

Orientation to Independent Living for New CIL Personnel

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IL T&TA

Independent Living
Training & Technical Assistance Center

Orientation to Independent Living for New CIL Personnel, ©2020, 2022, 2025

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This reprint is provided by the IL Training & Technical Assistance Center operated at the Rural Institute for Inclusive Communities at the University of Montana. The IL Training & Technical Assistance Center is supported by contract number 75P00125C00005 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201.

This publication was previously produced by the IL-NET National Training and Technical Assistance Center for Independent Living operated at ILRU (Independent Living Research Utilization) at TIRR Memorial Hermann Research Center, Houston, Texas. The previous publication was supported by grant number 90ILTA0002 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201.

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Important Contact Information

Technical Support and Course Materials

If you experience technical problems, need assistance with materials, or accessibility, please contact the Independent Living Training and Technical Assistance Center.

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Course Description / Overview

During this six-week distance course, you will develop a solid understanding of the philosophy of independent living and the principles that define and guide a center for independent living (CIL). The course is designed to provide information about important concepts and strategies that will help you be a better staff or board member of a CIL. It may also be of benefit to staff and members of Statewide Independent Living Councils.

Course Objectives

Through this course you will learn:

- 1) The elements of independent living philosophy.
- 2) The origins and history of the independent living social movement and federal CIL program.
- 3) The meaning and importance of such concepts as consumer control, peer support, self-determination, and self-advocacy.
- 4) The federal Standards that provide a framework for the CIL's operations and services.
- 5) Basics of the required core services of a CIL.
- 6) How the CIL can celebrate and foster disability pride.

Course Materials

The course utilizes both this training manual, and the Internet. The manual is designed to provide sufficient background information to make it possible for all students to assume an active role in online discussions. Additional learning materials may be recommended, but not required, to enhance the participant's understanding of the topic. The manual also contains the plan and the assignments for each session.

IL-Related Assignments

Discussion at your own organization or work site will enhance the learning experience. Participants are encouraged, but not required, to consult with coworkers prior to completing the assignments. You are also encouraged to give feedback on what you are learning to your supervisor or CIL's executive director which may assist in internal planning and implementation of new or expanded services and programs.

Session One: Orientation, Expectations, and Introductions

Preparation for Session One

- Review course objectives, structure, and requirements.
- Complete the pre-test.
- Introduce yourself and learn about your classmates.
- Share information about your perceptions of people with disabilities.
- Read “Introduction to the Topic” below.

Introduction to the Topic

Welcome to *Orientation to Independent Living for New CIL Personnel* (CIL stands for Center for Independent Living). As a new employee or board member in the field of independent living, you are learning new skills. You may be discovering that there is a whole set of principles that define and guide what a CIL does.

This course will be easier if you have already been exposed to concepts like consumer control, peer relationships, and a cross-disability orientation to the provision of services. However, if you have not, there are readings in this manual that will give you some of the background information you need.

The Independent Living Program is based on a philosophy that sets forth a way of thinking and living. It is also a statutory program guided by the law, regulations, standards and assurances. These standards and assurances show consumers, funders, legislators, communities, and all stakeholders that a CIL is accomplishing what it was created and funded to do. In independent living there is no aspect of a CIL that is more important than whether the IL philosophy is fully integrated into all CIL operations. This course is designed to help you understand how to put independent living philosophy to work. Together, we will apply the principles and philosophy of independent living to day-to-day situations. We will discuss and share ideas about actions that you may take. Finally, we will look at how requirements from the federal or state funder may impact those decisions.

We will briefly review the statute governing CILs and the Standards and Assurances for Independent Living, including Philosophy, Provision of Cross-Disability Services, Equal Access, Core Services, and more. The most fun and, hopefully, useful element of this course, will be a series of scenarios designed to promote lively discussion—to make you think about the impact of your actions on the consumer, on your organization, and the community.

Assignment for Session One

Each day you will find assignments for that session both here and posted on the day's discussion topic. Here is your first assignment.

- 7) Go to the discussion area and tell us a little about yourself, for example:
 - Name and pronouns (for example, "Jane Smith, she/her/hers pronouns")
 - To learn more about gender pronouns, visit "Why We Ask Each Other Our Pronouns"
 - Where do you work and where is your CIL located? What is your position and how long have you been there?
 - What do you enjoy doing in your spare time?
 - Why are you interested in this course and what do you hope to gain from it?
- 8) How did you first learn about disability as a child? How did that experience affect your view of people with disabilities? In what ways has your view changed?
 - You may disclose your disability, if you choose to, and the impact it has had on your life and your work.

After you have written a little about yourself, read what others in the class have written, and feel free to comment or ask questions of your classmates.

Sessions Two & Three: Where Did Independent Living Come From?

Preparation for Sessions Two & Three

- Read “The Emergence of Independent Living” below.
- Watch/listen to the IL-NET streaming video *Module One: A Brief History of Disability*. All video modules can be found at: https://www.youtube.com/watch?v=mv_Jw_Xe1t0 . The module is also available in transcript form to assist you in your review.
- Refer to the IL-NET streaming video *Module Two: Emergence of Independent Living* at: <https://www.youtube.com/watch?v=-9wxJBIQxsl>.

In each of these two videos, pay particular attention to the discussion of how society’s attitudes impacted the lives and choices available to people with disabilities.

- Read *History of Independent Living*, a short monograph by Gina McDonald and Mike Oxford. This is a slightly edited version: <https://www.accessliving.org/newsroom/blog/independent-living-history>
- Read the following article, *National Park Service Disability History Series introduction* at: <https://www.nps.gov/articles/disability-history-series-introduction.htm>

The Emergence of Independent Living

Independent Living (IL) values and philosophy emerged from hundreds of years of discrimination, stigma, and oppression. The history of people with disabilities reflected the medical, physical, and economic burdens that an inaccessible and unenlightened society provided for people with disabilities. There were few if any options for generations, and many people with disabilities died young from lack of appropriate medical interventions. There was a pervasive belief that if the patient couldn’t be cured, the only available response was to remove the person from society’s consciousness.

Many people with disabilities were isolated at home or forced into dehumanizing institutions, prisons, and poorhouses. Once segregated, it was easy for society to slip into disdain for those who were “different.” Giving to charity for the “poor unfortunates” became the norm, which served to perpetuate the inequality and exclusion. It has been a long, difficult road to change how society views those with disabilities. Changing perceptions has been critical for people with disabilities to become fully recognized members of their communities.

Even more critical were the roles and responsibilities that people with disabilities took to become valued citizens. It began with people with disabilities valuing themselves and their rights to claim the life they want. Gradually, people with disabilities have been using their voices to gain society's attention. As the 1960s began, there were a number of social movements that helped the general public begin to think differently about people with disabilities and their rights. They also helped people with disabilities claim empowerment and follow their hopes and dreams. *Deinstitutionalization*, the *civil rights movement*, *demedicalization*, and *consumerism* changed how individuals with and without disabilities see themselves and the power they have to choose and change their lives.

The history of how people with disabilities were viewed and treated, and the social movements, set the stage for the emergence of the independent living movement. Visionary leaders across the United States organized first at the community level and later on a national basis. As the numbers grew, the mantra of "Nothing about us without us" became the basis for national legislation to ensure the rights and full protection of the law for all people with disabilities. As the independent living movement grew, the values of empowerment, consumer control, access, and self-determination became embedded in the larger disability rights movement and guided the establishment of centers for independent living. CILs must reflect these values at all levels of the organizations and in their interactions with consumers and the community.

Assignment for Sessions Two & Three

- 1) Although attitudes and circumstances have improved for people with disabilities over the past century, there are still challenges that demonstrate the need for centers for independent living. Please identify and discuss the three most serious challenges you believe people with disabilities face today.
- 2) Discuss the similarities between the civil rights movement and the independent living movement. What were the barriers that both movements were trying to address? Why is it critical for CILs to partner with other community organizations that serve marginalized populations and are not disability specific such as the NAACP, housing and transportation coalitions, Human Rights campaigns, etc.

Session Four: Laying the Groundwork—The Rehabilitation Act

Preparations for Session Four

- Read the background information below on the Rehabilitation Act and the definition of a center for independent living.
- Review the actions taken by the disability community to get the regulations for Section 504 of the Rehabilitation Act signed:
<https://www.youtube.com/watch?v=SyWcCuVta7M>.
- Think about how your CIL meets the description of a center for independent living as defined in the Rehabilitation Act, as amended.

Moving the Rehabilitation Act and Regulations into Law

The Rehabilitation Act as reauthorized in 1972, extended the provision of grants to States for vocational rehabilitation services. It emphasized services to those with the most severe disabilities. Disability rights activists cheered Section 504 of the Act because it created and extended civil rights to people with disabilities, becoming the first disability civil rights law to be enacted in the United States. Section 504 prohibits discrimination against people with disabilities in programs that receive federal financial assistance.

However, President Richard Nixon's veto prevented this bill from becoming law. During the era of political activity at the end of the Vietnam War, Nixon's veto was not taken lying down by disability activists who launched dramatic protests across the country. In New York City, an early leader for disability rights, Judy Heumann, staged a sit-in on Madison Avenue with eighty other activists. Traffic was stopped. After a flood of angry letters and protests, in September 1973, Congress overrode Nixon's veto, and the Rehabilitation Act of 1973 finally became law. Passage of this pivotal law was the beginning of the ongoing fight for implementation and revision of the law according to the vision of independent living advocates and disability rights activists.

Key language in the Rehabilitation Act, found in Section 504 of Title V, states that:

No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Advocates realized that this new law would need regulations in order to be implemented and enforced. By 1977, Presidents Nixon and Ford had come and gone. Jimmy Carter

had become president and had appointed Joseph Califano his Secretary of Health, Education and Welfare (HEW). Califano refused to issue regulations and was given an ultimatum and deadline of April 4, 1977. April 4 went by with no regulations and no word from Califano.

On April 5, demonstrations by people with disabilities took place in ten cities across the country. By the end of the day, demonstrations in nine cities were over. In one city—San Francisco—protesters refused to disband. These demonstrators, more than 150 people with disabilities, had taken over the federal office building and refused to leave. They stayed until May 1. The Black Panthers provided meals and other supplies to the protestors. Califano had issued regulations by April 28, but the protestors stayed until they had reviewed the regulations and approved of them.

This victory was viewed among activists at that time and decades later as demonstrating the power of Martin Luther King's advocacy principle when he said,

It is an historical fact that the privileged groups seldom give up their privileges voluntarily. Individuals may see the moral light and voluntarily give up their unjust posture, but, as we are reminded, groups tend to be more immoral than individuals. We know, through painful experience that freedom is never voluntarily given by the oppressor, it must be demanded by the oppressed.

To learn how leaders in the civil rights movement supported the disability rights movement, read the short article about some unsung heroes at [The 504 Sit-in: Disability Community and Civil Rights – National Park Service Black History](https://www.nps.gov/articles/000/504-protest-disability-community-and-civil-rights.htm) (<https://www.nps.gov/articles/000/504-protest-disability-community-and-civil-rights.htm>)

Definition of Centers for Independent Living and Key Principles

The 1978 amendments to the Rehabilitation Act authorized the establishment of the Independent Living Program which includes the centers for independent living with principles founded on a “philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society...” This powerful statement embodied the values of the disability movement and served to guide the establishment of CILs.

The following is the official definition of a CIL which is found in the Rehabilitation Act, as amended (the Act) and Part 1329 of the Independent Living Program regulations¹:

Center for Independent Living means a consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agency for individuals with significant disabilities (regardless of age or income) that is designed and operated within a local community by individuals with disabilities; provides an array of IL services as defined in Section 7(18) of the Act, including, at a minimum, independent living core services as defined in this section; and complies with the standards set out in Section 725(b) and provides and complies with the assurances in section 725(c) of the Act and the regulations at §1329.5.

As you can see, CILs are NOT just another worthy community agency providing services to unserved and underserved populations. CILs must reflect the core values and clearly have consumer control at all levels. This was a radical concept over 40 years ago and still is today. There are still only a few more agencies directed by those from the groups they serve. Consumer control is generally not part of most agencies providing services and support to individuals with disabilities.

