KU SCHOOL OF SOCIAL WELFARE
The University of Kansas

To: Robert G. (Bob) Bethel Joint Committee on Home and Community Based Services and KanCare Oversight

From: Carrie Wendel-Hummell, PhD; Director, Center for Research on Aging and Disability Options

Date: October 2, 2023

RE: HCBS COVID-19 Study

Chairwoman Landwehr, Vice-Chair Hilderbrand, and Members of the Committee:

Thank you for this opportunity to provide written testimony. My name is Dr. Carrie Wendel-Hummell and I direct the Center for Research on Aging and Disability Options (CRADO) in the KU School of Social Welfare.

My center is concluding a 2.5 year study on the Home and Community Based Services (HCBS) system response to the COVID-19 pandemic in Kansas, funded by the federal Agency for Healthcare Research and Quality (AHRQ). This study was based on 86 interviews and 339 surveys with adult HCBS consumers, workers, caregivers, and providers in Kansas. As we work to finalize our analysis and publish our findings, I wanted to share initial results that have key policy and practice implications.

1. **The most pressing and widely reported challenge reported by study participants was the Direct Support Worker (DSW) workforce shortage.** Although this shortage predates the pandemic, respondents reported it grew worse during the pandemic. Self-directed consumers, (those who hire their own workers rather than using an agency) reported increased difficulty finding and keeping workers. Providers reported increased vacancy and turnover rates, which resulted in turning away more referrals.
    - The workforce shortage was largely attributed to low pay and poor benefits. As entry-level workers, this workforce is offered better pay and benefits in the food and retail industries. Further, these industries were quick to increase wages in response to workforce shortages, whereas HCBS rate increases for personal care services did not occur until FY2023 and still lag behind. Although the ARPA-funded recruitment and retention bonuses were beneficial, this did not provide the sustained funding needed to grow the DSW workforce.
    - The lack of health care coverage and paid leave benefits became more problematic during the pandemic, as these are essential resources for managing exposure to COVID-19 or providing income stability during quarantines. Some workers left the field due to COVID-19 safety concerns.
    - Consumer self-determination was constrained by DSW workforce shortages. Many self-directed consumers ended up in this model not by choice, but rather because agency-

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based care was not available – a problem that grew during the pandemic. Additionally, self-directed consumers reported having to make difficult choices between accepting lower quality care or going without care at all, because they felt they would not be able to find new workers to replace any they let go. This also limited their ability to set and enforce COVID-19 safety practices by their workers.

2. **Self-directed consumers assumed a lot of responsibility as employers with limited resources.** In contrast to agency-based providers who could apply for CARES and other pandemic related funds to help cover hazard pay, sick pay, overtime, PPE, and other pandemic related needs, there was no viable pathway for self-directed consumers to access these resources. Additionally, FMS providers were instructed that they could not access these funds for this purpose as they are not the employer. The PPE made available to HCBS consumers by the State was widely commended, however, it did not cover all needs and some self-directed workers reported never receiving these supplies. Both consumers and workers reported paying for PPE out-of-pocket, despite their low wages and limited income.

3. **One-third of surveyed consumers reported they did not have a backup care plan.** An additional 20% and 11%, respectively, were neutral or disagreed that their backup care plans prepared them well for the pandemic. It was noted that backup plans were not tailored for a prolonged pandemic situation, relied on potentially unsuitable backup supports, and lacked details.

   Further, due to workforce shortages, backup caregivers were simply unavailable even though the pandemic created a greater need to cover times when workers were out ill or in quarantine. There was heavy reliance on unpaid caregivers to cover care needs, but some consumers were hesitant to rely too much on unpaid supports. There was also lack of knowledge around rules that may have allowed many unpaid supports to receive payment through the self-directed program.

   This survey finding is incongruent with MCO performance measures indicating that 89-97% of consumers, across all waivers, have a disaster backup plan on file.[i] A likely explanation is that the individuals reporting the absence of a backup plan in our study actually do have one but are not familiar with it. Regardless, if individuals do not recall their backup plans, they cannot draw on the strategies in them and thus in practice this is equivalent to not having a plan.

4. **HCBS consumers and caregivers expressed widespread dissatisfaction with the MCO care coordination model**. Though some participants thought individual care coordinators were doing the best they could, several respondents reported it was difficult to keep track of who their care coordinator was or how to reach them due to constant turnover. Only 54% of surveyed consumers reported receiving any pandemic related support from their care coordinator, and 18% said their care coordinator did not communicate with them at all during the pandemic or were uncertain if they did.

5. **Study participants widely reported unmet care needs.** 40% of consumers surveyed reported going without formal home care services for at least 2 consecutive weeks during the pandemic. Of those who specified how long they went without care, 45% went more than 3 months, 32% went 1-2 months, and 23% went 2-3 weeks. Workforce related issues were far more commonly cited as the reason for going without care compared to turning down care for safety reasons. These care gaps led to missed medical appointments, going without essential hygiene and showers, food insecurity, adverse health events (such as falls and pressure ulcers), and unnecessary institutionalization.

Ultimately, we found that an already strained HCBS system struggled to effectively address new pandemic related challenges. These findings point to several policy and practice implications to strengthen the HCBS system in general and to ensure it is better prepared for future pandemics or other public health emergencies:

1. **Improve DSW wages.** Although recent HCBS rate increases for personal care services help, they are still much too low to attract and sustain a quality direct support workforce. It is difficult for providers and self-directed consumers to compete with other entry level fields, and HCBS rates are also lower than those offered through Medicare and the Older Americans Act/Senior Care Act. Additional rate increases are needed to offer wages that can compete with the food and retail industry, and cost of living increases should be built into reimbursement rates.

2. **Ensure benefits for DSWs, including healthcare coverage and paid leave.** While agency based DSWs often have access to employer-covered benefits, self-directed DSWs do not. Reimbursement rates should be increased to cover paid leave. Medicaid expansion or adding HCBS-funded DSWs to the Kansas State Employee Health Plan are two routes by which healthcare coverage could be extended to self-directed DSWs.

3. **Provide individualized budget authority across all services for all waivers.** For most waivers in Kansas, self-directed consumers only have employer authority and not budget authority. This contrasts with the vast majority (75%) of self-directed programs nationwide that allow for budget authority.[ii] We commend the 2022 Special Committee on IDD Waiver Modernization for recommending that the proposed Community Supports Waiver include individual budget authority. We recommend that existing waivers be amended to also include this authority. Budget authority would give consumers more flexibility in setting wages, including paid leave. It could have also provided an avenue for the more even distribution of pandemic funds to help manage pandemic related needs, such as purchasing PPE.

4. **Lower MCO care coordination case load sizes with state-set standards.** Currently, KanCare MCOs are allowed to set their own caseload sizes. Although current contracts indicated that caseloads sizes must ensure the health, safety, and wellbeing of consumers, this goal is clearly not being met. There is, unfortunately, a lack of research on optimal caseload sizes, but caseload requirements that were in place under the previous targeted case management model can serve as a starting point. The upcoming re-procurement of KanCare contracts is an opportune time to

strengthen care coordination requirements or to move towards an alternate model, for example, independent care coordination or case management.

5. **Strengthen Backup Care Plans.** Backup care plans should be reviewed more frequently with consumers and caregivers, including during an emergency or shortly thereafter. At a minimum, this requires incentivizing smaller caseloads and more frequent client contact in care coordination requirements, as recommended above. Additional guidelines are needed to ensure that backup care plans address a wide variety of emergencies, including prolonged infectious disease pandemics, and address both medical and long term care support needs. These findings also indicate a need for performance measures to move beyond the mere existence of a backup plan to also assess whether these plans are personally relevant, meaningful, and accessible to consumers. Finally, additional steps should be taken to meet the US Department of Health and Human Services recommendation that individuals willing to serve as backup caregivers be added to payroll in advance of the need to provide backup care.[iii]

Additionally, our study found that while the **Appendix K flexibility allowing parents, guardians, and spouses to be paid as DSWs** did not resolve the DSW workforce challenges, it did help alleviate these shortages. We therefore commend the Kansas Department for Aging and Disability Services (KDADS) for their actions to make this policy permanent through waiver amendments.

I was unable to attend the October meeting of the Bob Bethel Joint Committee on HCBS and KanCare Oversight to provide in-person testimony, but welcome any opportunity to meet with members of the committee for further discussion. More detailed information on findings 1, 2 and 5 can also be found in a recent publication in the *Journal of Applied Gerontology*.[iv] A manuscript covering the findings 3, 4, and 5 is currently under peer review for publication. I look forward to sharing additional findings with the committee as we finalize our analysis in the coming months.

Please reach out to me if you are interested in learning more about our study or have any questions.

Sincerely,

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[i] Kansas Department of Health and Environment (2023). Fourth Quarter & Annual Report to CMS Regarding Operation of 1115 Waiver Demonstration Program – Quarter Ending 12.31.2022 - Year Ending 12.31.2022. https://www.kancare.ks.gov/docs/default-source/policies-and-reports/annual-and-quarterly-reports/2022/kancare-quarterly-report-to-cms---qe-12-31-2022.pdf?sfvrsn=5a7b521b_2 Retrieved 8/31/23.

[ii] Ujvari, K., Edwards-Orr, M., Morris, M., Deluca, C., & Sciegaj, M. (2020). *National Inventory of Self-Directed Long Term Services and Supports Programs.* AARP Public Policy Institute: USA.

[iii] United States Department of Health Human Services. Office of the Assistant Secretary for Planning Evaluation, Aspe, A.S.P.E, DHHS/Aspe, & D.H.H.S./A.S.P.E. (2010). *Understanding Medicaid home and community services : A primer.* (2010 ed.). Washington, D.C.: U.S. Dept. of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

[iv] Wendel-Hummell, C., LaPierre, T.A., Sullivan, D.L., Babitzke, J., Swartzendruber, L., Barta, T., & Olds. D. (2023). "'Anything that Benefits the Workers should Benefit the Client': Opportunities and Constraints in Self-Directed Care during the COVID-19 Pandemic." *Journal of Applied Gerontology* 42(4): 524-35.