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Independent Living in America

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RESUMEN

El Movimiento de Vida Independiente, como ha acontecido en los Estados Unidos de América, ha tenido un profundo impacto en la inclusión en la comunidad y la igualdad de las personas con discapacidades severas. Este artículo proporciona una descripción histórica y filosófica del Movimiento de Vida Independiente. Los Centros de Vida Independiente son la manifestación de la filosofía de Vida Independiente. Se discuten los servicios básicos ofrecidos por estos centros. También se destacan algunos temas emergentes que pueden influir en el futuro del Movimiento de Vida Independiente.

ABSTRACT

The Independent Living Movement, as it has occurred in the United States of America, has profoundly impacted the community inclusion and equality of people with significant disabilities. This article provides a historical and philosophical description of the Independent Living Movement. Centers for Independent Living are the manifestation of the IL philosophy. These are discussed in terms of core services offered. Emerging themes which may influence Independent Living in the future are also highlighted.

PALABRAS CLAVE: Movimiento de Vida Independiente; Empoderamiento; Personas con discapacidad severa.
KEYWORDS: Independent Living Movement; Empowerment; People with significant disabilities.

INTRODUCTION

> The ultimate goal of independence, of independent living programs, of advocacy and communication of the disability rights movement is the conscious assumption by each human being of complete responsibility for his or her existence, and a fulfillment of that responsibility which results in maximal productivity in terms of life quality for the self and for society as a whole. (Nosek, Narita, Dart & Dart, 1982)

When evaluating the human experience and quality of life of individuals with disabilities in the United States, the impact of the Disability Rights and Independent Living Movement of the 1960's to present time is paramount. This movement spurred the socio-political empowerment of people with disabilities (PWD) in pursuit of social justice and integration. Progress has been made, however, prejudice and discrimination toward people with disabilities remains a salient civil rights issue today. Consider the current state of the disability experience in the United States:

- Unemployment of individuals with significant disabilities remains high with figures ranging from 20 to 69%; underemployment and poverty are prevalent (Erickson, Lee, & von Schrader, 2010; U.S. Department of Labor, 2011);
- A lack of integrated, affordable and accessible residential living options (National Council on Disability, 2010);
- Community access barriers (i.e., architectural, transportation and technology).
- Limited access to, or graduation from, post secondary education (Getzel & Thoma, 2008);
- Health care disparities; lack of healthcare and barriers to healthcare (National Council Disability, 2009); and,
- Incidents of violence and abuse (Teplin, McClelland, Abram , & Weiner , 2006; Petersilia, 2001; Fitzsimmons, 2009).

As with any civil rights endeavor, there is a persistent need for sustained effort to eradicate injustices and inequality of the marginalized population. This article will discuss the IL movement in the United States within a historical, social, and legislative context as it seeks the integration of individuals with disabilities.

ORIGIN AND HISTORY OF INDEPENDENT LIVING

The Disability Rights and Independent Living movement, which began in the 1960's, was influenced by several social movements within the United States. While the civil rights movements of African-Americans and that of Women are well-known; the self-help; de-medicalization; consumer; and the de-institutionalization movements feature prominently for PWD (DeJong, 1979).

In describing the self-help movement, it is a movement whereby PWD engage in activities that may improve upon psychological, social, financial, and/or educational aspects of the person's life. The individual is not dependent upon a professional per se to achieve optimal functioning. Improvement strategies may include involvement in self-help groups that share a common interest. VandenBos (2007), editor of the APA Dictionary of Psychology, states that potential benefits of self-help groups include friendship, emotional support, experiential knowledge, identity, meaningful roles, and a sense of belonging.

Through the de-medicalization movement, individuals are no longer defined through labels of deviance, illness and sickness (Zola, 1982; Conrad & Schneider, 1992). Disability and sickness are viewed as a part of the human experience. Whereas previously the "medicalized" patient was perceived as abnormal or unwell, he/she passively received medical advice and treatment deferring entirely to the medical expert. De-medicalization empowered patients to be viewed holistically, and to question, to gather additional information, and to determine the course of treatment based upon medical advice.

That is, an individual is responsible for his/her own healthcare. This is closely tied to the consumer movement.