You have probably been exposed to most of the components of the definition of CILs since you joined IL, but there may be some aspects of the definition that you don't understand. This is a good time to get them on the "discussion" table where we can explore them together. If you still have questions, jot them down. You will have ample opportunity to ask them. First, let's take the key elements in order.

Consumer-controlled

We will discuss this further when we turn our attention to philosophy, but notice this is not optional. A CIL *by definition* is consumer-controlled.

*The term "consumer control" means, with respect to a Center or eligible agency, that the Center or eligible agency vests power and authority in individuals with disabilities, including individuals who are or have been recipients of IL services, in terms of the management, staffing, decision making, operation, and provision of services. Consumer control with respect to an individual, means that the individual with a disability asserts control over his or her personal life choices, and in addition, has control over his or her independent living plan (ILP), making informed choices about content, goals and implementation.*²

¹ 45 C.F.R. 1329.4

² 45 C.F.R. 1329.4

This means that more than 50% of the CIL's staff positions and employees in decision-making positions are filled by persons with disabilities and more than 50% of the board of directors must be persons with significant disabilities. The disabilities are self-disclosed—no medical diagnosis or proof is required—but it is essential that people with disabilities control the CIL and that individuals with disabilities control their own lives and planning.

Is it obvious to the community that your center is consumer controlled?

Community-based

How is your center "community-based?" What does that mean to you? With regard to being community-based, statewide independent living councils (SILCs) were created to coordinate the assessment of needs of people with disabilities across all of the communities within the state. The primary method for doing this is the State Plan for Independent Living (SPIL), which is developed every three years to identify goals and objectives, unserved and underserved populations and geographic locations, and other things.

Does your CIL accurately represent, conduct outreach to, welcome and include disabled people from all other identity groups? It is crucial to recognize the interconnected nature of race, gender, sexual orientation, etc. with disability. It's much easier to find your target audiences if you go where they are likely to be rather than waiting for them to come to your office. Watch the on-demand training "Disability, Diversity, and Intersectionality in CILs: Making New Friends & Playing Well with Others" (<https://www.youtube.com/watch?v=xe7eJLAOoZY>) to learn more.

From the state level to your local community, you should be able to see how the CILs, including the one where you work or volunteer, are part of the community rather than part of a larger bureaucracy. For this reason, CILs may have a different approach or style from city to city as they reflect the needs of their local communities.

The other language in the definition of a CIL above relating to this and to consumer control includes: "is designed and operated within a local community by individuals with disabilities."

Cross-disability

Cross-disability means, with respect to services provided by a Center, that a Center provides services to individuals with all different types of significant disabilities, including individuals with significant disabilities who are members of unserved or underserved populations by programs under Title VII. Eligibility for services shall be determined by the Center,

and shall not be based on the presence of any one or more specific significant disabilities.³

To reach the full community of persons with disabilities, CILs must address the overlapping or intersecting social identities of the CIL's stakeholders. Race, sexual orientation, gender—all identities—do not and cannot exist separately from a person's disability identity. Intersectionality (multiple social group memberships and identities) expose an individual to different types of discrimination and disadvantage. The focus on equity, inclusion, and intersectionality needs to be embedded in your organization's core values and services.

Nonresidential

Community-based means more than simply being located in the community that you serve. It also means being responsive to the needs of people with disabilities in your community. There aren't many needs more critical than housing, right? Centers, however, are dedicated to assisting people to find their own housing, not to providing the housing to them. In other words, CILs empower people with disabilities to advocate for the services and supports they may need to live in the community of their choice. If such services do not exist, the CIL through system advocacy can work with consumers to effect change and garner public-funded programs. As noted elsewhere, CILs do not "do for consumers, but enable consumers to do for themselves."

Private, nonprofit

Note that centers are expected to be part of the nonprofit sector in the community. That doesn't mean that they can't have earned income; it just means that they are not established for the purpose of making a profit or sharing profits with shareholders. Indeed, CILs are required to conduct resource development activities to leverage their funds, an activity from which the majority of other types of federal grantees are barred. Private means that CILs are not part of the bureaucracy of any governmental entity.

Provides an Array of Independent Living Services

The Act also designates core services that every center must provide, and other services that they may⁴ provide. Required core services include: information and referral; individual and systems advocacy; peer support and peer counseling; independent living skills training; transition from nursing homes and other institutions; transition of youth who have completed secondary education to postsecondary life; and

³ 45 C.F.R. 1329.4

⁴ See Appendix B for further information on the array of services.

diversion from institutional living (provides assistance to those who are at risk of entering institutions so that the individuals remain in the community).

Assignment for Session Four

- 1) In what ways does your CIL demonstrate that it is consumer-controlled?
- 2) Which elements of the definition of a CIL do you consider most important? Why?
- 3) Which elements of the definition of a CIL do you consider as the most challenging for a CIL to implement? Why?

Session Five: Philosophy—Consumer Control and Informed Choice

Preparations for Session Five

- Read *Consumer Control Principles in Independent Living* starting on page 51 in Appendix C.
- Read the background information below on the Evaluation Standard 1 for CILs regarding philosophy.

In the case of CILs, what we believe—our philosophy—is written right into the federal law that created CILs. Often as legislation is written, the problems that the legislation will address are listed. However, in the case of the Rehabilitation Act that led to the development and implementation of CILs, the philosophy and values of the independent living movement became the focal point of the legislation itself. Again, this did not occur because legislators were knowledgeable and fully committed to the IL philosophy. It occurred because disability advocates were at the table using all the advocacy strategies they had developed over the past several decades; they advocated! Disability advocates were intensely involved in setting the standards that govern CILs because we knew from the beginning that this was one area on which we could not compromise. These words (our philosophy) had to be ours, not just legalese. We will talk in this course about how to implement this philosophy, but first here is what the law says in the Standards and Assurances for CILs. Again, jot down your questions. You will have a chance to ask for clarification.

Evaluation Standard 1 – Philosophy

The center shall promote and practice the IL philosophy of—

- (A) *Consumer control of the center regarding decision making, service delivery, management, and establishment of the policy and direction of the center;*
- (B) *Self-help and self-advocacy;*
- (C) *Development of peer relationships and peer role models to provide peer mentoring;*
- (D) *Equal access for individuals with significant disabilities within their communities and to all of the center's services, programs, activities, resources, and facilities, whether public or private, and regardless of the funding source.⁵*

⁵ Title VII Sec. 725(b)(1)

This Standard means that it must be the foundation of all the CIL does—both as an organization and in its interactions with the disability community and consumers. It mandates consumer control in all aspects of the CIL—from services and supports for individual consumers to organizational control of the CIL.

Informed Choice and Individual Consumer Control

The philosophy of consumer control for individuals means that consumers determine the types of assistance they want and how they want to receive it. It is their life and their choices. This approach is a sea change from the medical model where the health professional or rehabilitation services provider decides what is best for the individual.

Consumer control must be based on an informed choice. Informed choice is a decision made by the consumer after the consumer has reviewed and understands the alternatives that are possible. The concept implies that the consumer has the ability to understand the information and communicate the decisions. When someone is not able to do these things, a guardian or conservator is sometimes appointed by a court. Unless someone has a court-appointed guardian, no matter what your personal opinion is of the person's ability, the individual can legally make their own choices. Your role, typically, is to assist the individual in knowing the available options before he or she makes a choice and to support the person through the decision-making process. That is the “informed” part of the philosophy of informed choice. Without the “informed” part of this concept, real consumer control is not possible. (Just a side note – some centers work with consumers who have a guardian or conservator to reverse this court decision and assist the person with regaining legal rights.)

Consumer Control of the Organization

Let's look for a moment at what consumer control means at the organizational level. The CIL must be governed at the board level by a majority of individuals with significant disabilities. The management and staff must be comprised of more than 50% people with disabilities. But, these are not the only measures of a consumer-controlled center. When the Administration for Community Living (ACL) monitors a CIL, they consider a number of things in assessing how the CIL is meeting Standard 1. Among these are—

- Reviewing organizational and consumer files
- Interviewing board, staff, and consumers
- Reviewing center brochures and procedures to be sure they reflect consumer control

- Checking accessibility of programs, buildings, and CIL-sponsored events. (If the CIL is not fully accessible, it's pretty difficult, if not impossible, for people with disabilities to be authentically engaged.)

In addition to Independent Living Program rules, there are rules that CILs must follow to maintain their status as non-profit and federally funded organizations. Consumer control does not mean using public or private funding to allow individuals to do anything and everything they please. There are restrictions on how federal funds are used; these fund most CILs, at least in part. There may at times be tension between honoring consumer, staff, and board wishes and appropriately spending federal and state funds.

Assignment for Session Five

- 1) Why is it that, in the case of CILs, philosophy is not just a bunch of nice-sounding words? Why is it critical to CILs to thoughtfully and consistently apply the consumer control philosophy? How does the CIL ensure that individuals who have intersecting identities (such as race, ethnicity, and sexual orientation) fully participate in the consumer control at the CIL?
- 2) Read the scenario below and answer the question: Based on the IL philosophy of consumer control, should the CIL accept the funding that is being offered? Please describe why or why not.

BUT FIRST, A WORD ABOUT SCENARIOS: The scenarios used in this course will present you with dilemmas that test the application of the IL philosophy in real-life situations faced every day by CILs around the country. These scenarios are meant to challenge your thinking and help you to understand how procedures and philosophy can sometimes be in conflict and what to do about it. Visit the discussion group as often as possible. You will benefit from reading the views of others and they will gain from reading yours, but the greatest benefit will be from the discussion that ensues.

You may also learn a lot by talking to your colleagues at your CIL. If you have an extra half-hour and four to eight colleagues who want to join in, set up your own small group session. This can also occur at a regular staff meeting. Form a circle, give everyone a copy of the scenario, have one participant read the scenario aloud, and answer question #2 above.

Scenario #1: A Funding Dilemma

A large foundation with a strong history of charitable contributions to disadvantaged populations is impressed with what the Eastside Center for Independent Living (ECIL) has accomplished in their state. They have approached the CIL's director, Anne Matthews, to offer funding for the center over the next five years. Funding would be in excess of \$500,000 per year. To receive this funding, the CIL would need to agree to

receive approval from the foundation about how the funds are spent and use the funding only in the following ways:

- Hire three qualified, licensed physical therapists, one occupational therapist, and two speech and language therapists to provide at least five hours of therapy to consumers who have spinal cord injuries.
- Remodel the center to better accommodate large group meetings of individuals with spinal cord injuries.
- Receive approval of all activities and expenditures from the executive board of the foundation.

The chairperson of the ECIL board of directors is eager to accept the funds since the center currently has only Title VII, Part C funding. She has repeatedly brought up the need to diversify the CIL's funding so that the CIL will not be too vulnerable in the case of federal funding cuts. Although Anne Matthews presented a strong case for not accepting the funds, at the last board meeting the president had said, "The board made a commitment at our summer retreat to bring in more funding, and here we have a chance to make easy money that the board will not have to bend over backwards to pursue." Several other board members had nodded their heads as if to approve of her point of view.

And now the choice has been put forward in the form of a motion and a board member who was tired of the debate, raised his hand to call for a vote on the motion to accept the funds.

Anne Matthews finally spoke up and said, "You all will be sorry if you accept this money. There are a whole bunch of strings attached to this that we won't be able to live with."

Share what you think Anne meant by that and answer question #2 above.

Session Six: Provision of Services

Preparations for Session Six

- Review the following descriptions of IL Standard 2—Provision of Services, Standard 3—Independent Living Goals, and Standard 5—Independent Living Core Services.

The services that CILs provide and the way they're to be provided were identified in the Act for a very specific reason. The required core services particularly were chosen with thoughtful intent because they have everything to do with the mission of the Independent Living Program which we will re-state here because it is so important: “to promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society....”

In this session we will explore the standards pertaining to services: Standard 2 – Provision of Services, Standard 3 – Independent Living Goals, and Standard 5 – Independent Living Core Services.

Let's look first at the standard for service provision.

