

Independent Living Glossary of Terms

Activities of daily living (ADL): Routine activities that a person does every day such as standing, sitting, eating, bathing, and grooming can be done by the individual or care provider.

Adaptive skills: These skills are typically needed to live and work in the community: communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics, community use and work.

Advocacy: Public activism and organized promotion of the rights of people with disabilities has created alliances between similarly concerned proponents of disability causes who demand solutions for the problems of independent living.

Accessibility: This is the ability of a house, product, place, program, etc. to be easy, not difficult, to use or reach.

Assistive technology: Equipment or devices, such as wheelchairs, walkers, or speech aids that help a person perform activities of daily living can be range from simple aids to complete machinery.

Center for independent living: Found in every major city in the United States, centers for independent living (also known as independent living centers) advocate for the rights of people with disabilities and provide them with support services and training programs they need to achieve self-sufficient and productive lives.

Consumer: Words like *patient*, or *client* have been used to describe people with disabilities. These terms imply that a person with a disability is someone who receives services but has little control over them. The term consumer grew out of the independent living movement and signifies someone who selects services and has some control over them.

Consumer control: Consumer control is the heart of independent living. It stresses the consumer's right to determine his or her life direction and to make all decisions related to that direction. A project or organization that is consumer controlled is directed, managed, and staffed to a large degree by qualified persons with disabilities.

Deinstitutionalization: Both a policy and a practice, this movement that began in the 1960s has reduced the number of people living in state-operated institutions and increased the number of people receiving support in their communities.

Diagnostic and Statistical Manual (DSM): Used mainly in clinical settings, this guide provides a classification and description of mental disorders and symptoms, and is cited in many disability studies.

Functional ability: How well a person can perform activities of daily living without help from someone else constitutes a measure of their functioning.

Home and Community Based Services Waiver Program: In 1981, legislation was passed to fund the HCBS program, which allows states to use Medicaid funds to pay for home and community services for Medicaid-eligible individuals who have disabilities. States must show that these individuals are at risk of being placed or remaining in institutions without these waiver-provided services. Additional legislation has provided Community Supported Living Arrangements for Medicaid-eligible persons with mental retardation and/or developmental disabilities that does not require the person to be at risk of institutionalization.

Inclusion: This is the process and outcome of including people with disabilities in the community, so they can live like other citizens, enjoy full civil rights, and contribute to the community. Involvement is at the consumer's desired level.

Independent living: A movement, philosophy, and way of service provision, independent living focuses on social attitudes and physical barriers rather than a person's limitations. Disability is not emphasized, but an individual's right to types of help and assistance to succeed are. Assistance can include supports such as adaptations to the living space, personal assistance, or changing policies to promote the ability to live independently.

Managed care: An approach to health care financing, this insurance form attempts to control the use and cost of health care services. Offering incentives, implementing cost restrictions, influencing a consumers' choice of providers, establishing networks, and improving coordination of services are used as methods to manage costs.

Natural supports: When friends, neighbors, relatives, coworkers, and others volunteer to help a person with a disability live a more independent life, they are called natural social supports.

Participatory Action Research: Common to studies on information dissemination is the principle that effective dissemination is the result of knowing the information that end-users identify as important (and that which they are likely to need). One way this information can be obtained is from Participatory Action Research (PAR), an approach that emphasizes a collaborative attitude toward research and training. A bridge between research and knowledge utilization, PAR in every research phase increases the probability that problems are not only identified and solved, but also that constituents find the solutions worthwhile.

Personal assistance: At first, this paid support was confined to medical, hygiene, and mobility assistance. It has now expanded to include everyday support, such as recreation, transportation, reading, interpreting, shopping, budgeting, and meal preparation.

Person-centered planning: Instead of focusing on a person's deficits and disability, this form of planning makes the most of a person's abilities, preferences, and ambitions. It is a changing problem-solving process that reflects the changes in the individual's life.

Rehabilitation: A process that maximizes individuals' ability to live independently in their community, rehabilitation traditionally has focused on employment.

Research and training centers: Funded by the National Institute of Disability Rehabilitation and Research, these organizations are designed to solve long-term issues in disability and are typically located at institutions where long-term support can insure that their missions are accomplished.

Self-determination: The consumer makes choices and decisions regarding his or her life without excessive influence or interference by others in this practice. This may vary for each person, depending on the person's circumstances and disabilities.

Social Security Disability Insurance: Monthly benefits are provided to disabled workers and their dependents through this plan funded by Social Security. Participants must have accrued sufficient quarter-years of employment and payment into the system to qualify for benefits.

Supplemental Security Income: The federal government provides income support to people 65 and over, adults and children with blindness or disabilities who have little or no financial resources. To be considered, an adult must not be able to participate in gainful activities because of physical or medical impairment that will result in death or at least 12 months.

Supported employment: The Rehabilitation Act of 1993 defines supported employment under Title VI Part C as competitive work in integrated work settings. It is for persons with severe disabilities who need support to find and hold a job. Supported employment includes pay for real work, working with nondisabled coworkers, ongoing support for job retention (for assistance, a job coach), and interagency cooperation and funding of these services.

Supported living: Central to the concept of supported living is the goal of a supportive environment, living in one's home, and being included in the community. Many states use the Medicaid HCBS waiver to finance supported living.

Transition: Transition is a term used for the systematic passage or bridge between one phase of life to another. Often, this term is used for when people with disabilities leave an institution for the community or school for adult life. Schools are required by federal law, especially the Individuals with Disabilities Education Act (IDEA), to provide transition planning and services. According to IDEA, by age 16 (age may vary by state), a student's individual education plan (IEP) should describe needed transition services and detail how the school will provide instruction, community experiences, the development of the IEP and other postschool adult activities.

Universal design: The design of products and environments to be usable by all people without the need for adaptation or specialized design is the basis of this principle.