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RESEARCH INFORMATION ON INDEPENDENT LIVING

Information for this review came from the interactive Research Information on Independent Living (RIIL) database at www.GetRIIL.org, which contains research summaries related to independent living with disabilities. A special effort has been made to include information that independent leaders in the field said they wanted, namely topics regarding accessible, affordable housing, effective advocacy for rural areas, effective transition from schools and nursing homes, accessible, affordable transportation, reaching underserved populations, policies that impede independent living, rural health care services, and Medicaid/Medicare regulations for durable equipment.

RIIL is a joint effort of the Research and Training Center on Independent Living at the University of Kansas and the Independent Living Research Utilization (ILRU) Program of TIRR.

Look up studies in:



www.GetRIIL.org

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Independent Living Concept

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"Independent living is not doing things by yourself, it is being in control of how things are done," said Judy Heumann, of the World Institute on Disability.

Independent living philosophy maintains that people with disabilities have the same rights, options, and choices as anybody else. Adolph Ratzka, a Swedish economist, defined independent living as: "The right of all persons, regardless of age, type or extent of disability, to: live in the community, as opposed to living in an institution; have the same range of choices as everyone else in housing, transportation, education, and employment; participate in the social, economic, and political life of their communities; have a family; live as responsible, respected members of their communities, with all the duties and privileges that entails; and unfold their potential."

Independent living is about exercising choice and having the right and the opportunity to pursue one's wants and desires. Choice means the risk of failure, which is also an opportunity to learn from one's failures, just as those without disabilities do.

Reasons given to justify making decisions for others include opposing values, a feeling that the decision will take too long or is too expensive, or lack of knowledge. However, when individuals can't make decisions by themselves, they give up responsibility for their lives. Society then takes over with its dependency-creating services.

Wrote James Budde, long-time director of the Research and Training Center on Independent Living at the University of Kansas, "Although decision-making is critical for consumer control, it is only one variable. Consumer control involves having the knowledge and the will to take responsibility and develop or use

While others from around the world embrace the independent living philosophy, some say the word "interdependent" rather than "independent" is more applicable to their culture.

Living on one's own or having a job that fits one's capabilities can be part of independent living. But, more importantly it is a person's decision to live or work how she or he wants that defines independent living.

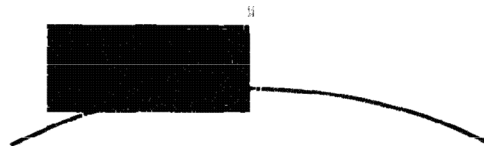
options that facilitate independent living. At the highest level, it involves improving society so that all persons who are included in elderly and disability populations have the opportunity to live independently."

Most agree that independent living started in Berkeley, California, in 1972 by Ed Roberts and other disability activists who rejected institutional living and set up a program that provided support services for people who wanted more control over their lives.

Independent living proponents in Houston, Boston, and other locations soon began independent living programs, adding the right for assistive services and improvement in the community environment to the definition of independent living. This expanded definition came, in part, by researcher Gerben DeJong, who in the late 1970s, introduced the independent living model (which works to change the environment and society attitudes) in comparison to the medical rehabilitation model (which tries to "fix" the individual).

DeJong and others have called for a level playing field for people with disabilities, including the removal of physical and societal barriers, universal design, and a supportive government ready to enforce penalties to those who refuse to cooperate.

In summary, independent living is a philosophy, movement, and way of service provision. — *Cindy Higgins, The Research and Training Center on Independent Living, The University of Kansas. This project funded by National Institute on Disability Rehabilitation Research grant #H133B000500.*



A person's disability is not emphasized in the independent living concept, but an individual's right to types of help and assistance to succeed are.

