

Title: Care and Safety Practices during the COVID-19 Pandemic in Home-Based Long-Term Services and Supports

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Structured Abstract

Purpose. This study examined the Medicaid-funded Home- and Community-Based Services (HCBS) system response to the COVID-19 pandemic in Kansas. *Scope.* Though home-based care may be safer than institutional care settings during an infectious disease pandemic, it is also less regulated and not guided by a clear chain of responsibility. Research on infection control and emergency management in home care is sparse. Furthermore, this industry is plagued by long-standing workforce shortages. *Methods.* In depth interviews and surveys were conducted with HCBS consumers, direct support workers, family caregivers, and providers in Kansas in this mixed-methods study. Study design was guided by the SEIPS 2.0 model in close consultation with community-based stakeholders. *Results.* We found that direct support workforce issues intensified during the pandemic; access to COVID-19 emergency resources was uneven; effective communication, care coordination, and resource management were challenging in a fragmented system; and implementing safety guidelines in home settings was complex. These findings have several implications for policy and practice.

Key Words: Home and Community Based Services, COVID-19, Medicaid, Mixed Methods, Community engaged research

Purpose

Older adults and individuals with disabilities prefer to receive long-term services and supports (LTSS) in home- and community-based settings (HCBS), especially as nursing facilities became hotbeds for the spread of COVID-19. Many LTSS consumers were at increased risk of COVID-19 complications due to their age and pre-existing health conditions. LTSS involves hands-on care that could not be postponed or replaced by telehealth, and although home-based care may be safer than institutional care settings during an infectious disease pandemic, it is also less regulated and not always guided by a clear chain of responsibility. The flexibility in home-based settings supports individualized care practices but can also make it challenging to identify, implement, and enforce best practices, including safety practices. Political rhetoric, and the unknown and rapidly changing nature of the COVID-19 pandemic, only exacerbated these complications. Furthermore, private homes are not isolated settings but rather are networks of care in which disease can be spread across connected households.

This mixed-methods study examined the Medicaid-funded Home- and Community-Based Services (HCBS) system response to the COVID-19 pandemic in Kansas through interviews and surveys with HCBS consumers, direct support workers (DSWs), family caregivers, and providers. The specific aims of this project were to:

- Aim 1: Understand how the delivery of Medicaid home-based LTSS changed in response to the COVID-19 pandemic, highlighting challenges and adaptations in the care system response. Central to this aim was understanding how COVID-19 safety practices were identified, negotiated, implemented, and managed, with an emphasis on point-of-service interactions between DSWs and consumers.
- Aim 2: Investigate the relationships between external and structural factors (e.g., policy, physical environment, organizational environment, community environment, and equipment/supplies); worker and consumer attitudes, belief, and behaviors related to COVID-19; and care processes.
- Aim 3: Connect the challenges and adaptations from Aims 1 and 2 to consumer and worker outcomes in order to recommend policy and practice strategies that can improve the care system response during pandemics and similar situations. Outcomes include the degree to which

consumer care needs were met or unmet; satisfaction with care received or provided; consumer, caregiver, and worker well-being; and DSW job satisfaction and intent to quit.

Scope

Background and context

The vast majority of LTSS is delivered in home and community settings, rather than in institutions,¹ and much of this care is non-medical in nature. Yet, there are few to no regulations guiding safety or emergency planning in non-medical home care services, and those that do exist are interpreted differently across providers.² Prior to the COVID-19 pandemic, literature on infectious disease control and emergency response in home care was sparse, with the former focusing primarily on isolated patient infections and the latter focusing on natural disasters. Nonetheless, this body of literature has identified many challenges. Infection control protocols in home care largely model acute care practices, but this neglects the unique nature of home settings in which homes may be unsanitary, be in disrepair, have incompatible space layouts, have inadequate adaptive equipment, have unkempt pets, have pest infestations, or be cluttered environments, and these issues often go unacknowledged and unaddressed.²⁻⁴ People with disabilities are largely unprepared for natural disasters, communities are ill equipped for meeting their needs, and home care agencies are also insufficiently prepared.⁵⁻⁸ Household culture and traditions do not always promote best practices in health and safety.^{2,3} Additionally, consumers and their family caregivers are often willing to accept a fair amount of risk and compromised safety in order to remain at home and avoid institutionalization.³ These studies have focused primarily on professional or agency provider perspectives, leaving out the perspectives of individuals with disabilities, who have also largely been excluded from disaster planning efforts.⁵ Although sparse, the combined body of literature on infection control and disaster planning points to a complex combination of policy, organizational, professional provider, staff, and client factors.^{5,7}

Research on care quality in HCBS is also limited due to the lack of federal standards regulating care quality for non-medical home care as well as limited data measures.⁹ Nonetheless, unmet care needs are widely reported.¹⁰ Among community dwelling older adults in the U.S., over 2 million reported an adverse event related to unmet household assistance needs, and over 3 million reported an adverse event related to unmet mobility-related needs.¹¹ Those with unmet care needs have higher emergency room admissions, typically for falls, injuries, and skin breakdown.¹⁰

The quality of home-based care cannot be separated from direct care workforce issues. Home care workers are the largest segment of the direct care workforce, with 2.3 million workers nationwide.¹² There are little to no training requirements for this entry-level workforce. One study revealed that 36% of paid care workers had inadequate health literacy.¹³ Boundaries between medical and personal care tasks are often blurred in home settings, where there is no supervision or where the DSW may be the only one available to provide care, even if it is outside their scope of work.² Additionally, this is a low-wage workforce, with poor access to benefits, making it difficult to meet the growing demand. The Affordable Care Act has helped reduce the uninsured rate among DSWs, but it is still high compared to the general population. Rigorous studies are lacking, but DSW turnover is estimated to be between 40% and 60%.¹²

Most LTSS is provided by family caregivers. Over one in five Americans provides care to older adults or loved ones with disabilities, providing on average 24 hours of care per week. Care recipient needs are becoming more complex, and most caregivers do not feel they received adequate training or support for managing these complex health and functional needs, and they struggle to coordinate care.

