niagara Falls, NY 14302-9945

IT'S OK!

Living with a disability, putting it in perspective. Focuses on relationships and sexuality. Quarterly. Sureen Publishing, Box 23102, 124 Welland Ave., St. Catherines, ONT, Canada L2R 7P6

ABILITY

Health, Disability, Human Potential, Personal stories and resources. P.O. Box 4140 Irvine, AZ 92716-9919

MOUTH

Grass roots, hard hitting and humorous look at the disability movement, oppression and the proactive action being taken to set things right. Articles, poetry and cartoons. 61 Brighton St., Rochester, NY 14607. Bi-monthly.

EXCEPTIONAL PARENT

Support for parenting with a disability. 209 Harvard St., Suite 303, Brookline, MA 02146-5005

NEW MOBILITY

Disability Lifestyle, Culture and Resources. Monthly. P.O. Box 15518 North Hollywood, CA 91615-5518

RAGGED EDGE

The Disability Experience in America (formerly the Disability Rag & Resource) The voice of a mighty revolution, spirited and provocative stories that strive to change the way people view what it means to have a disability. The Avocado Press, Box 145, Louisville, KY 40201.

SUGGESTED READINGS

A Sourcebook for Families Coping with Mental Illness: A Guide for Preventing the Other Shoe from Dropping, Edited by Michael R. Berren, Ph.D.; McMurray Publishing, Inc.; Phoenix, Arizona; 2002.

Freedom of Movement: Independent Living History and Philosophy, by Steve Brown; Institute on Disability Culture, **ilrubookshelf** series, ILRU; Houston, Texas; 2000.

From Good Will to Civil Rights: Transforming Federal Disability Policy, by Robert K. Scotch; Temple University Press; Philadelphia; 1984.

Moving Violations by John Hockenberry; Hyperion Press; NY; 1995.

Nothing About Us Without Us: The Dialectics of Disability by James Charlton; University of California Press; Berkeley; 2000.

No Pity: People with Disabilities Forging a New Civil Rights Movement, by Joseph P. Shapiro, Times Books, A Division of Random House; NY; 1993.

This is a very brief list of readings. There are hundreds of excellent books on disability culture and issues. One book always leads to another.