

## Independent Living Research Utilization



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



**Independent Living Research Utilization**

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# IL-NET

CIL-NET · SILC-NET

## Liberation to Leadership: The Role of CILs in Transforming Communities

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

September 16, 2015

Berkeley, CA

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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](http://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](http://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](http://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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**Developed as part of the CIL-NET, a project of the IL-NET, an ILRU/NCIL/APRIL National Training and Technical Assistance Program.**