Evaluation Standard 2—Provision of Services

The center shall provide IL services to individuals with a range of significant disabilities. The center shall provide services on a cross-disability basis (for individuals with all different types of significant disabilities, including individuals with significant disabilities who are members of populations that are unserved or underserved by programs under Title VII of this Act). Eligibility for services at any center for independent living shall be determined by the center, and shall not be based on the presence of any one or more specific significant disabilities.⁶

The cross-disability standard was always intended to encourage centers to include people with all types of disabilities in every aspect of center operations and services. The reasoning behind the concept is that people with disabilities are more alike than different, and that drawing lines by type of disability creates artificial barriers within the disability community, unnecessarily separating one group from the rest. As a civil rights

⁶ Sec. 725(b)(2)

movement, we have learned firsthand that “separate” is not “equal.” In addressing the provision of services, CILs need to partner with all stakeholders and determine how best to be culturally responsive to all consumers.

After the reauthorization of the Rehabilitation Act in 1992, this standard became the basis upon which many single-disability centers throughout the country were either closed or merged with centers that were cross-disability. This doesn’t mean that CILs can’t provide a support group for people with a particular disability if the consumers request it. For example, a CIL might provide a peer group for women with spinal cord injuries who want to share IL solutions pertinent to them. It does mean that a specific disability cannot be a requirement to receive services.

Evaluation Standard 3—Independent Living Goals

A central feature of service provision in CILs is the process of goal setting with consumers. Standard 3 states:

INDEPENDENT LIVING GOALS—The center shall facilitate the development and achievement of independent living goals, selected by individuals with significant disabilities who seek such assistance by the center.⁷

To receive continued funding, CILs must demonstrate that they are providing support for the development and achievement of IL goals chosen by the consumer. Goal setting by consumers is fundamental to the principle of individual consumer control. Consumers increase their independence, leadership, empowerment, and productivity through achieved goals. Developing goals jointly with consumers is a critical step in ensuring that their needs are addressed and that requested services take place in a timely manner. Reported completed goals also demonstrate to funders that the core services provided by CILs are making a difference in the lives of individuals with disabilities and in their communities.

Goals identify the consumer’s specific desires. All of us are far more likely to attain what we want by identifying and setting goals, thinking through a logical plan to achieve them, and then taking action in a timely manner. Requesting a specific service is not the same as identifying a goal in a significant life area. Goals are what we want to accomplish (ends), and the services are the means to achieving these goals or ends. It is important to remember that these are the consumer’s goals, not yours, and that differing identities and cultural beliefs may shape the goals.

⁷ Sec. 725(b)(3)

Goals should be clearly stated in the consumer information file, whether the consumer develops an Independent Living Plan or chooses a waiver.⁸

- See “Resources on Consumer Information Files” at <https://www.ilru.org/resources/resources-consumer-information-files>

Evaluation Standard 5—Independent Living Core Services

Once a consumer is able to state what they want to accomplish, service provision follows naturally. If the goal the person has chosen is to manage a budget better, participation in an independent living skills class in managing finances might be an obvious choice. If they want to move out of a nursing home into a community-based residence, there are probably a number of services they would need to accomplish that goal, such as housing location and referral; referral to or provision of personal assistance services, independent living skills classes in using public transportation, budgeting, and managing a PCA; individual advocacy with public benefits agencies; and peer mentoring from someone who has successfully transitioned and is living independently in the setting of their choice.

Provision of the IL Core Services is another fundamental principle and these services are required for an organization to meet the definition of a CIL in the Act, as amended. This requirement is reflected in Evaluation Standard 5:

*The center shall provide independent living core services and, as appropriate, a combination of any other independent living services.*⁹

The Core Services, that is the services that MUST be provided by a CIL, are specified in Section 7. Definitions of the Act:

(17) INDEPENDENT LIVING CORE SERVICES—The term “independent living core services” means—

- (A) Information and referral services;*
- (B) Independent living skills training;*
- (C) Peer counseling (including cross-disability peer counseling);*
- (D) Individual and systems advocacy; and*
- (E) Services that—*

⁸ Sec. 725(c)(14)

⁹ Sec. 725(b)(5)

- i. *Facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences, with the requisite supports and services;*
- ii. *Provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community; and*
- iii. *Facilitate the transition of youth who are individuals with significant disabilities, who were eligible for individualized education programs under section 614(d) of the Individuals with Disabilities Education Act (20 U.S.C. 1414(d)), and who have completed their secondary education or otherwise left school, to postsecondary life.*

See Appendix B for a list of other independent living services that a CIL MAY provide.

Assignment for Session Six

- 1) The cross-disability principle for CILs was a notably unique feature of the Rehabilitation Act definition of these organizations. Historically, most disability service organizations focused only on specific disability populations. Why do you think the founders felt so strongly that it should be in the law?
- 2) How does your CIL demonstrate that it is cross disability in its materials, website, staffing, board of directors, and programs?
- 3) What is the purpose of goal setting? Why is it not enough to simply ask a person what services they want to receive?

Session Seven: Core Service—Information & Referral

Preparations for Session Seven

- Read the summary of the Information & Referral Core Service below.
- Complete the on-demand training on Information and Referral services at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVoKeXK6oWXDSwBx35cSgZhg>

The first service mentioned in the Act that CILs MUST provide is Information and Referral (I & R). I & R is often the first point of contact between the center and a new consumer. The intent is to provide consumers with information and referral to community resources that meet their immediate needs. It is often also the only chance the CIL has to provide information on the other services available at the CIL, so is sometimes considered a gateway to providing other services.

I & R is a primary means to promoting consumer empowerment. The old saying that “knowledge is power” is true in many ways, especially for those who are seeking control over their own lives. Service systems and resources for people with disabilities are complex and often fragmented. Resources for accessible, affordable housing; legal remedies; financial benefits; and other supports aren’t helpful unless people know about them. I & R service supports an individual’s capacity for self-reliance and self-determination—an essential component of personal empowerment.

I & R has often been viewed as a less important service than other core services, but nothing could be further from the truth. Effective I & R services support individuals in planning for their lives and developing self-advocacy skills, not just dealing with the immediate crisis.

Information and Referral service is currently the only core service provided by CILs that do not require two things:

- 1) The person served does NOT have to be deemed eligible for services. (Remember that to be eligible, an individual must self-declare that they have a significant disability.)
- 2) The person served will not be asked to have a written Independent Living Plan or, if the plan is waived, to have written goals in a consumer information file.

Assignment for Session Seven

- 1) How are the Information and Referral services handled at your center, including those for culturally and linguistically diverse individuals (i.e. materials used in different languages, utilizing language translators, etc.)?
- 2) Have you seen an Information and Referral call turn into services requiring the opening of a consumer information file and setting goals? How did that happen?

Sessions Eight & Nine: Core Service—Individual and Systems Advocacy

Preparations for Sessions Eight & Nine

- Read the summary below of Individual and Systems Advocacy.
- Complete the on-demand training on Individual Advocacy at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVqpnQAaxlvQHOTF0SjVCDgI>
- Complete the on-demand training on Systems Advocacy at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVqpnQAaxlvQHOTF0SjVC DgI>.

Before core services were defined in law, Ed Roberts (the “father” of independent living) was asked what the three most important services were. He replied, “Advocacy, advocacy and advocacy.” That was because Ed knew that if the environment, systems, policies, and community options didn’t change for people with disabilities, services by themselves would not (could not) be effective.

Advocacy on behalf of people of color is also needed. Working to eliminate racist policies in housing, criminal justice, employment, and other systems will help all people with and without disabilities. Changing detrimental state and federal laws is an effective way to reduce barriers that disproportionately impact people of color such as unemployment, homelessness, and incarceration rates. It’s important for us as a disability community support social justice movements. Join with other groups and organizations to strengthen your voice and advocacy efforts.

In addition to Evaluation Standard 5—Independent Living Core Services, which lists Individual and Systems Advocacy among the core services, there are two other Standards that address the role of CILs in expanding choices and opportunities for “equal access for individuals with significant disabilities within their communities and to all of the center’s services, programs, activities, resources, and facilities.”

Individual Advocacy

Standard 4 states:

COMMUNITY OPTIONS—The center shall work to increase the availability and improve the quality of community options for independent living in order to facilitate the development and

achievement of independent living goals by individuals with significant disabilities.¹⁰

The philosophy of independent living at its most basic means controlling and directing your own life. It means taking risks and being allowed to succeed and fail on your own terms. Sometimes individuals need and want assistance from others because they are still in the process of developing the skill of speaking up for themselves. Individuals may need to be supported in learning how to approach people that have power over them, how to formulate their thinking, and what words to say. They often want to understand what their rights are.

Sometimes it may also involve supporting and communicating with the consumer's caregivers, other community-based agencies, and others in the consumer's circle of support.

Individual advocacy often evolves into the core service of Independent Living Skills Training as the consumer receives mentoring about how to communicate and make their needs known to family members, landlords, neighbors, legislators, and the nondisabled community. The Independent Living Specialist may do role-playing with the consumer in how to make a phone call to the Social Security Administration, or talk to the owner of an inaccessible store he or she would like to get into, or how to push back with a landlord that is being difficult. Sometimes a CIL will take direct action and intervene on the person's behalf when it has been requested to do so.

Individual Advocacy services are provided in the context of written goals, either in a formal Independent Living Plan or, if the consumer waives the plan, in other written form that captures the goal or purpose for the advocacy service for the individual consumer. As services begin to blend together, that demonstrates movement toward accomplishing goals because it's not possible to completely segregate core services from one another. Keeping the person's goals at the forefront of all services will guide the process.

It is important to understand and respect that not all cultures have the same values as they relate to the independent living core services. For example, many cultures do not expect an adult child with or without a disability to live independently or have competitive employment. Too often individual who have lived experiences with disabilities believe that professionals are the experts and the guidance from these experts should be followed. As you support the consumer in developing their individual advocacy skills, cultural perspectives must be considered.

¹⁰ Sec. 725(b)(4)

Systems Advocacy

Standard 6 states:

ACTIVITIES TO INCREASE COMMUNITY CAPACITY—The center shall conduct activities to increase the capacity of communities within the service area of the center to meet the needs of individuals with significant disabilities.¹¹

Often the similar needs of multiple consumers will lead a center to conduct Systems Advocacy. Many times the same barriers occur over and over again for a wide variety of people. Not only is it okay for centers to do Systems Advocacy, it is a requirement that they do so.

Every center in every part of the nation is familiar with the lack of affordable, accessible, integrated housing; people in nursing homes who can't get out; the absence of or inaccessibility of transit systems; exclusive education practices; and a host of other situations that are caused by systemic policies, procedures, and practices. By conducting systems advocacy, not only at the local level but also the state and national levels, centers have had a significant and lasting impact on barriers that affect a lot of people.

Systems Advocacy can take several forms, including—

- Providing testimony at public hearings.
- Serving on local and state councils, work groups, and task forces that are examining policies and practices.
- Writing letters to the editor.
- Proposing new policies and regulations to legislators and local governments.
- Using the media to change public opinion.
- Conducting protests in the streets.
- Taking legal action.

No one form of advocacy is the “right” approach. Sometimes all approaches must be used to have the degree of impact necessary to bring about change. However, it's also important that each center evaluates its own abilities and the resources it has in the community and do what works in its own situation. It's essential that every center

¹¹ Sec. 725(b)(6)

engage in systems advocacy because without removal of barriers, independence is an elusive dream for many people. It is also essential that CILs understand the difference between *systems advocacy* and *lobbying*, explained in the guidance mentioned below.

- See “Allowable Advocacy Activities for Federal Grantees FAQ” at https://acl.gov/sites/default/files/about-acl/2020-06/FAQ%20-%20Allowable%20Advocacy%20Activities_1.pdf under “Other ACL Guidance.”

Assignment for Sessions Eight & Nine

- 1) How does your center provide individual advocacy as a core service? Give an example of individual advocacy and how it has changed an individual’s life through empowerment and choice.
- 2) How does your center provide systems advocacy? Give an example of something that has been changed in your community because of the center’s systems advocacy.

Session Ten: Core Service—Peer Counseling (including cross-disability peer counseling) Services

Preparations for Session Ten

- Read the summary of the Peer Counseling Core Service below.
- Complete one of the following on-demand trainings on Peer Support at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVp3GS0cKNp1nU6fdQr8xPa0>

OR

<https://www.youtube.com/playlist?list=PLM1Y3X9vijVpKH6Mb6Z0gPSDfUPzmVaYy>

Although the Act uses the term *Peer Counseling* for this core service, most CILs use terms such as peer support, peer mentoring, and peer advocacy because early on in the Independent Living Program it was noticed that the term “counseling” misled many to expect a form of clinical services rather than peer sharing. Peer support and peer mentoring are at the heart of the Independent Living Program and philosophy. A person with life experience with a disability can be a valuable resource and offer encouragement and practical solutions to a person who is adapting to a new disability, or who wishes to increase their independence.

