

Independent Living Research Utilization



We create opportunities for independence for people with disabilities through research, education, and consultation



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Liberation to Leadership: The Role of CILs in Transforming Communities

Using Disability Liberation Theory In Centers for Independent Living—One CIL's Approach

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Reminder: What is Disability Oppression/Ableism?

- Ableism: a form of discrimination or social prejudice against people with disabilities
- **It stereotypes people** with disabilities as less or non-productive, and by its own terms dis-values and further disables us.
- All people are both the objects and perpetrators of prejudice.

The Peer Power of the CILs

- CIL Core Services & Social/Civil Rights Model
 - Peer support is a cornerstone of the IL movement. Peers normalize our experience. “One in a million” becomes “One of many.”
 - Role models
 - Cheerleaders
 - Shared experiences and understanding
 - Sense of belonging
 - Independence skills
 - Resources – I&R
 - Advocacy – Skills + Action

Lifting as We Climb – The Gift that Goes on Giving



- It is about waking up!
- Understanding ourselves better
- Realizing those ableist concepts are not us and how they have held us back
- Helping others get it, that those stereotypes are not them either
- Reminding each other who we really are
- Cheering each other on as we pursue our goals

Identifying how Oppression/Ableist Internalized Messages Contribute to...

- Believing that negative message/concept is us
- Not feeling worthy, feeling like a burden
- Low self-esteem
- Lack of self-confidence
- Getting stuck
- Being unable to make decisions
- Not trusting our own judgement
- Getting caught in patterns of victimization

Changing How We Think About Ourselves

- Understanding how Oppression/Ableism works can move people from the personal perspective to the political perspective and empower leadership
 - New sense of identity
 - Civil rights perspective
- Meeting others with a variety of disabilities and learning this together. Light bulbs go off faster.

CILs Want to Empower Consumers...

- To take personal responsibility
- To achieve their goals
- To advocate for themselves and others
- To advocate for community and policy improvements
- To become leaders in the disability liberation movement and their wider communities

Learning how Ableism/disability oppression works provides an empowering perspective that the typical “counseling” or (worse) “case management” experience does not.

Learning in CILs breaks the isolation and we can feel part of a community. It’s the “man behind the curtain” (His name is Ableism!)

Where Else Will a Person Learn to Identify the Influence of Ableism/ Disability Oppression?

- Disability stereotypes abound in our culture and disempower people with disabilities
- **Media: We rarely get to see ourselves actually reflected in the media**
 - Lack accurate representation—Just another character that happens to have a disability
 - Hidden disabilities rarely portrayed
 - We are rarely in advertisements

Media—Agents of the Oppression/Ableism

- Newsletter article language:
 - Victim of...
 - Wheelchair bound...
 - Susan *suffered* her injury at the age of 18...
- Movie portrayals
 - Non-disabled actors playing disabled roles—a sure path to an academy award

We are More than a Medical Condition!

- **Medical Experiences**

- "Patient"
- The search for a cure – what if we aren't cured?
- Focus on "Impairment" as the problem
- Lack of partnership between professional and consumer: "compliant" vs "non-compliant"
- "Expert" knows more than "patient"
- "Expert's" time is more valuable than the "patient"
- Unpleasant and frightening experiences: hospitals, children's hospitals, research "subjects," abuse, forced to witness abuse.

Influence of Families

- **Families**

- We often don't see ourselves reflected in our families.
- They are hurt by ableism too.
- If there is a family member with a disability, how are they treated? Is it ever discussed? Do you get accurate information about their condition?
- Some identities can only be validated by peers, though family can be helpful allies.

The Power of Peers for Positive Identity Development



Vertical Identity ↓

Family

Race

PWD/Parent of ↔ **Horizontal Identity** ↔ GLBTQIAA/Parent of...

Ethnicity

Religion

Family Stories

A rendering of Solomon's theory of identity development

↔ Horizontal Identity ↔

- Solomon posits from his experience as a gay man who has studied families with children with disabilities
 - “ I was reminded how isolating an exceptional identity can be unless we resolve it in a horizontal solidarity.”
 - Some identities can only be embraced in a truly positive manner through peer support – others who understand through shared experiences of oppression fosters a sense of “normalcy” and disability pride.
 - A parent of a child with a disability can get a sense of solidarity from other parents of children with disabilities.

*Excellent book: Solomon, A. (October 2013). *Far from the Tree: Parent, children and the Search for Identity*. P. 13. *Scribner, A Division of Simon & Schuster, Inc.*

Teaching Oppression/Liberation Theory is a Perfect Fit for CILs



- Medical condition → Person
- Invalid → Valuable
- Victim → Survivor → Thriver
- Personal → Political → Activist → Leadership
- Isolation → Space to share experiences → Validation
→ A sense of community → desire to help others → Advocate
- Abnormal → Everybody is different
- Next Step → Celebrate Difference/Diversity and Involvement with Other Oppressed Constituencies

Sense of Identity & Internalized Ableism Effects

- Progress on goals
 - Career/ work / education
 - Home
 - Partnerships / marriage – safe, nurturing or not
 - Parenthood
 - Heart's Desires realized!
- Expectations—our own and others
- Relationships
 - Huddling with “our own kind” when we are stronger if we diversify
 - Avoiding hanging with others with disabilities

Internalized Ableism Effects

- Health
 - Whether health issues are attended to
 - Is the medical facility accessible
 - Lack of trust of medical professionals
 - Inability to self-advocate
 - Feeling like a burden or a bother
 - Addictions
 - Avoidance of uncomfortable feelings
 - Lack of proper treatment
 - Will to live – better off dead?

