



Kansas Association of Centers for Independent Living (KACIL)

**Report on Direct Service Worker Shortage
in Kansas Home and Community Based Services**

January 27, 2022

Background and Introduction

The COVID -19 pandemic has caused worker shortages in numerous industries. Recruiting and retaining Direct Support Workers for individuals with disabilities has not been immune. Volumes of personal testimony have been provided by consumer participants and their family members about the negative impact of not being able to recruit and retain Direct Service Workers (also known as DSWs, Direct Support Workers, Personal Care Attendants, home health aides, etc.) and the significant impact this has had on the health and well-being of Kansans with disabilities that receive Home and Community Based Services (HCBS) via the various Medicaid waivers. Individuals who self-direct their services are the sole employer of their Direct Support Workers and are essentially in-charge of recruiting and retaining their DSWs along with the support of the organization they receive Financial Management Services (FMS) from including payroll and information and assistance services.

What are self-directed services? Individuals that receive Medicaid and qualify for Medicaid to pay for them to live in long-term care facilities may choose to receive services similar to what they would receive in a long-term care facility in their own homes via the various Medicaid waiver HCBS programs. According to Medicaid.gov,

“Self-directed Medicaid services means that participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process.

Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided. For example, participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services. The Centers for Medicare & Medicaid Services (CMS) calls this *employer authority*. Participants may also have decision-making authority over how the Medicaid funds in a budget are spent. CMS refers to this as *budget authority*.”

What functions do DSWs perform? DSWs perform the Personal and/or Enhanced Care Services as approved in the service plan that is developed and authorized by the consumer’s managed care organization.

Personal Care Services include: bathing, dressing, oral hygiene, skin care, nail care, shaving, prosthetic/orthotic assistance, toileting, transferring, assistance with walking/mobility, wheelchair maneuvering, eating, meal planning/preparation/clean-up, shopping/errands, assistance with medication/treatments, transportation, use of telephone, laundry, housekeeping, minor sewing/mending, exercises/range of motion activities, other Health

Maintenance Activities, assistance in the community, non-physical support/supervision to assure health and safety, money management, teaching opportunities that may include therapeutic or academic components, and leisure and/or recreational activities.

Enhanced Care Services (also called ECS and formerly called Sleep Cycle support) provides support to the consumer during their normal sleep time and include activities such as toileting, mobility, turning or positioning in bed and medication management.

The work performed by DSWs is both physically and emotionally demanding. The pay is low (between \$7.25 hr. and \$11.70 hr. with the average wage being approximately \$10.70 hr.) and no benefits other than workers' compensation and unemployment insurance are provided. Their work is indeed essential to Kansans with disabilities that receive HCBS to live in their own home rather than in an expensive long-term care facility. Upon the suggestion of Kansas legislators during the Bob Bethell Home and Community Based Services (HCBS) Legislative Oversight Committee, the Kansas Association of Centers for Independent Living, Inc. (KACIL) and its member Centers for Independent Living, conducted a survey of Direct Support Workers and current HCBS consumer participants that employ DSWs.

The responses to KACIL's surveys confirm that the worker shortage has grown to crisis levels. Individuals are going without support, support that ensures basic needs such as bathing, toileting, eating, getting out of bed, going to the doctor and more, are being met.

Direct Support Worker and Consumer Surveys

Methodology

KACIL members that provide Financial Management Services (FMS) for the various Medicaid waivers developed two surveys that were used to gather feedback from 1. Direct Support Workers and 2. Consumers that receive HCBS and employ DSWs. Surveys were conducted over the telephone, through regular mail and via Survey Monkey in November and December 2021. Approximately 638 DSWs and 386 consumers provided feedback. Participation of DSWs and consumers was voluntary and the survey was open to all individuals served by the CILs participating in this project. It should be noted that the survey process was not scientific but rather designed to gather honest, meaningful information in terms that were intended to be accessible and easily understood by the respondents.

