



Improving Social Connection Among People with Disabilities

Administration for Community Living

March 30, 2021



Today's Webinar

- Highlight current research on social isolation and loneliness for people with disabilities
- Identify replicable strategies for social engagement and connection from the Center for Independent Living network

Announcements

- Commit to Connect
 - National campaign to combat social isolation and loneliness in all communities
 - Visit <https://acl.gov/CommitToConnect> to learn more
 - Upcoming webinar on ‘National Network of Champions to Address Social Isolation’ in mid-April
- ACL and Federal Communications Commission webinar on Emergency Broadband Benefit
 - April 15 @ 3pm ET
 - Registration info coming soon!

Presenters

- **Sean Barrett**, Team Lead, Office of Independent Living Programs, ACL
- **Anne Ordway**, Program Specialist, National Institute on Disability, Independent Living, and Rehabilitation Research, ACL
- **Maia Santamaria**, Executive Director, NWGA Center for Independent Living



Office of Independent Living Programs

Rehabilitation Act of 1973, as amended





What is Independent Living?

Philosophy

Culture

Federal Programs



Independent Living: A Culture

- Shared identity shaped by:
 - A common history of oppression;
 - The lived commitment to advancing the human and civil rights of people with significant disabilities;
 - The art, music, literature, and other expressions that individuals with significant disabilities create based on their lives and culture; and
 - The pride, identity and purpose claimed by people with disabilities.*

*adapted from Steve Brown Ph.D, [What is Disability Culture?](#) Institute on Disability Culture, 2001.

Independent Living: The Programs

- **Independent Living Services (ILS)**
Funding to States for the purpose of supporting and expanding the independent living network in a state (56 awards)
- **Centers for Independent Living (CILs)**
Funding to community based organizations for the purpose of providing independent living services to individuals with significant disabilities (352 awards)
- **Training and Technical Assistance Centers**
Funding to provide training and technical assistance to CILs, State Independent Living Councils (SILCs) and other eligible entities (2 awards)
- **Section 21**
Funding to address traditionally underserved populations (3 awards)

IL Programs and Philosophy

Title VII of the Rehabilitation Act

Purpose:

...**To promote a philosophy of independent living**, including consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to **maximize the leadership, empowerment, independence, and productivity of individuals with disabilities**, and the **integration and full inclusion of individuals with disabilities into the mainstream of American society**

Independent Living Programs

Historical Milestones

- **1972** The Center for Independent Living (CIL) is founded in Berkeley, California
- **1973** The Rehabilitation Act passes
- **1978** Title VII of the Rehabilitation Act established federal funding for independent living
- **1979** First 10 states receive Title VII funding
- **1992** Rehab Act restructured: Creates CIL Program, SILCs established
- **2014** The Workforce Innovation and Opportunity Act (WIOA) enacted



Independent Living

The philosophy + the culture + the programs =
INDEPENDENT LIVING



Centers for Independent Living (CILs)

- **Consumer-controlled**, community-based, cross-disability, nonresidential, private nonprofit agency for individuals with significant disabilities (regardless of age or income) [45 CFR1329.4]
 - Majority of Board must be persons with significant disabilities
 - Majority of staff, and people in decision-making positions must be individuals with disabilities [Sec. 725]
 - People with disabilities are always considered the primary person being served, not family members

Independent Living Core Services

CILs MUST provide:

“independent living core services”

- (A) information and referral services;
- (B) independent living skills training;
- (C) peer counseling (including cross-disability peer counseling);
- (D) individual and systems advocacy; **and**
- (E)** Services that facilitate the transition from institutions to community living, diversion from institutions to community living, and transition of youth from secondary education to post-secondary life

COVID-19 Aid, Relief, and Economic Security Act of 2020 (CARES Act)

- Project Period: Jan 20, 2020 – Sept 29, 2021
- Directed to utilize the entirety of the funds to respond to the COVID-19 pandemic and the surge of needs of individuals with disabilities to access or reconnect with the services and supports they need to remain safely in their communities.

CIL CARES Act Areas of Emphasis

1. Service coordination during and after the COVID-19 pandemic;
2. Services and activities that assist individuals with disabilities who are at risk of being institutionalized to remain in their communities;
3. Services and activities that assist individuals with disabilities to move from an institutional setting to a home in a community-based setting;
4. Services and activities that address the shortage of accessible housing;
5. Partnerships with local agencies that address food insecurity; and
6. Systems advocacy to ensure health equity in medical settings.

The OILP Team

1. Reyma Mccoy-Mcdeid, Commissioner of the Administration on Disabilities and Acting Director, OILP
2. Sean Barrett, Team Lead
3. Regina Blye - ILS
4. Kimball Gray - CIL
5. Veronica Hogan - CIL
6. Peter Nye - CIL
7. Jennifer Martin-CIL



The National Picture: Serving a Diverse Population

Who received services?