The consumer movement strove to protect consumers from unsafe and/or inferior products in the 1960s. It is founded upon the concept that consumers of goods and services are entitled to quality and choice. This belief implies that a recourse or redress is available should a product or service be hazardous, or not offer what it is intended or promised to offer. PWDs moved beyond being defined solely as patients and instead are seen as consumers of services and products, and as such, having access to, and selecting quality services.

De-institutionalization originated in response to the institutionalization of individuals with significant disabilities, primarily those with psychiatric and/or intellectual disabilities (Stroman, 2003). This movement spurred a demand for community based residential and health care options. However, the transition from institutions to communities has not been seamless, many communities continue to have inadequate resources and options to support community integration for PWD (Torey, 2008). Nonetheless, the policy implications of transitioning from institutional living to community living were apparent within the disability rights movement.

Fueled by these social movements focusing upon empowerment, the premise of the IL movement is that PWD, including those with the most significant disabilities, should have the right to make decisions and choices that impact their own lives, as well as, optimal access to the communities in which they live. The choices and goals of IL typically address access issues relevant to the following aspects: residential options; employment; social-recreational options; education; supports and services (such as attendant care, benefits planning, assistive technology and healthcare); physical and financial independence; legal rights and policy, and overall equality. Simply stated, the intent is the full and complete participation of the individual within the community of one’s choice. The movement also advocates for architectural and transportation accessibility which greatly impacts mobility and integration. Thus in 1972, disability activists established the first Center for Independent Living (CIL) in Berkeley, California. Early activists and progenitors of IL included Ed Roberts, Judy Heumann, Justin Dart, Jr, and Gerben DeJong, among others. Table 1 highlights the values typically associated with Independent Living. The reader will note that a ubiquitous theme of these values is the empowerment of the individual.

Table 1. Philosophy/Values Associated with IL

Value	Concept
Informed Choice	Informed connotes that one is familiar with all aspects of a decision, including potential outcomes. Choice implies more than one option from which to select. Thus, the individual has a menu of options and determines the optimal one.
Self-Determination	To direct one's own life experiences and decisions to the best of one's ability. To exert control over the course of one's life. Self-determination is closely linked to self-advocacy.
Self-Advocacy	The opportunity to assertively pursue outcomes and experiences of one's own choosing. To pursue individual rights typically afforded all members within a specific society.
Person First	Focus is upon the individual as a whole, including strengths and assets. The individual is not viewed primarily as a characteristic, impairment, label, or diagnosis. This is a capacity versus a deficit orientation.

DEFINING IL

In understanding IL we need to go back to an early definition as described by Frieden, Richards, Cole, & Baily (1979):

> Control over one's life based on the choice of acceptable options . . . managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of physical or psychological dependence upon others…Independent living is not dependent upon programs that foster functional independence. Instead, it is based upon the individual's ability to choose and achieve a desired lifestyle and to function freely in society. (p. 3).

The spirit of the Frieden et. al. definition of independent living is consistent with the independent living paradigm first depicted by DeJong (1979):

> The independent living paradigm has emerged, in part, as a response to the anomaly of the severely physically disabled person. According to the independent living paradigm the problem does not reside in the individual but often in the solution offered by the rehabilitation paradigm ---the dependency inducing features of the physician-patient or professional-client relationship. Rehabilitation is seen as part of the problem, not the solution. The locus of the problems is not the individual but the environment that includes not only the rehabilitation process but also the physical environment and the social control mechanisms in society-at-large. To cope with these environmental barriers, the disabled person must shed the patient or client role for the consumer role. Advocacy, peer counseling, self-help, consumer control and barrier removal are the trademarks of the independent living paradigm. (p. 66).

What these definitions express is the barriers and challenges to full inclusion typically experienced by PWD are a result of environmental or external causes versus the characteristics or inner workings of the individual. Such challenges are apropos to: societal attitudes which lead to stigma and prejudice; a professional culture which values an expert orientation; lack of physical accessibility of buildings, transportation, and communities; and lack of resources and options for housing, employment, recreation/leisure, health care and education. Therefore, it is the responsibility of society to eradicate these barriers to inclusion, i.e., to “fix” the community versus the individual. The individual with a disability may, to his/her maximum ability, assist in this process through self-advocacy and self-determination. A comparison of the traditional medical/rehabilitation model to the independent living model, as developed by DeJong (1979), is provided in Table 2

