

## THE STATE OF THE INDEPENDENT LIVING MOVEMENT

SIMI LITVAK, PH.D.

*World Institution on Disability, Oakland, California*

DOUGLAS MARTIN, PH.D.

*University of California at Los Angeles*

### ABSTRACT

The Independent Living Movement, over the past twenty years, is responsible for a major paradigm shift of services for people with disabilities from a medical/charity/pity model to a minority/civil rights model. Despite substantial improvements in the ability of disabled persons to live, work, go to school, and lead productive lives, the Movement is at a crossroads. Conflicts have arisen between old and new policies. While the Movement has become an expert player in the field of social change, securing civil rights and laying the groundwork for long-term policy influence, disabled persons remain among the poorest in the country. Unemployment and underemployment, inaccessible housing, homelessness, and exclusion from education and transportation remain difficult problems.

The twenty-year-old Independent Living Movement, the self-help movement for people with disabilities, is at a crossroads.

The extraordinary work of disability advocates, ranging from blocking public doorways to drafting legislation, has produced enormous improvements in our ability to live, work, go to school, and lead productive lives. The Movement has exposed and alleviated the architectural, psychological, and social barriers that have tended to exclude us. It is responsible for a paradigm shift of services for people with disabilities from a medical/charity/pity model to a minority/civil rights model. The new paradigm is based on the principle that we are experts on our own disabilities, and should be in control not only of the design and conduct

of services and support that we need, but also participants in the development of policies that directly affect our lives.

The crossroads we are at today is a conflict between old and new policies, a conflict that is partially a result of our past successes.

The substantial improvements in benefits, such as health insurance, assistive technology, and personal assistance, are for the most part available only to disabled people at or below the poverty level. Those of us who are not that poor still cannot afford them.

The hard-won right to accessible work conflicts with an entitlement to disability benefits based on an inability to work. In a recent case, a judge ruled that a person with AIDS cannot claim both SSDI and file suit for a wrongful discharge from his job due to disability discrimination. Those who need SSI and SSDI must prove they cannot work, yet more and more people with significant disabilities are demanding the opportunity to work, and proving that they can.

Many people with disabilities have entitlement to placement in nursing homes or other institutions, but they have no entitlement to support services when they live in the community.

The shift of Medicaid, Medicare, and group health insurance to managed care is an alarming development. Managed care literally discourages the enrollment of people with disabilities, because they are frequent users of health and rehabilitation services.

Finally, devolution of policy making to individual states will undercut the carefully-crafted network of Federal support for people with disabilities.

Yet never before has the Independent Living Movement been better able to advocate and bring about an improved quality of life for all disabled people. It has become a skilled and experienced player in the field of social change. Our numerous successes have been more than improvements in current services and policies. We have laid the groundwork for long-term influence, such as policy changes, placing our leaders in positions of power, building community-based services and political organizations around the world controlled by people with disabilities, and influencing other movements to take up our issues.

The Independent Living Movement was an important force in the adoption of the Section 504 regulations in the late 70s, and in the passage of the Americans with Disabilities Act in 1990 (ADA). The National Council on Independent Living and the Consortium for Citizens with Disabilities played pivotal roles in adding client choice and personal assistance services (PAS) planning to the Rehabilitation Act in 1992. The Act also mandated State Independent Living Councils controlled by people with disabilities with power equal to that of other state agencies.

The number of Independent Living Centers (ILCs) has grown from three in 1972 to more than 400 today. And the independent living idea has spread to nu-

merous other countries—to Japan, for example, where there are now fifty ILCs. Another significant development is that Russia and England have adopted their own version of the ADA.

New organizations have sprung up to focus on specific disability-related issues. The World Institute on Disability provides policy analysis, research, and public education from the point of view of people with disabilities. American Disabled for Attendant Program Today (ADAPT), a national direct-action organization, fought for accessible transportation and is now pushing for effective personal assistance services. Disability Rights Education Defense Fund (DREDF) is an important legal arm of the IL movement. Psychiatric survivors, deaf people, and those with mental retardation or brain injuries are beginning to assert their right to control of the institutions and organizations that serve them.

The Independent Living Movement (ILM) leaders have served on the Clinton Health Care Reform Task Force, on the Vice President's Telecommunications Task Force, and are now routinely invited to consult with General Accounting Office (GAO), Social Security Administration (SSA), Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services (ASPE), and other federal agencies on research projects. On both State and Federal levels, disabled appointees, many with long involvement in the IL Movement, either administer or have influential positions in government agencies responsible for disability programs.

The Independent Living Movement has come a long way toward increasing consumer control of the institutions that serve disabled people. But we remain among the poorest in this country, and continue to have very high unemployment and under-employment rates. Too many of us still live in inaccessible housing, and we make up too large a percentage of the homeless. We continue to be excluded from adequate education. Transportation remains a difficult problem, particularly in non-urban areas. The challenge for the Movement and its leaders who are in power now is to continue the revolution so that it truly meets the needs of those at the bottom of the disability ladder, not just the "talented 10%."

Direct reprint requests to:

Simi Litvak  
WID  
510 16th Street  
Oakland, CA 94612