- 55% female
- 48% identifying as a minority
- 43% 25–59 years old
- 39% 60 years old or over



Leadership

Who leads these programs?

- 76% of Board Members and 64% of staff had a significant disability

Services and Goals

- CILs work with each consumer to set independent living goals. Consumers often come to CILs looking for a specific service or services. CILs guide the discussion from the specific service(s) to what the consumer wants to accomplish by having that service. The consumer establishes a goal based on the discussion and the CIL and consumer determine the services that will help the consumer reach the goal(s).



Services and Goals

Services Provided:

- 837,623 Core Services provided
- 379,347 other services
- 72,708 goals met!

Resources

- CIL Annual Report:
https://acl.gov/sites/default/files/programs/2020-11/PY19CILReport508%20FINAL_0.pdf
- CIL page at ACL.gov:
<https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>



Improving Social Connection among People with Disabilities

Anne Ordway, PhD

National Institute on Disability, Independent Living and
Rehabilitation Research (NIDILRR)

Administration for Community Living (ACL)

March 30, 2021

We have a need for social connection.

- Changes to our social connections since the start of the pandemic
- Not new concepts but new insights into what it means to be socially isolated, lonely, or both
- Opportunity to build on today's imperative to address the social impact of COVID-19

What are social isolation and loneliness?

- **Social isolation:** having few social relationships or infrequent social contact with others¹
- **Loneliness:** the feeling of being alone regardless of the amount of social contact²

Social isolation ≠ Loneliness

What does current research tell us?

- Identified as a public health concern in the US and internationally³
- Associated with adverse health outcomes⁴, increased morbidity⁵, early mortality⁶
- Two thirds of adults reported social isolation during the pandemic⁷
- Younger people more at risk for loneliness during the pandemic⁸

Many studies do not include disability.

- Research mostly focused on the experience of older adults
- Disability included only as a risk factor for social isolation and loneliness
- Lack of early research on the impacts of COVID-19 on people with disabilities⁹

What do we know about disability?

- Pre-pandemic, individuals with TBI, SCI, serious mental illness had high levels of loneliness¹⁰⁻¹³
- Younger people are more at risk for loneliness during the pandemic
- Urban residents feel more isolated than rural residents during the pandemic¹⁴
- New novel surveys (e.g., COVID-DIS, NSHD) include questions on social isolation and loneliness¹⁵

Don't forget social participation!

Social participation? Community living and participation? Community integration?

- A treasure trove of research on all aspects of social participation for people with disabilities
- A substantial knowledge base may be overlooked

What are the next steps for research?

- Intervention research on social connection targeting now and beyond the pandemic
- A range of interventions centered on the individual, family, and health care providers
- Comparative effectiveness research on in-person vs. remote/digital interventions

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A close-up photograph of a field of purple lavender flowers. The flowers are in various stages of bloom, with some showing individual small blossoms. The background is a soft, out-of-focus field of more lavender. A dark green banner with white text is overlaid on the lower half of the image.

Using Peer Support to Address Social Isolation

Presented by Maia Santamaria, Executive Director

NWGA Center for Independent Living

Welcome!

About Us

Mission Statement

“To empower people who have disabilities so that they may determine their own future; to work towards a more user-friendly, accessible community.”



Northwest Georgia Center for Independent Living is an organization serving 15 counties in the northwest Georgia area. We serve all disabilities and all ages.

Our Staff

- **Maia Santamaria** *Executive Director*
- **Christina Holtzclaw** *Assistant Director*
- **Avis Elliot** *Business Manager*
- **Kathy Baker** *Program Manager*
- **Jill Baldwin** *Project Manager*
- **Erna Dobbs** *I&R Coordinator*
- **Tereasa Lowry** *IL Coordinator*
- **Quinn Durrant** *IL Assistant*

All of our staff have disabilities and are therefore well-suited to provide peer support to our consumers. We are a small team but we are experienced, dedicated and passionate about our work.

A background image of a vast lavender field with rows of purple flowers stretching into the distance under a soft, hazy sky. The focus is sharp on the flowers in the foreground, creating a sense of depth.

Peer Support is the Foundation of NWGA CIL

- Provided to consumers
- Provided among board members, management and staff
- Provided to community partners who are consumer-led

A background image of a field of purple lavender flowers in bloom, with some stems in sharp focus and others blurred in the background.

Enter the COVID-19 Pandemic...

*Our Center's Infrastructure Changes:
We were building the airplane as we were flying it!*

- *Keeping the team safe & healthy*
- *Developing remote working culture*
- *Incorporating influx of CARES Act funds*
- *Adding equipment & accommodations*
- *Finding and learning new digital platforms that are accessible*
- *Changing policies*

A background image of a field of purple lavender flowers. The flowers are in various stages of bloom, with some showing individual small blossoms. The background is slightly blurred, creating a sense of depth.

