Rural Institute
UNIVERSITY OF MONTANA

RTC:Rural
Research & Training Center
on Disability in Rural Communities

Using the National Survey on Health and Disability (NSHD) to Explore the Experience of Social Isolation and Loneliness among Rural and Urban People with Disabilities

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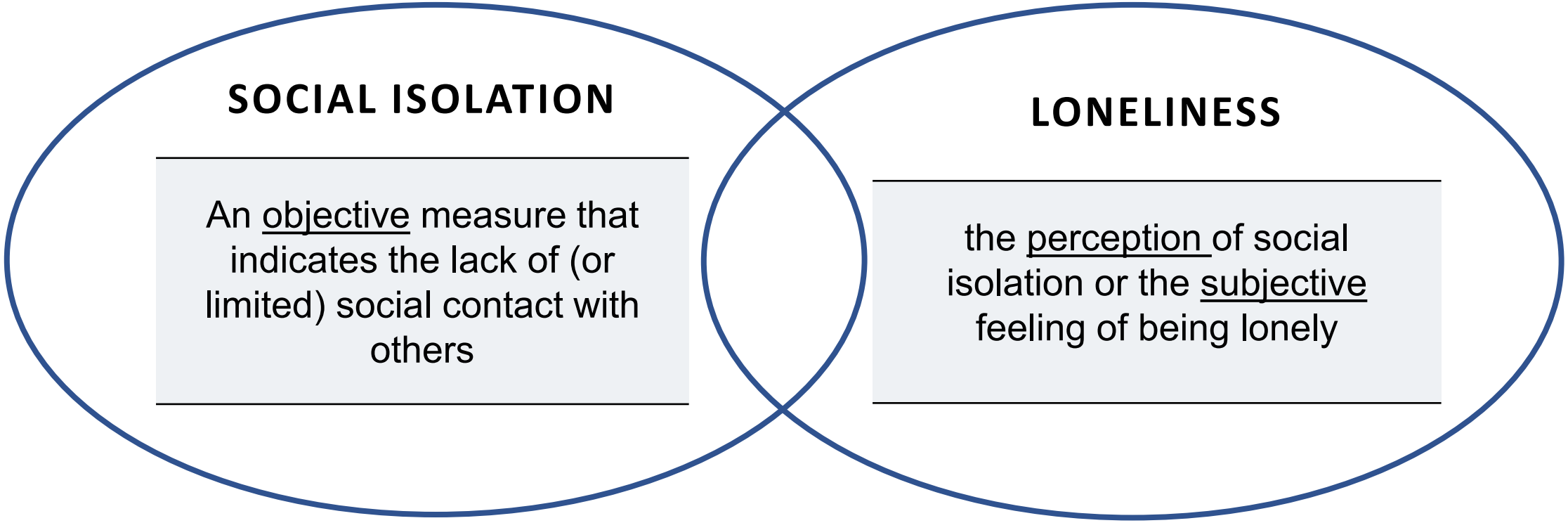
- The findings and conclusions presented here do not necessarily represent the views of NIDILRR, ACL, or DHHS. One should therefore not assume endorsement by the federal government.

What is Social Connection?

- **Social connection** is the experience of feeling connected to other people. It's a basic human need.
  - Our support networks help us to weather life's ups and downs (resiliency)
  - Also, they help us to build self-worth by fulfilling the needs of others
  - "Mattering" – concept discussed in a prior NIDILRR webinar (Aug. 5, 2021) by Mark Salzer, PhD and Bryan McCormick, PhD from Temple University

- **A lack of social connection** can lead to social isolation and loneliness, which are associated with worse physical and mental health outcomes.
  - More physician visits, hospitalizations, cardiovascular health issues
  - More depression, anxiety, declines in cognition

Social Isolation vs. Loneliness: 2 Distinct Concepts



Temporary vs Chronic Loneliness

- **Loneliness**
  - Signals a need to build new relationships and social connections
  - Natural adaptive process

- **Re-Affiliation Motive (RAM) – stages across the lifespan by Qualter et al., 2015**
  - Withdrawal from social interactions
  - Situational assessment – hyper awareness of social cues
  - Behavioral regulation
  - Reengagement

- **Temporary Loneliness**
  - Moving to a new location, starting a new job or school, etc.

