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Better Together: Enhanced Self-Directed Services Provided Through CILs

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Who are we?

- The Applied Self-Direction team works with self-direction programs to maximize the level of choice and control that participants can exercise over their services and supports
- We provide training to state program administrators, service coordinators, support brokers, Fiscal Intermediaries (FI) agencies, and stakeholders across the country

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Independent Living Research Utilization (ILRU)

- ILRU at The Institute for Rehabilitation and Research (TIRR) supports the independence, inclusion, and full participation of persons with disabilities through research, training, and technical assistance to community-based organizations.
- ILRU's IL-NET T & TA Center for Independent Living provides training and technical assistance to centers for independent living and statewide independent living councils.

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Agenda

- What is self-direction?
- Information & assistance in self-direction
- Peer support and self-direction now and in the future
- Time for Q&A

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What is Self-Direction?

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A quick introduction

- Press play to see a quick video

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What is self-direction? Cont'd.

- Self-direction is a model of delivering services in which the participant receiving those services has a high level of choice and control

- A participant in self-direction decides when, how, and from whom their services are delivered
- Self-direction is based on the principle that people with disabilities know their own needs best and should lead the planning and managing of their services
- In self-direction programs participants are empowered to hire and fire their own staff and manage a flexible budget

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Consumer Control and Self-Direction

- Definition:
 - 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
 - <https://www.ilru.org/book/export/html/4670>
- SD is a valuable service delivery mechanism that gives participants control of the services he or she receives for implementation of the ILP

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What is Self-Direction?

- Choice and Control: Large blue circle that says Participant controls with four smaller connected ones that are What, When, Who, and How

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Hallmarks of Self-Direction

- Graphic with Four boxes on top
 - 1. Choice of goods and services to purchase
 - 2. Freedom to develop workers' schedules
 - 3. Innovative use of community resources
 - 4. Honoring the dignity of risk
- Below are two boxes
 - 1. Flexibility
 - 2. Creativity
- One large box at bottom
 - Authentic choice & control

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History of Centers for Independent Living and Self-Direction

- Self-direction history is deeply rooted within the independent living movement
- Early versions of the program were developed and advanced by independent living leaders
- Ed Roberts and other activists launched a self-direction attendant care program at the University of California at Berkeley
- Then, made self-direction available to the broader disability community with the formation of the nation's first Center for Independent Living (CIL)

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History of Centers for Independent Living and Self-Direction, cont'd.

- The eventual adoption of self-direction more widely across the country was often seeded with the support of CILs
- The degree of involvement of CILs in self-direction programs varies considerably from state to state
 - CILs are consumer-controlled and rightfully determine their own areas of focus as an organization
 - Each CIL is a distinct nonprofit with its own unique goals and objectives, but must provide the five core services, including:
 - Information & Referral
 - Independent Living Skills Training
 - Peer Counseling
 - Advocacy (both individual and systems advocacy)
 - Life Transition Assistance

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Unique Aspects of Self-Direction

- Employer Authority
 - Participant recruits, hires, and manages their own worker
 - Participant sets the schedule for the workers
 - Participant provides training for the workers
 - Participant disciplines and terminates workers
- Benefits of Employer Authority
 - Empowering to participants
 - Participants are able to hire people they know and trust
 - Less unmet needs for the participant
 - Less turnover
 - Better care for the participant, which is better for overall health of the participant
 - Better work environment for the worker because they get to help someone they care about

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Unique Aspects of Self-Direction, cont'd.

- Budget Authority
 - Participant sets pay rate for workers, within state and federal guidelines
 - Participant can use the money from the budget to purchase other needed goods and services
 - Therapies
 - Home/Vehicle Modification
 - Assistive Technology
- Benefits of Budget Authority
 - Empowering to participants
 - In order to hire/keep quality workers, appropriate pay and benefits have to be offered
 - Participants are able get valuable goods and services that will improve freedom and quality of life

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Major Challenges with the Self-Directed Model

- Barriers to access
 - Self-direction participants must invest significant unpaid time and effort to successfully self-direct
- Insufficient resources for information and assistance (I&A)
 - I&A Providers have high participant counts which doesn't allow for the time that self-directing participants need
- Gatekeeping
 - I&A Provider decides self-directing is not a good fit
- Inclusion, diversity, equity, and accessibility (IDEA)
 - Self-direction tends to only be chosen by people who have greater resources
 - Major challenges in ensuring communities of color and communities for whom English is a second language have sufficient access

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Benefits of Self-Direction

- Self-direction allows people to hire who they want to be providers, expanding the pool of available workers
- The model can be cost effective, because the participant takes on the responsibility of being the employer which can lead to lower administrative costs
- Self-direction has a positive impact on satisfaction and involvement in the community
- Participants are more likely to choose self-direction because they retain control, choice, and flexibility
- The benefits of self-direction for people who live in rural settings and/or living with high care needs have been found to be especially pronounced

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The Truth about Self-Direction

- Four boxes
 - Blue says for everyone with the right supports.
 - Green says Increases choice and control.
 - Orange says Reduces unmet needs.
 - Blue that says No more fraud than traditional services.

