The Independent Living Movement: Its Roots and Origin

Session One

“Nothing about us without us”

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The Independent Living Movement

Roots and origin

Definition:
In its broadest implications the independent living movement is the civil rights movement of millions of Americans with disabilities. It is the wave of protest against segregation and discrimination and an affirmation of the right and ability of disabled persons to share fully in the responsibilities and joys of our society.

Edward V. Roberts,
1977
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- Philosophical Tenets
  - Consumer Control
  - Cross Disability
  - Right to Fail (Take risks)
  - Choice
  - The Exercise of Power
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- Philosophical Tenets

- Cross Disability
  - The practice of inclusion of all disability groups in the movement, to ensure independence for all. When we work together, in a unified voice, to advocate for basic survival resources such as housing, benefits and services, and civil rights housing, that cut across all disability types, we’re more powerful politically.
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Philosophical Tenets

Right to Fail

Everyone is entitled to take risks in life. Generally, institutions provide a false sense of security and require compliance and safety. Living in the community for people with disabilities often means trying new and different ways to live that are sometimes very difficult to learn and master. Along the way, like anyone else, some people with disabilities fail to do well enough to make it, and they may return to an institution.
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- Philosophical Tenets
- Choice

People with disabilities want to decide for themselves what services they want, how they want them delivered, by whom, and in what context. This means having personal control over life choices, services and activities.
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- The Exercise of Power

- A significant social movement becomes possible when there is a revision in the manner in which a substantial group of people, looking at the same misfortune, see it no longer as a misfortune warranting charitable consideration, but as an injustice which is intolerable to society.

Gerben DeJong, 1979
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The Struggle and the Journey

Disabled veterans in wheelchairs protest in late 1940’s.
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- Section 504 of the 1973 Rehabilitation Act prohibited discrimination against people with disabilities in federally funded programs.
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- In 1988, students and alumni of Gallaudet University defied their board of trustees to force the hiring of a deaf person as president.

- American Disabled for Attendant Programs Today (ADAPT) demonstration for (ADAPT) national Personal Assistance Services, Baltimore, 1990.
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- Signed into law in 1990, the Americans with Disabilities Act (ADA) is one of the most significant civil rights documents of the 20th century. Its purpose is to end discrimination, reduce barriers to employment, and to ensure access to education for people with disabilities.

Senator Tom Harkin, principal sponsor of the bill, urges its passage in the US senate using American Sign Language.
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- A Different Model of Services & Advocacy
  - Centers for Independent Living
    - The locus of the problem 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.

  Gerben D Gerben DeJong, eJong, 1979
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Centers for Independent Living

- Early Independent Living Centers (ILC’s)
- By the mid-1970s, organizations were being formed that put independent living philosophy and concepts into operation.
- In Berkeley, California, students from the University of California founded the first center for independent living in 1972 as a means of creating independent living options within the Berkeley community.
- The Boston Center for Independent Living was formed in response to student demands in the Boston area in 1974.
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- Centers for Independent Living
- Early Independent Living Centers

In most of these early centers, it was people with disabilities who were demanding respect through a different form of service delivery. They were putting these organizations together and securing funding for basic human needs based upon the models of service delivery they wanted in order to achieve their own independent living goals. Their services and advocacy activities fit the emerging independent living paradigm and not the rehabilitation or medical model.
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- Centers for Independent Living

- The core values of the Independent Living philosophy became the backbone of ILC Advocacy and Services.
  - **Consumer Control** - At least 51% of ILC Board of Directors, and staff at all levels must be *qualified* persons with disabilities.
  - **Cross Disability** - ILC’s serve people with all types of disabilities.
  - **Right to Fail** - By promoting and supporting community living, ILC’s recognized that there are inherent risks, and prepared consumers for that eventuality.
  - **Choice** - ILC’s assist consumers in understanding what choices they have in all aspects of their lives, and support them throughout the decision-making process.
  - **Exercise of Power** - Individuals and systems advocacy are a hallmark of ILC’s and unite the disability community to rise up against social injustice and other barriers to independence.
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Title VII of the Rehabilitation Act, as amended in 1984 defined core ILC services.

- **Information and Referral** - To persons with disabilities, service providers, families and community members on disability and independent living topics and issues; and, referral assistance to link individuals with appropriate organizations, services and resources.

- **Peer Counseling** - A majority of staff have disabilities and serve as role models to consumers, providing information and support, and facilitating decision making.

- **Skills Training** - Training activities which focus on consumer skill development to achieve or increase independence.

- **Advocacy** - A service process emphasizing consumer control and self reliance. An array of approaches aimed at assisting persons with disabilities to take charge of the life choices, act on their own behalf, and overcome situations that reduce the potential for independence.
Thank you for your time and attention. Please feel free to ask questions at this time!

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