Though caregivers value their role, 21% report physical, emotional, or financial strain, and a similar proportion report being in poor to fair health; rates that have increased compared to 5 years ago.¹⁴

Study Setting and Population

This study focuses on the Medicaid-funded HCBS system response in Kansas through interviews and surveys of HCBS consumers, DSWs, family caregivers, and providers. Nationally and statewide, Medicaid is the top payer for LTSS, including HCBS.¹⁵ In Kansas, the majority (72%) of Medicaid-funded LTSS dollars are spent in HCBS settings (72% in 2019).¹ We focused on the four Medicaid HCBS programs that serve adults, the Frail Elderly (FE), Physical Disability (PD), Brain Injury (BI), and Intellectual and Developmental Disabilities (IDD) waivers, which combined had over 20,000 enrollees as of March 2020.¹⁶ Kansas was one of the first states to privatize all LTSS in 2013, utilizing managed care companies (MCOs) in a program called KanCare. At least 22 states now operate managed LTSS programs.¹⁷

Self-Directed Care (SDC) refers to a care model in which care recipients can use LTSS funding to hire and manage their own workers instead of going through a home care agency. Self-directed care is available to all FE, PD, BI, and IDD consumers in Kansas. There are rural regions in Kansas where self-directed care is the only option because there are no home care agencies that accept Medicaid HCBS. In Kansas, approximately 39% of HCBS consumers self-direct their care (M. Heydon, HCBS Director, personal communication, 8/29/22). SDC consumers in Kansas have employer authority, but not budget authority; that is they manage their own workers but do not have control over an allotted budget for other goods and services. This contrasts with the majority (75%) of SDC programs in the U.S. that allow for budget authority.¹⁸ SDC consumers use a Financial Management Service (FMS) provider for payroll.

Turning to the DSWs, approximately 25,000 Kansans are employed in this field; this is about half the number of DSWs per HCBS consumer compared to the U.S. average.¹⁹ The median DSW hourly wage in Kansas of \$11.30 is lower than the national average and other Midwestern states¹⁹ and ranks 40/51 in LTSS worker wage competitiveness.²⁰ Data on access to healthcare benefits or paid leave for DSWs in Kansas are lacking, but Kansas remains one of 12 states that have not expanded Medicaid. Data on family caregivers in Kansas are also lacking, but a recent AARP scorecard ranked Kansas as 42/51 in support for family caregivers.²⁰

Methods

Study Design

This mixed-methods study examined the HCBS system response to the COVID-19 pandemic in Kansas through in-depth interviews and surveys with adult HCBS consumers, DSWs, family caregivers, and providers. An interactive, convergent mixed-methods design within a community-based participatory research framework was adopted.²¹ Semi-structured interview guides and surveys were developed in tandem and in close consultation with the Stakeholder Advisory Board (SAB). The 12-member SAB, composed of consumers, providers, DSWs, and advocates, collaborated on all aspects of the project, from proposal through dissemination. The study also included the Topeka Independent Living Resource Center (TILRC) as a funded subrecipient, which provided a higher level of guidance through more frequent meetings and also assisted with data collection. Self-advocates with cognitive disabilities reviewed draft interview guides and surveys closely to ensure plain language use. We conducted two or three cognitive interviews per survey with pilot survey participants to assess survey readability and validity and ensure that the wording of the survey questions and instructions were clear and adequately captured intended concepts, revising as needed after each interview.

The study was guided by the updated Systems Engineering Initiative for Patient Safety (SEIPS 2.0) model.^{22,23} This dynamic model highlights the interplay and feedback loops between the structure, process, and outcomes of care and emphasizes that patient and worker behavior cannot be separated from the systems in which they work and live.^{22,23} We modified this model for the home care and pandemic context. In our adapted model, the care system includes organizational environment, social and community environment, physical home environment, equipment and supplies, and home care tasks, all of which exist in the larger external environment of the pandemic and Medicaid-HCBS policy. At the center of the model is the person, which for our study expands beyond a single person to include the care triad of the consumer, family caregiver, and DSW. These interactions between the external environment, care system, and care triad influence care processes and outcomes. This model highlights the role of the adaptations and workarounds that occur when the system is out of balance, which may either benefit or compromise outcomes.

The modified SEIPS 2.0 model informed the development of our data collection tools. Interviews and surveys asked about the experience receiving or providing home care during the pandemic, including care and safety practices and, when applicable, how the pandemic impacted care needs, care satisfaction, work conditions, job satisfaction, employee retention, and resources accessed. Survey questions were piloted using a cognitive interviewing process. Qualitative and quantitative data were iteratively collected and analyzed, informing subsequent data collection tools and procedures. The study was approved by the KU Human Subjects Protection Program (# STUDY00146397).

Recruitment and data collection

Interview participants were recruited through community partners, snowball sampling, and social media. Recruitment materials were prepared in English and Spanish, and translators assisted with interviews and survey completion for Spanish speakers. Interviews were conducted by phone or Zoom between May 2021 through June 2023. They were recorded and professionally transcribed and lasted between 20 and 150 minutes, with most being around 90 minutes. Follow-up interviews were conducted with a small portion of early interview participants (9%), to better understand how changes in infections rates and COVID policy impacted their experiences. To ensure access, support persons were present as needed during consumer interviews to facilitate communication but were not counted as a respondent. Family members of individuals with cognitive impairment were interviewed as family caregivers, not as proxies. Provider interviews sometimes included more than one respondent, to include people equally involved in the pandemic response or in charge of different divisions in larger agencies. Interview participants provided verbal informed consent and were compensated \$25 per interviewee for each interview.

Survey recruitment for consumers and DSWs occurred primarily through Home Care Agency and FMS providers, who were asked to distribute study details to all clients. Provider gatekeepers were selected based on geographical representation and willingness to assist and were offered reimbursement for associated expenses. Recruitment flyers were also distributed through social media and advocacy networks, but this convenience sampling technique yielded relatively few valid responses. Providers were identified through KanCare MCO provider lists and recruited by email and phone to request their participation.

We used Qualtrics to administer the survey online, with a phone option in which project staff read questions and recorded responses. Surveys included informed consent procedures. Consumers with guardians could assent to participate without guardian consent if they passed screening questions demonstrating that they understood the nature of the research and their rights as human subjects. Survey participants were compensated between 5 and 10 dollars.

