

Title: “Anything that benefits the workers should benefit the client”: Opportunities and Constraints in Self-Directed Care during the COVID-19 Pandemic

Authors and affiliations:

Carrie L. Wendel<sup>1\*</sup> ([cwendel@ku.edu](mailto:cwendel@ku.edu)) ORCID: 0000-0001-7221-5674  
Tracey A. LaPierre<sup>2</sup> ([tlapie@ku.edu](mailto:tlapie@ku.edu)) ORCID: 0000-0002-7774-576X  
Darcy L. Sullivan<sup>2</sup> ([dsullivan10@ku.edu](mailto:dsullivan10@ku.edu)) ORCID: 0000-0001-9263-1368  
Jennifer Babitzke<sup>2</sup> ([jennifer\\_babitzke@ku.edu](mailto:jennifer_babitzke@ku.edu)) ORCID: 0000-0003-4228-9183  
Lora Swartzendruber<sup>1</sup> ([lrs@ku.edu](mailto:lrs@ku.edu)) ORCID: 0000-0002-5547-8947  
Tobi Barta<sup>1</sup> ([tobi.barta@ku.edu](mailto:tobi.barta@ku.edu)) ORCID: 0000-0002-7816-9100  
Danielle M. Olds<sup>3</sup> ([dolds@saint-lukes.org](mailto:dolds@saint-lukes.org)) ORCID: 0000-0003-0256-3889

\*Corresponding author

<sup>1</sup>School of Social Welfare  
University of Kansas  
Twente Hall  
1545 Lilac Ln  
Lawrence, KS 66045

<sup>2</sup>Department of Sociology  
University of Kansas  
Fraser 716  
1415 Jayhawk Blvd  
Lawrence, KS 66045

<sup>3</sup>St. Lukes Hospital  
Kansas City, MO

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**“Anything that benefits the workers should benefit the client”: Opportunities and Constraints in Self-Directed Care during the COVID-19 Pandemic**

**Abstract:** Self-directed care (SDC) models allow Home and Community Based Services (HCBS) consumers to direct their own care, thus supporting flexible, person-centered care. There are many benefits to the SDC model but access to resources is essential to successful outcomes. Considering the autonomy and flexibility associated with SDC, it is important to understand how SDC responded to the COVID-19 pandemic and the resources available to help manage this situation. We conducted 54 in-depth interviews with HCBS consumers, direct support workers (DSWs), family caregivers, and providers to examine the impact of COVID-19 on HCBS services in Kansas. Findings illuminate how self-directed consumers carried a lot of employer responsibility, with limited resources and systemic barriers constraining self-determination and contributing to unmet care needs, stress, and burden. Policy flexibilities expanding the hiring of family members were beneficial but insufficient to address under-resourced working conditions and labor shortages that were exacerbated by the pandemic.

What this study adds:

- Explores the impact of the COVID-19 pandemic on self-directed care (SDC)
- Examines SDC from multiple stakeholder perspectives, including consumers, workers, family caregivers, and providers
- Highlights the challenges of SDC within a specific policy context: a state with managed Medicaid and an employer-authority only model of SDC
- Demonstrates how low pay and poor benefits of DSWs undermines the self-determination, health, and safety of SDC consumers

Applications of study findings:

- Recommends permanent adoption of policies allowing self-directed consumers to hire parents, spouses, and guardians

- Suggests that a budget-authority model would provide self-directed consumers and their family caregivers with additional tools and resources for better managing care and safety needs during the pandemic
- Highlights need for emergency funding that is proactively tailored to meet the unique employer model of SDC

Self-directed care (SDC) models were developed to give home- and community-based service (HCBS) consumers more authority, self-determination, and flexibility in meeting their individual long-term services and supports (LTSS) needs. Once an alternative model that operated as a demonstration program, SDC is now common in HCBS and encouraged by Centers for Medicare and Medicaid Services (Bradley et al., 2021, Ujvari, 2020). This model allows care recipients to select, train, manage, and dismiss their own workers. SDC is linked to greater satisfaction with the paid caregiver and care-recipient relationship than found in the agency-based model and is associated with fewer unmet care needs (Bradley et al., 2021). Despite the benefits of this program, there are also challenges, specifically in managing bureaucratic requirements, recruiting and training workers with the appropriate skillset, and managing SDC hours and budget (Mahoney et al., 2019).

It is unclear how SDC consumers, workers, and family caregivers fared during the COVID-19 pandemic, especially given the high degree of autonomy in SDC, and the unprecedented, rapidly changing nature of the pandemic. Drawing on rich, in-depth interviews with a variety of stakeholders, this paper examines how opportunities and constraints during the COVID-19 pandemic shaped worker, caregiver, and consumer experiences in the SDC model in Kansas.

### *HCBS and SDC in Kansas*

States have a fair amount of flexibility in implementing Medicaid, resulting in wide variation across HCBS programs. SDC models were adopted in Kansas in 1989 and are available to all HCBS consumers. SDC consumers select a Financial Management Services (FMS) provider to manage payroll and for information and assistance. In Kansas, consumers have employer-authority but not budget-authority; that is, SDC consumers 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 (Ujvari, 2020). 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 (Advancing States, 2021). SDC consumers hire workers based on the number of care hours awarded by their Managed Care Organization (MCO) care coordinator, rather than a budget, and therefore have little control over worker wages. The state legislature sets the Medicaid reimbursement rates that determine worker wages, and only MCOs have the authority to exceed these wages.

