# A close-up of a logo Description automatically generatedA green and white logo Description automatically generatedThe Independent Living Advocate’s Toolkit for Mentoring Families of Children with Disabilities

## Brief #4: Overview of the Independent Living Movement

The first Center for Independent Living (CIL) was established in 1972 in Berkeley, California by Ed Roberts and other individuals with significant disabilities who were experiencing discrimination and exclusion. Independent Living as a federal program was created in law in 1978 as hubs for people with disabilities to get information, resources, skills, and advocacy. They are non-residential, cross-disability, and governed and operated primarily by people with disabilities. CILs are concerned with both the self-directed goals of individual consumers and with the accessibility and inclusiveness of communities and institutions.

Independent Living, as both a program and a philosophy, grew out of the disability rights movement which grew out of several social movements from the 1950s -1970s. Early leaders of the IL movement fought for the rights of people with disabilities to have equal opportunity to decide how to live, work, and take part in their communities As their advocacy spread nationwide, the message that people with disabilities have the right to make choices and to control the decisions in their lives started to take root. Researcher Gerbon DeJong compared the IL model to the prevailing medical and rehabilitation model in this chart (1979) (expanded by IL advocates Maggie Shreve and June Isaacson Kailes (2002))[[1]](#footnote-1):

|  |  |  |
| --- | --- | --- |
|  | **Medical Model & Rehabilitation Paradigm** | **Independent Living Paradigm** |
| **Definition of the problem** | Physical or mental impairment. Lack of vocational skills (in the VR system); lack of abilities | Dependence upon professionals, family members, and others; hostile attitudes and environments |
| **Focus of the problem** | In the individual (individuals are sick & need to be “fixed.”) | In the environment; in the medical and/or rehabilitation process itself |
| **Solution to the problem** | Professional intervention; treatment | 1. Civil rights & advocacy 2. Barrier removal 3. Self-help 4. Peer role models/peer support 5. Consumer control over options & services |
| **Social role** | Individual with a disability is a “patient” or “client.” | Individual is a “consumer,” “customer” or “user” of services & products. |
| **Who controls** | Professional | Consumer or individual |
| **Desired outcomes** | Maximum self-care (or “ADL”); gainful employment in the VR system | Independence through control over acceptable options for everyday living in an integrated community. |

1. <https://Pubmed.ncbi.nlm.nih.gov/496597> and [www.jik.com/ilcpara.html](http://www.jik.com/ilcpara.html) [↑](#footnote-ref-1)