Data analysis

The analysis combines data from semi-structured interviews with consumers, DSWs, paid and unpaid family caregivers, and providers and the surveys of consumers, DSWs including paid family caregivers, and providers. Qualitative and quantitative data were integrated through narrative at the interpretation and reporting level using a weaving approach.²¹ The authors employed a collaborative, iterative approach to inductive coding and analysis of the qualitative data following a negotiated, team-based consensus process,²⁴ facilitated with Dedoose software. Four members of the research team separately conducted first-level open coding of the transcripts. These initial codes and coding discrepancies were discussed by the entire research team that continued to meet regularly to refine coding, resolve discrepancies, and identify emergent themes and subthemes. Survey data were analyzed in Stata/MP 15.1 using descriptive and bivariate statistics. Data from open-ended survey questions were analyzed using content analysis and were consistent with codes and themes identified in the interview data, triangulating our findings and verifying the credibility of our analysis.

Sample

Demographic characteristics of consumer, worker, and family caregiver interview and survey participants can be found in Table 1. Program characteristics of consumer, worker, family caregiver, and provider interview and survey respondents are shown in Table 2. The final sample sizes were 78 interviews (consumers=27, DSWs=15, family caregivers=14, combined consumer and caregiver=1, providers= 21) and 390 surveys (consumers=110, DSWs=191, providers=89). Providers were broadly defined to include home care/home health agencies, FMS providers, and other providers who support the delivery of HCBS services but are not direct service providers. This latter category includes Aging and Disability Resource Centers, Community Developmental Disability Organizations, and provider associations (interview n=8, survey n=22). Several family caregivers were also paid as DSWs; see table notes for details on how they were classified.

Table 1: Demographic Characteristics of Consumer, Worker, and Caregiver Interview and Survey Participants

	In-Depth Interviews				Surveys	
	Consumers* n=27	Direct Support Workers^ n=16	Family Caregivers** n=15	Total Interviews n=57	Consumers n=110	Direct Support WorkersT n=191
Age						
Range	23-81	21-72	46-73	21-81	19-91	19-87
Mean	54	49	60	54	57	48
Gender						
Male	7	2	2	11	38	30
Female	20	14	13	46	72	161
Race/Ethnicity						
Hispanic/Latino	3	2	1	5	7	6
American Indian or Alaska Native	2	0	0	2	5	8
Black	5	3	0	8	10	25
Asian	0	1	0	1	0	5
White	20	12	15	46	100	159

Notes: Counts provided for qualitative variables. Race/Ethnicity categories are not mutually exclusive. *One respondent was both a consumer and a family caregiver (middle-aged, Hispanic, white female), and is included in both categories but not double-counted in totals. ^Two Direct Support workers were related to the service recipient and nine family caregivers were paid as DSWs; these participants are classified according to how they identified themselves for the study. T DSW survey population included paid family caregivers.

Table 2: Program characteristics of interview and survey participants

	In-Depth Interviews				Surveys		
	Consumers*	Direct Support Workers^	Family Caregivers*^	Service Providers^	Consumers*	Direct Support Workers^T	Service Providers^
	n=27	n=16	n=15	n=21	n=110	n=191	n=89
Waiver							
Physical Disability	12	11	4	14	50	-	48
Frail Elderly	5	11	1	14	17	-	56
Brain Injury	5	1	2	14	20	-	30
Intellectual/Developmental Disability	5	5	10	12	11	-	39
Care Model							
Agency based care	6	6	3	7	19	27	42
Self-directed care	15	9	6	3	88	147	11
Both	6	1	6	3	0	12	6
Unsure	0	0	0	0	3	5	0
Other	-	-	-	8	0	0	22

Notes: Counts provided for qualitative variables. *One respondent was both a self-directed PD consumer and a family caregiver to a self-directed PD consumer and is included in both categories but not double-counted in the total n. ^Some workers, family caregivers, and providers care for multiple types of service recipients and therefore subtotals are greater than the sample size. T DSW survey population included paid family caregivers.

Challenges and Limitations

Recruitment was challenging, especially for surveys. We did not have direct access to consumer and worker contacts and therefore largely relied on providers to recruit participants. Although 11 providers assisted as gatekeepers and sent out thousands of flyers directly to workers and consumers by mail or email (n>8,000), response rate was low. We could not identify a HIPAA-compliant method for tracking individual responses that was not unreasonably burdensome for providers, so we were unable to send reminders. Furthermore, we had better success in recruiting FMS providers as gatekeepers than we did with home care agencies (HCAs); the former also have a larger client and DSW base, resulting in a bias toward self-directed consumers. Additionally, survey links that were disseminated via social media were corrupted by scammers. We were able to identify and remove scam surveys from the sample, but this was labor intensive, so we stopped using social media as a recruitment tool. We employed many strategies for improving response rate, including increasing payment, reducing survey length, expanding eligibility criteria, and actively recruiting additional gatekeepers.

We had a strong response rate for the provider surveys (67.9%), which we attribute to our ability to track respondents and send reminders by phone and email. However, it was difficult to create a sampling frame, as we found that no single entity held a complete HCBS provider list. The state only kept lists for licensed home health providers, which excludes non-medical home care. We relied heavily on MCO provider lists, but these were not well organized and contained numerous errors. Many providers listed as providing personal care services were assisted living or other residential providers rather than home care providers. Additionally, we found that many listed providers no longer served HCBS clients, citing low reimbursement rates as the primary reason. Conversely, we occasionally found a provider through word of mouth and internet searches that serve HCBS clients but were not listed in the MCO directories. A great deal of time was spent creating the list of eligible providers due to these challenges, condensing the time available to collect survey data. Furthermore, it is possible that eligible providers remained unidentified and therefore did not receive an invitation to complete our survey.

A limitation of our study was that it was restricted to HCBS in Kansas. This was intentional to control for the policy context, but results may have limited applicability to states with differing policies and populations. Our study is also biased toward White participants, who, though fairly representative of Kansas, are less representative of the larger nation. In light of timeline challenges in data collection, analysis is ongoing, and results presented here are not comprehensive of all findings.

Results

Direct Support Workforce Issues Intensified During the Pandemic

Study participants across all stakeholder groups widely reported that pre-existing workforce challenges grew worse during the pandemic. The increased difficulty finding and retaining DSWs was attributed to low, stagnant wages, which made it more difficult to compete for this entry-level workforce, as shared by a rural FMS provider:

I talked to [a client] today whose worker went to Pizza Hut because they can make \$14 an hour driving delivery There's a ton of really good workers out there who want to do this kind of work, they have a passion to do this kind of work, but they can't afford to do it and support their family.