- **Chronic Loneliness**
  - A persistent state of loneliness that lasts for an extended period, is self-reinforcing
    - Shyness, anxiety, low self-esteem, depressed mood sustain withdrawal
    - Loss of social networks make it difficult to build new ones
    - Negative interpretations of social information – perceived threats

Structural and Environmental Barriers Affect the Experiences of People with Disabilities

1. Accessible and timely **public transportation** options
   Directly affects experiences with medical care, social visits, employment, etc.
2. Accessible **community infrastructure** (outside the home)
   Medical office facilities, businesses, sidewalks, parks, etc.
3. Accessible **housing environment** (inside the home)
   Can make it difficult to leave home or visit others in their homes.

Stigmas can reinforce these structural barriers, which limit confidence, choice and control in how one participates in the community. Stigmas increase feelings of social threat.

Evidence on Social Isolation and Loneliness in Older Adult Populations (65+ years)

- **Structural barriers related to mobility limitations among older adults**
  - Life changes – retirement, bereavement, housing changes
  - Health changes – higher rates of chronic illness and pain

- **Loss of established social networks and supports lead to isolation**
  - Approximately 1 in 5 older adult respondents (65+ years) indicate high levels of social isolation – National Health Aging Trends Survey (NHATS)

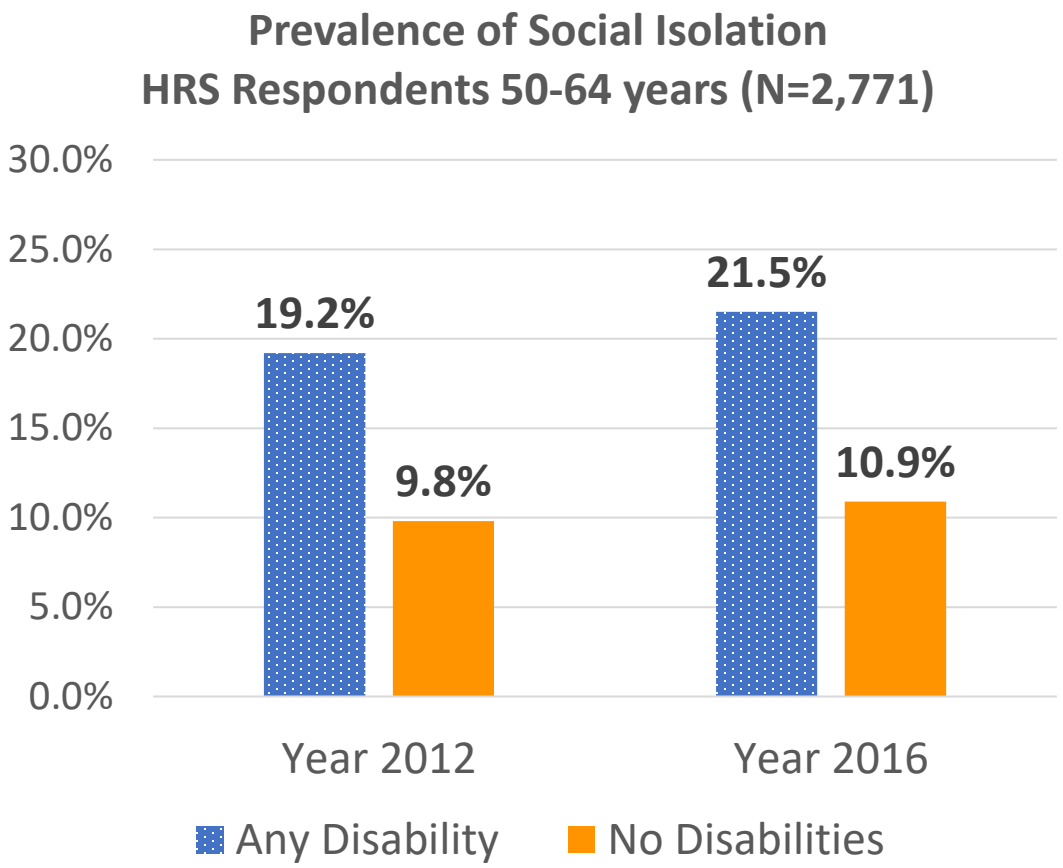
- **However, very limited evidence on SI and loneliness prevalence in younger adults (18-64 years) with disabilities, or by specific type of disability.**

