

Consumer Control in Michigan Centers for Independent Living

May 8, 2015



Who We Are

- We speak from experience.
- We are people with significant disabilities – consumers, advocates, and members of the Muskegon disability community.
- Our goal is a world-class CIL to “maximize the leadership, empowerment, independence, and productivity of individuals with disabilities.”
- We publish extensively on all of our advocacy efforts. If you wish to read about them, you may visit www.peeractionalliance.com.

Goal: SILC and the CIL Network will create a common vision for consumer control and involvement

Specific action steps:

Part 1: Explore current practices

Part 2: Identify strategies for enhancing consumer control / involvement

Part 3: Incorporate strategies into future SPIL

Defining “Significant Disability”

The Rehabilitation Act clearly defines “significant disability” for the purposes of consumer control at a CIL:

An individual with a severe physical, mental, cognitive or sensory impairment whose ability to function independently in the family or community or whose ability to obtain, maintain, or advance in employment is **substantially** limited *and* for whom the delivery of IL services will improve the ability to function, continue functioning, or move toward functioning independently in the family or community or to continue in employment.

Defining “Consumer”

A consumer:

- Identifies as a person with a disability and a member of the disability community
- Benefits *directly* from consumer-driven advocacy and therefore acts in the interests of the disability community
- Has experienced dependence
- Has experienced barriers

* People who have disabilities that are not *significant* do have a *place* in the disability community and at the CIL – ***in the 49%***.

What Is Consumer Control?

"Consumer control" is defined as: **significant representation, power, authority, and influence of individuals with varying disabilities in all aspects of an organization.**

- **authority by consumers over the organization itself,**
- **choice by consumers over the services they receive,**
- **influence by the organization in overcoming the community barriers that inhibit its consumer population.**

Achieving Consumer Control

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 CIL functions and operations need attention:

- Policy making (the Board of Directors);
- staffing;
- services; and
- community advocacy.

Consumer Control At the Policy Level: The Board

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 assumes an important "stewardship" function in ensuring that the mission is fulfilled and that **public funds** are efficiently and appropriately expended.

- The Board of Directors is responsible for strategic direction – *within the law*. If a Board is not comprised of a majority of persons with *significant* disabilities, the Board and the organization itself are operating illegally.

Consumer Control At the Policy Level: The Board

A board comprised of persons with *significant* disabilities is an important way of enacting consumer control. But it is not enough. Board members must subscribe to, believe in, and adhere to IL philosophy, including the principle of consumer control.

- The interests of able-bodied people or people with medical diagnoses who do not believe in IL philosophy are well represented in society. It is not ok to weigh their interests as equally important to the interests of the disability community.
- **Pro Tip:** If you're not 100% sure that your CIL is consumer controlled, *it is not consumer controlled*.

Consumer Control At the Policy Level: The Board

- **Cross-Disability:** Autistics, people with developmental disabilities, mental illness, sensory, and every type of **significant** disability *belong on your board*.
- **Community-Based:** Your board should truly represent the entirety of your local **disability** community. It should be young and old; gay and strait; black and white. It should be non-partisan (but not apolitical) and filled with people of color and people with every type of disability.

Creaming

Adjective

To advance individuals with the least significant disabilities in order to create the illusion of consumer control without having to do the hard work of affirmative action, workplace accommodation, and confronting ableism in our own spaces.

Consumer Control At the Staff Level:

The Executive Director

The ED's perspective on consumer control is a critical to translating principles into practices.

Q: Can a CIL have an ED who is not a person with a significant disability?

A: It's not common outside of Michigan, but it is legally possible if stringent safeguards exist to ensure their success. Safeguards:

- A strongly consumer controlled Board of Directors,
- strong affirmative action hiring and Board appointment processes,
- and dedicated measurement of and commitment to consumer control.

Every CIL should be able, willing, and happy to demonstrate their commitment to consumer control at any time, especially those with an able-bodied ED.

Consumer Control At the Staff Level:

Decision-Making Staff and Support Staff

- Consumer control = CIL staff reflect disability representation and provide substantive participation and input.
- Staff with disabilities who are grounded in IL philosophy, able to operationalize its values, and share the experience of disability are critical to enacting principles of consumer control.
- It is also important to recruit and hire people with disabilities in support staff and clerical positions. This demonstrates the CIL's commitment to consumer representation.