When consumers were asked to indicate their level of agreement with the statement “It is difficult to find and deep dependable DSWs,” 28.9% strongly agreed, 18.3% agreed, 18.3% were neutral, 15.4% disagreed, and 19.2% strongly disagreed. Among providers, 71.9% of agency providers and 75% of FMS providers agreed or strong agreed that it was more difficult to recruit and retain DSWs during the pandemic; 47.5% of agency providers reported an increase in turning away client referrals. Among current DSWs, one in five were actively looking for or considering a different job, overwhelmingly in a different industry, and 27.2% said that it was very likely or somewhat likely that they would stop working as a DSW within the next year. Whereas other industries were quick to raise wages in response to the workforce crisis, DSW wages are dependent on Medicaid rate increases, which require budget approval by state legislatures. These rates were not increased by the legislature until FY23 and are still too low to compete with the retail and food industries.

Some participants also spoke of DSWs who left due to fear of contagion, which was a new reason for workers leaving, unique to the pandemic. Many DSWs in Kansas do not have access to health insurance or paid leave; these benefits are not available to self-directed workers through their employer (the consumer) at all. Furthermore, Kansas has not expanded Medicaid. Among current DSWs, only 5% reported being eligible for health insurance through their DSW employer, and none reported this as the source of their health insurance. The most common health insurance category for current DSWs was uninsured (21.6%), but others reported receiving health benefits through a spouse or parental plan (21%), Medicaid/Kancare (17.3%), a second job in a different industry (13.0%), the individual marketplace (11.7%), Medicare and/or VA benefits (11.7%), Medicaid and Medicare (2.5%), and private pay or other not specified (1.2%). Yet, health insurance and paid sick leave were of additional importance during this time to help mitigate pandemic-related risks. DSWs reported going without pay when following quarantine protocols, including when their source of exposure was from work, leading to financial hardships. For example, a survey respondent reported having her car repossessed when she could not pay her bills due to unpaid leave while her client had COVID-19. Only 6.2% of DSWs reported being eligible for paid leave such as sick leave, personal days off, or paid vacation days, yet 23.7% had their work hours affected from being in quarantine due to COVID-19 symptoms, diagnosis, or exposure.

DSWs remained in this field despite low wages largely out of dedication to their clients or because they enjoy this type of work, as indicated in survey responses to an open-ended question about why they stayed in this field during the pandemic. For example, one participant wrote, “Because my client needs someone there and without us PCAs (Personal Care Attendants), he would be in a nursing home.” Yet, DSWs were neglected in the pandemic policy response and it was not initially clear if home-based DSWs were essential workers. Additionally, they felt their efforts and sacrifices were invisible to the public, as shared by an experienced DSW:

Then, when they were giving all these blessings and compliments to the nurses who are at risk in the hospital, they seemed to forget about us little people and the elderly there in the homes that are doing just as good as job as they were. We wasn't even mentioned.

The DSW survey included an open-ended question, asking "What was the most important thing others have done to support you in your role as a DSW during the pandemic?" Few respondents pointed to tangible supports, but several mentioned emotional support or feeling appreciated by their clients and their family. However, among those who provided a response, over a quarter indicated there was no support, with written responses such as "Umm... nothing" and "What support?"

Despite the dedication of some DSWs, consumers generally struggled to find and retain quality workers. The pool of DSWs was starkly divided between two extremes. On one hand were the dedicated, high-quality DSWs who were committed to caregiving despite low wages, often going above and beyond to provide good care, for example, by working uncompensated hours, incurring out-of-pocket expenses, securing resources for their clients, and drastically changing their lifestyles during the pandemic to keep their clients safe from the virus. For example, an agency-based worker with multiple clients shared, "I kind of stayed away from relatives and different things because I knew I was working with older people. I would call them and talk to them, but I didn't go and see them." These quality workers were difficult to retain, as the need for a living wage often drove them to leave – consumers and family caregivers often spoke of losing good DSWs. For example, a self-directed FE consumer shared:

She had a really good personality. She was jolly to be around. She did a fabulous job. She would come if I needed something after she had gotten home. She would come back over, just a very good person.... She left for full-time employment with benefits.

A caregiver to an adult son with IDD shared:

The individuals that are out there are just wonderful. They really are! They truly are doing the work that they're doing because they care about these individuals. So, [Home Care Agency] really, really have been able to assemble a really wonderful team of people. There is just not enough of them.

On the other hand were the poor-quality workers, who did not perform assigned care tasks or follow safety guidelines or, in some cases, were abusive, exploitative, or dishonest. A PD consumer described a series of bad DSWs, concluding that "Some of these workers not only are they immoral, but they're criminal.... Dangerous even, potentially. Unqualified." A few consumers and family caregivers spoke of firing DSWs who stole medications. However, it was more difficult to let go of poor DSWs who did not cross the line into abuse, given the difficulty replacing them. Consumers often had to choose between poor care or going without any care in the face of widespread workforce shortages.

Additional details from the qualitative data on this theme can be found in our *Journal of Applied Gerontology* publication²⁵ and a presentation delivered at *AcademyHealth*.²⁶

Access to COVID-19 Emergency Resources was Uneven

CARES (Coronavirus Aid, Relief, and Economic Security Act of 2020) funds were designed to support worker well-being and safety as well as to stabilize the economy. Nursing homes received direct CARES funding to support their workforce, but HCBS providers had to apply for funding, as shared by a combined HCA and FMS provider:

The response to the different sectors of long-term care was very inconsistent...There were things done for institutional care, skilled nursing, and assisted living. But the part of the long-term care spectrum in home care did not get the same attention or action, and that's what's frustrating.

HCAAs described devoting a lot of resources to applying for funding through various sources with different strings attached. Some HCAAs were successful in accessing these funds for hazard pay, sick pay, or additional overtime for their agency-based workers. Other HCAAs found the application system too complex or feared they would not be able to meet the requirements, as shared by a representative from a provider association:

There's some who also just didn't take [CARES funds] because they were concerned that they wouldn't be able to staff back up to be able to get the loans forgiven. They didn't want to be on the hook for something that they weren't gonna be able to comply with.

Nearly 2/3 (65.3%) of providers reported receiving CARES funds in general and about half reported receiving Paycheck Protection Program funds, although a fair portion (14.7%) were uncertain what COVID-19 related funding sources they received.

