



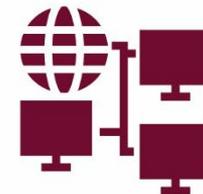
RTC:Rural

**Rural Institute
Research & Training Center**
on Disability in Rural Communities

2023 Rural Disability Research and Practice Summit



January 10 & 11



Captioning

- To use closed captioning select CC on your Zoom toolbar
- You may need to tap the “More...” button to access the menu
- You can adjust your view mode by selecting gallery or speaker view in the top right of your Zoom window
- Once in cc, tap your screen once to close the toolbar to make more room for captions

Rural Issues in Personal Assistance Services

PAS in America & Lived Experiences of People Receiving and Delivering PAS

The contents of this presentation were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90RTCP0002-01-00). 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.

Summit Outline - Research

- **Setting the Stage**
 - Personal assistance services (PAS) in America: A crisis in the making - Catherine Ipsen, RTC:Rural
 - Lived experiences of people receiving and delivering PAS - Rayna Sage, RTC:Rural

Summit Outline - Rural Voices

- **Solution-Focused Panelists**

- **Consumer Perspectives**

- Greg English, PAS consumer (rural WI)
- Chris Gaspari, PAS consumer (rural NE)

- **Worker Perspectives**

- Lacion Gordon, PAS worker (rural WI)
- Simone Tatman, PAS worker (rural CA)

- **Systems Perspectives**

- Jeff Hughes, ED
Progressive Independence
CIL (OK)
- Jane Johnson, ED of Florida
Association for CILs (FL)

Basics of PAS

- Personal assistance services (PAS) are provided to people who require assistance to perform activities of daily living
 - Cooking, cleaning, bathing, dressing, medications, toileting, etc.
- Personal assistance services
 - Support independence and life quality
 - Are cost-effective (relative to nursing home or congregate care settings)

Value of PAS

Personal Assistance Services enable people to:

- Live in their own homes
- Remain close to established friends and supports
- Participate in and contribute to community life
- People prefer PAS to other assisted living options
 - 77% of adults aged 50 and older want to remain in their homes over the long-term (AARP Research, 2021)

A Converging Crisis - Shrinking Supply

Supply of personal care aides is shrinking

- Low wages
 - \$14.15/hour (BLS, 2021)
- Covid-exits from health services sector
 - 1.5 million jobs lost in first two months
 - Rebounds, but still below pre-pandemic levels
- By 2025, home health and personal care aide shortages are estimated at 446,000 (Mercer)
- Substantial job exits due to retirement

A Converging Crisis - Increasing Demand

Demand for personal care aides is increasing

- Aging population (DHHS)
 - 54 million in 2019 to 95 million in 2060
 - 70% expected to need some basic assistance (Urban Institute)
- Increasing rates of disability
 - 40% of school age children have at least 1 chronic condition
 - Long-COVID - Estimated at 23 million Americans
- Projected demand to grow 25% between 2021-2031
 - 924,000 new jobs