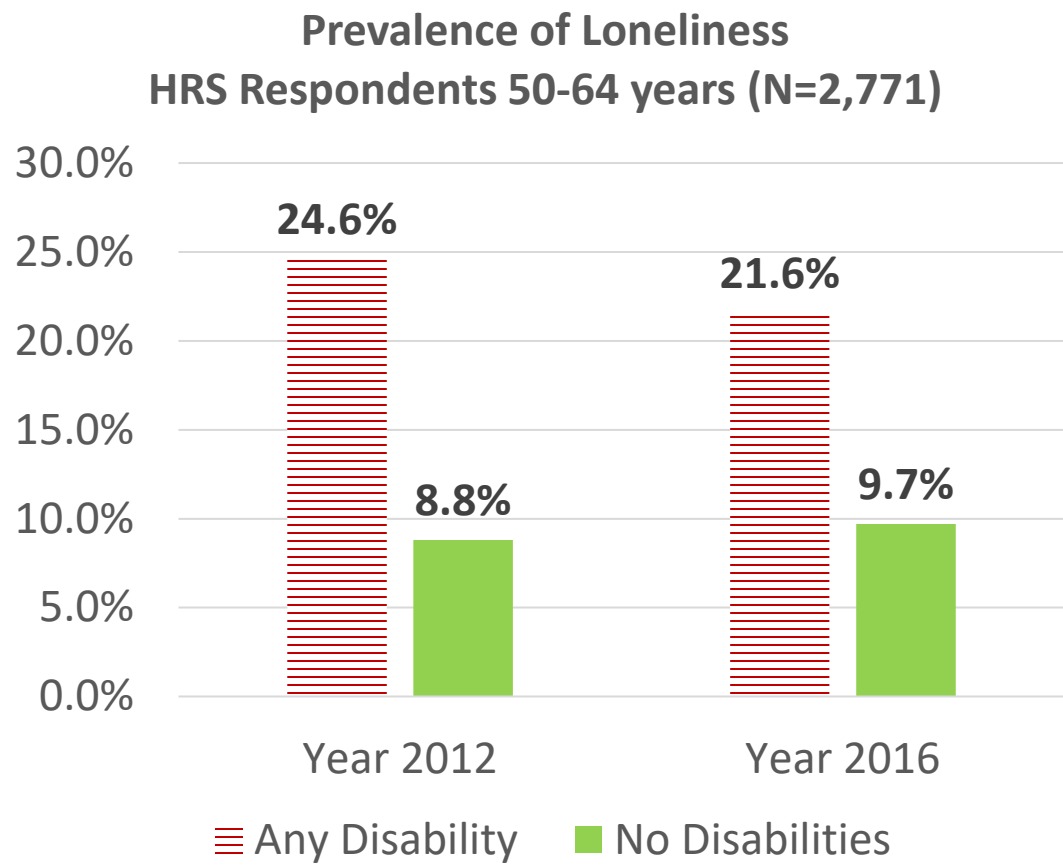
Health and Retirement Survey (HRS)

- **Longitudinal survey of adults** (50+ years) nationwide; used to develop a baseline national comparison of adults with vs. without disabilities.
  - National longitudinal sample (biennial surveys conducted since 1998)
  - Social isolation and loneliness (UCLA score) were added in 2006
  - Basic indicators of disability (i.e., work limitations + ADLs + IADLs)
  - Our analytic sample is limited to working-age adults (50-64 years)

- **Main Finding:** social isolation and loneliness are more than twice as prevalent among adults (50-64 years) with disabilities compared with those without disabilities.