Enter the COVID-19 Pandemic...

Our Concurrent First Response to the Pandemic

- *Checking on our consumers to see what they needed/wanted*
- *Finding accessible PPE (such as clear masks)*
- *Reaching out to community partners*
- *Helping community organizations who serve people who have disabilities*
- *Finding that contacts with people took longer & longer*
- *Finding that people wanted group interaction*

A background image of a vast lavender field with rows of purple flowers stretching into the distance under a soft, hazy sky. The flowers are in sharp focus in the foreground, while the background is blurred.

And so, we evolved to hold weekly group Peer Check-ins!

- Providing technology and training for consumers*
- Supplying/teaching on an accessible platform – Zoom*
- Providing a safe space, including a disclaimer*
- Providing most up-to-date and scientifically accurate information as possible*
- Team & consumers listening and sharing information, stories, fears, successes, coping strategies*

A background image of a vast lavender field with rows of purple flowers stretching into the distance under a soft, hazy sky. The focus is sharp on the flowers in the foreground, creating a sense of depth.

Using Peer Support for everyone, not just consumers...

- *Realized how much our team needed each others' peer support*
- *Increased our team meetings to two hours twice a week*
- *Received peer support from other CIL directors and national organizations*
- *Exchanged peer support with collaborative partners*

A background image of a field of purple lavender flowers. The flowers are in various stages of bloom, with some in sharp focus and others blurred in the background. The overall color palette is shades of purple and green.

Recognizing the increased impact of social isolation on people who have mental/emotional disabilities...

- *Offered Emergency Mental Health Preparedness in Rural Communities at 2020 APRIL Conference*
- *Hired an IL Coordinator who is trained in IL peer support and is also certified to provide mental health peer support*
 - *Along with management, she has been instrumental in making community connections with other organizations comprised of people who have different types of mental/emotional health issues*
 - *She has been able to provide peer support & education to these groups and their members, thus reaching more people and engaging the community*

A close-up photograph of a lavender field. The foreground shows several sharp, vertical lavender spikes with small purple flowers. The background is a soft, out-of-focus expanse of more lavender plants, creating a sense of depth and tranquility. The overall color palette is various shades of purple and green.

And then came the holidays...

- *We recognized and responded to the added stress & social isolation of the holidays*
 - *Coping with the Holidays event*
 - *Celebrating the Holidays event*

A background image of a field of purple lavender flowers. A dark green horizontal bar is positioned across the upper middle of the image, containing the title text.

Now that the vaccines are here...

- *Recognize that this is a new phase with peer support needing to focus on different topics:*
 - *Educating about vaccines*
 - *When and where to wear masks & socially distance*
 - *Offering our courses again: EmployABILITY, You & Your Money and Living Well*
- *Transitioning team to working in the office*
- *Peer supporting team with regard to working with consumers in person*
- *Incorporating the best of new practices in working with consumers*
- *Staying flexible & responsive to consumers, ourselves and our community*

A background image of a field of purple lavender flowers. The flowers are in various stages of bloom, with some in sharp focus and others blurred in the background. The overall color palette is shades of purple and green.

Taking a look at the challenges we have faced:

- *Engaging residents and staff in nursing facilities during lockdown*
 - *Nursing Transition Coordinator contacts residents as possible*
 - *Called social workers*
 - *Wrote letters to social workers*
 - *Put out press releases to community specifically about our transition & diversion services*
- *The Digital Divide*
 - *Provided technology to those who wanted*
 - *Contacted local newspapers, radio & TV stations to outreach to consumers and community*
 - *Have done press releases, newspaper interviews, and radio shows to get the word out about peer support calls & our services*

A background image of a lavender field with purple flowers in focus and a soft-focus path leading into the distance.

Taking a look at the challenges we have faced, continued:

- *Lack of transportation*

- *Limited public transportation, taxis, Uber or Lyft*

- *Lack of available housing*

- *Lack of accessible, affordable housing during bets of times; unhoused populations has increased due to COVID so the challenge is even greater*
- *Have assisted with hotels in a few cases*

A background image of a lavender field with purple flowers and green stems. A dark green horizontal band is positioned across the upper middle of the image, containing white text.

And through it all, the lessons we have learned:

- *Team learned how to work remotely and productively*
- *Team grew even stronger*
- *Learned to engage with consumers differently now compared to before the pandemic started*
 - *Even more Peer Support*
 - *Electronic Signatures*
 - *Zoom*
 - *Very limited consumer visits with masks and social distancing*

Q&A Time!



Contact us!

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Questions?