Through CIL surveys and feedback, Independent Living Research Utilization (ILRU) has learned that centers take a variety of approaches to meet the requirements of the core service of Peer Counseling. Some centers focus only on one-on-one peer relationships. Some centers provide peer mentoring support groups around various topics. Some are offered for specific groups of people such as youth, older adults, and specific disability populations. Others are more general. Some are modeled after the self-help approach of groups such as Alcoholics Anonymous, and others are more social or recreational in nature. Some centers have an organized group of volunteers with disabilities to provide peer mentoring, while others depend on the staff members who have disabilities to provide peer support as a natural part of every interaction with a consumer. Some centers implement a mix of these strategies.

Peer mentors are not only people who are personally living with a disability, but they are also individuals who are already living independently in their community and have a desire to help others achieve their independent living goals. Not everyone has the qualities to be a good peer mentor, so a center needs to have a clear definition of what it means by peer mentoring, and the qualifications that are required for someone to take on the role. Where possible, as you match peer mentors and mentees, take into consideration characteristics that may be relevant such disability, race, ethnicity, age, etc.

Having paid or volunteer peer mentors can expand the reach of a CIL, particularly those that are smaller and those with large service areas. Having a qualified, trained pool of individuals to provide mentoring can greatly multiply what a center is able to accomplish.

Peer mentoring services are provided in the context of written goals, either in a formal Independent Living Plan or, if the consumer waives the plan, in other written form that captures the goal or purpose for the service for the individual consumer. (A “waiver” form, signed by the consumer, includes goals but not a full written plan.)

Assignment for Session Ten

- 1) How does your center provide peer support (e.g. one-on-one, groups, disability or age specific, all of the above)?
- 2) What terminology does your center use to refer to this core service (e.g. peer support, peer counseling, peer mentoring, peer advocates)? Why was that term chosen?
- 3) What model(s) do you use and how do you think it/they are working (e.g. organized program, salaried employees as peers, or volunteers as peers)?

Session Eleven: Core Service—Independent Living Skills Training

Preparations for Session Eleven

- Read the summary of the Independent Living Skills Training Core Service below.
- Complete the on-demand training on IL Skills Training at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVrZRbw3ahDD4EbbbUIYolfH>

The program performance report (PPR), required annually, provides information about CIL activities, and defines IL Skills Training and Life Skill Training services to include "instruction to develop independent living skills in areas such as personal care, coping, financial management, social skills, and household management. This may also include education and training necessary for living in the community and participating in community activities."

Independent Living Skills Training is connected to individuals and their goals, and warrants the opening of a consumer information file and the development of goals. Having skills to make decisions and manage the day-to-day activities of one's life is basic to achieving the personal freedom consumers seek. IL Skills Training often happens one-on-one when CIL staff are facilitating the achievement of consumer goals, such as giving instruction on taking the bus. However, Independent Living Skills Training can take place in a variety of formats, such as workshops and small groups.

Groups can be cross-disability or consist of people with the same or similar disability. Groups may be organized for youth and young adults. Training may occur at the CIL, in the community, or in the consumer's home. Services for youth may occur in the school setting. In addition to the different skill areas listed in the definition, training may also be offered on Social Security benefits management, understanding resources, communicating effectively, job readiness skills such as resume writing and interviewing, assistive technology, recreational opportunities, navigating public transportation, maintaining healthy relationships, and other areas. IL Skills Training can be provided on any skill or topic that helps an individual with a disability to live more independently.

Sometimes training on life skills leads to the development of increased self-advocacy skills. When that happens, the core services of IL Skills Training and Advocacy/Self-Advocacy begin to blend together. Likewise, sometimes it can be difficult to know where Information and Referral leaves off and a more comprehensive sharing of information through training begins. Similarly, consumers may request one service, then realize while working with staff that they need a different service. One service can easily move toward another service, such as when a discussion about balancing budgets and financial management can lead to providing assistance with finding employment or housing. This blending of core services actually shows successful outcomes, but may

raise questions about how to classify a particular service in the PPR. Each CIL needs to have its own policy about this so that all staff are reporting as consistently as possible. It can be very helpful to have discussions about the blended nature of services and outcomes for this reason, but also to help staff think about consumers and the services of the CIL holistically. A truly effective center will have services that are so interconnected that they will appear seamless to a consumer. The staff, however, should be able to identify the service provided to meet a specific goal step. When services are blended, the goals or goal steps will help the CIL have accurate service reporting.

Many CILs offer training opportunities for family members of people with disabilities. This is also a good practice and can expand the reach of Independent Living Skills considerably. However, because family members are not the consumer, this should not be tracked and reported as IL Skills Training. Those services should be tracked separately. Many CILs record them as community activities.

Assignment for Session Eleven

- 1) How does your center provide Independent Living Skills Training?
- 2) What are four or five IL skills that consumers you know are learning? Are these taught in an individual or group setting?
- 3) Self-advocacy is a skill. How does learning this skill (through the core service of IL Skills Training) relate to the other core services of Individual and Systems Advocacy at your center?

Session Twelve: Core Service—Transition or Diversion from Institutions

Preparations for Session Twelve

- Read the description below concerning the Transition and Diversion Core Services.
- Scan the list of on-demand trainings on ILRU's Transition & Diversion webpage at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVq0f8zqPHdWjo8xcEgkeCMy> and choose one item to view or listen to.

Many CILs have been providing the service of assisting individuals to relocate to the community from nursing homes and other institutions for some time. On July 22, 2014, the Workforce Innovation and Opportunity Act (WIOA) was signed into law, bringing about a number of changes to the Independent Living Program, including adding core services that have both a “transition” and a “diversion” component.

The core services added by WIOA have three prongs:

- 1) facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences, with the requisite supports and services,
- 2) provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals remain in the community, and
- 3) facilitate the transition of youth who are individuals with significant disabilities who were eligible for individualized education programs under Section 614(d) of the Individuals with Disabilities Education Act (20 U.S.C. 14149d)), and who have completed their secondary education or otherwise left school, to postsecondary life.

The independent living field was then and continues to be extremely well positioned to take on the tasks of “transition” and “diversion” as part of “official” core services. Surveys and informal reports from centers suggest that the vast majority of them had been providing transition and diversion services for some time. This would be consistent with the Independent Living philosophy that centers practice, promoting the least restrictive environment and community-based choices for all persons with disabilities.

The independent living movement has been active in deinstitutionalization from its beginning, including supporting the initiatives where funding can follow the person from the nursing home into the community. Independent living advocates were involved in pushing for the Olmstead decision, a Supreme Court decision that requires that individuals be allowed to choose services in the community over institutional care if they

wish. Each state has its own strategy for implementing this landmark decision. Most states are not fully implementing it, and advocacy by CILs is still needed for full implementation to occur.

- See “ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators” at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVoJNs8rh64Mnp9BmXB8gYTt>

The second prong above that indicates centers are to “Provide assistance [to] remain in the community” is not quite as straightforward as institutional transition is. Transition is a tangible moving from one location to another. On the other hand, avoiding institutionalization may involve assistance through one service or a multitude of services and be offered as a one-shot service such as building a ramp or long-term supports through training, peer mentoring, housing location and referral, and other services. The independent living regulations which implement the Rehabilitation Act as amended under WIOA simply state: “Provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community. A determination of who is at risk of entering an institution should include self-identification by the individual as part of the intake or goal-setting process.” Centers had a head start on this service, because they have always assisted with the wide range of supports that individuals need to avoid institutionalization. For ease of discussion, this manual refers to this service as Diversion.

- See “Who’s ‘At-Risk’? How to Determine and Address Risk of Institutional Placement to Achieve the New Core Service of Diversion” at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVq0f8zqPHdWjo8xcEgkeCMY>

In CIL programs, the expectation is that Transition and Diversion services are provided in the context of written goals, either in a formal Independent Living Plan or, if the consumer waives the plan, in other written form that captures the goal or purpose for the service for the individual consumer.

Assignment for Session Twelve

- 1) What services does your center currently provide to relocate individuals from nursing homes to the community?
- 2) How does your center identify individuals who are at risk of institutional placement?
- 3) Read the scenario below and then complete this exercise: CILs are required by the Act to provide institutional transition and diversion services. They are also required to honor the self-chosen choices of consumers, although not required to assist someone to get into an institution. In the scenario, it would

seem there is a conflict between those principles. How then would you answer the following?

- Is Jim justified in helping someone get into a nursing home?
- Is Marcie right? If so, what could Jim have done differently?
- Was the supervisor responding appropriately to the situation?
- Does the board of directors have any responsibility for this situation?

Scenario #2: But It's the Best One in Town

Jim McCarthy is the newest member of the staff at Midvale Center for Independent Living (MCIL). He is working in the Personal Assistance Services (PAS) program and just been assigned his first 10 consumers.

This morning, Jim is reading files and, for the first time, taking his turn in the office. At 10:30 in the morning Jim received his first visit. Fred Martin, who had never been in contact with the center, is looking for a place to live. Fred told Jim that he needed to move someplace where “someone could take care of me.”

When Jim spoke to Fred he found that Fred had just been released from the hospital where he had received treatment for a severe bedsore. Fred asked Jim if the center had housing and seemed surprised when Jim explained that CILs offer non-residential community-based services.

Jim then went on to explain the PAS program provided by the CIL and funded through the state's Medicaid waiver. When Fred asked about access to the program, however, he was told that there was a nine-month waiting list. Jim spent the next hour going over other options at the center and in the community, telling Fred the strengths and weaknesses of each.

Frustrated by his situation, Fred asked Jim if he would help him get into a good nursing home. “I just need a place I can go for a year or so,” Fred said. “Besides, it's where my mother wants me to go and she says there are some really good ones out there.” Jim took Fred's phone number and promised to call him back.

Jim immediately went to his supervisor, who confirmed that there are no immediate PAS options for Fred. He commended Jim for his work, and suggested that Jim send Fred information on MCIL's advocacy program. The center had led the fight to bring PAS to the state and recently sued the governor because 70% of the state's community-based funds were still being spent in nursing homes.

Jim's supervisor also suggested that he call the Area Agency on Aging, which maintains a list of accredited nursing homes, and pass the information along to Fred.

Later that day, Jim was sharing his experience with a co-worker, Marcie. “How could you consider helping someone get into a nursing home?” she asked. “This isn't what

we're about! We're supposed to get people out of institutions and you're helping consumers get into them." Jim was confused. After all, there aren't any other options. "And besides," Jim protested, "it was Fred's choice."

Session Thirteen: Core Service—Transition of Youth to Postsecondary Life

Preparations for Session Thirteen

- Read the description below of the Transition of Youth to Postsecondary Life Core Service.
- Review the “Frequently Asked Questions: Independent Living Services for Children and Youth with Disabilities” guidance from the Administration for Community Living at https://acl.gov/sites/default/files/news%202017-05/ACL_ILA_Youth_Services_FAQ0417.pdf
https://acl.gov/sites/default/files/news%202017-05/ACL_ILA_Youth_Services_FAQ0417.pdf.
- Scan ILRU’s webpage on youth transition at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVog-BPizyZHMzcYfLqMpjcf> and make note of one or more on-demand trainings you would like to view or listen to.

CILs have been serving youth and young adults for decades, assisting in the transition from school and living with parents to post-secondary education, employment, and independent living. When WIOA was signed into law, it became a requirement that at a minimum CILs must “facilitate the transition of youth who are individuals with significant disabilities, who were eligible for individualized education programs under section 614(d) of the Individuals with Disabilities Education Act (IDEA) (20 U.S.C. 1414(d)), **and who have completed their secondary education or otherwise left school**, to postsecondary life.”

This core service includes any independent living service provided to youth with significant disabilities who:

- (A) Were eligible for an IEP while in school, and
- (B) Have left secondary school...

...that assists them in the transition to post-secondary life.