Approximately 8,500 HCBS consumers (39%) in Kansas self-direct their care (M. Heydon, Kansas HCBS Director, personal communication, 8/29/22). Kansans can hire some relatives but not spouses, guardians, or parents of minor children, unless a court-approved exception has been granted; although as will be further detailed below, this restriction was waived during the pandemic. Nationwide, a slight majority of SDC programs have similar hiring restrictions regarding relatives (Ujvari et al., 2020).

Those hired through the SDC model are part of the direct support workforce; data often do not distinguish between those in the SDC, agency-based, or residential care models, or use consistent terminology to distinguish these different subtypes. We use Direct Support Workers (DSWs) to refer to the HCBS workforce more broadly, and distinguish between SDC workers and agency-based workers whenever possible. Approximately 25,000 Kansans are employed as DSWs; this is about half the number of DSWs per HCBS consumer compared to the U.S. average (KDADS, 2021).

Low wages and poor benefits, as well as the devaluing of direct service work, have contributed to an ongoing nationwide shortage of DSWs (Spetz, Stone, Chapman, & Bryant, 2019). Approximately half of DSWs in the U.S. have incomes below the federal poverty level and many rely on public assistance to meet their needs (Scales, 2020). This problem is particularly acute in Kansas, where the median DSW hourly wage of \$11.30 is lower than the national average and other Midwestern states (KDADS, 2021). Data are not available in Kansas to compare wages of agency-based and self-directed DSWs, but reimbursement rates are comparable. Benefits and paid leave are not available to SDC

workers in Kansas, and Kansas remains one of 12 states that have not expanded Medicaid. Low reimbursement rates also do not build in sufficient overhead to support overtime pay.

### *Home Care during the COVID-19 Pandemic*

The limited research available on how the COVID-19 pandemic impacted home care has focused primarily on agency-based care. At the beginning of the pandemic, homecare agency (HCA) leadership had to influence, interpret, and implement state policies, while agency-based workers had to balance job duties, agency policies, and daily reality of providing care in the home (Markkanen et al., 2021). In many instances, agency-based clients and workers reported feeling at increased risk for COVID-19 infection due to workers visiting multiple client homes (Markkanen et al., 2021). SDC was not immune to these concerns, with evidence of some SDC workers electing to stay home to protect themselves or being fired for not adhering to the safety protocols required by their client/employer (Caldwell et al., 2022). Safety considerations are important given that HCBS consumers are at increased risk of adverse COVID-19 outcomes due to their age, health conditions, or disabilities. Many DSWs are also at high-risk from COVID-19 infections, with more than a quarter of the workforce over age 55 and high rates of being uninsured (Scales, 2020). Overall, Personal Protective Equipment (PPE) was more difficult to distribute and manage in home care settings (Kerley et al., 2021, Markkanen et al., 2021), and many SDC consumers have reported out-of-pocket costs in securing PPE (Caldwell et al., 2022).

### **Methods**

The qualitative data for this paper are part of a larger, multi-disciplinary, mixed-methods study broadly examining the HCBS system response to the pandemic. This study was approved by the University of Kansas Human Research Protection Program (# STUDY00146397). Community engagement was a central component of this research. HCBS consumer, DSW, family caregiver, HCA provider, FMS provider, and advocacy group representatives were recruited via aging and disability networks to a Stakeholder Advisory Board (SAB) that was engaged in all phases of the research process. The 12-member SAB met

via Zoom bi-weekly, monthly, or quarterly depending on the stage of the research process, collaborating on research questions, data collection instruments, participant recruitment, interpretation of results, and dissemination. A funded community partner also participated in weekly research team meetings.

Data come from 54 in-depth interviews with 59 HCBS stakeholders in Kansas, conducted via phone or Zoom between March 2021 and August 2022. Sixty-six percent of the interviews were with stakeholders directly engaged in SDC. Respondents included HCBS consumers, DSWs, family caregivers, and HCA and FMS providers. All HCBS waivers serving adults in Kansas were represented in the study, which include the Frail Elderly (FE), Physical Disabilities (PD), Brain Injury (BI), and Intellectual and Developmental Disabilities (IDD) waivers. To ensure access, support persons or interpreters were present as needed to facilitate communication but 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. A breakdown of the HCBS role (consumer, non-family DSW, paid family caregiver, non-paid family caregiver, or service provider), waiver type (BI, FE, IDD, or PD), care model (SDC, HCA, or both), and primary region (metro, non-metro, or mix) of respondents can be found in Table 1. Additional demographic characteristics of consumers, DSWs, and caregivers can be found in Table 2. Despite targeted efforts to recruit minorities, respondents in these roles were predominantly non-Hispanic white and female.

*Table 1. Program Characteristics Associated with each Stakeholder Interview by HCBS Role (n=54)*

	n	Waiver type**				Care Model			Primary Region		
		BI	FE	IDD	PD	SDC	HCA	Both	Metro	Non-metro	Mix
<b>Consumers</b>	20	3	2	5	10	14	3	3	14	6	n/a
<b>DSWs (non-family)^</b>	10	1	5	4	8	7	3	0	8	2	n/a
<b>Paid family caregivers*</b>	8	0	1	7	0	7	1	0	7	1	n/a
<b>Unpaid family caregivers^</b>	5	1	1	3	2	5	0	0	1	4	n/a
<b>Service Providers</b>	12	9	9	8	9	3	7	2	6	5	1

\* DSW: Direct Support Workers. 4 family caregivers were paid as workers under the Appendix K exception; 2 were paid under preexisting rules; 2 were paid under the adult foster care model

\*\*6 DSWs, 2 unpaid family Caregivers, and 9 providers support individuals on different waivers, and therefore these subtotals are greater than sample size. BI: Brain injury, FE: Frail elderly, IDD: Intellectual and Developmental Disability, PD: Physical Disability.