1. Summary of Data from Direct Service Worker (DSW) surveys completed by KACIL members between October and December 2021.

Q. 1 How long have you worked as a Direct Service Worker?

576 workers answered this question. Most workers (41%) responded they had worked 5 or more years as a Direct Service Worker. 25% reported 1-3 years, 20% have worked less than 1 year and 14% have worked between 3-5 years.

Q. 2 Are you related to the person you care for? (workers were instructed to select yes, if they worked for more than one consumer but were related to one or more of those consumers)

588 workers responded to this question. A slight majority, (51%) responded they were related to a person they care for. 49% responded no.

Q. 3 If you live in a rural area, how many miles do you drive to reach your consumer/employer's home? (one way)

563 workers responded. 78% reported they travel less than 30 miles one way, 6% reported they travel more than 30 miles one way, with one DSW reporting they travel 47 miles one way. 11% reported not applicable which could be interpreted to mean they live with the person they provide care for.

Q. 4 Please select the answer that best reflects why you are a direct service worker?

A total of 638 workers responded to this question. The overwhelming majority (60%) say they do this job because they enjoy helping others. 26% said they enjoy the flexibility of the work and 15% responded they are only working because the consumer can't find the help they need.

Q. 5 What things would increase your desire to maintain this job? (Respondents could select multiple answers)

Higher wage was selected by 459 workers

Benefits was chosen by 325 workers

Stable working hours was selected by 114 workers

Additional training was selected by 91 workers

Respondents were able to provide comments. The majority reiterated that higher wages were needed. Seven commented that paid holiday and paid leave time is needed. Several commented that all the above items are needed. Only 7 responded "not applicable" OR that none of the items listed in the survey were sufficient to keep them employed. The only additional item suggested was student loan forgiveness and 1 respondent suggested that CNA training should be paid for. Several individuals commented on their frustrations with the EVV system. The EVV system or Electronic Visit Verification is the timekeeping program required by the State of Kansas.

Q. 6 If you selected training as something that would increase your desire to maintain this job, please share a little more information:

326 individuals responded to this question. 44% stated they would be willing to participate in additional training if it would result in higher wages. 41% said they would be willing to participate in training if their time and training materials were paid for by the State or some

other source. And 15% stated they felt that additional training would help them in their job and did not need compensation for the training, they would simply like access to training(s).

Q. 7 If you were to accept a job somewhere else, what would the main reason be? (select top two)

Higher wages was selected by 397 workers

Benefits was selected by 269 workers

Stable working hours was selected by 92 workers and

Driving distance was selected by 52 workers

Under comments, the most frequent response (other than those items above) was the worker was either employed by a family member or someone they have become friends with and will only quit their job when the individual either passes away or is able to find another quality worker. Many family members commented they were very concerned about the lack of reliable, quality workers available.

Q. 8 Can you see yourself doing this job one year from now?

The good news is that 91% of the 562 respondents stated yes, they can see themselves doing this job one year from now. Only 9% responded no.

Of the 75 comments received, the majority reported that wages need to be increased and paid time off and mileage is needed. Numerous respondents that are family members commented on their frustration with the lack of quality workers and that they are tired of attempting to care for their family members while trying to maintain their regular job. They also expressed concern that they don't see this getting better even after the COVID 19 pandemic ends.

A few commented on their frustrations with the EVV system. One commented on frustration that their consumer/employer's budget does not cover overtime and there are not enough workers to cover the hours the consumer needs to remain safe in their home, leaving them no choice but to work overtime.

Trends and Interpretations

Survey responses were largely what we anticipated. A slight majority, 342 of Direct Service Workers (59%) have worked in their job less than 5 years. Of those 342 workers, 45% reported working less than 3 years: demonstrating the high turnover rate for these positions. 41% of workers reported tenure of 5+ years. The highest turnover is with the DSWs that have less than 3 years on the job. High turnover is incredibly disruptive for any employer but is detrimental for employers that rely on employees for their personal care and health.