Consumer Control Over the Advocacy Agenda

The involvement and control of consumers in a CIL's advocacy efforts is fundamental to the mission of creating change and empowering people with disabilities to expand options and enhance the quality of their lives.

There is one sure fire way to tell if a CIL is consumer controlled:

- *Is the organization pursuing charity or advocacy?*

Charity is the Opposite of Advocacy

- Members of the IL community understand, through direct experience, that charity is the antithesis to advocacy.
- CILs that operate as charities are doing direct harm to the advocacy community.
- Charity remains the favorite activity of “well meaning” able-bodied people who do not understand IL, but nonetheless feel entitled to speak for us while actively silencing our voices.

Affirmative Action vs. Non-Discrimination

CILs are required by law to employ affirmative action. Some CILs substitute non-discrimination policies and practices for affirmative action policies and practices. *There's a big difference.*

Affirmative Action

- Active: Ableism is acknowledged and addressed
- Experience with significant disability is *actively valued*

Non-Discrimination

- Passive: Ableism is ignored
- Disability and discrimination are not considered at all; ableism is reinforced through neglect

It's Time to Discriminate!

Affirmative action takes the discrimination people with significant disabilities experience every day in society into account. *Affirmative action is the law for CILs.*

How to Affirmative Action:

1. **Create an affirmative action** plan so that your CIL is prepared to outreach to people with significant disabilities.
 2. ***Hire people with significant disabilities.*** Absolutely no more excuses – period.
- * If you “cant find qualified individuals with significant disabilities” to staff your CIL, you need to check yourself for internalized ableism.

Looking for Consumer Control

The difference between an organization that is consumer controlled and one that isn't **is super obvious**. It can be seen in priorities, activities, materials, language, and partnerships. It can be directly observed through the ways representatives of the CIL speak about their own experiences and their relationship to their local disability communities.

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
- community advocacy priorities

What Consumer Control Looks Like

Good CILs:

- Recruit, train, and support people with significant disabilities

Bad CILs:

- Try to think of who they can justify as a person with a disability at 704 time

Measurement: *How many of your staff members require an accommodation to perform their job duties?*

- Embrace, enhance, lead, and support disability rights advocacy in their communities
- Silence advocates; sideline the voice of people with significant disabilities trying to create change

What Consumer Control Looks Like

Good CILs:

- Do advocacy
- Identify with the Independent Living model and see the disability community as its peers
- Build community; serve as a gathering point for the disability community and its agenda

Bad CILs:

- Do charity
- Identify with the business model, charities, and see other service providers as its peers
- Only welcome consumers they receive additional funding to serve through fees-for-service

What Consumer Control Looks Like

Good CILs:

- Led by people with significant disabilities who have experienced oppression
- Use the Independent Living model to define disability – disability is experienced through purposefully constructed and maintained physical and attitudinal barriers

Bad CILs:

- Led by rehabilitation and social service *professionals* with minor or no disabilities
- Use the medical model to define disability – any diagnosis will do

Excuses

- CILs are private non-profits
- There's no requirement that staff (or Board) have *significant* disabilities / We all have some type of disability!
- Charity is a valid form of advocacy
- We can't *make* people disclose a disability
- We don't consider disability at all – we don't want to discriminate

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A. Strategies to Prepare for Consumer Direction at the Organizational Level

There are many strategies that, if combined and pursued with some determination, will make a measurable difference.

- 1. Make Consumer Direction a *Central Goal***
- 2. Provide Opportunities for Service Users, Staff, Board, Funders, and Others to *Learn More about Self-Directed Services***

Seek out CILs who can show you real life examples of systems led by and for consumers.

B. Strategies for Effective Leadership in Consumer Directed-Systems *(Continued)*

- 3. Select Managers and Service Leaders Who Are Committed to Enhancing Their Own Competencies in Consumer Direction**
- 4. Promote Collaborative Leadership Approaches**

The complexity of managing any service system increases when those who are the recipients of services are involved in leadership.

Relinquishing paternalism in favor of welcoming the contributions of others is significantly more enabling. Agencies can select leaders with this competency and support leaders in acquiring it.

