Tailoring Your Knowledge Translation Strategies for Your Intended Users

KTDRR's 2023 Virtual KT Conference

November 6, 8, and 9

Center on
KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH





Community Based Participatory Research with Rural Centers for Independent Living

Sequoia Commins, Tri-County Independent Living

Lillie Greiman and Rayna Sage, The Rural Institute for Inclusive Communities

Acknowledgements

The contents of this presentation were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DPKT0005). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

We have no conflicts of interest to disclose.



Introductions and statements of positionality

- Rayna Sage, Rural Institute for Inclusive Communities at the University of Montana in Missoula, MT
- Lillie Greiman, Rural Institute for Inclusive Communities at the University of Montana in Missoula, MT
- Sequoia Commins, Tri-County Independent Living in Crescent City, CA







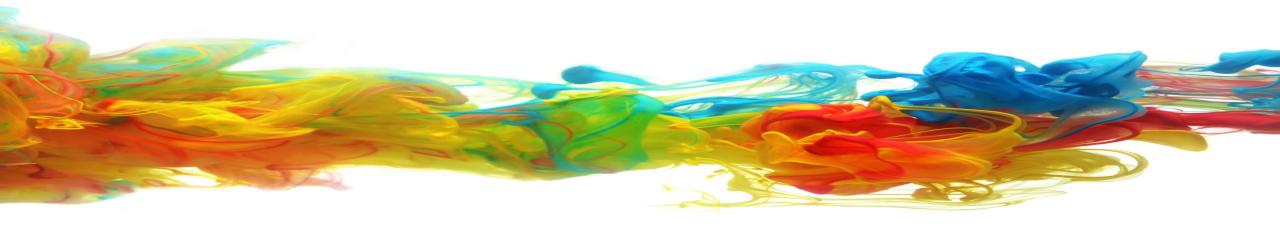
Community-Based Participatory Research and Rural Disability – Why it matters

- Historical exclusion and exploitation, rural social movements and development efforts
- Nothing about us without us and the Independent Living Movement
- The intersection of rurality and disability
 - Disability and rural are both difficult to define
 - Disability and rural are both undervalued and under resourced
 - Resulting in some shared and amplified experiences of marginalization and exclusion



Community-Based Participatory Research and Rural Disability – Why it matters cont..

- CBPR as a strategy to address past injustice and neglect from the academic/research community
- CBPR functions along a spectrum (e.g., informed by, engaged, participatory, driven by)



Centers for Independent Living

- Centers for Independent Living are community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities. CILs operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization.
- CILs provide 5 core services:
 - Peer Support
 - Information and Referral
 - Individual and Systems Advocacy
 - Independent Living Skills Training
 - Transition (to adulthood AND out of institutional settings)
- Today there are <u>more than 350 CILs</u> serving hundreds of rural counties. CILs are valuable members of the <u>U.S. Administrating on Community Living's</u> <u>Aging and Disability Network</u>.



The RTCs and Rural CILs*

- The RTC:Rural has a long history of partnering with CILs and other RTCs for field-informed research
 - Documenting distribution of CILs across rural and urban spaces since 1999
 - Collaborating to create rural outreach tools since 2001
 - Elevating CIL peer support and advocacy work in relation to services and nursing home emancipation
 - Working to create models to better understand and promote community participation



^{*}See recommended references at the end of this presentation

About the Rural Community Living Development (RCLD) Peer Mentoring Program

- Why?
 - Identified need to support CILs in reaching rural communities they serve
- Who?
 - Rural serving CILs, APRIL, RTC:Rural
- When?
 - KTDRRP funded through NIDILRR starting in 2019
- What?
 - Collaboratively developed Rural Outreach Curriculum and Peer Support Network
 - To identify what works and support rural CILs, consumers and communities





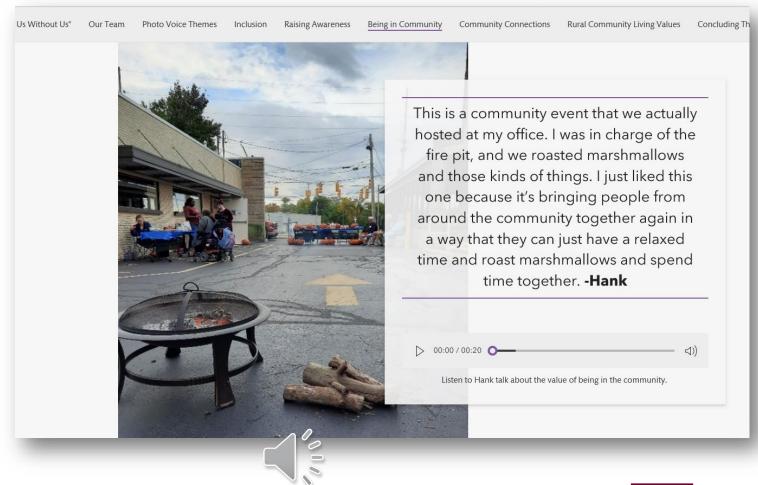
Participatory process and outputs...

