The challenge of middle age for the Independent Living Movement

by Gerben DeJong

Ten years ago, the U.S. Congress passed the 1978 amendments to the Rehabilitation Act. These Amendments included Title VII, a new grant program for Independent Living centers. Title VII was hailed as a victory for the Independent Living Movement. Today, there are approximately 200 Independent Living centers, many of which had their beginnings in the Title VII program. But with the passage of the 1978 Amendments, the Independent Living (IL) movement crossed a threshold and entered a new stage in its life cycle as a social movement.

Social movements, like the rest of us, go through life cycles. Knowing where we are in our life cycle can significantly enhance our understanding of who we are, where we have come from, and where we might be going. In an analogous way, the IL movement has gone through various developmental stages. The 10th anniversary of the 1978 Amendments offers a propitious occasion on which to reflect on Independent Living as a social movement.

In the early stages of our own development, we seek to establish our identity as individuals with distinct interests, commitments, and needs. We seek to communicate to the rest of the world who we are. We tend to be self-absorbed with our own identity. Later, as we become more secure about ourselves, we also have an enhanced capacity to reach out to others and help meet their needs through friendships, marital relationships, business relationships, and through participation in the larger life of the community. More secure in the knowledge of ourselves, we make selected accommodations with the larger society and its institutions. We do not necessarily "sell out," but we tend to have a deeper understanding of the tensions between our individual values and the values of the institutions in which we are involved.

I would like to suggest that this scenario is not unlike some of the developmental issues faced by the IL movement. At present there are two major developmental issues for the IL movement that can be better understood in the context of "life cycle theory."

The first issue is the tension between the movement’s "grass rootsy" origins and the movement’s willingness to take on providers status. It is the old advocacy versus provider status issue. The 1978 Amendments, in a sense, conferred official legitimacy on the movement by offering provider status for IL centers - the main service delivery vehicle of the IL movement. The real significance of the 1978 Amendments is that they signified a shift in movement history away from the in-the-streets advocacy to the nurturing of institutional

structures committed to movement goals.

The second issue is the movement's ability to broaden its base to incorporate persons with disabilities whose disabilities are different from those of the movement's original adherents. The early leadership of the movement was largely drawn from the ranks of those with disabilities such as spinal cord injury, post-polio, cerebral palsy, and a few others. This problem has been particularly acute in regard to the ability of the movement to assimilate persons who have a diminished capacity for self-direction such as persons who have mental retardation or brain injury.

The issue of provider status

A social movement cannot sustain itself by being in the streets indefinitely. Eventually, the ideals and values of the movement are assimilated by others and achieve sufficient social legitimacy to by incorporated in legislation and in various societal institutions. At that stage, the identity and legitimacy of the movement is no longer the focal issue. Instead, attention can be turned to how the movement can sustain itself financially and institutionally.

The 1978 Amendments offered IL Centers a funding source that allowed IL Centers to become more financially viable despite the very limited availability of Title VII funds. IL centers, like other provider groups, have organized themselves into a national organization known as the National Council on Independent Living (NCIL) which has also become the IL movement's focal organization. Instead of marching and wheeling in the streets, NCIL's membership ply the halls of Congress and various governmental organizations. Instead of demonstrating at the gates of the White House, members are giving cocktail parties on Capitol Hill. The IL movement has come of age.

However, the basic conflict between advocacy and provider status has not been resolved. Nowhere is this issue more apparent than in the hotly contested issue of whether IL centers should be accredited by an external accrediting body such as the Commission on Accreditation of Rehabilitation Facilities, an accrediting body developed within the framework of the movement, or in some other group. The fundamental issue, I believe, is not whether IL centers should be accredited but rather the extent to which movement organizations are willing to take on the additional trappings of provider status in the hopes of achieving greater organizational legitimacy while coping with all the baggage that comes with being a service provider.

There are enormous economic advantages in acquiring provider status. External accreditation legitimizes IL centers as service delivery organizations in the eyes of funding sources. Provider-based financing also pays the salaries of movement leaders and offers resources for travel that enable movement

leaders to participate in movement activities.

The down side is also apparent. Being beholden to certain funding sources does tend to blunt the sharpness of one, advocacy. The old adage still applies: It is difficult to bite the hand that feeds you. However, movement ideas and ideals must be operationalized institutionally if they are to survive the convictions of the movement's original leaders and adherents. Institutions offer a framework in which human energy can be harnessed (and compensated) in the pursuit of specific movement goals. I am not advocating accreditation, but if social movements are to be mainstreamed into American life, they cannot just be viewed as fringe elements. They must become part of the system - on their own terms, of course.

Persons with disabilities want to be included in the mainstream of American life. However, at the risk of some generalization, I am not sure that leaders within the IL movement are prepared to see movement organizations such as IL centers fully mainstreamed into the fabric of America's health and human services system for fear that the movement's cutting edge will be blunted. Thus, at midlife, the movement remains torn as to the nature of its accommodation within various social institutions.

The issue of incorporating new groups

The other issue for the IL movement is its ability to fully assimilate persons whose disabilities have compromised their capacity for self-direction. Some observers speak of the movement's original spinal cord injury bias or the movement's bias toward disabled persons who are young and fit.

At the outset of the movement in the early 1970s, persons with physical disabilities wanted to be viewed as competent, self-directed, and capable of managing their own lives. The participation of persons, whose capacity for self-direction had been compromised, threatened that image of competence.

Many IL programs deserve credit for reaching out to groups who earlier had been overlooked as partners in the IL movement. However, the broadening of the IL movement in recent years comes as much from overlooked groups seeking the help of IL programs. Nowhere is this more evident than among persons with brain injury and their advocates who have looked to IL programs for support. The brain injury community has become increasingly organized and has challenged many of the assumptions of the IL movement such as the IL movement's traditional aversion to transitional living programs.

As the movement becomes more secure about its own identity, it will assimilate disability groups from outside its original group of adherents. The people with persons who are less self-directed is that their participation in IL programs is often attended by the not-too-distant and heavy hand of professional paternalism or

by anxious parents who have continued/resumed their parenting role in the lives of their adult children. Such participation is viewed as an affront to the very principles on which the IL movement was founded.

Mid-life crisis?

The IL movement is now about 17 years old depending on how one chooses to date the movement. As far as social movements are concerned, the IL movement is well into middle age. Some might argue the IL movement is in late adolescence or young adulthood, depending on the issue at hand. In any case, issues that remain unresolved in the early stages of a movement's life cycle are sure to resurface as the movement ages and matures. The assumption of provider status and the broadening of its constituency challenge the very assumptions and identity of the IL movement and its place in American social and political life.

The stage theory of life-cycle approach to understanding the IL movement - and its closely related movement, the disability rights movement - can also be misleading. The theory assumes that the IL movement has affected all disability groups uniformly. A more accurate assessment is that specific disability groups are at various stages of development in terms of their own identity and role in American life. We have only to witness the recent uprisings of students with hearing impairments at Gallaudet University in Washington, D.C. to remind us that all disability groups have not benefited equally in the quest for full equality and full participation in American life.

I am not prepared to describe the IL movement as having a mid-life crisis but I do believe that a life-cycle understanding of social movements can give us a better understanding of the issues and tensions within the IL movement.

Source: Disability Studies Quarterly, Summer 1988. Editor Kenneth I. Zola, Dept of Sociology, Brandeis University, Waltham,MA 02254, United States.

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