Self-directed care teams did not have the same access to these funds for strengthening the workforce. FMS providers were instructed at both the state and federal levels that they could not use these funds for DSW pay because they were not the employer, as shared by an urban FMS provider:

If I could've done it, I would've done it in a heartbeat. I didn't wanna risk recoupment when I'd already been told that it's not really what the money is intended for.... I would've loved if somebody'd come to me and said, "Hey, we found a way to do this for our [DSWs]." I just think about all the meetings that I have been in with Centers for Independent Living, the KanCare Advocates Network group, the state of Kansas, Administration on Community Living at a federal level. Nobody could give us that information or no one was willing to say, "Hey, take a chance with this money. You'll be okay."

Simultaneously, there was no viable mechanism for self-directed consumers to access these funds directly as individual employers.

Turning to state-level efforts, Kansas drew on CARES funds to distribute PPE to HCBS providers, including to FMS providers for self-directed consumer and worker use. This effort was largely seen as beneficial and successful, as shared by an urban FMS provider, "I feel good about the fact that, as soon as we got our CARES Act money, we ordered a bunch of PPE and we had it available for those who wanted it." Yet access to this PPE was also uneven. Some self-directed consumers noted it was simply not enough PPE to cover their more intensive care needs. A few self-directed workers reported never receiving PPE from their consumer-employer or the FMS agency, including a worker for her uncle on the FE waiver who took precautions very seriously by donning masks, gloves, and gowns, who shared, "I pay for my own stuff. ... I don't know of any organization that would pay for anything like that I couldn't even tell you exactly how much I've been spendin'... It adds up." In the surveys, one of every three DSWs and 40.2% of consumers reported incurring out of pocket expenses to make home care services safer (e.g., masks, sanitizer, etc.).

The State of Kansas used the enhanced Federal Medical Assistance Percentage (FMAP) for HCBS provided through ARPA to fund a recruitment and retention bonus, offering each DSW up to \$2,000.²⁷ This was targeted as the largest use of these funds but was structured as a bonus because sustained pay increases would have required legislative budget approval. These funds were not distributed until late 2022 and were complex to access, and some HCBS providers were unaware of these funds, as indicated by a provider survey comment, "We got to know about it too late to apply." FMS providers also noted that it was especially difficult to administer to self-directed workers, "It was very difficult to administer, the providers were tasked with getting the word out about this program [to self-directed consumers] and not enough funds were provided for this." Among the 53 provider study participants who were eligible

for this bonus, about half applied for this bonus. Over 90% of FMS providers sought these funds, compared with only a third of HCAs (who were not also FMS providers), suggesting that outreach to HCAs was less successful or that the application process was more difficult for them.

Additional details from the qualitative data on this theme can be found in our *Journal of Applied Gerontology* publication,²⁵ *AcademyHealth* poster,²⁸ and *Gerontological Society of America* presentation.²⁹

Effective Communication, Care Coordination, and Resource Management was Challenging in a Fragmented System

The HCBS delivery system is characterized by a fragmented, siloed service system that posed challenges to continuity of care and communication. Informal networks helped disseminate knowledge and facilitate creative solutions during the pandemic, but providers wanted more guidance and direction from oversight entities, as shared by an IDD provider:

We were just left high and dry figure it out on your own, do what's best, and then when we asked questions, there were no answers.... We've got all these people to go to for hopefully help, but none of them are providing help.

There were multiple systems overseeing HCBS in the pandemic environment, such as the Kansas Department for Health and Environment, Kansas Department for Disability and Aging Services, county health departments, and the KanCare MCOs, but there lacked clear, coordinated guidance across these entities.

The pandemic was a situation that brought together two systems, the LTSS system and the public health emergency response system, that did not typically work together and, as noted by a state administrator, “speak different languages.” When asked about the support and guidance provided by different oversight entities, 57.3% of providers were satisfied with support from the Kansas Department for Aging and Disability Services; 66.2%, with that from the Kansas Department of Health and Environment; 82.1%, with that from the County Health Departments; and 34.3%, with that from KanCare MCOs. Satisfaction with tangible support followed a similar pattern, with providers most satisfied with health departments (63.5%) and least satisfied with MCOs (32.9%).

Although County Health Departments were generally seen as a helpful resource, frustration was sometimes expressed about the impact of politics on their operations as well as inconsistent protocols and standards across different counties, as shared by a rural IDD provider:

It was very different based on the county that we were operating in, and so our main county [health department] was tremendously helpful when we had questions and when we needed guidance the other counties, the significant barrier was testing.

Vaccination prioritization and distribution also varied across health departments and indicated the unclear status of DSWs as essential workers. HCBS DSWs were not initially classified by the state as a priority group for vaccination, but the state amended this policy to include HCBS DSWs as high priority along with other healthcare workers and moved HCBS care recipients up the priority list. However, there remained a lot of confusion, with many health departments not prioritizing HCBS participants as well as many DSWs and consumers not realizing they were in the first priority groups. A home care agency provider survey participant wrote:

Convincing the Health Department that our staff needed vaccinations was a problem! Since our caregivers may not be a medical professionals, we were left out and it took much convincing that we indeed did need the vaccines due to working in clients' homes!

HCA providers who were unaware of the ARPA-funded recruitment and retention bonus, described above, also exemplifies the difficulty experienced in communicating pandemic resources and guidelines to stakeholders. Ultimately, we found that the State does not keep a list of home care providers in a managed care environment and that the MCO provider listings were not always accurate. This made it difficult for them to notify all potentially eligible providers of this bonus and to distribute other pandemic-related communication. The State regularly posted pandemic-related updates on their website and pushed this information out to their networks. However, providers found it difficult to check the website on a regular basis when already overwhelmed during the pandemic, and not all providers were well integrated into networks where this information was shared.

Communicating Appendix K flexibilities provides another example. Appendix K is a standalone appendix to state waiver applications that allows states to temporarily amend certain waiver policies during an emergency. A key Appendix K flexibility implemented in Kansas was to allow parents, guardians, and spouses to be paid as caregivers during the pandemic. We found this to be a popular policy in helping to address the workforce shortages and providing families with more financial stability. However, Appendix K flexibilities were not always well communicated, and confusion over rules and processes limited their impact for others. For example, one mother of an adult son on the BI waiver was told by her MCO care coordinator that she could not receive this payment for unclear reasons, which later turned out to be inaccurate information. A grandparent guardian of siblings on the IDD waiver was informed by their care coordinator that they were at risk of being removed from the waiver if they did not find a worker soon but was not informed that she could be hired as the worker under this new flexibility.

