



RESEARCHER STUDYING CARE AND SAFETY PRACTICES IN HOME-BASED CARE DURING COVID-19 PANDEMIC

FINDINGS WILL HELP PREPARE FOR FUTURE HEALTH CRISIS



In the early days of the COVID-19 pandemic, when the world was reeling from the growing threat to our health and wellbeing, Carrie Wendel-Hummell's thoughts went immediately to a group of people she knows well and is passionate about serving: older adults, people with disabilities, and the workers and caregivers who make it possible for these folks to remain in their own homes.

Wendel-Hummell, Ph.D., is the director of the Center for Research on Aging and Disability Options at the University of Kansas School of Social Welfare. While everyone else was hoarding toilet paper, mastering the art of the Zoom call, and wiping down their groceries, Wendel-Hummell got to work on winning a highly competitive federal grant to study how the pandemic has challenged those who receive and provide support, how they have adapted, and how in-home services can adjust, both now and in the future.

She had four weeks to build a research team, prepare research questions, connect with community stakeholders, and write the grant. "It was an intense few weeks," she laughs, remembering her scramble. Only the top two percentile of the grants submitted were selected for awards, she later learned, and she was delighted her team's application was one of them.

Awarded \$646,620 in funding from the U.S. Department of Health and Human Services

Fueled by \$646,620 in funding from the U.S. Department of Health and Human Services, through the Agency for Healthcare Research and Quality, her research team will conduct more than 100 in-depth interviews and over 800 surveys with home-based long-term services and supports consumers, personal care attendants, family caregivers, and agency providers in Kansas. The topic will be safety measures, and delivery of services during the pandemic.

Tracey LaPierre, associate professor of sociology, and Danielle Olds, research assistant professor in the KU School of Nursing, are co-principal investigators, along with Wendel-Hummell. Topeka Independent Living Resource Center is also a partner in the research. The grant term began in January 2021 and will conclude June 2022.



RESEARCH WILL EXPLORE WHAT WORKED WELL, AND WHAT CAN BE IMPROVED

During the pandemic, it seemed there was nowhere safer than their own home for people who were at increased risk for contracting COVID-19. But home-based care is not without its own risks. It is less regulated than care provided by institutions, like skilled nursing centers. There is an increased risk of health workers spreading the disease to multiple families as they visit home after home. And the very flexibility and freedom that comes with providing care in home-based settings can make it challenging to identify, implement, or enforce best practices, especially when guidance is changing rapidly and surrounded by many myths and unknowns, as was true during the COVID-19 pandemic.

These challenges left the KU research team with some big questions to explore during this study:

- How did the system respond to the long-term services and supports care needs of Medicaid Home and Community Based Support (HCBS) consumers during the pandemic?
- How did external and structural factors combined with worker and consumer attitudes, beliefs, and behaviors toward COVID-19 affect care processes?
- How did adaptations to COVID-19 impact (1) the degree to which consumer care needs were met; (2) how satisfied consumers were with their care; and (3) overall consumer, caregiver, and worker well-being?

The answers to these research questions will help the team identify policy changes and care practices that can improve long-term services and support care for home-based consumers during future pandemics, Wendel-Hummell says. The team will share their findings with stakeholders throughout Kansas, Medicaid administrators and policymakers at the federal and state level, and fellow researchers.

RESEARCHER WANTS TO IMPROVE THE LIVES OF BOTH SERVICE RECIPIENTS AND DIRECT CARE WORKERS

Wendel-Hummell’s interest in long term services and support care isn’t just academic. It’s very personal, too. “My first job was as a home care aide for older adults and people with disabilities who were living in their own homes,” she explains. From there, she worked as a direct care aide for a government-run institution for people with severe intellectual and developmental disabilities. She also provided direct care in group home settings.

“That exposed me to the challenges and struggles that older adults and people with disabilities are facing when they are trying to live and thrive in communities,” she explains. It also gave her firsthand experience with the challenges direct care staff encounter, including low wages and lack of benefits.

“I loved this job – if you asked me what my favorite job was, even today as a researcher and Ph.D., I would say my favorite job was when I was a personal care attendant, as far as loving the work I did. But I couldn’t pay my bills on it,” she explains. “Ultimately, that low wage led me to go to college, as a first-generation college student, and seek a better paying job and advance my career.” She carried her experience as a direct service worker forward into her academic career, focusing her graduate studies on health care systems and policy towards her goal of using research to improve systems and to continue to serve this population throughout her career.



HER HOPE FOR THE FUTURE?

There will be no unmet needs for care. Through her research and advocacy work at KU, she is working to create a world where all people who need support, whether because they are older or have disabilities, receive all the care they need. And, where the workers are not only paid a living wage with benefits but are also valued as an essential workforce.



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The University of Kansas

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University of Kansas
1545 Lilac Lane
Lawrence, KS 66045-3129
Phone: (785) 864-4720
Fax: (785) 864-5277
socwel.ku.edu

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