

Care and Safety Practices during the COVID-19 Pandemic in Home and Community Based Services

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Center for Research on Aging and Disability Options

ABOUT THIS REPORT

This is the first of four Research Briefs to share findings of an ongoing study examining the impact of the COVID 19 pandemic on Medicaid funded Home and Community Based Services (HCBS) in Kansas, with the end goal of improving HCBS policy and practice. This research is conducted by Dr. Carrie Wendel (School of Social Welfare), Dr. Tracey LaPierre (Department of Sociology), and Dr. Danielle Olds (School of Nursing), at the University of Kansas/ University of Kansas Medical Center, in partnership with the Topeka Independent Living Resource Center. The project is funded by the Agency for Healthcare Research and Quality (AHRQ).

This report shares initial findings from our first 25 in depth qualitative interviews with 10 service recipients, 4 direct support workers, 6 caregivers, and 5 provider or community agencies, across the frail elderly (FE), physical disability (PD), brain injury (BI), and intellectual and developmental disability (IDD) Medicaid HCBS waivers in Kansas. Interviews are still in progress and we are also conducting quantitative surveys to further explore these themes and more.

Future Research Briefs will update these preliminary results and share additional findings. A final report will be released in Summer 2022 to bring together all results.

Health and Safety Concern 1: Delayed testing results hindered efforts to keep group home residents and workers safe.

Accurate and timely COVID-19 testing is essential for containing the spread of the disease, especially in congregate settings, as demonstrated by a comparison of two IDD providers who deliver HCBS in both residential and private home settings. Provider A operates in a multi-county mixed rural and micropolitan area. Provider B operates in a single urban county. They developed similar COVID-19 safety plans that followed CDC guidelines including use of personal protective equipment (PPE), social distancing, and symptom screening. In regard to infected clients, their plans called for quarantining, use of additional PPE, and dedicated staff.

Provider A relied on county health departments for COVID-19 testing; however, each county had different criteria and procedures for testing. One county they worked with always provided tests upon request, but it took two weeks to receive results. Another county had restrictive criteria that delayed testing of an individual with multiple COVID-19 symptoms. By the time Provider A received the testing results for suspected cases, it was too late. They had an outbreak impacting the majority of their clients and group homes, and several clients were hospitalized. The client whose testing was delayed died of COVID-19. Delayed testing and results interfered with their ability to effectively quarantine positive cases and complicated contact tracing. As a lesson learned, this provider noted a need for a better testing plan that gave them more direct control over testing decisions and ensuring timely results.

In contrast, Provider B used CARES Act Provider Relief funds to contract with an independent testing agency. This allowed them to set their own criteria for testing and receive testing results within a few days. Even though they were short staffed, this enabled them to effectively quarantine suspected cases while awaiting results based on the expectation they would receive results quickly. This also helped support effective contact tracing and testing of anyone who may have had contact with an infected person. Although they also experienced positive cases, including clusters and hospitalizations, they were largely able to contain infections so that only a minority of group homes and clients were infected. This provider cited their independent testing contract as *“one of the best decisions we made.”*

A key implication of this finding is that residential HCBS providers can benefit from contracting testing services directly, allowing more control over testing criteria and quicker results.

Health and Safety Concern 2: The lack of a contact tracing system in self-directed care puts service recipients and workers at increased risk.

The experience of Gloria*, a direct support worker (DSW), highlights the need for contact tracing in self-directed care. Self-directed care is a service model in which care recipients draw on Medicaid HCBS funds to hire and manage their own direct support workers, and thus are responsible for communicating their needs and expectations. During the pandemic, Gloria provided housekeeping and errand services for three separate self-directed HCBS recipients, all of whom were more vulnerable to adverse COVID-19 outcomes due to age or health condition. Gloria was also at increased risk, as an older, African American woman with a chronic health condition.

Gloria's client, Rose*, was hospitalized with a severe case of COVID-19 but could not inform Gloria that she had COVID-19 as she was too sick to communicate. Although Gloria was calling the hospital to check on Rose and identified herself as Rose's worker, the hospital could not inform Gloria that Rose had COVID-19 due to HIPAA. About a week into her hospitalization, Rose recovered enough to talk to Gloria by phone and inform her that she had COVID-19. However, during that time, Gloria continued to work for her other two clients as she did not know that Rose was hospitalized for COVID-19. Upon notification, Gloria immediately sought a COVID-19 test, which fortunately came back negative. Gloria took COVID-19 safety guidelines very seriously, and this on-the-job event was her only exposure. Although Gloria ultimately did not catch COVID-19 from Rose, this caused great anxiety and demonstrates that home-based care settings do not necessarily shield HCBS consumers from COVID-19 exposure when they are connected through a shared workforce.

A key implication of this finding is that an effective contract tracing system for HCBS, including self-directed care teams, should be developed.

There is effectively no contact tracing system for HCBS and while agency-based providers often came up with their own systems, self-directed care teams were left out on their own. In discussing the need for contact tracing with our Stakeholder Advisory Board, they recommended the development of an app for the HCBS system that supports both symptom screening and contact tracing, with a back-up option for those who do not use technology. In Kansas, Medicaid services are privatized and therefore stakeholders felt this should be the responsibility of the Managed Care Organizations (MCOs) with strong State oversight and end-user input from those who provide and receive HCBS. It was noted that while self-directed care is in most need of such a system, this app may also be beneficial for agency-based care where separate systems were developed with minimal guidance and resources. Three MCOs manage Medicaid in Kansas, but it was advised that this be a single app that works across MCOs and service settings, as providers and workers often serve clients across MCOs, and the goal is to reduce burden and avoid duplicated systems. Further, the app and associated processes must respect the tenets of self-determination and autonomy in the self-directed care model.

