



## Independent Living Lunch & Learn

Friday May 28, 2021, Virtual Meeting

### Presenters

Amber O’Haver, Executive Director of Indiana Statewide Independent Living Counsel (INSILC)

### Learning Topics

What is independent living? What makes it unique?

Role of INSILC

Role of Centers for Independent Living (CILs)

### Agenda

1. Welcome and Meeting Purpose
2. INSILC Presentation on Centers for Independent Living
3. Questions and Discussion

### Summary of important facts from the presentation

Amber O’Haver, INSILC

Note additional information is available in the PowerPoint provided by Amber.

- Dan Rusyniak provided a brief overview of the LTSS reform effort. Kim Opsahl introduced Amber O’Haver and thanked her for presenting to the group. Kim noted the Centers for Independent Living (CILs) are an important component of our LTSS system, especially in helping people transition from institutions to community settings.
- While beginning the presentation, Amber noted that she has a disability herself and has been served through independent living.
- It is important to consider the intersection of aging and disability: the number of older adults with disabilities is growing, and based on the ADA definition (experiencing a physical or mental impairment that substantially limits one or more major life activities), most adults with a nursing facility level of care meet the definition of disability.
- What is independent living?
  - It is decades old and is a movement and a philosophy that emphasizes control and choice, as well as the right for people with disabilities to lead / direct their lives.
  - It is not a congregate setting. We also are not talking about what is branded as “independent living” facilities.



- The independent living movement was created by people with disabilities for people with disabilities. This can be traced back to the 1850s when people in the Deaf community began to advocate. In the 1960-70s as institutions closed, the movement grew as people returned to living in the community. The national organization called American Disabled for Attendant Programs Today (ADAPT) is one of the organizations many people know in the advocacy movement.
- The movement is: 1) grassroots, 2) cross-disability and ages which unites into a cohesive group for societal change, 3) disability-led and directed rather than led by service providers or parents of people with disabilities, for instance, 4) grounded in a social model of disability.
- Ed Roberts is the father of the independent living movement. He had polio at a young age and when he attended University of California Berkeley, he and his peers began protesting against some of the decisions made by vocational rehabilitation counselors. Later in life, he ran vocational rehabilitation for California.
- What makes independent living unique?
  - The philosophy emphasizes 1) control and choice and the right to lead/direct (self-direction), 2) independence and interdependence, 3) disability as a natural part of life, and 4) the right to succeed and fail which means permitting individuals the dignity of risk and recognizing the reality we are all human. We want to equip people to make their own decisions.
  - The philosophy emphasizes the right to live in the community, not institutional or congregate facilities.
  - The philosophy emphasizes society and environments create barriers, not disabilities.
  - The philosophy states that each individual is the best expert on their needs and solutions to address barriers.
  - The philosophy emphasizes we are deserving of equal opportunity and freedom and the right to thrive. Surviving is not enough, and barriers that prevent thriving need to be removed.
- About INSILC
  - INSILC is a non-profit entity. The mission statement is “to empower our peers with disabilities to lead and control their own lives.”
  - INSILC provides oversight of the Indiana State Plan for Independent Living and coordinates services between public and private entities. The organization advocates for meaningful systemic change.
    - INSILC does community organizing and community building and we host listening sessions throughout the year to make sure we hear directly from individuals who are being directly impacted. INSILC also advocates with legislators.
    - INSILC provides training and networking opportunities.
    - INSILC provides technical assistance to decision makers related to implementation of programs and services.
  - About Centers for Independent Living



- CILs are consumer-controlled, community-based, cross-disability, non-residential, private nonprofit organizations designed and operated within local communities led and directed by people with disabilities.
- The first CIL was established in 1972 in California. Centers were established across the nation in 1978. Currently there are over 400 CILs nationwide. Indiana has 10 CILs.
- CILs provide five federally mandated services working with consumers: 1) Advocacy (informal and systemic), 2) Information and referral, 3) Independent living skills training, 4) Peer support, and 5) Transition and diversion.
- CILs are different from other types of disability providers. CILs are not social service organizations. CILs are advocacy organization created by people with disabilities for people with disabilities, and the majority of CIL staff, management, and board must be people with disabilities. CILs utilize a peer-to-peer, empowerment model of service delivery and support, and CILs ensure self-determination and honor the individual's right to try and fail.
- A map of Indiana CILs can be found at:  
[https://www.in.gov/fssa/ddrs/files/Independent\\_Living\\_Centers\\_Map.pdf](https://www.in.gov/fssa/ddrs/files/Independent_Living_Centers_Map.pdf)
- INSILC and CILs have different but related roles. INSILC is the statewide organization that influences public policy and system changes. CILs, meanwhile, are local and provide value-added services for people with disabilities.