Disparities in Social Isolation and Loneliness among HRS Adult Participants (50-65 years), by Disability Status





National Survey on Health and Disability (NSHD)

- **National convenience sample of adults with disabilities (18-64 years)**
  - Cannot be compared to other national datasets (e.g., Health and Retirement Survey) of older adults, but we can describe the experiences of younger more educated groups
- **Opportunities to examine the experiences of specific disability groups**
  - Based on ACS questions of functional disability (Yes/No) and Washington Group Qs
  - NSHD included a second measure based on self-identified disability types
    - Open-ended responses classified into 6 categories by researchers
      - ❑Mental illness/psychiatric, physical, I/DD, sensory, neurological and chronic illness
- **3 NSHD waves were administered – we focus on comparing Wave 2 vs. 3**
  - 2018 (Wave 1), 2019/20 (Wave 2 – pre-COVID), and in 2021 (Wave 3 – post-COVID)

NSHD Measures: Social Connection and Loneliness

- Satisfaction with social activities
  - 0 = not at all to 4 = very much
- Quantity of social connections – number of close contacts you saw or heard from in last month
  - 0 to 9+
- Quality of social connections – someone close to talk to about important decisions
  - 0 = never to 5 = always

- **UCLA 3-item Loneliness Scale**
  - A. How often do you feel you lack companionship?
  - B. How often do you feel left out?
  - C. How often do you feel isolated from others?
    - 1 = hardly ever to 3 = always
    - Total Loneliness Score has a range of 3 to 9.

Research Questions using NSHD Data

1. Which factors predict social isolation and loneliness?

- Socio-demographic characteristics (e.g., age, race, gender)
- Disability type
- Environmental factors (e.g., rural/urban, access to transportation for daily needs vs. social needs, living alone)

2. Did rates of social isolation and loneliness change due to the COVID-19 pandemic and the March 2020 lockdowns in the U.S.?

- Are these differences consistent across rural and urban samples?

2019/20 NSHD Participant Characteristics (Wave 2: Pre-COVID)

Participant Characteristics	% of Total (N=2,161)
Age 35+ years	64.8
Gender (Male)	32.9
Race (not-white)	18.7
Some college	85.8
Employed	62.7
Below 138% of FPL	36.4
Mental illness/psychiatric disability	46.5
Physical disability	37.1
Chronic illness	43.7
IDD/ASD	7.1
Sensory disability	9.7
Neurological disability	27.8

Results – Multivariate Analysis of Loneliness

- **Socio-demographics**
  - Race, education, gender, age, 138% of FPL, employment
- **Disability type**
  - Psychiatric, physical, chronic illness, IDD, sensory, neurological
- **Environment**
  - Rural, transportation problems - daily needs, transportation problems -social needs, live with others

- **Significant predictors of loneliness (scale of 1-9)**
  - Not employed (β = .608)
  - Mental illness/psychiatric (β = .876)
  - Transportation problems - social needs (β = 1.00)
  - Live alone (β = .463)
  - 138% of FPL or below (β = .119)

Predictors Across Models

	Satisfaction with social activity ↓	Quantity of contacts ↓	Quality of contacts ↓	Loneliness ↑
Race (not white)			●	
Gender (male)		●	●	
Age 35+ years	●	●	●	
Below 138% FPL		●	●	●
Not employed (highlighted)	●	●	●	●
Mental illness/psychiatric (highlighted)	●	●	●	●
Rural location		●		
Transportation problems – daily needs			●	
Transportation problems – social needs (highlighted)	●	●	●	●
Live alone		●	●	●

COVID-19 Pandemic – Increased Social Isolation

- **Social isolation as a public health crisis**
  - In 2017, Dr. Vivek Murthy, the U.S. Surgeon General, called the rising prevalence of social isolation and loneliness a public health epidemic.
- **March 2020 lockdowns and mandatory social distancing**
  - Referred to as a "double pandemic" – social isolation + COVID-19
- **Disproportionately adverse impact on vulnerable populations**
  - Exacerbates prior health disparities (i.e., social determinants of health)
  - Greater risk of mortality and complications if exposed to COVID-19 (i.e., older adults, people with disabilities, or pre-existing health conditions).