The law’s post-secondary focus does not mean that CILs can’t also serve youth who are still in school or who weren’t eligible for an IEP. CILs have always been defined as organizations that serve all age groups. However, the required *core service*—something you need to measure—is specific to the above definition. The broader definition of youth in the law includes individuals who are aged 14-24 who are still in school as well as those who have left school. For purposes of the annual Program Performance Report (PPR) sent to ACL, the CIL must keep track of who meets the legal definition of the core service so it can be demonstrated that this core service is being delivered. Youth who

do not meet the above definition would be reported in the other appropriate service

categories. A number of CILs wrap their youth programs into their overall core services. Successful and effective CIL youth services are integrated, not separate from the other services of the center.

ILRU surveys of CILs show that they are involved with youth and young adults in a variety of ways. This includes comprehensive youth programs, collaborating with community youth groups or organizations on youth projects or services, sponsoring youth support groups, and engaging youth and young adults in systems advocacy activities such as visits to legislators.

Many CILs assist youth and young adults with IL Skills Training (e.g., managing their IEP process, budgeting, self-advocacy, home management), transition from school, support with assistive technology, locating housing, and finding employment.

- See “Expanding CIL Capacity through Youth-Driven Transition Services” at <https://www.youtube.com/playlist?list=PLM1Y3X9vijVqBGGcjgR4x2YmUSAk3nklq>

The expectation is that services to assist individuals in transition to postsecondary life are provided in the context of written goals, either in a formal Independent Living Plan or, if the consumer waives the plan, in other written form that captures the goal or purpose for the service for the individual consumer.

Assignment for Session Thirteen

- 1) What ages of youth are currently served by your center and what services do you provide?
- 2) Are you serving youth that are not eligible for an IEP (Individualized Education Plan) in addition to those who are eligible? Are there any differences in services?
- 3) What planning for services to youth is underway at your CIL?

Session Fourteen: The CIL as the Center of the Disability Community – Disability Pride

Preparations for Session Fourteen

- Consider what your CIL represents in your community.
- Read the discussion below of the role of a CIL within the disability community.

While CILs are certainly service providers and agents of change in the community and the larger service systems, they are also something more. One of their most critical functions is supporting individuals with disabilities to view themselves and the disability community with pride. Strong, effective centers are a place where the disability community can gather and provide role modeling and peer support. They can ignite a greater perceived value of the disability experience.

“People with disabilities are the largest and most diverse minority within the population representing all abilities, ages, races, ethnicities, religions, and socio-economic backgrounds. *Disability Pride* has been defined as accepting and honoring each person’s uniqueness and seeing it as a natural and beautiful part of human diversity. Disability Pride is an integral part of movement building, and a direct challenge of systemic ableism and stigmatizing definitions of disability.”¹²

CILs provide the most meaningful venue for people with disabilities to better understand and incorporate disability pride into their daily lives. With the independent living philosophy as the foundation and the strength of peer support available, disability pride flourishes at CILs.

Independent living philosophy should be evident when you enter a center. Maybe you have posters and photos of people with disabilities (visible or not visible) of different races and ethnicities in action on the walls, or quotes from disability leaders. If not, think about this as a powerful strategy for communicating that the consumers, board, and staff are peers, not a social worker or client and service provider relationship. Is it evident to your consumers that your organization is run by people with disabilities and is consumer-controlled?

Also, find ways to celebrate and welcome the intersection of identities that consumers may have including race/ethnicity, gender, sexual orientation, etc. For example, does your staff use or welcome gender pronouns when speaking with consumers, do you offer materials and translation in other languages, do you celebrate holidays that are

¹² Retrieved from <https://www.ameridisability.com/post/how-to-display-disability-pride>

representative of culturally diverse communities, are the staff and board representative of the diverse populations in your community, etc.?

In previous sessions, we talked about peer support being a core service, but just like the center itself, peer support is something more. It often flows out of the rich diversity of board, staff, and consumers who participate in a center in some way. While you may have groups or a volunteer matching program for peer support, there is an element that should occur of its own accord. People with various disabilities, of different ages, races, ethnicities, and cultures are active in and around the center. It may be natural, then, to share life experiences or to ask a person with a similar disability or from the same ethnic or linguistic background about the how-to's of their life with a disability. The intangible, growing sense of pride and empowerment, which is an internal process within the individual, will begin to happen spontaneously without planning or direction by staff or management.

When the larger disability community participates in your center and begins to understand the importance and depth of real consumer control, you will have a significant impact on the larger community. Interacting with other disability-serving agencies can be accomplished by—

- Having them come to your center for events or meetings.
- Having CIL staff and volunteers sit on community boards and councils.
- Active discussion and role-modeling that occurs at multiple meetings and sites across your community.

For real change to take place, it is imperative that other disability agencies understand the power and strength that comes from people with disabilities leading others. The power of seeing consumer control in action will open minds to the authentic meaning of self-determination, independence, choice, and empowerment.

Assignment for Session Fourteen

- 1) How does your center celebrate and encourage Disability Pride?
- 2) How could your center be more involved and more visible in your community?
- 3) Read the following scenario and share your thoughts about it on the discussion board.

Scenario #3: Walking the Walk

Greg Mitchell is the Transition Specialist for the East Lakes Center for Independent Living (ELCIL). He is the center's first point of contact for consumers wishing to maintain

or pursue community-based living, and his responsibilities include assisting consumers as they develop their transition plans.

Greg has been in this position for four years and has become knowledgeable about independent living resources in the community. In spite of Greg's knowledge, consumers often pass by his office to speak with other IL staff at the center.

The center recently hired a new executive director, Pete Williams, who has been directed by the board to improve ELCIL's adherence to the IL philosophy. He is particularly concerned about the nursing home transition program, believing that it is one of the most important services offered by a center.

In discussions with Greg, Pete has expressed concern that consumers rarely spend more than a few minutes with him. He feels that a Transition Specialist should work with consumers to better identify their barriers to independence and sort through options available in the community, including discussing the strengths and weaknesses of each option. In addition to giving him several training manuals that had been developed by the field, Pete sent Greg to a three-day transition training in another state.

In spite of these efforts, there has been no noticeable change in the response of consumers to Greg's efforts. They just don't seem to respond to him.

Pete believes he knows what the root of the problem is: Greg's living situation. Pete overheard a group of consumers discussing Greg's preference "to live in an institution." When asked about their comments, they told Pete that Greg "tells us to move into the community, but won't do it himself."

Greg has lived for the last eight years in the Good Samaritan Rehabilitation Center, a nursing home on the outskirts of the city. In spite of the center's assurances of housing, transportation, and personal assistance services, Greg has been unwilling to even explore moving into the city. Greg says he likes living in the nursing home because "it's easy."

In Pete's mind, Greg will never be an effective role model or Transition Specialist as long as he continues to live in an institutional setting and use the nursing home's transportation services. None of the other staff at ELCIL were willing to trade jobs with Greg. After clearing his intentions with the center's attorney, Pete gives Greg an ultimatum: Move into the community within six months or lose his job.

Session Fifteen: Summary Discussion

Preparations for Session Fifteen

- Read *History of Independent Living* beginning on page 47 in Appendix C.
- Read the following summary paragraph, then answer the assignment questions.

Based on your understanding of the IL philosophy at this point, you may feel ready to begin applying the philosophy to your day-to-day work. Think about examples of situations at your center where application of the philosophy could be strengthened and what you might be able to do personally to address the situations. For example, you may believe that your CIL's skills training manual doesn't promote consumer choice. Or, you may feel that you don't understand IL history as much as you would like to or as much as needed to make you fully effective in your job. Once you've identified some areas that could be strengthened, begin to formulate a plan for steps you want to take that will support your center's highest capacity for implementing the independent living philosophy.

- 1) What situations can you identify at your center that could be strengthened philosophically?
- 2) What might you do personally to have an impact on them?
- 3) Share any final comments you have about specific scenarios or the content of the course, in general.
- 4) Complete and submit the End of Course evaluation and post-survey by clicking on the "Evaluations" icon on the Home page.

National Resources on Independent Living

The following is a list of several national organizations that have been established to provide technical assistance on independent living issues.

Independent Living Research Utilization Program

ILRU Program is a national center for information, training, research, and technical assistance on independent living. Founded in 1977, its goal is to expand the body of knowledge in independent living and to improve utilization of results of related research and demonstration projects. Website: <https://www.ilru.org/>

National Council on Independent Living

Founded in 1982, NCIL is a membership organization representing independent living centers, statewide independent living councils, and individuals with disabilities. NCIL has been instrumental in efforts to incorporate independent living philosophy in federal legislation and regulations. Website: <https://ncil.org>.

Association of Programs for Rural Independent Living

One of the best resources for information about rural independent living is APRIL. Established in 1986, APRIL is an association of centers and other organizations and individuals across the country serving a predominantly rural constituency and focus. Website: <https://www.april-rural.org>.

Disability and Business Technical Assistance Centers on ADA

There are 10 regional DBTACs funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the U.S. Department of Health and Human Services, to provide technical assistance and training on the Americans with Disabilities Act (ADA). The Southwest DBTAC, operated by ILRU, features a Hispanic outreach program. By calling 1-800-949-4232 from anywhere in the country, your call will be routed automatically to the appropriate regional DBTAC. Website: <https://adata.org>.

American Disabled for Attendant Programs Today

ADAPT is one of the oldest and most active grassroots disability rights advocacy groups, including civil disobedience as an advocacy tool. Following its tremendous success in advocating for accessible transportation, ADAPT now focuses its mission on personal assistance services and the full implementation of the Supreme Court's Olmstead ruling. Website: <https://adapt.org>.

Disability Rights Education and Defense Fund

DREDF is an organization dedicated to promoting the civil rights of individuals with disabilities through research, education, and advocacy. Website: <https://dredf.org>.

World Institute on Disability

Originally founded in 1983 from within the grassroots disability rights movement, WID's focus is now international in scope. WID conducts research and training in public policy, personal assistance services, and independent living. Website: <https://wid.org>.

Research and Training Center on Independent Living at the University of Kansas

The University of Kansas operates a national research and training center that focuses on aspects of independent living. Its research is used in a variety of ways, including training in the field, conference presentations, policy decision-making, and useful products. Website: <https://rtcil.ku.edu>

Rural Institute for Inclusive Communities at the University of Montana

The Rural Institute offers professional and community education training on several disability-related topics. Several of these are used by centers, especially the 2nd bullet:

- [Leadership Education in Neurodevelopmental and related Disabilities \(URLEND\)](#)
- [Living Well with a Disability and Working Well with a Disability](#)
- [Including People with Disabilities in Healthy Communities](#)
- [Montana Disability & Health Program](#)
- [Montana's Deaf-Blind Project](#)
- [Montana and Autism: Next Steps](#)
- [Movin' On in Montana](#)

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Updated May 2017

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- Kailes, J. I. (Revised 1997). *Advocacy: Reality or Rhetoric Inventory*. 5 pages. A popular questionnaire tool used to help evaluate if an independent living center or other disability related organization is truly committed to advocacy and systems change. Self-published.
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- Lachat, Mary Ann. (1988). *The Independent Living Service Model: Historical Roots, Core Elements, and Current Practice*. Hampton, NH: Center for Resource Management.
- National Council on the Handicapped (now the National Council on Disability). (1986, February). *Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities – With Legislative Recommendations*. Available from NCD, 1331 F Street, NW, Suite 1050, Washington, DC 20004 (202) 272-2004 (v), 272-2074 (TTY).
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Ragged Edge Online. An online source for articles on a wide range of topics related to the disability rights movement. Website: <https://www.raggededgemagazine.com>

Richards, Laurel and Quentin Smith. (1987). *An Orientation to Independent Living Centers*. Houston: ILRU Program.

Shapiro, Joseph P. (1993). *No Pity*. New York: Random House, Inc.

Shreve Maggie, Patricia Spiller, Eric Griffin, Nancy Waldron, & Lynda Stolzman. Martha Williams, ed. *Consumer Control in Independent Living*. Available from: Center for Resource Management, 2 Highland Road, South Hampton, NH 03847; (603) 394-7040 (v/TTY), 394-7483 (fax).

We Won't Go Away, videocassette. Sells for \$20 each, including postage, from the World Institute on Disability, 510 16th Street, Suite 100, Oakland, CA 94612 (510) 763-4100 (v), 208-9493 (TTY).

