

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

---



**Independent Living Research Utilization**

**[www.ilru.org](http://www.ilru.org)**

# IL-NET

CIL-NET · SILC-NET

## Disability, Diversity, and Intersectionality: An American Journey for CILs

July 10, 2018

*Presenters:*

**Susan Dooha**

**Jesse Bethke Gomez**

**Stanley Holbrook**

IL-NET is a project of Independent Living Research Utilization (ILRU) in partnership with the National Council on Independent Living (NCIL), the Association of Programs for Rural Independent Living (APRIL), and Utah State University Center for Persons with Disabilities (USU-CPD)

# Contact Information

- Jesse Bethke Gomez - [jessebg@mcil-mn.org](mailto:jessebg@mcil-mn.org)
- Susan Dooha - [sdooha@cidny.org](mailto:sdooha@cidny.org)
- Stanley Holbrook – [sholbrook4@verizon.net](mailto:sholbrook4@verizon.net)

Visit the ILRU Disability, Diversity, and Intersectionality in CILs website at [CIL-diversity.org](http://CIL-diversity.org) to find the nine CIL case studies and other information gathered from this project.

# What You Will Learn

- The purpose and framework of the Disability, Diversity, and Intersectionality (DDI) research project and its importance to centers for independent living.
- Overarching findings of the DDI research study that spotlight how nine centers for independent living are improving services, programs and outreach for racially/ethnically, culturally, and linguistically diverse groups.
- The intersectionality of disability and diversity as the disability rights movement began and has grown.
- Elements of dynamic, vibrant organizational cultures that promote conversations around affinities, connectedness, unconscious bias, and positive change.

# Disability, Diversity and Intersectionality (DDI) Project



Independent Living Research Utilization (ILRU) in collaboration with Public Research and Evaluation Services (PRES)

- Conducted a three-phase research study entitled, Disability, Diversity, and Intersectionality (DDI) project.
- To determine how CILs are designing and improving services, programs, and outreach for racially/ethnically, culturally, and linguistically diverse groups.

# The American Journey: Laws

The American journey of intersectionality is about the dignity of humanity.

- Legal responses to racial and ethnic discrimination
  - 1955 Brown v. Board of Education
  - 1960's-Civil Rights Act, Voting Rights Act, Fair Housing Act
- Legal responses to disability discrimination
  - Section 504 of the 1973 Rehabilitation Act
  - The Individuals with Disabilities Education Act (IDEA), 1975, 1990
  - Americans with Disabilities Act 1990, amended 2008

# The American Journey: Civil Rights and Disability Leaders



- Elizabeth Freeman – 1781, *Brom and Bett v. Ashley*
- Harriet Tubman – abolitionist and humanitarian 1910's
- Dr. Martin Luther King Jr. – civil rights movement, 1950's – 1960's
- Edward Roberts – Independent Living Movement, 1970's – 1990's
- Caesar Chavez & Dolores Huerta – worker rights, 1960's, 1970's
- Suzan Shown Harjo, recovered one million acres of Native land, 1960's
- Judith Heumann, Internationally recognized leader in disability communities, 1970's – present

# The American Journey: Civil Rights and Disability Leaders, cont'd.



- Joyce Jackson, participated in sit-ins at HEW, Washington DC 1970's
- Seema Agnani, National Coalition for Asian Pacific American Community Development (National CAPACD) 2018
- Brad Lomax who documented the struggle for disability rights in his documentary "The Power of 504"
- Alice Wong, Director of the Disability Visibility Project
- Johnnie Lacy who faced disability-based discrimination at a University, but got her degree and went on to establish Community Resource for Independent Living (CRIL-Hayward)
- Kathy Martinez, former Executive Director of the World Institute on Disability

# The American Journey: Community Organizations



- The role of non-profit 501 (c ) (3) community organizations is critical to the diversity and disability movements.
- Non-profit sector in the US economy is 2.26 trillion dollars.
- Role of Centers for Independent Living in advancing quality of life for people with disabilities.
- NAACP, Unidos US, National CAPACD and other diverse serving community organizations also play major roles in advancing quality of life for diverse populations that also grew out of civil rights era.

# The American Journey: Affinities & Charting the Future



- Growing racial and ethnic diversity in United States
- Intersectionality of Diversity and Disability in America
  - "...The HHS Advisory Committee on Minority Health has described living as a member of a racial or ethnic minority group with a disability as a "double burden" due to the added sociopolitical challenges encountered."
- Intersectionality of Aging and Disability.
- Common challenges and barriers—disenfranchised, low income, unemployment, completing high school, greater health disparities, lack of transportation, placement in special education, behavior problems, inadequate housing, etc.
- A time of change, yet principles of civil society remain.

# DDI Project: Definitions Used

- **Diversity**: Differences in culture, ethnic or racial classification, self-identification, tribal or clan affiliation, nationality, language, age, gender, sexual orientation, gender identity or expression, socioeconomic status, education, religion, spirituality, physical and intellectual abilities, personal appearance and other factors that distinguish one group or individual from another. (Adapted from Goode & Jackson, 2009)

## DDI Project: Definitions Used, cont'd.

- **Intersectionality**: The multiple social group memberships and identities that expose an individual to different types of discrimination and disadvantage. (Sue, Rasheed and Rasheed, 2016)

# Questions & Discussion

# Research Project

- The research project included—
  - Key informant interviews.
  - A focus group.
  - Interviews with CILs to select those to complete a case study about their work.

