

Self-Empowerment: The Independent Living Movement

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by Lisa Tarricone

“No one can make you feel inferior without your consent.”

Eleanor Roosevelt

In the Beginning — Birth of the Independent Living Movement

When Ed Roberts entered the University of California at Berkeley in 1962, the headlines of a local newspaper announced his arrival: “Helpless cripple goes to school.” But to Roberts, a post polio quadriplegic who slept in an iron lung at night, Berkeley would be his message out to the nation, heralding a new disability rights movement built on self-belief, determination, and independence.

“Independent living had become a full-fledged civil rights issue...”

At Berkeley, Roberts, in unison with other disabled student activists, started the Physically Disabled Students Program (PDSP) to address the rampant inaccessibility on campus, by setting up an advocacy department to assist disabled students with accessible living arrangements, benefits, and services. Utilizing the principles established by PDSP as an advocacy tool for disabled students, the Center for Independent Living was created in 1972 as a parallel program for disabled people in the community. *Independent living* had become a full-fledged civil rights issue, prompting enactment of the Civil Rights Act for the Disabled (Section 504 of the Rehabilitation Act) in 1973. This legislation prohibits discrimination against disabled persons in programs, services and benefits that are Federally funded, and set the foundation for future generations of disabled individuals to have access to and be able to engage in life pursuits not

afforded previous generations of disabled individuals. By 1978, under Rehabilitation Act Amendments, the Federal Government began to provide funding to establish Independent Living Centers (ILCs) in virtually every state and U.S. territory. To date, over three hundred Independent Living Centers, or ILCs, exist nationwide based on the tenants of self-empowerment that Roberts established for himself and his peers.

The Philosophy of Independent Living

Independent Living is based on the belief that persons with disabilities have the same basic human rights as persons without disabilities to participate in and contribute to community life. The philosophy behind the Independent Living Movement is defined in terms of the *control* that a disabled person has over his or her life. As such, the ILCs ideally and mostly are operated by disabled people serving as models and experts in running their own self-help programs. Independent Living is a drastic shift away from the view that disabled is equivalent to sick and dependent — that persons with disabilities need to be looked after, cared for, and pitied, because they’re disabled. Independent Living’s fundamental principle is **empowerment** rather than “care”. In the words of Ed Hooper who writes for *The Disability Rag* magazine: “If we agree that the status quo is unacceptable, we must affect change, or start wheeling back to our place in society’s shadows and corners.”

Westchester Independent Living Center — Services, Outreach, and Advocacy

The Westchester Independent Living Center (WILC), located at 297 Knollwood Road in White Plains, New York, is part of the national network of Independent Living Centers and serves as both a resource and referral center for persons with disabilities who reside and/or work in Westchester County, New York. WILC’s services are non-residential, non-medical, and delivered by qualified individuals with various disabilities. Executive Director Joseph Bravo says that optimally the services offered at WILC should provide the incentive for disabled consumers to eventually advocate for themselves. “I would like to see our disabled constituency

become more proactive in making their voices heard and their needs known,” states Bravo. He stresses the importance of “personal responsibility” and leadership development to consumers: “No one else will state your case for you, not even WILC. In the meantime, maximize what is available and have a plan to move on with your life.”

What is available at WILC are a broad range of programs and services provided free of charge to any disabled individual and/or his/her family members. The programs that follow are offered without regard to age, sex, ethnicity, or religious affiliation, and additional services can be custom designed to meet individual or family needs.

- **Peer Advisor Advocacy Program:** The Center provides individual and group counseling services, offering individuals with disabilities emotional support and practical advice on issues such as educational and vocational opportunities, housing, adaptive equipment, and financial management.
- **Benefits & Entitlements Services:** Assistance is provided to help consumers understand what resources are available to them and how to effectively make informed choices regarding: Social Security Disability, Supplemental Security Income, Medicare, Medicaid, food stamps, and work incentive programs.
- **Information and Referral:** The Center provides information on, and referrals to, services available for individuals with varying disabilities, and in addition, offers a resource/legal library on issues related to disability.
- **Mental Health Advocacy Program:** This service supports the empowerment of individuals labeled mentally ill by helping them identify and make quality of life choices, increasing opportunities in the community, and by providing advocacy and benefits counseling to mental health recipients/consumers/survivors throughout Westchester County.
- **Client Assistance Program (CAP):** WILC serves as the regional office for this program, servicing seven lower Hudson Valley counties. CAP provides information and advocacy services to individuals trying to access vocational and rehabilitation

Family Caregivers Take Charge

(Editors Note: This article was compiled by Irene Selver from material provided by the National Family Caregivers Association.)