Willig, Chava Levy. *A People's History of Independent Living*. (1988). Available from the Research and Training Center on Independent Living, 4089 Dole Building, University of Kansas 66045; (913) 864-4095 (v/TTY).

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Clay, Julie Anna. Native American Independent Living, 41-50.

Nosek, Margaret. The Personal Assistance Dilemma for People with Disabilities Living in Rural Areas, 36-40.

Potter, Carol G., Quentin W. Smith, Huong Quan, & Margaret A. Nosek. Delivering Independent Living Services in Rural Communities: Options and Alternatives, 16-23.

Seekins, Tom, Craig Revesloot, and Bob Maffit. Extending the Independent Living Center Model to Rural Areas: Expanding Services through State and Local Efforts, 11-15.

Most of the readings cited above can be obtained from resource clearinghouses. Several are listed below and can be reached for further information about publications and modem-accessible databases by mail or telephone.

- National Clearinghouse of Rehabilitation Training Materials, Oklahoma State University, 816 West Sixth Ave., Stillwater, OK 74078 (800) 223-5219.
- National Rehabilitation Information Center (NARIC), 8455 Colesville Road, Suite 935, Silver Spring, MD 20910 (800) 346-2742 (v), 227-0216 (TTY).

- ERIC Clearinghouse on Disabilities and Gifted Education (formerly the ERIC Clearinghouse on Handicapped and Gifted Children), 1920 Association Dr., Reston, VA 22091, (800) 328-0272 (v/TTY) at the Council for Exceptional Children, (703) 620-3660, ext. 307 (v).

Disability, Diversity, and Intersectionality Resources Updated 2022

- Acho, Emmanuel. (2020). *Uncomfortable Conversations with a Black Man*. Flatiron Books: an Oprah Book. ISBN 1250800463.
- Alexander, Michelle. (2012). *The New Jim Crow: Mass Incarceration in the Age of Colorblindness*. New Press. ISBN 1620971933.
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- Coates, Ta-Nehisi. (2015). *Between the World and Me*. Text Publishing. ISBN 1925240703.
- DiAngelo, Robin. (2018). *White Fragility: Why It's So Hard for White People to Talk about Racism*. Beacon Press. ISBN 0807047414.
- Dolmage, Jay T. (2018). *Disabled Upon Arrival: Eugenics, Immigration and the Construction of Race and Disability*. Ohio State University. ISBN 0814254675.
- Fleming, Crystal M. (2019). *How to Be Less Stupid about Race—On Racism, White Supremacy, and the Racial Divide*. Beacon Press. ISBN 0807039845.
- Hunter, Daniel. (2015). *Building a Movement to End the New Jim Crow: An Organizing Guide*.
- Johnson, Allan G. (2017). *Privilege, Power, and Difference*. ISBN 0073404225.
- Kendi, Ibram X. (2019). *How to Be an Antiracist*. One World. ISBN 0525509283.
- McGhee, Heather. (2021). *The Sum of Us; What Racism Costs Everyone and How We Can Prosper Together*. One World. ISBN 05255095689.
- Menakem, Resmaa. (2017). *My Grandmother's Hands: Racialized Trauma and the Pathway to Mending Our Hearts and Bodies*. Central Recovery Press. ISBN 1942094477.
- Mwatangi. (2021). *Black Disability History, Volumes I, II, and III: Reclaiming the Black Disabled Experience*. AfroSapiophile. Available from mwatangi.medium.com.
- Rothstein, Richard. (2018) *The Color of Law: A Forgotten History of How Our Government Segregated America*. Liveright. ISBN 9781631494536.

- Smith, Clint. (2021). *How the Word is Passed: A Reckoning with the History of Slavery Across America*. Little, Brown and Company. ISBN 0316492930.
- Wong, Alice. (2020). *Disability Visibility: First-Person Stories from the Twenty-First Century*. New York: Vintage Books. ISBN 1984899422.

ILRU also offers a number of publications and other materials on various independent living subjects. For a listing of resource materials, visit the ILRU website at <https://www.ilru.org/resources/cil-net> or contact ILRU at 1333 Moursund Street, Houston, TX 77030, (713) 520-0232 (v), 520- 5136 (TTY); e-mail:

Appendix A: Standards and Assurances for Centers for Independent Living (CILs)

45 C.F.R. §1329.5: To be eligible to receive funds under this part (Independent Living Services and Centers for Independent Living), a Center must comply with the standards in section 725(b) and assurances in section 725(c) of the Act.

STANDARDS

EVALUATION STANDARD 1—PHILOSOPHY

The center shall promote and practice the independent living philosophy of—

- 5) Consumer control of the center regarding decisionmaking, service delivery, management, and establishment of the policy and direction of the center;
- 6) Self-help and self-advocacy;
- 7) Development of peer relationships and peer role models; and
- 8) Equal access for individuals with significant disabilities within their communities and to all services, programs, activities, resources, and facilities, whether public or private and regardless of the funding source.

EVALUATION STANDARD 2—PROVISION OF SERVICES

- 1) The center shall provide IL services to individuals with a range of significant disabilities.
- 2) The center shall provide services on a cross-disability basis (for individuals with all different types of significant disabilities, including individuals with significant disabilities who are members of populations that are unserved or underserved by programs under Title VII of this Act).
- 3) The center shall determine eligibility for IL services. The center may not base eligibility on the presence of any one or more specific significant disabilities.

EVALUATION STANDARD 3—INDEPENDENT LIVING GOALS

The center shall facilitate the development and achievement of independent living goals selected by individuals with significant disabilities who seek such assistance by the center.

EVALUATION STANDARD 4—COMMUNITY OPTIONS

The center shall work to increase the availability and improve the quality of community options for independent living in order to facilitate the development and achievement of independent living goals by individuals with significant disabilities.

EVALUATION STANDARD 5—INDEPENDENT LIVING CORE SERVICES

The center shall provide independent living core services and, as appropriate, a combination of any other independent living services.

EVALUATION STANDARD 6—ACTIVITIES TO INCREASE COMMUNITY CAPACITY

The center shall conduct activities to increase the capacity of communities within the service area of the center to meet the needs of individuals with significant disabilities.

EVALUATION STANDARD 7—RESOURCE DEVELOPMENT ACTIVITIES

The center shall conduct resource development activities to obtain funding from sources other than this chapter [Chapter 1 of Title VII of the Act].

ASSURANCES

The eligible agency shall provide at such time and in such manner as the Administrator may require, such satisfactory assurances as the Administrator may require, including satisfactory assurances that—

- 1) The applicant is an eligible agency;
- 2) The center will be designed and operated within local communities by individuals with disabilities, including an assurance that the center will have a Board that is the principal governing body of the center and a majority of which shall be composed of individuals with significant disabilities;
- 3) The applicant will comply with the standards set forth in subsection (b);
- 4) The applicant will establish clear priorities through annual and 3-year program and financial planning objectives for the center, including overall goals or a mission for the center, a work plan for achieving the goals or mission, specific objectives, service priorities, and types of services to be provided, and a description that shall demonstrate how the proposed activities of the applicant are consistent with the most recent 3-year State plan under section 704;

- 5) The applicant will use sound organizational and personnel assignment practices, including taking affirmative action to employ and advance in employment qualified individuals with significant disabilities on the same terms and conditions required with respect to the employment of individuals with disabilities under section 503;
- 6) The applicant will ensure that the majority of the staff, and individuals in decisionmaking positions, of the applicant are individuals with disabilities;
- 7) The applicant will practice sound fiscal management;
- 8) The applicant will conduct self-evaluations, prepare an annual report, and maintain records adequate to measure performance with respect to the standards, containing information regarding, at a minimum—
 - i. The extent to which the center is in compliance with the standards;
 - ii. The number and types of individuals with significant disabilities receiving services through the center;
 - iii. The types of services provided through the center and the number of individuals with significant disabilities receiving each type of service;
 - iv. The sources and amounts of funding for the operation of the center;
 - v. The number of individuals with significant disabilities who are employed by, and the number who are in a management and decisionmaking positions in, the center; and
 - vi. A comparison, when appropriate, of the activities of the center in prior years with the activities of the center in the most recent year;
- 9) Individuals with significant disabilities who are seeking or receiving services at the center will be notified by the center of the existence of, the availability of, and how to contact, the client assistance program;
- 10) Aggressive outreach regarding services provided through the center will be conducted in an effort to reach populations of individuals with significant disabilities that are unserved or underserved by programs under this title, especially minority groups and urban and rural populations;
- 11) Staff at centers for independent living will receive training on how to serve such unserved and underserved populations, including minority groups and urban and rural populations;
- 12) The center will submit to the Statewide Independent Living Council a copy of its approved grant application and the annual report required under paragraph (8);

- 13) The center will prepare and submit a report to the designated State unit or the Administrator, as the case may be, at the end of each fiscal year that contains the information described in paragraph (8) and information regarding the extent to which the center is in compliance with the standards set forth in subsection (b); and
- 14) An independent living plan described in section 704(e) will be developed unless the individual who would receive services under the plan signs a waiver stating that such a plan is unnecessary.

Appendix B: Array of Services

As mentioned in Session Four, there is an array of other independent living services listed in the Act that CILs may provide. The Administration for Community Living, Office of Independent Living Programs has determined that Standard 5, which states that “the center shall provide...as appropriate, a combination of any other independent living services” means that centers are also expected to provide at least two of the following of a range of services found in Section 7(18)(B) of the Act.

(18) Independent living services.—The term “independent living services” includes—

(A) independent living core services; and

(B)

- i. counseling services, including psychological, psychotherapeutic, and related services;
- ii. services related to securing housing or shelter, including services related to community group living, and supportive of the purposes of this Act and of the titles of this Act, and adaptive housing services (including appropriate accommodations to and modifications of any space used to serve, or occupied by, individuals with disabilities);
- iii. rehabilitation technology;
- iv. mobility training;
- v. services and training for individuals with cognitive and sensory disabilities, including life skills training, and interpreter and reader services;
- vi. personal assistance services, including attendant care and the training of personnel providing such services;
- vii. surveys, directories, and other activities to identify appropriate housing, recreation opportunities, and accessible transportation, and other support services;
- viii. consumer information programs on rehabilitation and independent living services available under this Act, especially for minorities and other individuals with disabilities who have traditionally been unserved or underserved by programs under this Act;
- ix. education and training necessary for living in a community and participating in community activities;
- x. supported living;
- xi. transportation, including referral and assistance for such transportation and training in the use of public transportation vehicles and systems;

- xii. physical rehabilitation;
- xiii. therapeutic treatment;
- xiv. provision of needed prostheses and other appliances and devices;
- xv. individual and group social and recreational services;
- xvi. training to develop skills specifically designed for youths who are individuals with disabilities to promote self-awareness and esteem, develop advocacy and self-empowerment skills, and explore career options;
- xvii. services for children;
- xviii. services under other Federal, State, or local programs designed to provide resources, training, counseling, or other assistance, of substantial benefit in enhancing the independence, productivity, and quality of life of individuals with disabilities;
- xix. appropriate preventive services to decrease the need of individuals assisted under this Act for similar services in the future;
- xx. community awareness programs to enhance the understanding and integration into society of individuals with disabilities; and
- xxi. such other services as may be necessary and not inconsistent with the provisions of this Act.

Appendix C: Readings on Independent Living

History of Independent Living¹³

By Gina McDonald and Mike Oxford

This account of the history of independent living stems from a philosophy that states that people with disabilities should have the same civil rights, options, and control over choices in their own lives as do people without disabilities.

The history of independent living is closely tied to the civil rights struggles of the 1950s and 1960s among African-Americans. Basic issues—disgraceful treatment based on bigotry and erroneous stereotypes in housing, education, transportation, and employment—and the strategies and tactics are very similar. This history and its driving philosophy also have much in common with other political and social movements of the country in the late 1960s and early 1970s. There were at least five movements that influenced the disability rights movement.

Social Movements

The first social movement was deinstitutionalization, an attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities. This movement was led by providers and parents of people with developmental disabilities and was based on the principle of “normalization” developed by Wolf Wolfensberger, a sociologist from Canada. His theory was that people with developmental disabilities should live in the most “normal” setting possible if they were expected to behave “normally.” Other changes occurred in nursing homes where young people with many types of disabilities were warehoused for lack of “better” alternatives (Wolfensberger, 1972).

The next movement to influence disability rights was the civil rights movement. Although people with disabilities were not included as a protected class under the Civil Rights Act, it was a reality that people could achieve rights, at least in law, as a class. Watching the courage of Rosa Parks as she defiantly rode in the front of a public bus, people with disabilities realized the more immediate challenge of even getting on the bus.

The “self-help” movement, which really began in the 1950s with the founding of Alcoholics Anonymous, came into its own in the 1970s. Many self-help books were published and support groups flourished. Self-help and peer support are recognized as

¹³ From IL-NET Training Manual, Standards and More: Beyond Compliance (1995) – <https://ilttacenter.org/library/>

key points in independent living philosophy. According to this tenet, people with similar disabilities are believed to be more likely to assist and to understand each other than individuals who do not share experience with similar disability.

Demedicalization was a movement that began to look at more holistic approaches to health care. There was a move toward “demystification” of the medical community. Thus, another cornerstone of independent living philosophy became the shift away from the authoritarian medical model to a paradigm of individual empowerment and responsibility for defining and meeting one’s own needs.

Consumerism, the last movement to be described here, was one in which consumers began to question product reliability and price. Ralph Nader was the most outspoken advocate for this movement, and his staff and followers came to be known as “Nader’s Raiders.” Perhaps most fundamental to independent living philosophy today is the idea of control by consumers of goods and services over the choices and options available to them.

The independent living paradigm, developed by Gerben DeJong in the late 1970s (DeJong, 1979), proposed a shift from the medical model to the independent living model. As with the movements described above, this theory located problems or “deficiencies” in the society, not the individual. People with disabilities no longer saw themselves as broken or sick, certainly not in need of repair. Issues such as social and attitudinal barriers were the real problems facing people with disabilities. The answers were to be found in changing and “fixing” society, not people with disabilities. Most important, decisions must be made by the individual, not by the medical or rehabilitation professional.

Using these principles, people began to view themselves as powerful and self-directed as opposed to passive victims, objects of charity, cripples, or not-whole. Disability began to be seen as a natural, not uncommon, experience in life; not a tragedy.

Independent Living

Ed Roberts is considered to be the “father of independent living.” Ed became disabled at the age of fourteen as a result of polio. After a period of denial in which he almost starved himself to death, Ed returned to school and received his high school diploma. He then wanted to go to college. The California Department of Rehabilitation initially rejected Ed’s application for financial assistance because it was decided that he was “too disabled to work.” He went public with his fight and within one week of doing so, was approved for financial aid by the state. Fifteen years after Ed’s initial rejection by the State of California as an individual who was “too” disabled, he became head of the California Department of Rehabilitation—the agency that had once written him off.

After Ed earned his associate degree at the College of San Mateo, he applied for admission to the University of California at Berkeley. After initial resistance on the part

of the university, Ed was accepted. The university let him use the campus hospital as his dormitory because there was no accessible student housing (none of the residential buildings could support the weight of Ed's 800-lb. iron lung). He received attendant services through a state program called "Aid to the Totally Disabled." This is a very important note because this was consumer-controlled personal assistance service. The attendants were hired, trained, and fired by Ed.

In 1970, Ed and other students with disabilities founded a disabled students' program on the Berkeley campus. His group was called the "Rolling Quads." Upon graduation, the "Quads" set their sights on the need for access beyond the University's walls.

Ed contacted Judy Heumann, another disability activist, in New York. He encouraged her to come to California, and along with other advocates; they started the first center for independent living in Berkeley. Although it started out as a "modest" apartment, it became the model for every such center in the country today. This new program rejected the medical model and focused on consumerism, peer support, advocacy for change, and independent living skills training.

In 1983, Ed, Judy, and Joan Leon co-founded the World Institute on Disability (WID), an advocacy and research center promoting the rights of people with disabilities around the world. Ed Roberts died unexpectedly on March 14, 1995.

The early 1970s was a time of awakening for the disability rights movement in a related, but different way. As Ed Roberts and others were fighting for the rights of people with disabilities presumed to be forever "homebound" and were working to assure that participation in society, in school, in work, and at play was a realistic, proper, and achievable goal, others were coming to see how destructive and wrong the systematic institutionalization of people with disabilities could be. Inhuman and degrading treatment of people in state hospitals, schools and other residential institutions such as nursing facilities was coming to light and the financial and social costs were beginning to be considered unacceptable. This awakening within the independent living movement was exemplified by another leading disability rights activist, Wade Blank.

ADAPT

Wade Blank began his lifelong struggle in civil rights activism with Dr. Martin Luther King, Jr. in Selma, Alabama. It was during this period that he learned about the stark oppression that occurred against people considered to be outside the "mainstream" of our "civilized" society. By 1971, Wade was working in a nursing facility, Heritage House, trying to improve the quality of life of some of the younger residents. These efforts, including taking some of the residents to a Grateful Dead concert, ultimately failed. Institutional services and living arrangements were at odds with the pursuit of personal liberties and life with dignity.

In 1974, Wade founded the Atlantis Community, a model for community-based, consumer-controlled, independent living. The Atlantis Community provided personal assistance services primarily under the control of the consumer within a community setting. The first consumers of the Atlantis Community were some of the young residents “freed” from Heritage House by Wade (after he had been fired). Initially, Wade provided personal assistance services to nine people by himself for no pay so that these individuals could integrate into society and live lives of liberty and dignity.

In 1978, Wade and Atlantis realized that access to public transportation was a necessity if people with disabilities were to live independently in the community. This was the year that American Disabled for Accessible Public Transit (ADAPT) was founded.

On July 5-6, 1978, Wade and nineteen disabled activists held a public transit bus “hostage” on the corner of Broadway and Colfax in Denver, Colorado. ADAPT eventually mushroomed into the nation’s first grassroots, disability rights, activist organization.

In the spring of 1990, the Secretary of Transportation, Sam Skinner, finally issued regulations mandating lifts on buses. These regulations implemented a law passed in 1970—the Urban Mass Transit Act—which required lifts on new buses. The transit industry had successfully blocked implementation of this part of the law for twenty years, until ADAPT changed their minds and the minds of the nation.

In 1990, after passage of the Americans with Disabilities Act (ADA), ADAPT shifted its vision toward a national system of community-based personal assistance services and the end of the apartheid-type system of segregating people with disabilities by imprisoning them in institutions against their will. The acronym ADAPT became “American Disabled for Attendant Programs Today.” The fight for a national policy of attendant services and the end of institutionalization continues to this day.

Wade Blank died on February 15, 1993, while unsuccessfully attempting to rescue his son from drowning in the ocean. Wade and Ed Roberts live on in many hearts and in the continuing struggle for the rights of people with disabilities. The lives of these two leaders in the disability rights movement, Ed Roberts and Wade Blank, provide poignant examples of the modern history, philosophy, and evolution of independent living in the United States. To complete this rough sketch of the history of independent living, a look must be taken at the various pieces of legislation concerning the rights of people with disabilities, with a particular emphasis on the original “bible” of civil rights for people with disabilities, the Rehabilitation Act of 1973.

Civil Rights Laws

Before turning to the Rehabilitation Act, a chronological listing and brief description of important federal civil rights laws affecting people with disabilities is in order.

- 1964—Civil Rights Act: prohibits discrimination on the basis of race, religion, ethnicity, national origin, and creed; later, gender was added as a protected class.
- 1968—Architectural Barriers Act: prohibits architectural barriers in all federally owned or leased buildings.
- 1970—Urban Mass Transit Act: requires that all new mass transit vehicles be equipped with wheelchair lifts. As mentioned earlier, it was twenty years, primarily because of machinations of the American Public Transit Association (APTA), before the part of the law requiring wheelchair lifts was implemented.
- 1973—Rehabilitation Act: particularly Title V, Sections 501, 503, and 504, prohibits discrimination in federal programs and services and all other programs or services receiving federal funding.
- 1975—Developmental Disabilities Bill of Rights Act: among other things, establishes Protection and Advocacy services (P & A).
- 1975—Education of All Handicapped Children Act (PL 94-142): requires free, appropriate public education in the least restrictive environment possible for children with disabilities. This law is now called the Individuals with Disabilities Education Act (IDEA).
- 1978—Amendments to the Rehabilitation Act: provides for consumer-controlled centers for independent living.
- 1983—Amendments to the Rehabilitation Act: provides for the Client Assistance Program (CAP), an advocacy program for consumers of rehabilitation and independent living services.
- 1985—Mental Illness Bill of Rights Act: requires protection and advocacy services (P & A) for people with mental illness.
- 1988—Civil Rights Restoration Act: counteracts bad case law by clarifying Congressional intent that under the Rehabilitation Act, discrimination in ANY program or service that is a part of an entity receiving federal funding—not just the part that actually and directly receives the funding—is illegal.
- 1988—Air Carrier Access Act: prohibits discrimination on the basis of disability in air travel and provides for equal access to air transportation services.
- 1988—Fair Housing Amendments Act: prohibits discrimination in housing against people with disabilities and families with children. Also provides for architectural accessibility of certain new housing units, renovation of existing units, and accessibility modifications at the renter's expense.

1990—Americans with Disabilities Act: provides comprehensive civil rights protection for people with disabilities; closely modeled after the Civil Rights Act and the Section 504 of Title V of the Rehabilitation Act and its regulations.

The modern history of civil rights for people with disabilities is three decades old. A key piece of this decades-long process is the story of how the Rehabilitation Act of 1973 was finally passed and then implemented. It is the story of the first organized disability rights protest.

The Rehabilitation Act of 1973

In 1972, Congress passed a rehabilitation bill that independent living activists cheered. President Richard Nixon's veto prevented this bill from becoming law. During the era of political activity at the end of the Vietnam War, Nixon's veto was not taken lying down by disability activists who launched fierce protests across the country. In New York City, an early leader for disability rights, Judy Heumann, staged a sit-in on Madison Avenue with eighty other activists. Traffic was stopped. After a flood of angry letters and protests, in September 1973, Congress overrode Nixon's veto, and the Rehabilitation Act of 1973 finally became law. Passage of this pivotal law was the beginning of the ongoing fight for implementation and revision of the law according to the vision of independent living advocates and disability rights activists.

Key language in the Rehabilitation Act, found in Section 504 of Title V, states that:

No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Advocates realized that this new law would need regulations in order to be implemented and enforced. By 1977, Presidents Nixon and Ford had come and gone. Jimmy Carter had become president and had appointed Joseph Califano his Secretary of Health, Education and Welfare (HEW). Califano refused to issue regulations and was given an ultimatum and deadline of April 4, 1977. April 4 went by with no regulations and no word from Califano.

On April 5, demonstrations by people with disabilities took place in ten cities across the country. By the end of the day, demonstrations in nine cities were over. In one city—San Francisco—protesters refused to disband.

Demonstrators, more than 150 people with disabilities, had taken over the federal office building and refused to leave. They stayed until May 1. Califano had issued regulations by April 28, but the protesters stayed until they had reviewed the regulations and approved of them.

The lesson is a fairly simple one. As Martin Luther King said,

It is an historical fact that the privileged groups seldom give up their privileges voluntarily. Individuals may see the moral light and voluntarily give up their unjust posture, but, as we are reminded, groups tend to be more immoral than individuals. We know, through painful experience that freedom is never voluntarily given by the oppressor, it must be demanded by the oppressed.

Leaders in the Independent Living Movement

The history of the independent living movement is not complete without mention of some other leaders who continue to make substantial contributions to the movement and to the rights and empowerment of people with disabilities.

- Max Starkloff, Charlie Carr, and Marca Bristo founded the National Council on Independent Living (NCIL) in 1983. NCIL is one of the only national organizations that is consumer-controlled and promotes the rights and empowerment of people with disabilities.
- Justin Dart played a prominent role in the fight for passage of the Americans with Disabilities Act, and is seen by many as the spiritual leader of the movement today.
- Lex Frieden is co-founder of ILRU Program. As director of the National Council on Disability, he directed preparation of the original ADA legislation and its introduction in Congress.
- Liz Savage and Pat Wright are considered to be the “mothers of the ADA.” They led the consumer fight for the passage of the ADA.