Stakeholder Advisory Board

This project is guided by a Stakeholder Advisory Board representing HCBS service recipients, workers, providers, and disability advocates in Kansas. The Stakeholder Advisory Board meets on a bi-weekly to monthly basis to advise on project design, interview and survey questions, and interpretation of findings. This involvement of stakeholders at every stage of the project helps ensure that the study is responsive to the real-world needs of the HCBS system.

Health and Safety Concern 3: Resistance to masks and other safety guidelines not only increases risk of catching COVID-19, it also impacts service recipient and caregiver mental health and limits self-determination.

CDC and WHO recommend masks and social distancing for reducing the spread of COVID-19, but these safety protocols have become politicized. HCBS recipients are often at increased risk of serious illness or death from COVID-19 due to age or preexisting conditions, and many of their caregivers and workers are also at increased risk. Community resistance to masks and other safety protocols is of great concern to HCBS consumers and their caregivers.

The increased risk of catching COVID-19 when community members did not follow recommended safety guidelines, such as wearing a mask or social distancing, caused a lot of anxiety among HCBS recipients and their caregivers. One service recipient spoke of the instant relief to her anxiety level as a high-risk individual the moment her county issued a mask mandate. Whereas others spoke to ongoing anxiety, and further, loneliness and isolation when they felt it still was not safe to re-enter communities or visit friends or family who did not follow safety precautions closely. Caregivers and workers often took great care to protect themselves and their care recipients, only to witness this disregard by others.

Further, the resistance to COVID-19 safety guidelines sent a message to the HCBS recipients that community members did not value their lives. For example, Jane* is a woman with Down Syndrome who is aware of the increased threat that COVID-19 poses to her life and thinks more people should wear masks. When asked why, Jane became tearful and had difficulty putting her thoughts into words. Her support person shared, *“When I would see people not wearing masks and Jane would see people not wearing masks, it’s like a statement that I don’t care about you.”* Jane nodded in agreement with this statement and added *“It made me so mad!”* In some instances, consumers spoke of personal relationships that were strained or will be forever altered when they felt their friends and family did not take sufficient steps to keep them safe.

“This man don’t care about himself, so if he don’t care about himself, he definitely don’t care about me.”

~Service recipient (PD waiver) discussing a man near her at a store who became belligerent when store staff asked him to wear a mask

As a key implication, there is a need to support effective self-advocacy among vulnerable populations that transcends the politization of public health. Additionally, public education is needed regarding the message that non-adherence to safety protocols sends to high-risk individuals signaling that they are not valued and the impact this has on their mental health.



Additionally, attitudes and behaviors around COVID-19 was a key contextual factor shaping self-determination. Thus far in our sample, most participants are providing or receiving care through the self-directed model. This is a care model in which consumers, or their caregivers, hire and manage their own workers, and thus are responsible for setting their own standards of care. Some consumers required their workers to wear masks in their home and were comfortable enforcing this rule. In other instances, consumers or their family caregivers decided against requiring their workers to wear masks while providing care in their homes. This decision often reflected a close relationship between the consumer and their direct support worker, as well

as trust that their workers introduced minimal risk because they were taking COVID-19 safety guidelines seriously outside of work. These decisions were very purposeful and conscientious, and also often flexible, in which the care team would adjust protocols, including mask-wearing, at times when they perceived a greater risk.

In other instances, however, family caregivers felt they could not require direct support workers to wear masks, even when they had other concerns about their safety behavior, out of concern their workers would quit. Most consumers and caregivers spoke to the ongoing difficulty of finding and retaining good workers, which only got more difficult during the pandemic. In this context, some had to choose between increased COVID-19 risks or going without care. **A key**

"I was afraid that [our workers] would not work if I made them [wear masks].... It's very controversial in the community I work in, so I think my fear level is even higher."

~Caregiver to two adults on the IDD waiver

implication is that the ability of HCBS service recipients to exercise control over their care, including safety standards, is compromised by direct support workforce shortages that predate COVID-19.

Our current sample has drawn heavily from urban communities with mask mandates and interview participants generally felt that it was important to follow CDC guidelines. We will continue to explore this theme as our sample expands into more rural regions, where care team attitudes about COVID-19 may be more diverse.

*All names are pseudonyms

Difficulty finding and retaining quality Direct Support Workers during the pandemic is a frequently cited challenge among consumers, caregivers, and providers. We will report on staffing challenges and work conditions of this essential workforce in a future issue of this series.



FOR MORE INFORMATION

For more information about the COVID-19 HCBS research project or to join the mailing list for future issues, email homecarestudy@ku.edu or contact the Principal Investigator, Dr. Carrie Wendel, at 785-864-3797.

If you are a HCBS recipient, direct support worker, caregiver, or provider in Kansas, you may be eligible to participate in this research by completing a survey or interview, conducted online or by phone.

Participation is completely confidential. Please reach out at the above contact information if interested!

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