“Anyone can become a caregiver at a moment’s notice” says Cindy Fowler, co-founder of the National Family Caregivers Association (NFCA). Though the circumstances are different for each individual caregiver, many share the same concerns, questions, fears and sense of isolation. “We all hurt the same way, feel the same guilt,” says Suzanne Mintz, NFCA’s other co-founder. “We all want our loved ones to be well, we all want a miracle. We all experience frustration more than other people do and we all start to feel invisible and isolated. We rarely get the help we need. What we have in common are our emotions.” Angry at being so isolated and ignored in their challenging role as caregivers, these two friends channeled their frustration and began the National Family Caregivers Association in 1993.

NFCA is a not-for-profit membership organization whose mission is to improve the overall quality of life of America’s more than 25 million family caregivers. As family caregivers focus on their loved one’s needs, NFCA focuses on family caregivers. It is the only national organization serving all family caregivers, regardless of their relationship to the person receiving care or the specifics of the medical situations they confront.

Membership to NFCA is open to family caregivers, their friends, and the professionals and institutions supporting them. Through its services in the areas of education and information, support and valida-

tion, public awareness and advocacy, NFCA strives to minimize the disparity between a caregiver’s quality of life and that of mainstream Americans.

Family caregivers are known to provide approximately 80% of all the home care in this country. Three-fourths of all caregivers are women. According to surveys conducted by NFCA and backed by other studies, caregivers tend to neglect their own health, developing what Suzanne Mintz refers to as “Caregiver Disorder”. She points out

*Taking care of yourself
as a Caregiver...
is a selfless act.*

that as family caregiving is about chronic, long-term care, occurring mostly in the home behind closed doors, it goes unnoticed in our current health care system. As caregivers struggle to create as good a quality of life for the family as possible, there is a loss of normalcy that needs to be recognized and addressed. “‘Caregiver Disorder’ needs to be recognized as a very real syndrome — one that is treatable with education, proper psychosocial and medical attention, and an appropriate level of help and support from others. But it can’t be treated until caregivers, the health care community, policy makers and the general public recognize its existence. Caregiving

needs to lose its cloak of invisibility.”

Quoting the founders of NFCA, “Taking care of yourself as a Caregiver is not a selfish act, it is a selfless act”, the organization provides a variety of services which include: a quarterly page newsletter, **TAKE CARE! Self Care for the Family Caregiver**; a **Caregiver to Caregiver Support Network**; the **NFCA Speaker’s Bureau**; the **NFCA Caregiver Member Survey Report**; a new **Bereavement Program** for former family caregivers; **Cards for Caregivers**; and the **National Family Caregivers Week Celebration**, to raise public awareness and caregiver consciousness. Also available is NFCA’s resource guide, *The Resourceful Caregiver: Helping Family Caregivers Help Themselves*.

From their own personal experiences as family caregivers, Suzanne Mintz and Cynthia Fowler co-founded the National Family Caregivers Association around the following Principles of Caregiver Self Advocacy:

- Choose to take charge of your life.
- Honor, value and love yourself.
- Seek, accept and at times demand help.
- Stand up and be counted.

For additional information or to receive a membership packet, please contact: National Family Caregivers Association

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benefits and services through both government and private programs.

- **Traumatic Brain Injury Services:** Information, referral, and services are provided to individuals with traumatic brain injury and their families. In addition to assisting consumers with TBI with relocation opportunities, this program helps to identify and address the gaps that exist in the continuum of care for TBI in the region — from coma to re-entry into the community.
- **Minority Outreach & Integration Project:** This project seeks to build lasting bridges to the African-

American and Hispanic communities in Westchester by ensuring that minority consumers have full-range access to the resources available for people with disabilities and equal opportunity to participate in all aspects of community life.

- **Social Integration Program for Visually Impaired Elderly:** Community specialist and older adult volunteers assist visually impaired clients, 55 and older, with activities linked to maintaining or re-establishing social integration.
- **Mentoring Program for Individuals who are Legally Blind:** The Mentoring Program provides individuals who are legally blind with peer assistance to challenge and inspire them to pursue a realistic goal and to strive for a new level of personal satisfaction.

Westchester County is home to approximately 150,000 persons with varying disabilities. WILC’s Systems Advocacy Services will take necessary actions to make systematic changes on community issues that effect people with disabilities as a group. “We need to collectively work toward changing our communities in order to positively affect the quality of disabled individual’s lives,” affirms Joe Bravo. For more information about what you can do to get involved and/or participate in any of the services that WILC offers, contact The Center at: 914-682-3926.

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