MCO care coordinators carry the official responsibility of ensuring that HCBS consumers have their care needs met and keeping them apprised of rules and resources, but this service was often found to be lacking by study participants. Out of the 100 surveyed consumer respondents, 39% were very satisfied with the services provided by their care coordinator during the pandemic, 21% were satisfied, 21% were neither satisfied nor dissatisfied, 10% were unsatisfied, 2% were very unsatisfied, and 7% were not even sure if they had a care coordinator. Forms of pandemic-related support received from care coordinators included education and guidance on COVID-19 (n=34), personal protective equipment (n=31), and reviewing and updating care plans (n=31). Overall, only 54% of respondents reported receiving any pandemic-related support from their care coordinator, and 18% said that their care coordinator did not communicate with them at all during the pandemic or were uncertain if they did.

Care coordinators are also responsible for developing and updating person-centered support plans annually, which must include a backup care plan. When asked about their agreement with the statement "My backup care plan prepared me well for the pandemic," 33% of surveyed consumers said they did not have a backup care plan, 16% strongly agreed, 20% agreed, 20% were neutral, and 11% disagreed. Qualitative data indicated that backup care plans were not necessarily tailored for a prolonged, pandemic situation, relied on potentially unsuitable backup supports, and lacked details.

In interviews, participants expressed widespread dissatisfaction with care coordination under managed care, although some participants were pleased with their individual care coordinators. These participants typically noted that their care coordinators kept in good communication and were working hard to meet their needs but were limited by the bureaucracy they worked in. As shared by an interview participant on the PD waiver:

She's a really good case manager [and] support service, but [MCO] is a very dysfunctional company that's very compartmentalized, and she goes, "I can't talk to that department. They're

not returning my calls. I can't answer your question. I can't get through to those people"..... She does work through the system with me. It takes a long time to fix problems, much longer than it should.... She stays on top of it. I'm not complaining about her as a case manager. I am complaining about [the MCO].

Interviews and open-ended survey responses pointed to high turnover and heavy caseloads as key barriers, as demonstrated by a paid family caregiver to a son on the IDD waiver:

KanCare care coordinators are switched around frequently.... And it's without warning that you're switched. It's without any contact information to your new person! So, you have no idea that you have even switched... If you have an issue, you contact your care person who may or may not respond.... And it may be another 3 months before you hear anything, if you hear anything at all.... It is just an exercise in futility, really.... You don't know who to talk to anymore. And you don't get an answer when you do reach out [to care coordinators].

A survey participant on the IDD waiver noted that they had three different care coordinators since the start of the pandemic.

Findings from these themes are further detailed in a manuscript under review as well as a poster presented at Academy Health.²⁸

Implementing COVID-19 Safety Guidelines in Home Settings was Complex

Home care settings were undoubtedly safer than congregate settings during the pandemic; however, home care is not without risk, and implementing safety practices in these settings was complex. The churn of different people in and out of home care settings contributed to this risk. Some consumers have multiple DSWs, and some DSWs work for multiple clients or have other, more public jobs. As shared by a DSW, "Other people's decisions greatly affect me because [my client's] other care providers' choices got her and her entire household sick. The (family) caregiver was old and sick for a long time." A caregiver to an adult with IDD who had several DSWs shared that most of the team was on the same page in following safety protocols, but a single careless DSW ended up spreading COVID-19 to 11 other people on the care team. In sum, the virus can spread across a complex network of caregivers, care recipients, and household members who have varying levels or exposures or risky behavior; 39.5% of DSWs and 22.5% of consumers reported COVID-19 exposure through their home care work or services.

Home care is largely unregulated and more difficult to monitor or enforce expectations. Safety practices are negotiated between consumers, family members, and DSWs in private home environments. This is especially the case in self-directed care, where consumers have the authority to set rules, but, even in agency-based care, there is little control over whether rules are being followed in private home settings outside of supervisor oversight. Nevertheless, most agency-based providers required mask use, at 93.8% requiring for DSWs and 53.5% requiring for consumers. Of positive note, members of the care team often agreed on safety practices, with 83.1% of workers and 86.3% of consumers reporting that they always or usually agreed on the safety practices that should be followed during the delivery of home care. Interviews indicated that care team members reached consensus through discussion, taking into consideration perceived risk and adjusted expectations and behaviors when risks levels changed.

However, when DSWs and consumers did not agree, this caused a lot of tension and forced difficult decisions. The politicization of the pandemic in which some DSWs were resistant to masks or vaccines, combined with the workforce shortages described above, often meant that consumers or family caregivers had to choose between accepting an increased risk or having no care at all, as indicated by a

family caregiver: "I was afraid that they would not work if I made them [wear masks]." An FMS provider described a conversation they had with a self-directed consumer:

You wanted to cry for the consumer, because he said, "I'm so very concerned that my Personal Care Attendant (PCA) doesn't have a vaccine, but I need the services so bad I can't do anything about it." It was just, he was between a rock and a hard place, and he chose to keep the PCA, because he was unable to do all the household chores that needed to be done.

HCA's also sometimes struggled to set and enforce safety expectations in this politicized environment. For their part, although a notable subset of DSWs objected to safety mandates, far more were concerned about the risk of themselves or their clients catching COVID-19. Furthermore, some DSWs also reported difficulty getting clients to follow COVID-19 protocols, with 31.1% reporting that they worked with consumers with impaired cognition, which impacted their ability to follow safety protocols, and some noted in open-ended comments that they had to be the "bad guy." They also expressed concern over having little influence or control over the behavior of friends and family who had contact with clients.

The impact of the politization was not limited to point-of-care interactions but also impacted access to resources at the organizational or community level. County health departments controlled the local public health response, including access to testing and vaccine distribution, and county commissioners controlled local mandates and the distribution of local COVID funding. Several providers noted the difficulty in tracking different rules and mandates across different counties that they operated in and the impact of politicization on accessing key resources in some counties. An IDD provider operating across state lines shared:

In two of the other counties we support... there was a lot of political issues with testing.... we had staff that tested positive and exposed clients that are medically fragile and the county refused to test them because they were not symptomatic. Unfortunately, one of those individuals that they refused to test did pass away from COVID and we did not know that they were positive until 14 days after their exposure... by that time, he was too late to get any treatment.