Sense of Identity & Internalized Ableism Effects, cont'd.



Ability to—

- Be resilient
- Cope with difficulties
- Protect ourselves
- Believe in ourselves and our value
- Know and use our rights

Internalized Oppression Hurts Others

- Internalized oppression can manifest—
 - ...by not validating people with unseen disabilities.
 - ...by not wanting to “hang out” with or be involved with others who are disabled.
 - ...by attacking our leaders within the disability community – this can be destructive for constituent groups.

Unseen Disabilities

- People with unseen disabilities struggle to find a sense of “peer”ness or belonging.
- It is important that they feel recognized and included.
- Often they lack understanding from friends and family members.

Those Needing Personal Assistance

The pressure of needing help all the time:

"It's better to give than receive."

"This tells me I am a failure."

- Those needing care givers / personal assistance really benefit from learning about these concepts. Especially women in our culture who are typically expected to take care of others.
- Real dependence on others = real safety issues that are ongoing.
- Self-concept of being too needy → being an employer and manager.
 - Think of all the people who are employed because of your "need."

Double Jeopardy Hurts from More than One Oppression

- Negative stereotypes and prejudices double the impact on a positive sense of identity. For instance:
 - Gay and disabled
 - Aging and disabled
 - African American and disabled
 - Latino, lesbian, and disabled
- The healing path is similar and peers are essential for development of pride.

Steps to Empowerment

- Consumers, volunteers, board members, and staff need to understand that healing the effects of oppression involves—
 - Understanding what oppression/ableism is
 - Recognizing the negative stereotypes and identifying which ones have been internalized
 - Contradicting stereotypes
 - Ability to share our stories/ hurts/ indignities
 - Ability to discharge off the **feelings** that go along with the hurt

Ways ABIL Uses Liberation Theory

- CIL Front Line Staff
 - Training to be better prepared to work 1-on-1 with consumers
- Leadership Development
 - We incorporate this into our peer mentor volunteer orientation and ongoing training
 - Structured Disability Liberation Workshops
- Integrated into Disability Awareness Presentations

Benefits for CIL Front Line Staff

CIL staff may or may not have a social work or counseling training and may not have exposure to oppression theory.

- We encourage new staff to attend Disability Liberation workshops
- This gives understanding of the value and importance of listening and allowing their consumers to tell their stories and express feelings.
- This helps staff identify their own prejudices about different disabilities.
- Helps them be more supportive and more able to identify where and why their consumers get stuck.
- Staff become better advocates because they understand the social and political ramifications of oppression.

Tips for Front Line CIL Staff

- Allow consumers to tell their stories and discharge off feelings in safe place.
- Keeping relaxed attitude of delight & respect contradicts internalized feelings of being a burden or a bother.
- Discharge off your own feelings elsewhere so you can let them have theirs! Explore early memories of need & help.
- If the person is discharging off feelings, don't interrupt them or distract them. This is the healing taking place.
- If they distract themselves and change the subject and stop discharge, you can reassure them that feelings are Ok, or repeat what they said that first brought the feelings up.

Tips for Front Line CIL Staff cont'd.

- Keep an eye out for people describing themselves in terms that mirror negative stereotypes & interrupt them.
- Teach them about Oppression / Ableism.
- Invite them to participate in a Disability Liberation workshop.
- Ask them to tell you what's good about themselves.
- If they have been discharging big feelings, when they are done, offer them an "up and out" question to redirect attention off the distress. (For example, "Tell me the name of a song you like?" or "What are you looking forward to?" — Something totally unrelated and easy to answer.

Leadership Development with Peer Mentor Volunteers— Peer Mentor Volunteer Orientation



- So they can identify their own prejudices.
- They get a chance to explore their own internalized oppression.
- They understand value of letting their mentees tell their story & express feelings, thus becoming better listeners.
- Helps them be more supportive to their mentees, more able to identify where they are stuck.
- Mentors become better advocates. The move from personal perspective to community perspective means they are more likely to be moved to take action as self-advocates, teachers of self-advocacy, activists, & leaders in their community.

Leadership Development through Group Workshops



- Provide safe place to explore concepts of ableism/oppression, internalized oppression, experiences, understand role of emotional discharge in healing hurts.
- Place to have a structured conversation by taking turns.
- Method to uncover oppression that has been internalized and its effects while contradicting isolation in a peer environment.
- You can decide whether to include allies or restrict to people with disabilities only.
 - Family members often benefit as well.
- Way to experience what liberation looks like.