## Questions/Answers

**FSSA Div. of Aging:** How do the CILs interface with the Developmental Disabilities and Rehabilitative Services (DDRS) waivers?

**INSILC:** It depends on what the individual or the consumer needs. Individuals may need help accessing/applying for the waiver, getting advocacy or developing self-advocacy skills, learning how to do something in their home, accessing skills training for living on their own (e.g., learning how to do laundry or navigate conversations with their landlord). Whatever the individual needs drives how the CILs work with them. So, the way that CILs interface with DDRS waivers can really vary.

**FSSA Div. of Aging:** Do CILs provide case management or other specific waiver services?

**INSILC:** No, CILs don't provide specific waiver services necessarily, but the centers do create "Independent Living Plans" to help consumers plan to live independently. These plans include a set of goals, objectives, and activities that the individual works on, and can be similar to or supplement what the waiver is providing. It is a value-add that could address a gap that the waiver isn't providing or filling.

**FSSA Ombudsman Office:** Do CILs work with folks who have a TBI waiver or diagnosis?

**INSILC:** Yes, they do. Our CILs serve people on both the DDRS waivers and the A&D



waiver. To qualify for CIL services, you just have to agree that one meets the definition of disability. There is no eligibility screen and no income requirement. There are no specific diagnosis requirements. The reality is, there are many individuals in our community who identify as someone with a chronic health condition or illness that is a disability, but have never received a diagnosis. The last thing that we want to do is create more red tape and barriers to folks with disabilities to get access to services that help them stay in their community and be more independent or interdependent.

**FSSA:** Do you have a network of providers who do home modifications?

**INSILC:** I can connect the LTSS group with resources who both provide financial assistance and support for home modifications and who do home modifications. The Back Home in Indiana Alliance’s executive director, Deborah McCarty, focuses solely on deinstitutionalization and helping individuals get access to home modifications. She is like the “guru of home modifications.”

**FSSA:** Thank you. One of the challenges we think about as we move into a managed LTSS system is how we can identify those types of providers and resources for individuals that may be new to managed care. Knowing who in the community already has and knows networks of providers would be really helpful for our efforts.

**FSSA Div. of Aging:** Where does the federal funding come from for CILs? The federal Administration for Community Living (ACL)?

**INSILC:** Centers utilize both federal and state funds. We are housed within the ACL in the Office of Independent Living Programs (OILP). That's where the majority of our funding flows through, but CILs also do a lot of resource development, and one of them in particular utilizes an endowment. CILs can be unique in that they have a multitude of layers of funding that they utilize to provide the services they do for the disability community.

## Closing comments

### **Dr. Jennifer Sullivan, FSSA**

As we look at this project which brings the idea of aging in Indiana to the forefront, and how we do it well and thoughtfully and how we think about people in their surroundings rather than just a payment model, we've essentially—with this group of folks that are here—built a small company. With this presentation, it becomes even more clear that the company includes so many facets that we have not been able to take advantage of in the past. I really am grateful for Amber and INSILC’s engagement in this process and for helping us become experts in places that we never thought we could be. We have an opportunity to be incredibly proud of the way that we include folks who feel constantly every day that they are left behind and forgotten. I know that this is Amber’s personal passion, and we have all felt it very strongly during this presentation. I



know that we all get really energized by bringing that passion from the community and applying it where we can to best practices, and bringing them into the work that we do here as well.

## Follow-up

Please contact [backhome.indiana@fssa.in.gov](mailto:backhome.indiana@fssa.in.gov) or with any additional questions.

## Stakeholder Attendees

Amber O'Haver, INSILC; Beth Skinner, CICOA; Elizabeth Eichhorn, IHCA; Eric Essley, LeadingAge Indiana; JoAnn Burke, Indiana Commission on Aging; Kelli Tungate, Caregiver Homes of Indiana; Kim Dodson, the Arc of Indiana; Laura Altenbaumer, Active Day; Megan Smith, IAADS; Michelle Stein- Ordóñez, IAHHC; Sherri Hampton, ASC; Terry Miller, HOPE

## FSSA Attendees

Allison Taylor, Amy Gilbert, Andrew Bean, Breanca Merritt, BreAnn Teague, Cathleen Nine-Altevogt, Dan Rusyniak, Elizabeth Peyton, Hamilton Smith, Jesse Wyatt, Jim Gavin, Kim Opsahl, Lucy Morrell, Lynn Clough, Maggie Novak, Mary Swinford, Meredith Edwards, Natalie Angel, Pearl Barnett, Reiko Osaki, Sarah Renner, Shannon Effler, Steve Counsell, and Tom Arnold