

Disability and aging
Judith HEUMANN, Summer 1984.

Independent Living Movement: organizing for an active, disabled old age

Controlled by disabled elders and younger people, the movement promotes Independent Living through education and advocacy.

The Independent Living Movement is becoming more actively involved with the community of elders. For the past few decades, persons with various types of disabilities have been organizing the Independent Living Movements to gain control over their lives. This movement, which began to pick up steam in the late 60's, is represented by people who have various physical disabilities - people who are blind, deaf and hard of hearing; people with invisible disabilities such as epilepsy, cancer, heart disease, back problems; people who are mentally retarded and mentally disabled; people of all races and ages. Like other movements, the Independent Living Movement works to protect the rights of its constituency. And like such groups as the Grey Panthers, one of the ways this has been achieved is through the creation of organizations that are significantly controlled by the affected constituency. The organizations are called Centers for Independent Living. The first program was started in Berkeley in 1972; since then more than 150 programs have been developed in the United States and throughout the world.

These centers for Independent Living are committed to the development of a social system in which all people with disabilities have the opportunity to lead productive, meaningful lives as integrated and valued members of their communities. One of the reasons why these programs are successful is that many of the staff providing services are disabled people themselves. They developed the programs to prove to themselves and to others that people with the severest of disabilities can live independently, integrated into the community. Advocacy and a peer approach are integral to the philosophy of this movement. The workers in these programs seriously want to reach out and work with people who are in institutions, and they want to prevent other from entering institutions' doors. The reasons are simple: personal experience or having visited too many friends in these facilities have made us want to provide the tools to allow people to make it in the community with appropriate supports.

There are twenty-two Independent Living centers in California. Their statistics for the quarter ending September, 1983 show that 27% of their clients were 61 or older. This may be a conservative estimate. Elderly people with disabilities have very similar needs to younger disabled people. Some of the most commonly used services are attendant referral, housing placement and transportation services. There are large numbers of other elderly disabled people who could benefit greatly from services delivered by Independent Living centers. The cause of many elderly disabled people not using these programs is attributable, we believe, to lack of knowledge of the programs, and/or discomfort elderly disabled people may have about being categorized with younger disabled people.

As many of us who have been disabled for many years begin to acknowledge that we too will become old, we have started to look at the elders in our communities. We have begun to join such groups as the Grey Panthers and have sought to actively participate in the discussions concerning long term planning. We see that the prejudicial attitudes that non-disabled people have historically held towards disabled people take a large toll on older people as they acquire disabilities and lose some functional capabilities. As the younger, non-disabled become the older disabled, they become increasingly isolated from friends because of transportation problems, architectural barriers and prejudice. We see they are plagued by an attitude which has taught them to think that to be disabled is a tragedy. Younger people fail to recognize that the likelihood of their becoming disabled is significant and that they must be adequately prepared. So we see a community of elders today who fear disability because they believe it means an end to their lives as independent people. The World Institute on Disability's objectives are to work with appropriate organizations to:

- Enable people who are elderly and disabled, and those who are elderly and might well become disabled, to see that their lives are not over.
- Conduct workshops run by younger and older disabled individuals where people can discuss their concerns about being disabled and learn how to do such things as hire and work with attendants, use accessible public transit, order para-transit systems and articulate their true concerns and desires to the medical profession, other health professionals and family members.
- Conduct workshops where people can have hands-on experience with technical aides such as speaker phones, communication devices, push and motorized wheelchairs, closed captioned TV units, ramps, electric beds, inexpensive modifications to kitchens and bathroom, etc.
- Ensure that elderly disabled individuals are actually involved in the development of programs and are workers in the projects.
- Conduct media campaigns to educate the younger population to the positive realities of ageing and disability.
- Assess current public policy to determine where weaknesses currently exist, to make recommendations and to help convince people that it is in their best interest to prepare for the future by working for change.
- Review policies in other countries as they pertain to disabled and elderly disabled individuals and, where appropriate, work towards adoption of these policies.

The Independent Living Movement has begun to positively affect the lives of many disabled people. Our vision is one that leads people to see a future that they previously have denied - life as active, disabled elders.