B. Strategies for Effective Leadership in Consumer Directed-Systems *(Continued)*

5. Learn To Share Control and Authority

One meaningful way to share control is to establish an advisory board or task force that includes a substantial number of service users and other advocates who have authentic power to influence policy, service delivery, and evaluation of services.

6. Acquire a Level of Comfort with the Messiness of Participatory Processes

Once we open the door to participation, we begin to share the public space with others. By relaxing and accepting a more open-ended approach to how participation might take place, we can allow others to shape the experience and to make their own unique contributions.

B. Strategies for Effective Leadership in Consumer Directed-Systems *(Continued)*

7. Restrain Vested Interests That Might Limit Service Users' Potentials

When users of service have an *authentic* role in directing the systems that affect their lives, it is much more likely that the focus will remain on what is in the best interest of all concerned.

C. Strategies for Working with Service Users

1. Properly Support People with Their Efforts to Have More Control

Providing self-direction opportunities may not be enough to assure empowering self-direction outcomes. Systems should be designed from the outset to provide additional support in the form of training or continuing facilitation.

2. Avoid Structures and Practices That Undermine Personal Power of Service Users

Some aspects of current systems can take on a life of their own and inadvertently take personal power away from staff and service users alike. Leaders should create continuing dialogues with users, staff, and other stakeholders to prevent the drift toward prescriptive practices common in service systems.

C. Strategies for Working with Service Users *(Continued)*

3. Make Efforts to Relieve People of Their Fears of Change, Uncertainty, and Reprisal

Service users report fears of retaliation for making complaints related to the services they receive. Advocates express similar concerns that they will experience a backlash from officials when they take a strong advocacy stand. One way to diminish reprisal and the fear of it is to create clear, emphatic policies prohibiting reprisal and then enforcing those policies.

C. Strategies for Working with Service Users *(Continued)*

4. Foster Ties to and Cooperation with Independent External Advocates

Independent advocates can be fearless in their ability to attend to contentious issues; they are excellent sources of challenge for complacent systems. Keeping service users silent and isolated from independent advocacy is not consistent with providing consumer-directed services.

5. Welcome Thoughtful Dissidence as a Natural Part of Expressing Autonomy

When people feel free to express disagreement, this is usually a sign that they do not feel threatened or intimidated by conflict with people in roles of authority.

Recommendations to Create or Enhance Consumer Direction in Service Programs

Implementation of Standards, Indicators and Measures of Consumer Direction

Ensure that service users have leadership roles from the very outset of all policy development, program design, program implementation, and related research initiatives.

Policies and Systems Design Enhancements Related to Consumer Direction

Address the fear of reprisal experienced by consumers, advocates, families, service workers and others by implementing policies and procedures that afford methods of informing leaders of problems and that provide for harsh punishment for any act of reprisal against persons who raise concerns.

Recommendations to Create or Enhance Consumer Direction in Service Programs *(Continued)*

Approaches for Consumer Leadership in Decision Making

Employ service users as consultants in policy review and in systems analysis as another means of securing end-user perspectives in systems design and enhancement.

Equalization of Knowledge

Create materials and other resources that support informed consumer leadership at the federal, state, and local level, ensuring those leaders have full knowledge of funding, legislation, policies, management systems, services, service systems, system constraints, and other matters about which they will be called to make decisions.

Establish independent bodies, primarily of consumers, to create and review the materials and information that support informed choice by those who receive services and by consumer leaders.

Consumer Directed Services

Needing support is an ordinary human condition; most people are both dependent and interdependent on others. Truly responsive systems can allow for support and facilitation of decisions about the services provided and how they are provided.

- Training Information and guidance
- Exposure to optimal role models and practices
- Access to experienced peers
- Consciousness raising related to consumer direction
- Assistance with “start up”
- Help with supervision and negotiation Administrative and technical help
- Assistance in planning safeguards Assistance in ensuring quality
- Support with decision-making Problem and crisis solving

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Sources

Large portions of this presentation were taken directly from the following sources:

1. [Shreve, Spiller, Griffen, Waldron, and Stolzman. *Consumer Control Principles in Independent Living*, Chapter 2, Center for Resource Management, Inc., South Hampton, NH, 1988 and Cyber CIL](#)
2. IL-NET's [Attract and Retain Your Best CIL Board Members](#)
3. IL-NET's [Promoting Self-Direction and Consumer Control in Home-and Community-Based Service Systems](#)