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Information & Assistance in Self-Direction

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Information and Assistance Provider

- Person provided by the state to provide information and assistance to the participant to ensure the participant understands and can be successful when self-directing
- Other names:
 - Case Manager
 - Service Coordinator
 - Support Broker
- Responsibilities include:
 - Informs the participant of program guidelines
 - Informs the participant of their responsibilities
 - Works with the participant to be an effective employer
 - Provides guidance and resources on all aspects of self-direction
 - Provides support and encouragement for self-directing

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How the Information and Assistance Provider is Different from a Case Manager

- Fully understands and supports the self-directed experience
- Understands the importance of independence and cultivates it
- Works with the participant to create a person-centered plan
- Empowers vs. manages
- Uses a personalized approach
- Cares about participant's goals and personal outcomes
- Cultivates problem solving techniques
- Does "with" instead of does "for"
- Understands "Important To" vs "Important For"
- Provides tools for continued success instead of solving the current problem

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I&A Challenges in Self-Direction

- I&A is often under funded
- Insufficient resources for information and assistance
 - Combined with case management as an afterthought
 - With the high participant counts and lack of time available to support someone to self-direct, I&A Providers steer participants away from self-directing
 - Happens most in programs where the case manager is the participant's sole support
- No standard performance measures for I&A Providers
- No standard qualifications for I&A Providers
 - Competence of I&A professionals is varied

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Peer Support in Self-Direction Now and in the Future

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Peer Support

- Definition:
 - A person that recruits, trains, assigns, and supervises a group of individuals with disabilities whose role it is specifically to provide either one-on-one or group support to other individuals with disabilities. This may include individuals who are paid or volunteers, excluding full or part-time staff who are hired to fill basic positions within their centers, who also have a disability
 - Microsoft Word - Peer Support Course Manual_May 2011 _2_.doc (ilru.org)
- Peer support is a mainstay of CILs
- They are best in class at providing these services

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Peer Support Currently in Self-Direction

- Likely occurs via CIL peer support programs, but the extent is unclear and not formally advertised
- Happens informally, via Facebook groups and other social media where participants connect with one another for questions and concerns
- Long-time, "veteran" participants may agree to serve as a representative on behalf of newer participants
- Some participants in the program become support brokers, skills trainers, consultants, or other roles

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Why Peer Support is Needed in Self-Direction

- Builds a strong mentoring relationship with someone who is using the program

- Nothing can substitute for lived experience to give participants the truth about what to actually expect
- People implementing the program and training participants actually understand the program and are experts
- Peer support has been especially impactful in the mental health sector
 - Has helped participants get support from people who understand
 - Has helped peer supports find purpose
- Disabled people and advocacy groups are currently using peer support and trying to expand the concept

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Why CILs are Perfect for Peer Support in Self-Direction

- Important to note that some programs already offer outstanding programs offering peer support with self-direction
- CILs can serve as partners for program players for contracting, billing and other administrative purposes
- CILs can provide supervision and oversight to ensure peer support is high-quality and responsive to participants' needs
- Offer unique opportunities for equity
 - Have a peer with similar background, culture, experiences, etc.
 - Minimizes the risk of the ableist views from someone in the case management type role
 - Minimizes the power dynamic for participants if the person is a peer, instead of a case manager

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Discussion Questions

- What is the current involvement in Self-Direction at your CIL?
- What is your CIL doing currently with Self-Direction in your Peer Support Programs?
- What changes or improvements do you think could be made in your CIL in regard to peer support and self-direction?
- Philosophically, is peer support something that should or should not be paid? Why?

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- Additional Resources
 - Core Standards for Information & Assistance Professionals in Self-Direction | [appliedselfdirection](#)
 - Core Standards for Information & Assistance Professionals in Self-Direction | [appliedselfdirection](#)

- Welcome | [appliedselfdirection](#)
- Home | Independent Living Research Utilization ([ilru.org](#))

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Questions?