^One respondent was both a self-directed PD consumer and a family caregiver to a self-directed PD consumer and represented as such in each category

*Table 2. Consumer, Worker, and Caregiver Demographic Characteristics.*

	n	Gender		Ethnicity	Race				Age	
		F	M	Hispanic	White	Black	Asian	Native	Range	Mean
<b>Consumers^</b>	20	17	3	3	14	4	0	2	24-81	50
<b>DSWs*</b>	10	8	2	1	7	2	1	0	21-72	45
<b>Paid family caregivers</b>	8	7	1	1	8	0	0	0	50-70	59
<b>Unpaid family caregivers^</b>	5	5	0	1	5	0	0	0	46-69	55
<b>Totals</b>	42*	36	6	5	33	6	1	2	21-81	51

^ 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

\* DSWs: Direct Support Workers

Semi-structured interview guides were developed and tailored for each participant group in collaboration with the SAB. A SAB member with cognitive impairments helped refine the consumer instruments for accessibility and recruited peers for pilot testing. Respondents were asked questions about their homecare experiences during the pandemic, including care and safety practices and, where applicable, how the pandemic impacted care needs, care satisfaction, work conditions, and job satisfaction. Respondents were recruited through community partners, social media, and snowball sampling. Inclusion criteria included: 1) involvement with HCBS services in Kansas during the pandemic; 2) age 18 or older; and 3) ability to communicate in English or Spanish. Respondents were offered \$25



for participation. Interviews lasted between 20 and 150 minutes (median length 84 minutes). Interviews were recorded and transcribed verbatim. All respondents provided verbal informed consent.

Data collection and analysis occurred simultaneously, with interview guides being refined in response to ongoing analysis (Merriam & Tisdell, 2015). Data were coded and analyzed by the authors using an inductive, team-based, iterative, negotiated, consensus-based process (Cascio et al., 2019), facilitated by Dedoose software. Team members immersed themselves in the data through narrative summaries of each interview and by reading the transcripts in their entirety. First-level open coding of the transcripts was conducted separately by four members of the research team. These initial codes were discussed by the entire research team and coding discrepancies and challenges were resolved through discussion, producing the initial codebook that included descriptions and examples of each code. The codebook was iteratively refined during weekly team meetings as new transcripts were coded.

The analysis presented here was guided by the research question: How did opportunities and constraints during the pandemic shape worker, caregiver, and consumer experiences in the self-directed model in Kansas? Using a constant comparative method, codes were grouped into broader categories (axial coding), themes across categories were identified, and linkages between themes were explored to fully answer the research question (Merriam & Tisdell, 2015). Team members constantly revisited the data to confirm, reject, or refine themes and linkages. Findings and policy implications were reviewed and discussed with the SAB. All authors read the results and substantiated their consistency with the data.

Overall, these methods incorporated multiple strategies identified to enhance credibility and dependability in qualitative research, including engaging multiple researchers, respondent validation, triangulation, and using verbatim quotes to support findings (Noble & Smith, 2015). Additional details can be found in the supplemental COREQ checklist.

## **Results**

This paper focuses on four key interwoven themes that influenced outcomes for SDC consumers and workers: 1. Pre-existing workforce shortages were exacerbated by the pandemic; 2. Self-directed consumers assume a lot of responsibility as employers with limited resources; 3. Appendix K flexibilities demonstrated potential to alleviate unmet care needs; and 4. Structural constraints had adverse impacts on caregiver, worker, and consumer outcomes. We begin by describing these themes and their subthemes in more detail (see Table 3 for a summary). We further elaborated on how these themes are interconnected in complex and reinforcing ways, as demonstrated in Figure 1.

Figure 1. Interrelationships Across Themes and Subthemes

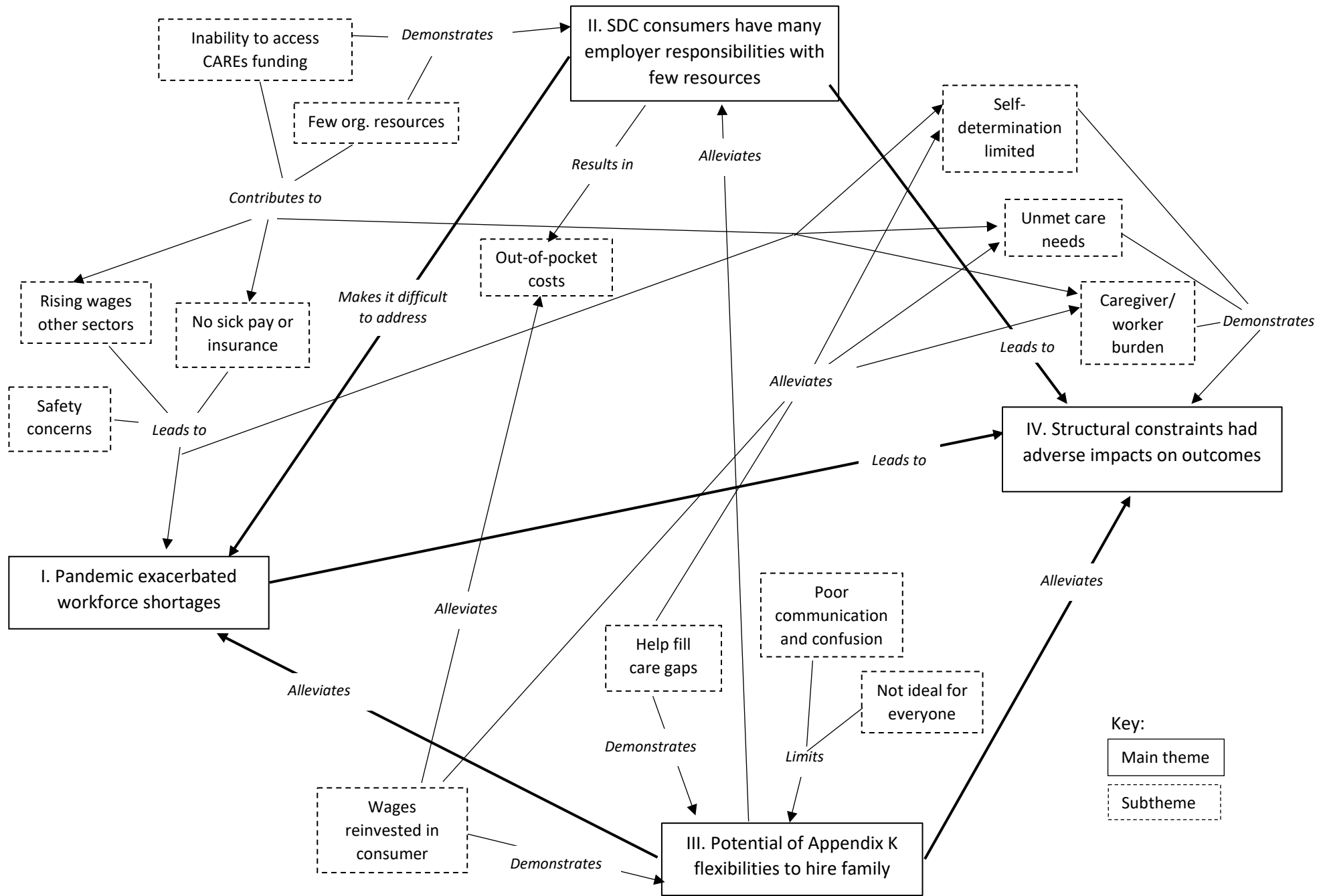


Table 3. Themes and Subthemes.

Theme I: Pre-existing workforce shortages were exacerbated by the pandemic.	
<i>Subthemes</i>	<i>Illustrative Quotes</i>
Some workers left due to COVID-19 safety concerns.	The reasons that were being given were not ones I'd had before as for why they were quitting when they would give me a reason. A few of them would list fear. That wasn't a reason I had ever heard of before that they were afraid. (Consumer on Physical Disability (PD) waiver)
Direct Support Worker (DSW) wages remained stagnant and could not compete with rising wages in other sectors and more generous unemployment benefits.	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. (Rural Financial Management Systems (FMS) provider)
Self-directed workers did not have access to insurance or paid leave, which became more important during pandemic to help mitigate new risks.	They lost out at pay wages [when out sick with COVID-19].... I really was sad about that because—I mean, this was a state-of-emergency situation, and they couldn't get paid for having this illness that was all over the world.... That was very hard on them 'cause they rely on the little bit of pay they get. (Self-Directed Care (SDC) Consumer on PD waiver)
Theme II: Self-directed consumers assume a lot of responsibility as employers with limited resources.	
<i>Subthemes</i>	<i>Illustrative Quotes</i>
SDC consumers and workers were not able to benefit from the pooling of organizational resources like home care agencies.	The self-directed model is great, but it's pushing a lot of responsibilities on people without the same resources in regards to things like being able to offer benefits and hazard pay and things like that. (Rural FMS provider)
CARES funds were not accessible to SDC consumers to increase wages or offer benefits.	I mean, if I could've done it (enhance wages with CARES funds), 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 direct-service care attendants." 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." (Urban FMS provider)
Many SDC consumers- and workers incurred out-of-pocket expenses (e.g., PPE, hiring expenses).	Self-directed folks are Medicaid recipients on social security... Even though they're the employer, they don't have the funds to buy me PPE. (SDC worker for consumer on Intellectual and developmental disability (IDD) waiver)
Theme III: Appendix K flexibilities demonstrated potential to alleviate unmet care needs.	
<i>Subthemes</i>	<i>Illustrative Quotes</i>
Appendix K flexibilities that allowed additional types of family members to be hired helped fill care gaps.	I certainly think that family members ought to be able to provide some services. We're very rural... out in the middle of nowhere, and without family I don't know how they [would] live... that family member would be working somewhere else if they [did not get paid as a caregiver]. (Rural FMS agency)

Paid family members reinvested their wages into consumer care.	What I can say the silver lining in all of the pandemic... being a paid caregiver has given us some financial stability that we did not have. I'm going be able to open an ABLA account [for qualified disability expenses] for my son and actually put some money in there.... And I've been able to pay off some debt and that's been huge. (Paid family caregiver to son on IDD waiver)
Appendix K flexibilities were surrounded by confusion and not always well communicated.	I brought it up to our [MCO care coordinator]. I reached out to her and said, 'Why can I not get paid, because I'm having to take vacation days on days that I cannot balance my work and life balance here.' And she's like, 'Nope, you can't.' And she said she would pass it along to her boss, but I never heard back from her. (Unpaid family caregiver to son on Brain Injury (BI) waiver)
Hiring family members was not possible or ideal for everyone.	Those family members really shouldn't be doing my care. They have their own health issues. It's just we can't find [outside] help...due to the pandemic. (SDC consumer on PD waiver)
Theme IV: Structural constraints had adverse impacts on caregiver, worker, and consumer outcomes.	
Caregiver and worker burden increased in response to pandemic conditions and workforce shortages.	I can't emphasize this enough, who's going to take care of the caregivers? So that's why those sick days and vacation time, that's really important. If you want your client to get top quality care, we need care too. Because, like I say, I got underlying issues too .... I had enough strength to do what I could do in my client's house, but when I came home and was like I'm just here to sleep and rest... I was neglecting me. (SDC worker for frail elderly (FE) and PD consumers who do not have backup caregivers)
Consumer self-determination is limited by workforce shortages and the pandemic.	We have one [consumer] currently that is pretty insistent that their worker should be vaccinated. The worker doesn't really want to get vaccinated, but they want to keep the worker.... people have kept workers that they really didn't want to keep because they couldn't find anybody else. (Rural FMS provider)
Workforce shortages led to unmet care needs.	There's the increased depression and anxiety that I have, skin breakdowns and pressure sores, and those kind of things I didn't really have to deal with that much before.... Now, it's pretty much constant. I got a big area on my lower leg that's not healing. Since I'm diabetic, it scares me. (SDC consumer on PD waiver who could not find workers capable of meeting her transfer/repositioning needs)

*Pre-existing workforce shortages were exacerbated by the pandemic*

The direct service workforce shortage was the most consistently cited challenge across all stakeholder groups. While this issue pre-dates the pandemic, respondents widely agreed that COVID-19 exacerbated the problem. One urban FMS provider described COVID-19 as “the straw that broke the camel’s back... it made people more concerned about doing that kind of work, but we already had widespread state

shortages long before COVID.” Some SDC consumers reported workers citing safety as a reason for quitting, noting that this was a new reason they had not heard pre-pandemic. Additionally, some family caregivers paused formal care services during the early days of the pandemic due to safety fears, but when they were comfortable resuming care, they often found it difficult to bring their workers back or find replacement workers.

Participants widely agreed that low wages and lack of benefits drove workforce shortages. Low wages became an even greater obstacle during the pandemic as the wages in other entry-level job sectors rose in response to broader workforce shortages, while Medicaid reimbursement rates remained stagnant, as demonstrated in the following quote:

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. (Rural FMS provider)

SDC worker wages were often lower than the enhanced unemployment benefit offered early in the pandemic. A caregiver trying to hire a worker for her adult son with a brain injury described, “We had one gal that ... needed full-time work. We offered her a full-time job, and then she realized that she could stay home with her kids and get more money on unemployment.”

According to both workers and consumers, the pandemic directly contributed to more missed days of work due to illness, quarantine, and childcare demands related to school closures. SDC workers in Kansas were particularly vulnerable in this regard as they do not receive any job benefits such as health insurance, hazard pay, or paid leave, benefits that were seen as vital to navigating the COVID-19 pandemic.

I feel one of the basic needs, because our pay is so low, and we do so much, and we're in a higher health risk than some other people, they need to start giving us healthcare workers a special credit or something for health insurance or offer it at least. (58-year-old, uninsured SDC worker).

SDC consumers noted the importance of their workers monitoring for symptoms and following quarantine protocols, especially since they were at increased risk of adverse COVID-19 outcomes. Yet they also recognized the difficult position this puts their workers in when they cannot provide sick pay:

They lost out at pay wages.... I really was sad about that because—I mean, this was a state-of-emergency situation, and they couldn't get paid for having this illness that was all over the world.... That was very hard on them 'cause they rely on the little bit of pay they get. (SDC Consumer on PD waiver)

Further, due to the worker shortages, SDC consumers often did not have back-up care while their workers were out.

*Self-directed consumers assume a lot of responsibility as employers with limited resources*

As employers, SDC consumers have full responsibility for recruiting, hiring, and training workers to fill the hours of care they have been awarded. In Kansas, associated costs for job advertising, required background checks, and training must be paid for out-of-pocket. SDC consumers wanted their workers to receive higher pay and benefits but had no control over wages set by state reimbursement rates and no way of offering benefits such as health insurance or paid time off.

HCA's also reported the importance of higher wages to attract and retain good workers and struggling to provide better pay and benefits to their workers given low Medicaid reimbursement rates. However, some HCA's described drawing on other sources to help subsidize these low rates. One urban HCA that pays their workers above reimbursement rates notes, "We do the best we can, but a lot of that is from donations and fundraising." Additional resources mentioned that were used to enhance agency-based worker pay and benefits included local county funding, higher-paying private-pay clients, and revenue from more profitable departments. SDC consumers did not have access to similar organizational resources. As noted by a rural FMS provider, "The self-directed model is great, but it's pushing a lot of responsibilities on people without the same resources in regard to things like being able to offer benefits and hazard pay and things like that."

CARES (Coronavirus Aid, Relief, and Economic Security Act of 2020) funds were designed to provide resources to enhance worker wellbeing and safety, as well as to stabilize the economy. While nursing homes received direct CARES funding at both the state and federal level to support the workforce, many HCBS providers expressed frustration that they had to apply for funding:

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

HCAAs described devoting a lot of resources to applying for funding through various sources with different strings attached. Although this was difficult, some HCAAs were successful in accessing these funds for hazard pay, sick pay, or additional overtime for their agency-based workers. However, FMS providers and SDC consumers did not have any access to CARES funds for these purposes; FMS providers were excluded because they were not the employer and there was no viable pathway for SDC consumers to apply for CARES funds as individual employers. Further, some FMS providers reported being instructed by government administrators that CARES funds could be recouped if used to provide hazard pay to SDC workers, as there was no evidence that workers faced increased risk of catching COVID-19 as long as they had access to PPE. An urban FMS provider spoke of her inability to find a way to enhance worker pay with CARES funds despite her efforts:

I mean, 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 [SDC workers]." 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." (Urban FMS provider)

Thus, in contrast to some agencies, SDC consumers were not able to offer higher wages to compete with growing wages in other sectors, paid leave to support workers in quarantine, or overtime to allow fewer workers to cover more care hours.



Accessing CARES funds for PPE was more successful, as the state drew on these funds to provide all HCBS providers, including FMS providers, a PPE budget. This was widely cited as beneficial across stakeholder groups, and FMS providers felt successful in distributing these supplies to SDC consumers. However, this did not completely cover PPE expenses for SDC consumers and workers; for example, before these funds were available or when the supplies provided were insufficient for those with higher care needs. A PD consumer spoke of how helpful it was to get supplies dropped off by her FMS provider, but they did not adequately cover her nearly around-the-clock care. She noted, "It's better now, but I can't afford a lot of it." Optimal access to PPE in SDC was therefore constrained by insufficient personal resources to cover out-of-pocket costs. As one experienced worker for IDD consumers noted "self-directed folks are Medicaid recipients on social security... Even though they're the employer, they don't have the funds to buy me PPE." SDC workers were sometimes hesitant to ask their low-income employers for these supplies and often paid for this out of their own pocket, but as low-wage workers this was also challenging for them.

*Appendix K flexibilities demonstrated potential to alleviate unmet care needs*

One policy that was widely cited by FMS provider, SDC consumers, and family caregivers as beneficial was the new opportunity to hire additional types of family members as workers. This flexibility was granted through Appendix K, whereby the federal government allows states in emergency situations to adjust HCBS rules, regulations, or rates. These are designed as temporary measures to avoid interruptions and delays in home-based care and are only in place during the emergency and post-emergency transition period (CMS, 2022). A key flexibility implemented in Kansas was to relax the restrictions on who could be paid as a DSW by allowing typically excluded family members such as parents, spouses, and guardians, as well as workers aged 16-17. This policy response was particularly well-suited for the SDC model.

In the face of workforce shortages, the ability to hire those previously ineligible to serve as paid workers helped fill care gaps. This was especially important for rural consumers and their caregivers who lived in regions without access to agency-based services, as reported by a rural FMS provider serving nearly 50 consumers who were able to hire family members under this Appendix K flexibility:

I certainly think that family members ought to be able to provide some services. We're very rural... out in the middle of nowhere, and without family I don't know how they [would] live... that family member would be working somewhere else if they [did not get paid as a caregiver] (Rural FMS agency).

This income not only provided much-needed financial support to low-income families, family caregivers who were now getting paid often reinvested their income into the consumer's care needs.

What I can say the silver lining in all of the pandemic... being a paid caregiver has given us some financial stability that we did not have. I'm going to be able to open an ABL account [for qualified disability expenses] for my son and actually put some money in there.... And I've been able to pay off some debt and that's been huge. (Urban caregiver to son with IDD)

Significant concern was expressed across stakeholder groups about what will happen to these consumers and their paid family caregivers when this Appendix K flexibility expires (6 months after the federal emergency ends).

Of additional concern, Appendix K flexibilities were not well communicated and confusion over eligibility and implementation limited their impact for others. Whereas providers generally knew to consult the state website for policy updates and also kept each other informed through professional networks, SDC consumers and their family caregivers found out about this policy flexibility more haphazardly or received mixed information. For example, a mother of an adult son was told that she was not eligible to be paid under this policy.

I brought it up to our [MCO care coordinator]. I reached out to her and said, 'Why can I not get paid, because I'm having to take vacation days on days that I cannot balance my work and life balance here.' And she's like, 'Nope, you can't. And she said she would pass it along to her boss, but I never heard back from her. (Rural caregiver to son with BI)

Another caregiver was informed by her MCO care coordinator that her adult child risked being removed from the HCBS program if they did not find a worker soon but was not informed that she could be hired as the worker under this new flexibility.

It should also be noted that while this flexibility was an ideal solution for many, it does not solve the workforce shortage issue. FMS providers shared that some SDC consumers prefer an unrelated worker, particularly for intimate care tasks such as bathing and toileting. Others did not have family members available for this care, or their family members did not have the skill set or strength to perform the needed tasks, as noted by a consumer-employer with complex medical conditions, “Those family members really shouldn't be doing my care. They have their own health issues. It's just we can't find [outside] help...due to the pandemic.” Additionally, many providers we interviewed were disappointed that the state did not take advantage of all the allowed Appendix K flexibilities they believed could have helped alleviate workforce shortages; notably, the state did not increase reimbursement rates.

*Structural constraints had adverse impacts on caregiver, worker, and consumer outcomes*

The growing workforce shortage combined with inadequate resources to address this issue had adverse impacts on caregivers, workers, and consumers. SDC workers and family caregivers widely reported increased burden and stress during the pandemic. Their caregiving responsibilities increased in response to pandemic conditions and they had fewer workers with whom to share caregiving duties. In the face of workforce shortages, it was difficult for family caregivers to find respite and SDC workers often felt they could not take time off because their care-recipients would go without care. Both groups reported putting their care recipient's needs before their own needs.

I can't emphasize this enough, who's going to take care of the caregivers? So that's why those sick days and vacation time, that's really important. If you want your client to get top quality care, we need care too. Because, like I say, I got underlying issues too .... I had enough strength to do what I could do in my client's house, but when I came home and was like I'm just here to sleep and rest... I was neglecting me. (SDC worker for FE and PD consumers)

As a result, SDC workers and caregivers felt both their mental and physical health suffered.

The advantages of SDC model are premised on increased choice and self-determination in directing one's own care, but this was constrained by workforce shortages. Many SDC consumers ended up in the SDC model not by choice, but rather because agency-based care was not available. Some consumers spoke of being dropped by HCAs or not being able to find an agency accepting new HCBS clients.

I looked on my own [and] couldn't find anyone so I called my [MCO care coordinator] and she was looking for agencies... the agencies here ... they don't want to take people. (SDC consumer on BI waiver)

This issue grew worse during the pandemic according to both providers and consumers. For example, a large provider reported having to move over 50 clients from their agency side to their FMS side in the first year of the pandemic because of lack of workers, observing, "It becomes a necessity. It really doesn't have much to do with choice." HCAs also reported limiting the number of Medicaid clients they accept due to low reimbursement rates. The challenges associated with workforce shortages and low reimbursement rates that home care agencies were dealing with were passed on to consumers who were left with no choice but to self-direct and with fewer resources to manage this issue, as previously discussed.

SDC consumers and caregivers noted they had limited options in finding workers best suited for their care needs, especially when they could not find a worker at all. This is another issue that existed well before the pandemic but took on new meaning with additional COVID-19 safety practices for workers. Most SDC consumers and workers we interviewed were satisfied with their safety protocols, making calculated decisions that were often shared among care team members and flexible by taking into account personal and community level risk factors as well as the relationship and level of trust between consumers and workers – this exemplifies the advantages of self-direction. However, when

there was not agreement, the workforce shortage limited the ability of SDC consumers to implement their preferred safety practices.

We have one [consumer] currently that is pretty insistent that their worker should be vaccinated. The worker doesn't really want to get vaccinated, but they want to keep the worker.... people have kept workers that they really didn't want to keep because they couldn't find anybody else. (Rural FMS provider)

A rural caregiver to two adults with IDD spoke of tolerating workers who were perpetually tardy or absent because she felt she would not be able to replace them. She also wanted her workers to wear masks but shared: "I was afraid that they would not work if I made them."

In the face of workforce shortages, consumers prioritized their care needs and often relied on family, friends, and neighbors to fill gaps. Yet, many under-met or unmet care needs remained, ranging from poor hygiene to life threatening events. For example, a BI consumer experienced food insecurity when she no longer had a worker to assist with shopping and suffered another brain injury when she fell during an unassisted transfer. A SDC consumer with physical disabilities reported getting pressure ulcers because her family caregivers did not have the strength to implement her transferring and repositioning protocols:

There's the increased depression and anxiety that I have, skin breakdowns and pressure sores, and those kind of things I didn't really have to deal with that much before.... Now, it's pretty much constant. I got a big area on my lower leg that's not healing. Since I'm diabetic, it scares me. (Consumer on PD waiver with complex medical conditions)

Unmet care needs have cascading effects on mental and physical health and led to conditions that increase the risk of institutionalization.

They're isolated. They're depressed. They're not having human contact... Not to mention the fact that their home is not being cared for, or that they're not getting bathed as often as they would like to be bathed.... Their nutrition, I mean, every part of a person's life that it's been determined that they need the services. If they're missing any of those can impact them. (Combined FMS and HCA provider)

In the most extreme example, an FMS provider shared that a SDC consumer died in a home emergency during a timeframe that she was supposed to have a worker, but was unable to hire anyone.

These themes and subthemes interact with each other in complex ways (see Figure 1). To overview key linkages, SDC consumers were faced with workforce shortages (Theme I) but had few resources (Theme II) to address the structural roots of the workforce crisis. Their lack of access to organizational resources and CARES funds made it difficult to compete with rising pay in other industries. Further, it prevented them from offering sick pay or health insurance to help attract workers and mitigate new COVID-19 safety risks. Appendix K flexibilities allowing additional types of family members to be hired (Theme III) provided some SDC consumers and caregivers with a new resource to alleviate the impact of workforce shortages but did not resolve them altogether. The impact of Appendix K was limited because not everyone had or desired family caregivers and further, others were not aware of this option. These factors combined have an adverse impact on workers, caregivers, and consumers (Theme IV). These outcomes make clear that the strength and health of the workforce have a direct impact on care quality and the autonomy of consumers to self-direct their care. As expressed by an SDC worker, “My concern is always about the client. Anything that benefits the workers should benefit the client.” He further noted that his care-recipient’s struggle to find additional workers, “limits choice and reduces quality of care.”

## **Discussion**

The SDC model is premised on the value of self-determination in allowing HCBS consumers to manage their own care with flexibility and according to their individualized care needs and preferences. However, our findings demonstrate that in actual practice, self-determination and choice is severely limited by workforce shortages, funding structures, and state regulations. This contrasts somewhat to Caldwell and colleagues’ (2022) finding that SDC consumers exercised their hiring and firing authority to enforce their safety practices. The difference may be that they drew on a national sample whereas our study is focused on Kansas where workforce shortages are more severe than the national average (KDADS, 2021). Appendix K flexibilities expanding who could be hired as a worker were helpful, but the

overall COVID-19 policy response was inadequate for meeting the needs of SDC consumers, workers, and caregivers. Even though SDC is now a well-established model for delivering HCBS, state and federal policy makers failed to provide accessible emergency funding sources that adequately addressed the needs of this population. Workforce shortages increased caregiver and worker burden and also resulted in unmet care needs. Unmet care needs increase the risk of institutionalization (Kalankova et al., 2021), which is especially concerning during the pandemic when nursing homes were among the most dangerous places for the spread of COVID-19. While many workers remained dedicated to this line of work, this job is increasingly untenable considering wages offered elsewhere, and some felt the risk outweighed the benefit during the pandemic. Our findings point to policy changes and resources that could strengthen the SDC workforce, improve care quality, and expand SDC consumers' autonomy in directing their care.

To begin with, the Appendix K flexibility allowing parents, spouses, guardians, and 16-17 year olds to be paid as caregivers should be made permanent. Advocates in Kansas also made this recommendation, and State HCBS administrators are in the process of amending HCBS policies accordingly. Many other states also have restrictions against hiring family members who carry legal responsibility for the care recipient (e.g., spouses, guardians) (Ujvari et al., 2020). The main concern has been over potential conflicts of interest that could lead to abuse or financial exploitation of dependent adults, but with proper oversight and supports, these concerns can be mitigated. Prior research demonstrates that there is not a higher risk of abuse in SDC compared to agency-based care, and care recipients fare better physically, psychologically, and in their sense of security with paid family caregivers compared to non-family caregivers (Matthias and Benjamin, 2003). During the pandemic, the ability to hire family members has been linked with the prevention of gaps in care, trust in the safety measures the family member uses, and increased social connection (Caldwell, Heyman, & Atkins, 2022).

Additionally, if these flexibilities are made permanent, there needs to be clear communication of the new rules to all consumers and family caregivers.

Next, we recommend Kansas adopt a budget-authority model for SDC. New Mexico, Tennessee, and Texas are examples of managed LTSS states that allow budget-authority (Sciegaj et al., 2013). If SDC consumers and their family caregivers had more control over the dollars funding their care, they would have more tools and resources for addressing the many challenges they faced during the pandemic. With budget-authority, budgets can be used to cover other expenses such as job advertising, required background checks, worker training, and PPE, which proved to be burdensome or prohibitive expenses for SDC consumers in our study. Many states added PPE as a permissible purchase and some states, such as North Carolina, even increased budget limits for SDC consumers to be able to purchase PPE (Mahoney, 2020). 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 covered, a budget-authority model would provide the option of sacrificing some hours for higher pay to fill other hours. It is of course best for consumers to have all their care hours filled, which at minimum requires increasing reimbursement rates.

Regarding emergency funding, it is critical that funds be specifically targeted at the direct care workforce, including SDC workers. Many of the workforce challenges and unmet care needs could have been reduced if Kansas had used Appendix K flexibilities to temporarily increase reimbursement rates. The additional expenditure could then have been covered by COVID-19 emergency funding. But as demonstrated above, COVID-19 emergency funds were largely not accessible for the SDC model where 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. Future



emergency planning efforts need to proactively tailor the distribution of resources to be compatible with SDC as a unique delivery system.

Finally, investments in the HCBS workforce are needed more broadly. This work is critical to the health and wellbeing of older adults and individuals with disabilities, and living wages and benefits are essential to attract quality workers who can provide quality care. SDC consumers and caregivers especially struggle to recruit and retain workers when they cannot offer benefits that are more widely available in agency-based or residential care settings, as well as the retail and food industries. Medicaid expansion is a key missed opportunity for providing health insurance to DSWs and family caregivers in Kansas. Direct support workers are 55% more likely to be uninsured in non-expansion states compared to expansion states (Marquand, 2015). Opportunities for extending group-based health insurance coverage to SDC workers could also be explored, as is done for example, in the state of Washington (Tilly & Weiner, 2001).

A limitation of our study is that it is restricted to HCBS in Kansas during the pandemic. Findings may not apply to other states where HCBS structure and COVID-19 policies differed; however, they do highlight important strengths and challenges of the SDC model that policy makers should consider. 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, different Appendix K adoptions, Medicaid expansion, and different rate and benefit structures.

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