Disability Liberation / Attitudinal Barriers Workshop Sample Outline

- Who are we really?
- Disability Oppression/Liberation theory – who cares?
- Causes and results of oppression.
- RC theory about hurts. Oppression isn't just intellectual; it is set in with emotions. Discharging off hurts helps us think better.
- Disability stereotypes – ouch! Brainstorming Session
- Results of oppression

Workshop Sample Outline, cont'd.

- How oppression affects peoples attitudes about people with disabilities.
- Internalized oppression and its effect on people with disabilities.
- Liberation! What a person with a disability can do to liberate themselves from disabling attitudes.
 - Identifying internalized oppression messages/ identities
- What is an ally and how can they help fight oppression?

Exercise for Workshops Trading Time



- Trading time on a variety of topics (Helps people process information and stay present with attention.)
 - To start the day: “How was your morning?” Helps bring people’s attention out.
 - Negative disability stereotypes
 - Positives about people with disabilities
 - Earliest memory of anyone with a physical or mental difference.
 - Helps identify where attitudes about disability and people with disabilities were formed.

Exercise for Workshops Trading Time , cont'd.

- Imagine what your infancy was like. How did your family treat you? (You know your family even if you don't remember, tell a story)
 - Helps identify learned attitudes towards needing help
 - all babies are “disabled”

Exercise for Workshops Trading Time, cont'd. 2

- How long: 1 minute to 1 hour
- Good to use throughout a workshop
- Explain the rules:
 - One at a time.
 - Take turns that are timed.
 - Decide who goes first.
 - Listener looking for lost treasure. No interrupting!

Tips for Sharing Stories

- Kinds of stories
 - Earlier the better – easier to empty out a bathtub by pulling the plug than bucket by bucket.
 - What's your earliest memory in any way at all related to...(i.e., doctors, people with physical or mental difference, being called...)
- People are not good at listening for long, especially without a turn so...
 - Take turns and time them
 - Holding a hand can be reassuring

Helpful Tool: Offering Contradictions

Why? Stimulate discharge of hurts → Leading to clearer thinking

- Useful whether caused by outward oppression or internalized oppression
- These are statements of believable reality not affirmations.
 - Not: "I am lovable."
 - More like: "I may not be totally unlovable." or "Some part of me somewhere is totally lovable."
- You know they are working because the person discharges.
- Re-Evaluation counseling has developed some for different constituencies. (www.rc.org)

Contradiction Example for Persons with Disabilities



"I cheerfully promise that from now on I will always remember that my body/mind is wonderful and that I am fully human, that I am totally admirable and lovely to be close to, and I will confidently expect to be cherished exactly as I am by all human beings."

www.rc.org

Contradiction Example for Reluctant Leaders

"I am obviously completely incompetent and completely inadequate to handle the challenges which reality places before me. However, (fortunately or unfortunately), I happen to be the best person available."

www.rc.org

Contradictions We Can All Remember

- Listen with an attitude of a treasure box being opened before you.
- Beam relaxed delight toward the speaker.
- If the person is blind, get their permission to set up a signal when you want to express delight (i.e., a gentle squeeze of the hand)

Workshop Demonstration Using Contradictions



- Demonstration in front of the group – demonstrates the use of contradictions and discharge – 3-10 minutes.
 - Remind group of confidentiality
 - Invite a volunteer to come up and demonstrate use of contradictions with you
 - Hold hand with permission and ask them to identify the internalized negative false pattern
 - Help the participant repeat an identified contradiction and stick with what brings discharge. Adjust as needed.
 - Point out the discharge to participant and group as a sign of choosing the right contradiction and healing taking place.

Workshop Demonstration Using Contradictions, cont'd.



- Thank the participant when done. Ask class to give them a hand for their bravery
- Give the participant an “up and out” question when done to take attention off the distress. (i.e., Tell me the name of a song you like? – Something totally unrelated and easy)

Note About Confidentiality

- Whether working 1-1 or in groups remind participants of confidentiality.
- This means that no one discusses casually what comes up in a “session” when someone is discharging. **This includes not bringing it up to the person themselves.**
- A relationship may be established where there is a mutual agreement that they will help each other notice when they are acting, thinking, or behaving from an oppression pattern rather than reality.

When a Referral May be Needed

- Feelings are nature's healing process. Look at any 2 year old.
- Feelings usually come and go, though they may be really big.
- If a person continues over and over to express one feeling only, they may be stuck in a pattern and not really healing from the emotional discharge. In this case they may need a referral for formal counseling.

Using Internalized Oppression Patterns to Set Personal Strategic Goals

- Taking on leadership is always and reliably a contradiction to internalized disability oppression.
- Peeling the onion. It never ends!
- Ask the question – where am I holding back?
 - ID the internalized oppression.
 - Don't let fear hold you back.
 - Take action to step forward, while discharging feelings along the way.
 - Get allies to cheer you on. Don't do it alone!

Disability Liberation Theory

Instigator of Disability Pride and Activism

- Helps people see their personal experiences in a new light → From “invalid” to Valid and Worthy.
- Moving beyond self to a sense of shared experiences within a diverse community of peers.
- Which empowers to self-advocacy → community advocacy → and leadership through—
 - Mentoring
 - Participating in public policy advocacy
 - Joining boards and councils
 - Pursuing careers and other interests as self-advocates

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