Providers operating in more liberal or moderate counties reported being granted local funding to cover COVID-19 related expenditures, whereas providers operating in more conservative counties reported being denied similar funding.

In addition to the challenges posed by politicization and misinformation, the decentralized nature of home care also made it challenging to support safety practices. For example, PPE had to be delivered to DSWs and consumers who typically did not report to a central work site, although most providers reported providing PPE despite this challenge. Providers found creative ways of distributing PPE, for example, redirecting labor and transportation resources that were in less use during the pandemic to secure, package, and deliver these supplies. Yet, as noted above, consumers and DSWs reported inconsistent access to PPE from HCA's or FMS providers, with many incurring this as a personal expense. Additionally, formal symptom screening was not a widely reported practice, with 33.3% of workers and 27.8% of consumers reporting symptom screening of consumers and 48.2% of workers and 39.4% of consumers reporting screening of workers prior to the delivery or home care. However, interviews indicated there was typically an expectation that care team members would monitor their own health and let each other know if either the worker or consumer felt ill. Nonetheless, some providers and DSWs reported that their consumers did not report when they had symptoms or a positive test.

It was also more difficult to provide education and guidance in this decentralized work environment. A self-directed worker shared:

I bought my own masks so I'd just wear them to a client's house ... Yeah, other than that, [payroll provider] never really told me what to do or gave me anything to do. Yeah, we were left in the dark.

Over 89% of agency-based providers reported delivering training on COVID-19 safety practices compared with 54% of FMS providers. Overall, 49.1% of DSWs reported not receiving guidance or training from their employer related to COVID-19, and an additional 13.8% were uncertain.

Additional details on this theme were presented at Associate of Professionals in Infection Control and Epidemiology (APIC)³⁰ and the International Sociological Association.³¹

Key Recommendations for Policy, Practice, and Additional Research

Based on study results, the following policy changes and practice strategies have potential to improve the HCBS system response to future pandemics or similar emergency situations:

- **Improve DSW wages and benefits.** Increased wages and benefits are needed to compete with other entry-level job sectors to recruit and retain quality workers. Additionally, health coverage and paid leave are needed to manage increased risks during public health emergencies. Medicaid expansion is a missed opportunity for ensuring that DSWs have health coverage in Kansas. DSWs are 55% more likely to be uninsured in non-expansion states compared with expansion states.³² Competitive wages would also enable consumers to better enforce their expectations for safety and care quality. As Medicaid reimbursement rates are set by state legislators, policymakers should be educated on the importance of DSWs. Additionally, HCAs and the DSW workforce should be included in measures of network adequacy to help measure whether reimbursement rates are sufficient for supporting an adequate HCBS network.
- **Professionalize the DSW workforce.** In addition to improved wages and benefits, there is a need to professionalize this workforce by improving education and training as well as elevating their status in acknowledgment of their key role in supporting the health and safety of LTSS consumers. Many DSWs were susceptible to misinformation around COVID-19. Others struggled with setting boundaries or understanding the system they worked in. Some DSWs also felt their voices were ignored in care planning or advocating for consumers. Professionalizing the workforce could address these issues as well as improve the respect and acknowledgment they receive as essential workers with a vital role in the system.
- **Proactively target emergency funding for HCBS, including the SDC model.** COVID-19 emergency funds were distributed unevenly to HCBS providers and therefore, in turn, to consumers and DSWs. Furthermore, these funds were largely inaccessible for those in the SDC model in which HCBS consumers, rather than agencies, are the employers. FMS agencies could have potentially supported the distribution of these funds as the payroll managers, but policymakers and administrators at both the federal and state levels failed to provide structure or guidance for doing so. As a unique service delivery system, SDC stakeholders and experts need to be at the table during emergency planning to advise on system needs and manageable processes for distributing aid in an equitable manner that does not leave them behind.
- **Establish and utilize centralized communication systems.** Many providers reported being unaware of key resources or pandemic policies or finding out about these haphazardly. In turn, many consumers, DSWs, and family caregivers were also out of the loop. State administrators should develop and maintain a comprehensive list of HCBS providers to disseminate updates

and resources in real time and effectively field questions. Additionally, there should be stronger requirements for care coordinators to disseminate accurate information in a timely manner.

- **Expand SDC care in Kansas to include budget authority.** Additional control over HCBS funds would provide SDC consumers with more tools and resources for addressing challenges faced during the pandemic. Self-controlled budgets can be used to cover other expenses, such as job advertising, background checks, worker training, and PPE, which proved to be burdensome expenses in our study. Budget authority would also increase flexibility to compensate for other system deficiencies observed in our study, such as workforce shortages. For example, when consumers are getting little to none of their hours filled, budget authority would provide the option of sacrificing some hours for higher pay to fill other hours.
- **Make Appendix K flexibilities that allowed parents, guardians, and spouses to be paid as DSWs permanent.** This adaption implemented during the pandemic was widely cited as beneficial; though it did not solve workforce issues, it did help ameliorate them while also providing more financial security to families. Previous prohibitions against allowing certain relationships to provide paid care have been due to concerns about the potential for abuse and exploitation; therefore, research to establish best practices in oversight and support would also be beneficial.
- **Identify and implement best practices in care coordination or case management.** Care coordination or case management is intended to ensure that care is delivered and well-coordinated and, furthermore, can be a key service for updating care plans during emergencies and disseminating information on new guidelines and resources. In Kansas, care coordination is provided by MCOs, which are allowed to set their own caseload size standards. Current contracts indicate that caseloads sizes must ensure the health, safety, and well-being of consumers, but this goal is not being met, so MLTSS contracts require clearer standards. There is, unfortunately, a lack of research on optimal caseload sizes and other best practices; therefore, additional research is needed. Ultimately, formal care coordination systems should be improved so that eliminating unmet care needs, rather than efficiency, is the primary goal and incentive.
- **Strengthen Backup Care Plans.** Backup care plans are considered integral to HCBS delivery and are required by CMS,³³ but little is known about these plans in practice. Our study found shortcomings in backup care plans, indicating they should be reviewed and updated more frequently, including during/after an emergency, but more research is needed to identify best practices. Additionally, guidelines are needed to ensure backup care plans address a wide variety of emergencies, including prolonged infectious disease pandemics, and address both medical and LTSS needs.

As noted for some of these recommendations, above, additional research is also needed to establish best practices and guidelines.