# The Focus Group

- Informant interviews
  - Conducted to identify potential CILs for participation.
- Focus group
  - Conducted focus group with nine individuals at the 2017 SILC Congress.
  - Purpose was to identify CILs who were known for their work serving ethnically/racially, culturally, linguistically diverse groups.
  - Group also suggested questions for CIL interviews.

# Next Steps

- 38 CILs were nominated and contacted
- 20 responded and completed telephone interviews regarding interests and eligibility
- Interviews were reviewed and rated by a panel
- 9 were selected for case studies

# Sites Selected for Case Studies



- **Access Living** (Chicago, Illinois) – Marca Bristo
- **Center for Independence of the Disabled in New York** (Manhattan, New York) – Susan Dooha
- **Central Coast Center for Independent Living** (Salinas, California) – Elsa Quezada
- **Central Iowa Center for Independent Living** (Des Moines, Iowa) – Reyma McDeid
- **Community Resources for Independent Living** (Hayward, California) – Ron Halog
- **disABILITY Link** (Atlanta, Georgia) – Kim Gibson
- **Illinois/Iowa Independent Living Center** (Illinois/Iowa: Rock Island, Illinois) – Liz Sherwin
- **IndependenceFirst** (Milwaukee, Wisconsin) – Lee Schulz
- **Metropolitan Center for Independent Living** (St. Paul, Minnesota) – Jesse Gomez

# What Do the 9 CILs Want Other CILs to Know?



Some things we learned include...

- It is important work and we all know we have a long way to go.
- Increasing our representation of all members of our community is an ongoing journey.
- The work changes as our communities change, as board members and staff members leave or join our work.
- The journey is a moving target!

# What Contributed to our Progress?

- CIL values
- We value learning from the Civil Rights and other movements that have come before us.
- We believe in the inalienable right to life, liberty, and the pursuit of happiness for all of us.

# What are our Organizational Capacities that Help Us?



- Board and staff education, skill development, and orientation to the needs of our communities.
- Hiring staff who are bilingual and bicultural and using a language line and translators to interpret.
- Stating in our policies and procedures that we affirmatively engage people of all races, ethnicities, genders, and sexual orientations.
- Understanding what disability data tells us about our community—how are we doing in many areas that define our “well-being?” Do some experience greater inequities than others?

# How Do We Use Our Understanding of the Community to Include All People?

- Create an outreach position to engage the community and address concerns of undocumented immigrants.
- Locate our office in a community that will be inclusive.
- Expand to new areas.
- Engage in strategic planning to improve services.

# How Do We Use Our Understanding of the Community for Systemic Advocacy Opportunities?

- Provide leadership training on an array of advocacy skills to systems change advocates with disabilities who are racially/ethnically/linguistically diverse.
- Join in community meetings, coalitions and membership organizations to learn and contribute, including: Black Lives Matter; the Immigration Coalition; the NAACP and the Hispanic Chamber of Commerce, ACLU, and others.

- Identify and work on issues that affect people of color with disabilities, spearhead conversations and provide training (including topics such as police shootings and the school to prison pipeline, address savings thresholds; immigration issues).

# What are the Thoughts that the 9 CILs Participating in the Project want to Share?

- Show respect and take time to connect.
- Be willing to think in new ways.
- Address prejudices with facts and avoid assumptions.
- Listen, listen, listen.
- Staff the right people.

# Importance of Organizational Culture

- One of most important aspects of a nonprofit enterprise is organizational culture.
- Organizational culture is as important as mission, strategy, and business model.
- Think about how culture aligns with the notion that people are meeting their hopes and dreams – culture nurtures the energy toward discovery – such as data mining, community mapping, innovative outreach/partnerships.

# Importance of Organizational Culture, cont'd.



- Culture is just as important as mission...what is it in your culture that drove you to do such extraordinary work? Do you want a culture that responds to change? Helps the CIL think and move forward?
- Vibrant culture is a distinctive competency. Put people in the driver's seat.
- Bring attention to these 9 Centers because they speak powerfully of having sense of culture and connectivity. Prompt others to think about, What is our culture? What happens in a dynamic organization?
- We have awareness of organizational culture. Our leaders act with integrity in alignment with our values, in nurturing an engaged employee workforce. The collective energy of everyone contributes to nurturing a conducive organizational culture.

# Questions & Discussion

# Preview of Upcoming Webinars

- Data Mining and Community Mapping to Support DDI
- Playing Well with Others
- CIL Organization, Culture, and Infrastructure
- Ensuring Core Services are Responsive to DDI

# Final Questions and Evaluation Survey

Any final questions?

Directly following the webinar, you will see a short evaluation survey to complete on your screen. We appreciate your feedback!

[https://usu.co1.qualtrics.com/jfe/form/SV\\_cFLzj7Kd7AbvT5r](https://usu.co1.qualtrics.com/jfe/form/SV_cFLzj7Kd7AbvT5r)

# CIL-NET Attribution

This project is supported by grant number 90ILTA0001 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.