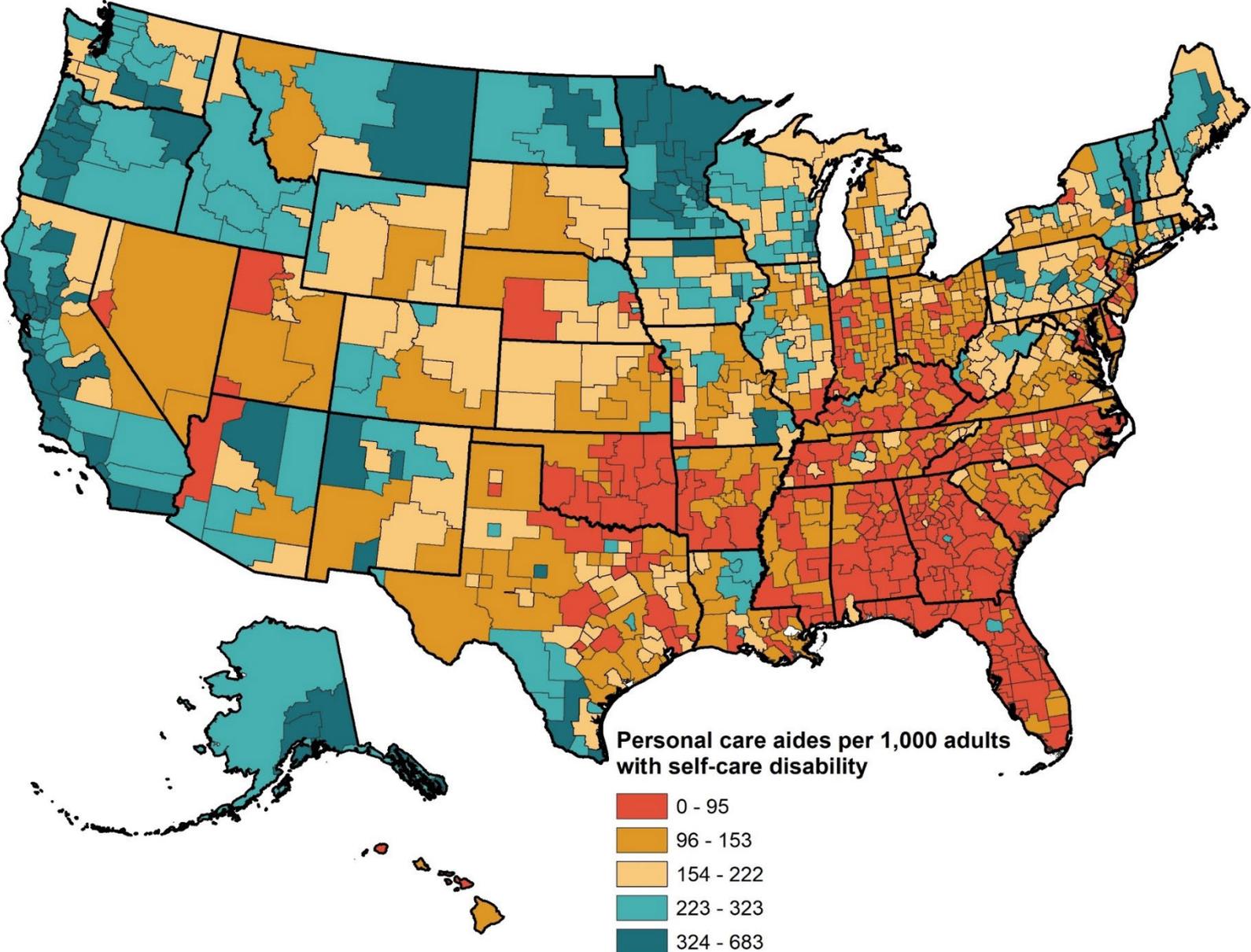
A Note on Advocacy and Policy

- Mismatch between home-based care policies and policies governing workers (Iezzoni et al., 2019)
- Patchwork of local, state, and federal funding and policies (PHI, 2022)
- Advocacy and policymaking has been urban-centric (Sage, Standley, & Mashinchi, 2022a)

Self-care Need-to-Worker Ratios

- Self-care disability and the presence of workers varies across geography (Chapman et al., 2022)
- Ratios of need to workers are higher in rural America and in the south (Chapman et al., 2022)

Self-care Need-to-Worker Ratios Map



Rural Workers' Perspective

- Rural resources and rural resiliency
- Meaningful work
- Community participation
- The relational work of rural caregiving



How are Rural Consumers Different?

- In urban and rural comparisons of a low-income, primarily Medicaid sample of consumers, rural consumers (Sage, Standley, & Mashinchi, 2022b):
 - Were more likely to be white, were more likely to be self-directed, had lower rates of difficulty dressing and bathing, but much higher rates of difficulty running errands
 - Reported fewer total disabilities
 - No differences in levels of satisfaction with services or satisfaction with community participation

Rural Living and PAS

- Barriers related to rural living
 - Transportation and distance to services
 - Local worker shortages and sharing workers, no back ups
 - Fewer services, especially accessible ones
- Opportunities related to rural living
 - Relationships, tight knit, people watch out for each other
 - Recreation opportunities, connection to land and nature
 - Affordable housing
 - Slower pace of life

The Consequences of Going Without are Dire

- Housekeeping, meals and food preparation, health management needs, personal care

“...COVID has made a bad situation WORSE. It didn’t break a well-oiled machine. It just sank the already-sinking ship a little further under.”

Lee, a non-Hispanic White 49-year-old mother of two, with a disabling chronic illness (Sage, Standley, & Ipsen 2022)

Solutions for Building and Maintaining Supply

- What has been helpful for you in finding and maintaining workers?
- What makes it easier for you to get personal care aide jobs and stay in them?
- What systems level factors can we change to increase the supply of workers in rural places?

Solutions for Finding and Maintaining Workers

Consumer Perspectives, Chris and Greg

- What has been helpful for you in finding and maintaining workers?
 - Recruiting in community
 - Word of mouth
 - Good relationships and working conditions
 - Joint decision making

Solutions for Finding and Keeping Good PCA Jobs

Rural worker perspectives, Simone and Lacion

- What makes it easier for you to get personal care aide jobs and stay in them?
 - Using technology, like app to coordinate
 - Meaningful
 - Good personal relationships
 - Pay and unionization

Solutions for Systems Change

Systems perspectives, Jane and Jeff

- What systems level factors can we change to increase the supply of workers in rural places?
 - Partnering with managed care organizations
 - Speaking the language of policy makers
 - Reimbursement rates
 - Bridging the gap between social and medical model

Solutions for Decreasing Demand

- What factors influence your need for services?
- What factors improve your ability to provide high quality services?
- What policy changes could happen to help reduce the demand for home-based services in rural places?