- Rural Outreach Curriculum tailored for CIL staff
 - Participatory Curriculum Development (PCD; Taylor, 2006; Boehm-Barrett, 2019)
 - Harnessing the power of peer support



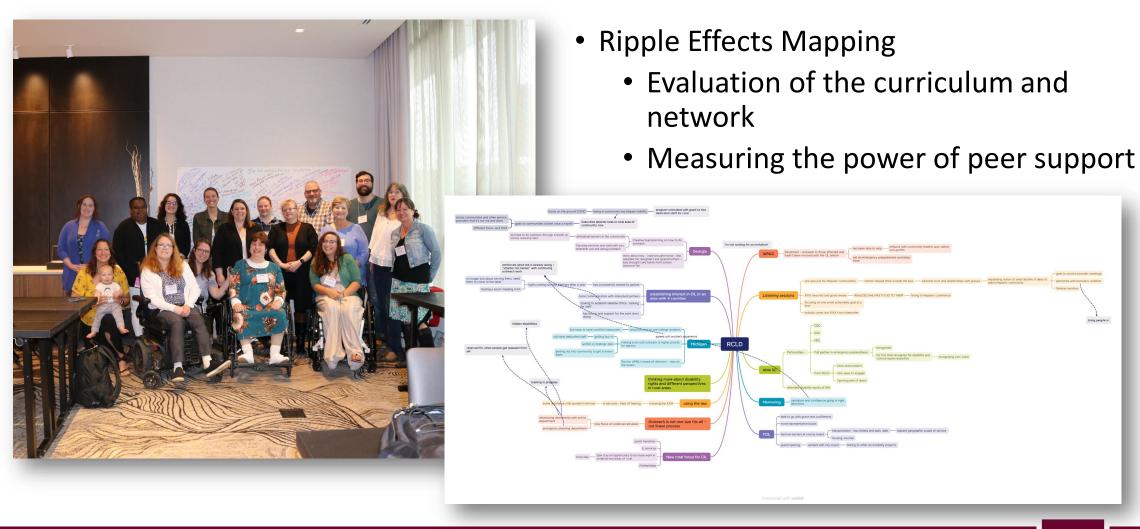
Participatory process and outputs...

- Photovoice Evaluation and Storymap
 - Communicating The Value of Rural Independent Living
 - https://arcg.is/01aGOf





Participatory process and outputs...



Takeaways and lessons learned

- Examples from the field Sequoia and her own ripple effects
- Hot tips maybe we glean some stuff from the curriculum?
 - Partner-driven elements
 - Meeting people where they are (literally)
 - Learning from "failure" (always an opportunity to learn; e.g., hosting a meeting in the disability benefits office no one coming to the Hispanic Outreach event)
 - Being flexible, making the most of what you have
 - Where we (university researcher staff) struggled
 - Still learning (e.g., plain language)
 - Navigating power, resources, ownership (in-person meeting)
 - Navigating expectations (Is this engagement, partnership? How do you know? Krys has some new resources about defining community-based work from SSSP)
 - Elevating and utilizing all strengths
 - Continuous "voice checking" (Storymap)



Is there one thing you learned about today that you want to try in your work?

Questions and follow-ups welcome!

Sequoia Commins, <u>sequoia@tilinet.org</u>
Lillie Greiman, <u>lillie.grieman@umontana.edu</u>
Rayna Sage, <u>rayna.sage@umontana.edu</u>



Recommended references

Innes, B., Enders, A., Seekins, T., Merritt, D. J., Kirshenbaum, A., & Arnold, N. (2000). Assessing the geographic distribution of centers for independent living across urban and rural areas: Toward a policy of universal access. *Journal of Disability Policy Studies*, 10(2), 207–224. https://doi.org/10.1177/104420730001000205

Johnson, K. B., Greiman, L., VonReichert, C., & Altom, B. (2021). Exploring Access to Independent Living Services for People With Disabilities Through a Transportation Network Analysis. *Journal of Disability Policy Studies*, 10442073211027527. https://doi.org/10.1177/10442073211027527

Ravesloot, C., Liston, B., & Institute, U. of M. R. (2011). Peer Support in Centers for Independent Living: What Do We Know? *Health and Wellness*. https://scholarworks.umt.edu/ruralinst_health_wellness/6

Seekins, T., Innes, B., Enders, A., & Institute, U. of M. R. (1999). Centers for Independent Living: Rural & Urban Distribution. *Independent Living and Community Participation*, 12. https://scholarworks.umt.edu/ruralinst-independent-living-community-participation/12

Seekins, T., Katz, M., Ravesloot, C., & Institute, U. of M. R. (2008). Nursing Home Emancipation: Accomplishments of Urban and Rural Centers for Independent Living. *Health and Wellness*. https://scholarworks.umt.edu/ruralinst_health_wellness/11

Standley, K., Mashinchi, G. M., Greiman, L., & Sage, R. (2023). "Just trying to adjust to the new reality that seems to be changing every hour": Lessons learned from nation-wide peer meetings on COVID-19 with rural disability service providers. Community Development, 1–18. https://doi.org/10.1080/15575330.2023.2244573

White, G. W., Lloyd Simpson, J., Gonda, C., Ravesloot, C., & Coble, Z. (2010). Moving from Independence to Interdependence: A Conceptual Model for Better Understanding Community Participation of Centers for Independent Living Consumers. *Journal of Disability Policy Studies*, 20(4), 233–240. https://doi.org/10.1177/1044207309350561









800.266.1832

Center on
KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH