

Independent Living Philosophy

Disability does not mean incapability. It does not mean that a person is “sick,” needs to be “fixed,” or is “less” than any non-disabled person. Most living with disabilities also don’t need decisions made for them, when they are perfectly capable of self-determination.

If you have ever been in a situation in which someone made an assumption about your capabilities and, without consulting you, tried to make the situation better but, really, only made things worse or made you feel inadequate through their actions then you have had a small taste of what many disabled people experience every single day. This is where the Independent Living (IL) Philosophy comes in.

The IL philosophy was developed by a large movement of people with disabilities and their supporters who worked for freedom of choice, equal opportunities and equal respect for those living with disabilities. The disability rights movement gave voice to a minority group for whom others have spoken and about whom others have made decisions throughout history.

The IL Philosophy is based on the belief that people with disabilities are the experts in their own lives and no decision about their care should be made without them participating. The IHSS program is based on a Consumer Directed model of care which recognizes that people with disabilities are not patients, their homes are not medical settings, and IHSS services do not have to be performed by medical personnel.

We must keep in mind that people with disabilities primarily just see themselves people, as citizens of the world. It is only secondarily that they think of themselves as consumers of healthcare. IHSS care providers need to embrace the Consumer Directed Model and move away from the medical model in



which the consumer is a patient who needs to be told what to do and when to do it. Under the Consumer Directed Model, the person receiving care is the one that does the directing. This is person-centered care, which honors the importance of keeping the consumer at the center of the care planning and decision-making process.

The Consumer Directed Model is a key factor in respecting the fact that people with disabilities are the best experts on their own needs. It also identifies barriers in care systems and in communities that create negative attitudes, exclusion, and inequality. This is why advocates use the term “consumer” as opposed to “client” or “patient,” which creates the impression that care recipients are taking advice from experts. The IL movement and Consumer Directed Model believe people with disabilities are their own experts.

Advocates believe that healthcare professionals, and society at large, need to honor the consumer’s wants and not just do what others may think is best. A consumer’s choices and expressed needs should be treated with respect.

Independent living and person-centered care promote self-determination, choice, independence, purpose and meaning in daily life for consumers. The philosophy is “Nothing about us, without us.”

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10 Principles of Independent Living

1. **Civil Rights** – equal rights and opportunities for all; no segregation by disability type or stereotype.
2. **Consumerism** – a person ("consumer" or "customer") using or buying a service or product decides what is best for him/herself.
3. **De-institutionalization** – no person should be institutionalized (formally by a building, program, or family) on the basis of a disability.
4. **De-medicalization** – individuals with disabilities are not "sick," as prescribed by the assumption of the medical model and so not require help from certified medical professionals for daily living.
5. **Self-help** – people learn and grow from discussing their needs, concerns, and issues with people who have had similar experiences; "professionals" are not the source of the help provided.
6. **Advocacy** – systemic, systematic, long-term, and community-wide change activities are needed to ensure that people with disabilities benefit from all the society has to offer.
7. **Barrier-removal** – in order for civil rights, consumerism, de-institutionalization, de-medicalization, and self-help to occur, architectural, communication and attitudinal barriers must be removed.
8. **Consumer control** – the organizations best suited to support and assist individuals with disabilities are governed, managed, staffed, and operated by individuals with disabilities.
9. **Peer role models** – leadership for independent living and disability rights is vested in individuals with disabilities (not parents, service providers or other representatives).
10. **Cross-disability** – activities designed to achieve the first five principles must be cross-disability in approach, meaning that the work to be done must be carried out by people with different types of disabilities for the benefit of all persons with disabilities.