Conclusion

In conclusion, we found that a system that was already under strain struggled during the pandemic, with many pre-existing issues and challenges growing worse. Additionally, access to key resources to manage the pandemic, such as PPE and workforce funding, was uneven. Nevertheless, many DSWs, family caregivers, and providers went above and beyond to deliver safe care during the pandemic. Analysis of study data is ongoing, including multivariate analysis to connect care contexts, processes, and outcomes as well as to more closely compare experiences and outcomes across consumers, DSWs,

caregivers, and providers in different care models and geographic settings. Future research would benefit from direct comparison of experiences and outcomes across states with different policy and practice contexts, such as employer versus budget-authority models in SDC, managed care versus fee-for-service, different Appendix K adoptions, Medicaid expansion, and different rate and benefit structures.

List of Publications and Products

Academic Dissemination

Wendel-Hummell C, LaPierre T. Lessons in Community Engaged Research: The COVID-19 Home Care Study. Invited Lecture presented at: KU Disability Studies Seminar. 2021 Sep 23. Lawrence, KS

Wendel-Hummell C, LaPierre T, Olds D, Sullivan D, Babitzke J, Swartzendruber L. Multi-level barriers and facilitators to rapidly implementing safety practices in home and community based services during the COVID-19 pandemic. Poster presented at: AcademyHealth 14th Annual Conference on the Science of Dissemination and Implementation. 2021 Dec. 14-16. Virtual.

Sullivan D, Wendel-Hummell, C, LaPierre, T, et al. “They Don’t Get Paid Even Half of What They’re Worth to Us”: Worker Shortages and Unmet Care Needs during the COVID-19 Pandemic. Paper presented at: Midwest Sociological Society Annual Conference; 2022 Apr 13-16; Chicago, IL.

Babitzke J, LaPierre, T, Wendel-Hummell, C, et al. “He Definitely Don’t Care About Me”: COVID-19 Politicization and the Marginalization of Americans with Disabilities. Paper presented at: Midwest Sociological Society Annual Conference; 2022 Apr 13-16; Chicago, IL.

Olds D, Wendel-Hummell C, LaPierre T, Sullivan D, Babitzke J, Swartzendruber L, Mullen G.* Provision of Home-Based Long-Term Services and Supports to Vulnerable Populations During the COVID-19 Pandemic. Poster presented at: Association of Professionals in Infection Control and Epidemiology. 2022 Jun 13-15. Indianapolis, IN.

Wendel-Hummell C, LaPierre T, Olds D, Babitzke J, Sullivan D, Swartzendruber L. Care and Safety during the Pandemic in Home and Community Based Services: Challenges of a Fragmented System. Poster presented at: AcademyHealth Annual Research Meeting. 2022 Jun 4-7. Washington D.C.

Wendel-Hummell C, LaPierre T, Olds D, Sullivan D, Babitzke J, Swartzendruber L, Barta T. “They Seemed to Forget about Us Little People”: The Invisibility and Neglect of Essential Home care Workers during the COVID-19 Pandemic. Paper presented at: AcademyHealth Annual Research Meeting. 2022 Jun 4-7. Washington D.C.

LaPierre T, Wendel-Hummell C, Olds D, Babitzke J, Sullivan D, Swartzendruber L, Barta T. Stakeholder Engagement Strategies and Impact on Patient Centered Research in Home and Community Based Care. Poster presented at: AcademyHealth Annual Research Meeting. 2022 Jun 4-7. Washington D.C.

Wendel-Hummell C, LaPierre T, Sullivan D, Babitzke J, Swartzendruber L, Olds D. Self-Directed Care in Home-Based Long-Term Care during the Pandemic: Policy and Practice Implications. Symposium paper presented at: Gerontological Society of America. 2022 Nov 2-6. Indianapolis, IN.

Wendel C, LaPierre T, Sullivan D, Babitzke J, Swartzendruber L, Barta T, Olds D. ‘Anything that’s good for the worker, should be good for the client’: Opportunities and Constrains in Self-Directed Care

during the COVID-19 Pandemic. *J Appl Gerontol.* 2023; 42(4): 524-535. doi: 10.1177/07334648221143604

Wendel-Hummell C, LaPierre T. Community Stakeholders as Research Partners in Disability Research: A Case Study in Informed Consent.” Paper presented at: Midwest Sociological Society Annual Meeting. 2023 Mar 23-26. Minneapolis, MN.

LaPierre T, Wendel-Hummell C, Babitzke J, Sullivan D, Swartzendruber L, Olds D. Politization of COVID-19 and Experiences of Care and Disability in the United States: The Case of Home Care in Kansas. Paper presented at: International Sociological Association World Congress of Sociology. 2023 Jun 5- Jul 1. Melbourne, Australia and Virtual.

Public Dissemination

Wendel-Hummell C, Smith K.* Nothing About Us Without Us Includes Research. Session presented at: Seeking Opportunities for an Advocacy Revolution (SOAR 2021 Sep 18. Virtual.

Wendel-Hummell, C. The LTC Workforce Needed for Long and Productive Lives. Panelist at: KU School of Social Welfare Grand Challenge Event. 2021 Oct 7. Virtual.

Wendel-Hummell C, Hyten A.* Direct Support Workers: An Essential Workforce Surviving on Poverty Wages. Research brief distributed to state and national legislators, including as testimony for the Robert G. (Bob) Bethell Joint Committee on Home and Community Based Services and KanCare Oversight. 2021 Sept. Lawrence KS: CRADO; Topeka KS: TILRC.

Wendel C, LaPierre T, Olds D, Sullivan D, Babitzke J, Swartzendruber L, Mullen G.* Care and Safety Practices during the COVID-19 Pandemic in Home and Community Based Services: Research Brief. 2021 Jul. Lawrence, KS: CRADO.

Wendel-Hummell C, LaPierre T. Home and Community Based Services (HCBS during COVID-19: Challenges, triumphs, and implications. Invited Presentation for: KU School of Social Welfare Research Impact Talk. 2022 Apr 6. Virtual.

Wendel-Hummell, C. HCBS COVID-19 Study. Written testimony presented at: Robert G. (Bob) Bethell Joint Committee on Home and Community Based Services and KanCare Oversight. 2023 Oct 2. Lawrence KS: CRADO.

*Community partner co-presenter or co-author

Additional products are in progress, including a manuscript currently under review.

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