There are countless other people who have and continue to make substantial contributions to the independent living movement.

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Consumer Control Principles in Independent Living¹⁴

“In matters of principle, stand like a rock...” Thomas Jefferson

In many organizations, the consideration of principles, values, and mission is a rare occurrence seldom connected to planning and action. In independent living centers, however, such considerations need to occur on a continual basis. These discussions are necessary for the formation of a collective consciousness that connects daily operations, successes, and dilemmas to the principle of consumer control. However, in developing a common understanding of the principle of consumer control, centers must also arrive at a common definition for the term “consumer.”

Within the independent living field, precisely defining “consumer” and developing policies that address the role of consumers in governance, administration, staffing, service delivery, and advocacy proved to be a complex task. Early definitions focused on the participant in services, but ignored other individuals who are intended beneficiaries of independent living activities—both direct and indirect.

A broader definition of “consumer” has evolved and is now commonly used in the independent living field:

A consumer is any individual with a disability who may be a past, present, or future participant in independent living services or one who may indirectly benefit from independent living advocacy efforts.

This definition, which is reflected in this monograph, addresses the pivotal interaction of the independent living center with the larger community and the center’s need to respond to a broad array of issues facing citizens with varying disabilities and ethnic, economic, and cultural differences. It addresses the need for broad-based representation of persons from cross-disability and demographic categories and lays the foundation for an organization that can serve as “a source of support and pride to [all] disabled people in the community and as a symbol of productivity and self-reliance for the broader social and economic community” (Challenge of Emerging Leadership, Mott Foundation Report, 1983). With this broader definition, organizations are charged with creating policies and establishing practices that emphasize the principle of consumer control as representing the cross-disability and social/cultural diversity that exists within their communities.

¹⁴ This article is excerpted and reprinted with permission from Shreve, Spiller, Griffen, Waldron, and Stolzman. (1988). Consumer Control in Independent Living, Chapter 2, Center for Resource Management, Inc., South Hampton, NH.

Defining Consumer Control

“Consumer control” is defined as: significant representation, power, authority, and influence of individuals with varying disabilities in all aspects of an organization that provides services to enhance independence and that seeks to change the political, social, and economic environment and quality of life possible for all disabled persons.

Translating consumer control principles into consumer control practices requires the exercise of authority by consumers over the organization itself, the exercise of choice by consumers over the services they receive, and the exercise of influence by the organization in overcoming the community barriers that inhibit its consumer population.

Consumer control practices apply to

- organizational decision-making,
- policy development,
- planning,
- staffing patterns,
- service approaches,
- volunteer involvement,
- approach to the community,
- definition of target population, and
- community advocacy priorities.

Consumer control is achieved and sustained by an organization that maintains the ability to be molded by its constituency. To implement consumer control principles, four areas comprising the full range of center functions and operations need attention: policy making, staffing, services, and community advocacy.

In the remainder of this chapter, the principle of consumer control is defined in the context of major functional areas of an independent living center’s operations.

Consumer Control at the Policy Level

In nonprofit corporations, the board of directors is the legal entity empowered to establish the value base of the organization, develop policies, and oversee the affairs of the corporation. The board of directors assumes an important “stewardship” function in ensuring that the mission is fulfilled and that public funds are efficiently and

appropriately expended. Since independent living centers are a product of consumer self-advocacy, it follows that the board of directors is defined as a majority of individuals with disabilities who are knowledgeable about the desires and needs of consumers and who possess a critical range of other specialized knowledge and expertise relevant to governance in nonprofit organizations. Indeed, the standards issued by the National Council on the Handicapped in 1985, with broad approval from leaders in the field, state that the board of directors of independent living centers should be comprised of at least 51 percent representation by persons with disabilities.

A board of directors comprised of a majority of persons with disabilities is an important way of enacting the principle of consumer control. But it is not enough. The board must ensure that the sovereignty of consumers pervades the mission, long-range goals and plans, and policies that govern staffing, financial, and service delivery decisions. More than any other group or individual, the board influences the integrity and strength of the organization's commitment to consumer control and other core values of the independent living movement.

Consumer Control at the Staffing Level

Consumer control at the staffing level means ensuring that the management and staff positions are held by people with disabilities. These employment opportunities ensure significant influence by people with disabilities in administrative decision-making, service design and delivery, and community advocacy activities.

At the staffing level, consumer control can be viewed as a chain of management events and decisions. The executive director, who is a critical link in the chain, serves as the interface between the policy-making function at the board level and the implementation of policy at the staff level. The director is responsible for maintaining consistency between policy and practices and fulfilling the mission through achieving operational goals. As chief executive officer, the director is responsible for planning, staffing, resource development and allocation, and monitoring service quality. Thus, the executive director's perspective on consumer control is a critical variable in translating principles into appropriate and effective center practices.

Service delivery and support staff also constitute important links in the staffing chain. Adhering to the principles of consumer control assumes that center staff reflect disability representation and have opportunities for substantive participation and input. Staff with disabilities who are grounded in the philosophy of the movement, able to operationalize its values, and share in the experience of disability with consumers are critical to enacting principles of consumer control. By hiring people with disabilities, centers demonstrate an understanding of the need for consumer trust and acceptance and the importance of staff credibility. A unique and critically valuable feature of independent living center staffing is an emphasis on hiring persons with disabilities to provide consumer-defined services to their peers. Independent living centers committed to

consumer controlled service delivery have staffing plans that build upon shared life experiences as a means of enhancing communication about life options.

It is also important to recruit and hire people with disabilities in support staff and clerical positions. This demonstrates the center's commitment to consumer representation. Finally, another means of broadening consumer control within a center is to recruit and involve people with disabilities in volunteer positions. Volunteers can perform countless functions within a center. By promoting people with disabilities in these capacities, the center can be strengthened and the individuals volunteering can increase their skills and confidence.

Consumer Control over Services

While there is rich diversity in service delivery methods in centers across the country, the overriding commonality and central characteristic of the independent living service delivery model is consumer control over the design and direction of services. Consumer control over services means that it is the consumer who has the primary responsibility for identifying needs, setting goals, developing plans and strategies, and achieving independent living objectives. Consumers in this model are active participants in the service process rather than passive recipients, as in the traditional medical or rehabilitation model of service delivery. Staff function as resource identifiers, support providers, facilitators, and peer tutors.

The language commonly used in centers is itself consistent with this general theme: “consumer” of services, rather than “client,” is the term of choice because it assumes an active role based on equality and mutuality of experience and a participatory process.

Peer relationships are one of the key features of services organized around the principle of consumer control. In peer relationships, the two parties meet as equals. They share a common life experience with disability and have faced many of the same issues and barriers in their pursuit of independence. Services delivered by peers provide an effective avenue for dealing with a variety of issues within the context of a service relationship based on an understanding of common life experiences and barriers to independence.

Consumer control over services is, to borrow a phrase from the private sector, “a market driven economy” in which the consumer has primacy in the process.

Consumer Control over The Advocacy Agenda

Advocacy is an essential element in a center's programmatic design. Indeed, advocacy has been seen by many leaders in the field as the “cornerstone” of the movement in that its efforts and activities are designed to amplify the individual consumer's voice in order to change the political, social, and economic environment that prevents achieving

independence and maximum quality of life. Operationalizing the principle of consumer control in advocacy requires that all key players—board, staff, and consumers—be provided with opportunities to share perspectives, knowledge, and information about needed changes in the environment and participate in activities designed to affect the desired changes. Community advocacy activities involve knowledge of the external environment, a commitment to providing opportunities to participate in the development of the advocacy agenda, and the experience and skills necessary to achieve the desired results. Through individual and collective advocacy efforts, people with disabilities acquire skills, abilities, and a greater understanding of how to affect the world in which they live. The involvement and control of people with disabilities in an independent living center's advocacy efforts is fundamental to the independent living mission of creating change and empowering people with disabilities to expand individual and community options and enhance the quality of their lives.

Summary

Consumer control in independent living centers means having a governing body comprised of at least 51 percent of its membership with people with disabilities. It means having people with disabilities in key management roles. It means having direct service staff with disabilities who work with consumers to define their own needs, on their own terms, and with their own solutions. It means having people with disabilities in support and clerical staff positions. It means involving volunteers with disabilities in the center's daily operations. It means that stakeholders in the process—people with disabilities—play significant roles in deciding the issues and methods for advocacy efforts.

The principle of consumer control recognizes that people with disabilities should control their own destiny. It ensures their full control over the direction, composition, and operation of the organization that serves them. The principle of consumer control is translated into organizational policies by the board of directors and operationalized into practice by the management and staff of the center. This translation of consumer control principles into consistent, effective organizational practices results in the exercise of power by consumers over the center and its services, and contributes to its influence in the community it serves.

The practical applications of the consumer control principle must be flexible if services and advocacy efforts are to represent and respond to the varying interests and diversity among consumers in the communities served by the ILC. Across the country, independent living centers reflect wide diversity in practice while adhering to the principle of consumer controls.

Developing the Independent Living Service Model—Essential Features¹⁵

The essence of the independent living movement and its core values became the foundation for a consumer-oriented service model that emphasized individual choice, personal control, and the need for self-determination. In commenting upon the evolution of this model, DeJong (1983) stated, “The dignity of risk is the heart of the independent living movement. Without the possibility of failure, the disabled person lacks true independence and the ultimate mark of humanity, the right to choose.” As leaders in the movement translated philosophical principles into actual service programs and community advocacy efforts, they recognized that there would be a rich and necessary diversity in service approaches across centers. However, it was also clear that as centers evolved, certain key elements were essential to designing and maintaining effective community-based independent living services. These included:

Consumer control over policy and management decisions. Persons with disabilities would control decisions governing organizational policies and procedures, the provision of services, and community activities. In this sense, the term “consumer” is defined broadly to mean persons with disabilities who may be direct recipients of services as well as those who are not but who are secondary beneficiaries of advocacy efforts. Consumer control in decision-making is intended to ensure that policies, procedures, services, and activities are responsive to the needs and respectful of the rights of the disability population.

Consumer control over service objectives and methods. This aspect of independent living services places primary responsibility for identifying service needs, setting independent living goals and objectives and making decisions about service participation with the consumer who is receiving services. This means that the service provider role shifts from that of controlling and providing the services to one that consciously seeks to promote the independence and self-sufficiency of the consumer within the context of service participation selected by the consumer.

Cross-disability emphasis. Independent living emphasizes responsiveness to the needs of all persons with disabilities. At the national level, this separates the independent living program from programs that emphasize services to a particular disability group.

Community based and community responsive. Independent living centers are designed to be responsive and accessible to the disability community in their service locale, and to involve the community significantly in setting program priorities.

¹⁵ This article is excerpted and reprinted with permission from Lachat, M.A., The Independent Living Service Model, Center for Resource Management, Inc., South Hampton, NH, 1988, p.11-13.

Peer role modeling. The emphasis on peer role modeling in independent living reflects a belief that people with disabilities can greatly benefit from the perspectives and support of others with disabilities who have successfully struggled to lead productive and meaningful lives in their communities. Peers serve as strong role models and facilitators to consumers in their efforts to achieve a designed level of independence.

Provision of a range of services. Because independent living is responsive to the varied dimensions of knowledge, skills, options, and support associated with achieving personal independence, a range of services is provided. These include such core services as information and referral, skills training, advocacy, and peer counseling as well as others, such as attendant care services, housing services, transportation services, educational services, vocational services, equipment services, communication services, legal services, and social/recreational services.

A community advocacy thrust. Independent living recognizes that in order for consumers to achieve independent lifestyles, environmental and social barriers in the community must be eliminated. There is thus a dual commitment to both individual services and community advocacy—activities conducted to enhance opportunities for people with disabilities to have equal access to all aspects of community life and to achieve meaningful integration into society.

Open and ongoing access to services. Independent living is not a closure-oriented program. Services are open and available to consumers on an ongoing basis, reflecting consumers' evolving and continuing needs and interests.

These key features of the independent living service model underscore the importance of constituency control, the power of peer support, and the fact that independent living centers were established to meet the needs of specific disability populations that had been underserved and segregated by traditional rehabilitation services. Also, the independent living service model has been characterized by the dual thrusts of individualized support services to promote self-determination and community advocacy to promote integration in the social and economic mainstream.