Social Satisfaction changed after COVID-19 for people with vs. without disabilities.

- Prior to COVID-19, people with disabilities reported significantly lower rates of social satisfaction than people without disabilities
- **In early December 2020, differences were no longer present** in the domains of home, work, grocery, restaurants, retail, indoor recreation, worship, education, community service, or online engagement.
- However, social satisfaction with outdoor recreation and healthcare appts was significantly lower for people with disabilities compared to those without.

Data from NIDILRR grant (90DPCP0004) - A Socio-Ecologic Framework for Supporting Individuals with Disabilities' Community Living and Participation – Utah State University; Keith Christianson.

Results: Comparison of Wave 2 vs. Wave 3 NSHD Longitudinal Sample (n = 566)

	Pre-COVID	Post-COVID	P-value
Satisfaction with leisure activity (0-4)	1.94	2.41	.039
Satisfaction with social activity (0-4)	1.90	1.81	.734
Isolated from others in the community (score range of 0-4) (highlighted)	**1.85**	**2.53**	**.003**
Quantity of contacts	4.47	4.55	.459
Quality of contacts (0 = never to 5 = always)	3.80	3.85	.351
UCLA Loneliness Scale (3 items, score rate of 1 = hardly ever to 9 = often) (highlighted)	**7.31**	**6.29**	**.015**

CILs Help to Maintain Social Connections – Voices from the field in 2020 and 2021

- CILs have **scrambled to provide accessible ways for consumers to connect** for peer support both virtually and in-person for those without technology…to combat social isolation. (April 2020)
- "I have not found consumers [just] looking for resources as much as I have **consumers who simply want someone to listen**. Peer support [virtual] has really moved to the top of our core services list!" (May 2020)
- "I think these isolating **lockdowns are bringing a large number of people almost all at 'once' into our disability community** through a shared experience which is incredibly unique." (April 2021)

Role of Centers for Independent Living (CILs)

- **CILs play an important role in reducing social isolation**
  - Working to overcome structural barriers
  - Translating delivery to online methods (e.g., Zoom)
  - Supporting telecommunications literacy
  - Providing opportunities for shared experiences and peer support

- **Example: Living Well in the Community**
  - CILs support one another in transition to online delivery
    - Develop and share video instructions for how to run a zoom meeting – how to get on, use chat box, raise hand, turn on captioning, etc.
  - Participants overcome digital hesitancy to continue participation in peer programming
    - Attendance increases
  - Participants explore other online options
    - Quilting group, online searches, zoom meetings outside workshop

Summary of Key Findings from the NSHD

- Social isolation got worse after COVID-19, but loneliness did not.
- Temporary social isolation can lead to loneliness for people with disabilities.
  - CILs playing an important role in overcoming temporary social isolation
  - Telecommunication literacy and access is important
- Chronic loneliness may require more comprehensive programming
  - CIL peer support models (in-person and virtual)
    - Build self-determination and self-confidence
    - Create roles or mattering – teacher and learner roles
    - Create more opportunities to socialize
    - Build inclusive networks that overcome and address structural barriers
  - Cognitive behavioral components may improve outcomes

Conclusion and Policy Implications

- **Transportation is a key barrier** to participation (employment), and also affects social activities, connections, and loneliness.

- **Employment is also a consistent, independent predictor** of social connections and loneliness. Therefore, policies to support employment among people with disabilities can also reduce loneliness.

- **CILs play a key role in building social connections** and reducing temporary loneliness. However, expanded support for peer support services, and more evidence on interventions are needed to address chronic loneliness.

Thank You! (Q&A Discussion)

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