Solutions in Homes and Communities

Consumer perspective, Chris and Greg

- What factors influence your need for services?
 - Home modifications
 - Accessible housing and community
 - Access to other types of services

Solutions in Work Environments

Rural worker perspective, Lacian and Simone

- What factors improve your ability to provide high quality services?
 - Safety
 - Privacy and dignity
 - Efficiency
 - Ability to spend more time on meaningful activities

Solutions for Policy Changes

Systems perspectives, Jeff and Jane

- What policy changes could happen to help reduce the demand for home-based services in rural places?
 - Home modifications and assistive technology
 - Incorporating social determinants of health
 - Access to broadband

Takeaways

- Value the needs of both consumers and workers
- Recognize the role of the physical and social environment (the home and the community)
- Communication is key, especially with policymakers and people in power
- Rural perspectives are critical
- Need for improved data collection on both workers and consumers

Discussion & Wrap-Up

- Questions for presenters?

Related Research and Information

Two Storymaps highlighting some of our research

- “It’s a human connection...”: Paid caregiving in rural America - interviews with workers
- Personal Care Assistance in Rural America - analysis of national datasets

Housing and Home Usability Research

- People live in inaccessible homes
- Home usability impacts community participation

National Council on Aging’s Direct Care Workforce Capacity Building Center

PHI www.phinternational.org

References

- Binette, J. (November, 2021). Where we live, where we age: Trends in home and community preferences. AARP Research. See: <https://www.aarp.org/research/topics/community/info-2021/2021-home-community-preferences.html>
- Bureau of Labor Statistics, U.S. Department of Labor. (2022). *Home Health and Personal Care Aides: Occupational Outlook Handbook: : U.S. Bureau of Labor Statistics* (Occupational Outlook Handbook). Bureau of Labor Statistics, U.S. Department of Labor. See: <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm>
- Chapman, S. A., **Greiman, L.**, Bates, T., Wagner, L. M., Lissau, A., Toivanen-Atilla, K., & Sage, R. (2022). Personal Care Aides: Assessing Self-Care Needs And Worker Shortages In Rural Areas: Study examines self care needs for people with disabilities and worker shortages in rural areas. *Health Affairs*, 41(10), 1403-1412. See: <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00483>
- Dickler, J. (November 30, 2022). 'I never really got better' – long Covid patients share their struggle with ongoing systems and the health-care system. CNBC. See: <https://www.cnbc.com/2022/11/30/long-covid-patients-share-their-struggle-with-disability-coverage.html>
- Iezzoni, L. I., Gallopin, N., & Scales, K. (2019). Historical mismatch between home-based care policies and laws governing home care workers. *Health Affairs*, 38(6), 973-980,980A-980E. See: <http://dx.doi.org/10.1377/hlthaff.2018.05494>
- Johnson, R., Urban Institute (April 3, 2019) What is the lifetime risk of needing and receiving long-term services and supports. Office of the Assistance Secretary for Planning and Evaluation. See: <https://aspe.hhs.gov/reports/what-lifetime-risk-needing-receiving-long-term-services-supports-0>

References (Continued)

- Johnson, S.R. (July 28, 2022). Staff shortages choking U.S. health care system. U.S. News and World Report. See: <https://www.usnews.com/news/health-news/articles/2022-07-28/staff-shortages-choking-u-s-health-care-system>
- Sage, R. A., Greiman, L., Lissau, A., Chapman, S. A., Wagner, L. M., & Toivanen-Atilla, K. (2021). "It's a human connection": Paid caregiving in rural America. University of Montana, Rural Institute and University of California San Francisco, Health Workforce Research Center. See: <https://arcg.is/TbOqf>
- Sage, R., Standley, K., & Ipsen, C. (2022). "Everything is a mess. I'm just trying to survive it." Impacts of COVID-19 on personal assistance services. *Journal of Health Care for the Poor and Underserved*, 33(4), 1844–1864.
- Sage, R., Standley, K., & Mashinchi, G. M. (2022a). Intersections of Personal Assistance Services for Rural Disabled People and Home Care Workers' Rights. *Frontiers in Rehabilitation Sciences*, 3. See: <https://www.frontiersin.org/article/10.3389/fresc.2022.876038>
- Sage, R., Standley, K., & Mashinchi, G. M. (2022b). Exploring Metro and Non-metro Differences in Satisfaction With Services and Community Participation Among Low-Income Personal Assistance Service Users. *Frontiers in Rehabilitation Sciences*, 3. See: <https://www.frontiersin.org/article/10.3389/fresc.2022.876047>
- US Bureau of Labor Statistics (2022). Occupational Outlook Handbook: Home health and personal care aides. See: <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm>

Thank You!

Contact RTC:Rural

(800) 732-0323

rtcrural@mso.umt.edu

www.umt.edu/rural-disability-research/