Table 2. The Independent Living Paradigm

	Medical/Rehabilitation Model	Independent Living Model
Definition of the Problem	Physical or mental impairment; lack of vocational skill, lack of education, lack of socio-economic status, lack of political and cultural skills	Dependence upon professionals, family members and others; hostile attitudes and environments; lack of legal protection; lack of recognition of inherent worth of people with disabilities (stereotypes)
Locus of the Problem	In the individual (individual is “broken” or “sick” and needs to be “fixed” or “cured” to “fit” into society)	In the socio-economic, political, and cultural environment; in the physical environment; in the medical, rehabilitation, service delivery or charity processes themselves (dependency-creating)
Solution to the Problem	Professional interventions; treatment; “case management”, or volunteer work based on pity and related attitudes	Advocacy – Barrier Removal – Consumer Control over options and services – Peer role models and leaders – Self Help. All lead to equitable socio-economic, cultural and political options
Social Role of Person	Individual with a disability is a “patient”, “client”, or recipient of charity; in many situations, the social role is non-existent	Family and community members; “consumers” or “customers”, “users” of services and products – just like anyone else
Who Controls	Professional	Person with disability or his/her choice of another individual or group
Desired Outcomes	Maximum self-care (or “ADL” – activities of daily living as used in occupational therapeutic sense); gainful employment in the vocational rehabilitation system; no “social misfits” or no “manipulative clients”	Independence through control over acceptable options for living in an integrated community of choice; pride in unique talents and attributes of each individual; positive disability identity

(Developed by Gerben DeJong; adapted by Maggie Shreve.
www.umich.edu/~uminds/Lectures/2006Fall/IL%20Paradigm.doc)

LEGISLATIVE POLICY BASIS OF IL

Social change in the United States is a process often predicated upon a legislative policy foundation. Mandating policy on a federal level does not guarantee a pervasive adoption of a new policy or a new attitude; however, it may be a motivating factor in developing the systemic awareness that leads to societal change relevant to members of a marginalized culture. For example, civil rights and employment legislation such as the Americans with Disabilities Act and Amendments; the Individuals with Disabilities Education Act; the Developmental Disabilities Assistance and Bill of Rights Act; the Workforce Investment Act of 1998 (WIA); and the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) strive to improve the quality of life and employment opportunities for people with disabilities and end discrimination. With their enaction, many programs and services have been implemented using the standards of these legislative Acts.

For instance, CILs were established, and are regulated, by the Rehabilitation Act of 1973, as amended, Title VII, Chapter 1, Part C, Secs. 721-727; 29 U.S.C. 796f-796f-6. The Rehabilitation Act is included in the Workforce Investment Act (WIA). These regulations address the funding, planning, services, and evaluation of CILs.

CENTERS FOR INDEPENDENT LIVING

The first CIL was established in the 1972, today there are over 390 CILs, 56 Statewide Independent Living Councils and 330 branch offices across the country and U.S. territories (NCIL, 2010). Section 702 of the Rehabilitation Act of 1973, as amended, defines a Center for Independent Living as “a consumer-controlled, community-based, cross-disability, non-residential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services.” (Rehabilitation Act of 1973, 29 U.S.C § 702, 197)

It is important to stress that CILs are not a residential program. The IL movement does not support institutionalized or segregated living arrangements. It fosters inclusion within existing communities. Centers are non-profit organizations, funded by state, federal, local and private dollars. Part C of Title VII of the Federal Rehabilitation Act (monitored by the Rehabilitation Services Administration, Office of Special Education and Rehabilitative Services) provides operational money for CILs. Centers may also seek local and private funding to meet service needs which have been identified at the local level. Each state must establish a statewide independent living council (SILC) in order to receive federal assistance. The SILC typically develops a statewide strategic plan for CILs located within a respective state. Beyond individual advocacy, CILs are charged with systems change advocacy that builds community capacity to meet the needs of individuals with significant disabilities as well as improve quality of life.

Operational and administrative decision making and processes of the CIL must be controlled by individuals with disabilities. Typically, fifty-one percent of CIL personnel and fifty-one percent of the Board of Directors must experience a disability, thereby adhering to the grass roots advocacy foundation of the movement. CILs may provide a variety of services. However, there are four core services, which all CILs must provide. These include: individual and system’s change advocacy, peer counseling, independent living skills training (ILST), and information and referral (I & R). Additional services may include, but not be limited to: personal assistance services and referral; assistive technology; Housing; financial benefits counseling; deaf services; blind services; youth programs and/or support groups.

The following scenarios provide examples of the core services offered by CILs.

Savannah: Peer Counseling, ILST, and I & R

Savannah is 27 years old and has a Master of Arts in Education. She has one year of teaching experience. Nine months ago she experienced a traumatic brain injury as a result of a motorcycle accident. Her injury has impacted her memory and mobility. Savannah is not sure if she can return to work as an educator. She is working with a rehabilitation counselor to help her with her vocational goals. She rents a second floor apartment and has difficulty with the stairs, so she may need to locate alternative housing. She is aware that she has changed and that her life is different since her accident, however, she is anxious about these changes and the uncertainty in her life. Savannah's rehabilitation counselor referred her to the local Center for Independent Living where she is receiving peer counseling and skills development services. Her peer counselor, Jordan, has multiple sclerosis and is a chair user. Savannah and Jordan talk about living with a disability, particularly employment, building self-confidence, and social aspects. Savannah is taking two courses at the CIL where she is learning to be a stronger advocate for herself, and job seeking skills such as resume writing, interviewing and talking to employers. In one of her classes, she met another young woman with a brain injury and they have begun to socialize. They also attend a brain injury support group together. The CIL is working with Savannah to locate housing in an apartment building with an elevator, or on the ground floor.

Chase: I & R

Chase is a vibrant and active young man who is 31 years old. He experienced a spinal cord injury as a result of a skiing accident. This resulted in paraplegia and the need for a wheelchair. Chase has a good job, working as an instructional technology technician. He recently bought a van so that he can get to, and from, work independently. The van needs to be equipped with a lift and hand controls so that he can drive. Chase contacted the local CIL. They referred him to three community vendors that specialize in customizing motor vehicles with accessibility equipment. Chase contacted all three, and selected the vendor he believed would give him the best price and service. While in conversation with the CIL staff, Chase also mentioned that he felt his wheelchair was antiquated and did not meet the functional needs of his active lifestyle. The staff person, who is a wheel chair user as well, suggested that Chase look at a contemporary model specifically designed for athletes. Chase followed up on this suggestion and is now working with his health insurance company to purchase the newer model.

Josephine: I & R and Advocacy

Josephine is a 48-year-old woman who has bipolar affective disorder. She is a single mother and has very little work history. She has tried to work in the past, but has been unable to sustain employment. She has a nice home, but does not have any income and is on food assistance from the government. Josephine's niece works with people with disabilities and suggested she contact the Ability Center, which is a CIL. The CIL staff provided information and referral services for Josephine. They referred her to a disability benefits attorney. The attorney assisted Josephine in applying for federal benefits. Her initial application was denied. The attorney filed an appeal on Josephine's behalf, pro bono, and represented her during the appeal process. Her appeal was approved and she now receives a minor monthly benefit that will allow her to continue living in her home with her children.

EMERGING THEMES: IL TODAY

The climate of the IL Movement today is dynamic, with some elements of uncertainty. Emerging themes apropos to IL include: funding issues; management and oversight; and continued systems change (i.e., policy and practice based). These themes are not all inclusive, but are several themes of note to the authors, with potential consequences to full and equal access of PWD.

FUNDING

As mentioned, CILs depend primarily upon federal funding in order to provide services. The current economic climate in the United States has experienced sustained fiscal challenges that have, and will continue to, result in the need for a thorough evaluation of spending and potential areas of reduction (GAO, 2011 a&b). The past two presidential administrations (Presidents Bush and Obama) have recommended zero funding for several programs serving people with disabilities. The Fiscal Year 2012 Budget proposes to eliminate the current funding streams for Part B and C Centers for Independent Living program. The budget would replace the funding mechanism with a new grants program (National Council on Independent Living, 2011). This proposal would place federal dollars with the State governments to spend at their discretion. In order for a funding restructuring to occur the Rehabilitation Act would need to be reauthorized and significantly changed.

Should these programs continue to be vulnerable, the impact upon the integration of PWD may be highly detrimental. Most probably consumer control of CILs will be reduced and many CILs would close due to a lack of working capital (NCIL, 2011). To date, Congress has not approved budget recommendations to cut spending for these programs. However, the future is precarious, necessitating fiscal and outcome based accountability and perhaps re-structuring of programs. Even without the approval of the President's budget recommendations, fiscal reductions have been ongoing, requiring CILs to adjust services, restructure and/or terminate personnel, etc. It is anticipated that this struggle for survival will continue for many years to come.

CONTINUED SYSTEMS CHANGE

Access and policy/practice aspects comprise some of the emerging issues in IL today. They include the establishment of an IL Administration, a renewal of intent with the Americans with Disabilities Act, and the promotion of well being and health care for PWD, and improving access and service options to name a few.

ESTABLISHMENT OF AN INDEPENDENT LIVING ADMINISTRATION

Advocates of the IL movement have proposed the development of a national Independent Living Administration (ILA), separate from the federal Rehabilitation Services Administration, and housed within the Department of Education (NCIL, 2010). A bill to develop an ILA was recently filed with the HELP Committee of the U.S. Senate in June of 2011 (NCIL, 2011). NCIL contends that the Rehabilitation Act and the Workforce Investment Act must be reauthorized with consideration given to restructuring and strengthening of the IL programs. An ILA would increase efficiency and consumer control at the federal level. This would also provide an opportunity to further develop and benefit from a nationwide infrastructure of consumer controlled entities including CILs and SILCs (NCIL, 2010). NCIL lists several specific highlights of an ILA including: consolidation of funding streams; carryover authority of Part C funds; addition of a 5th core service (i.e., transitioning people with disabilities from nursing homes and other institutions to home and community-based residences); clarification of the role of SILC; funding Formula Change; and accessibility at WIA One-Stop Centers.

ADA AMENDMENTS

In 2008, President George W. Bush signed the Americans with Disabilities Amendments Act (ADAA). This Act was a restoration of the intent of the Americans with Disabilities Act (ADA) signed by President George H. W. Bush in 1990. Over the course of 18 years the United States Supreme Court consistently made decisions that substantially reduced the scope and intent of the original ADA. The Amendments clarify and expand the definition of disability, overturn prior Supreme Court decisions, and protect PWD from discrimination. The revitalization and strengthening of the ADA will be instrumental to the inclusion of PWD. The social justice values and philosophies of Independent Living will manifest within the case law and implementation of the ADAA in years to come.

HEALTH PROMOTION AND HEALTH CARE

The need for health promotion and the existence of health care disparities continue to plague PWD (Nosek & Simmons, 2007; Altman & Bernstein, 2008; Rimmer, 2005). PWD are an underserved population in the United States often experiencing disparities resulting from secondary conditions that typically are preventable (Nosek & Simmons, 2007). Disparities may be based upon several factors to include: attitudinal; physical, communication and cost; lack of information targeting the needs of people with disabilities; misinformation and lack of early intervention (Nosek, & Simmons, 2007; Altman & Bernstein, 2008).

LACK OF COMMUNITY BASED OPTIONS

De-institutionalization and the integration of PWD has been a positive occurrence overall in the lives of PWD and their families. However, there have been unintended consequences as a result of this movement. Many communities did not, nor do they, have the residential, employment, support options, and service providers to assist PWD to become contributing members. Many PWD remain without work, live below the poverty level, have little or no social interaction and often live in segregated settings. Services often are not coordinated and do not meet the multiple and complicated needs of PWD (Torrey, 2008). Employment support services continue to be of particular import (Wehman, Inge, Revell, & Brooke, 2005).

CONCLUSION

Going forward, while strides have been made to improve the inclusion and independent living of PWD, significant work remains. The continued support and development of IL better provides opportunities for PWD to live a life in which they have the freedom to choose and to contribute fully to their communities. System's change spurred by civil rights movements often takes decades to achieve, it is dynamic and based upon the realization of successive milestones. Independent Living continues to play a central role in the full inclusion of people with disabilities within the United States.

IL ONLINE RESOURCES:

ADAPT

http://www.adapt.org/

Independent Living Research Utilization Center

http://www.ilru.org/html/publications/directory/index.html

CIL Legislation, Regulation and Guidance

http://www2.ed.gov/programs/cil/legislation.html

Disability Rights and Education Disability Fund (DREDF)

http://www.dredf.org/

National Council on Independent Living

http://www.ncil.org/index.html

The Movement for Independent Living: A brief history

www.ilusa.com/articles/mshreve_article_ilc.htm

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