51% of DSWs reported they are related to the person they care for and this group of workers anecdotally shared information that many were only doing the work because they couldn't find quality, reliable workers or because of COVID 19 concerns. It was also reported that they were also worried that once the fear of the virus has passed, they would not be able to find reliable, quality assistance for their family member.

Travel distances reported were lower than we anticipated but DSWs consistently provided feedback that transportation expenses were a problem for them and reimbursement for mileage was viewed as an important and needed benefit. Again, with this question there were a few family members who reported they believed that travel was a reason they could not find workers for their family member.

Overwhelmingly, DSWs reported they do this job because they enjoy helping others (60%) and enjoy flexibility of hours (26%). 91% reported they see themselves remaining in this job one year from now. Unfortunately, 15% responded they are only doing this job because the consumer cannot find other reliable help and 9% said they do not see themselves in this job one year from now.

Low wages were a consistent theme throughout the survey, regardless of tenure, relationship to consumer or reported commitment to staying in the job. One DSW reported that she had started a job at a major retail store at \$17/hour and did not know how much longer she would continue to work as a DSW when she could get more hours at a much higher hourly rate working retail. Her conflicting emotions were shared by many respondents, they want to help, but need higher wages to remain in this field.

When asked to list the top two things that would increase their desire to remain in this field of work, higher hourly wages was the most frequently selected reason. Benefits was the second selected item.

Regarding benefits, DSWs stated, in order of preference; holiday pay, paid time off and paid mileage were considered important. Comments provided suggest that the benefits alone are not enough to compensate for the low wages. Therefore, benefits while important, were not the driving factor in turnover. Low hourly wages are the driving factor in DSWs resigning and changing their career path.

In summation, it is clear from data and comments that the majority of DSWs prefer to work in this field and are committed to the individuals they provide care for. It is also clear that despite this, it is becoming progressively more difficult for them to do so because of low wages, no benefits, and no guarantee of a regular work schedule. The high turnover rate of workers highlights the difficulties self-directing consumers face when seeking new workers.

It is also noteworthy that this high turnover rate could lead to lower quality care for consumers due to lack of training and experience when workers remain on the job for less than a few years. It also significantly increases costs for DSWs, consumer and FMS providers due to constant onboarding of new workers and background check expenses which can cost up to \$70 (including the staff time that it takes to process background checks) or more per new DSW.

2. Summary of Data from Self-Directing Consumers Surveys by KACIL members between October and December 2021

Q. 1 If you had a Worker leave your employment in the last six months, what reason did they give? (Please select all that apply)

386 consumers responded to this question and could choose multiple responses.

- Workers found jobs with higher wages (24% of responses)
- Workers needed insurance and/or benefits (13%)
- Workers found jobs with regular hours/or more hours (12%)
- 21% of respondents reported they had not experienced worker turnover in the past 6 months or more
- 6% shared difficulty getting anyone to apply for the position, or, after talking with the potential worker, they failed to appear for their interview, never showed up for work, or provided no explanation and did not respond to calls or text messages

Q. 2 Do you have enough workers currently to cover all your hours?

31% of consumers reported not having sufficient DSW coverage to meet their needs. When looking at rural consumers, 45% were not receiving the level of assistance they need.

Q. 3 When you interview a new potential worker and they decline to work, what is the most often stated reason why? (Select one answer)

364 consumers responded; 43% reported wages were the most often reported reason a worker declined to work. 15% said they were “ghosted” receiving no response from workers or struggled to even get anyone to interview. 19% reported the applicant cited lack of benefits and only 5% said workers declined due to job duties. 18% selected “Other” with potential workers declining the job due to minimal hours on the service plan and erratic work schedule being the most frequent comment.

Trends & Interpretations

A significant number of respondents reported that they had little or no turnover in staff for some length of time. But those that had turnover had an exceedingly difficult time finding individuals to apply for the job opening or simply show up for work. There was also a consistent

theme for these consumers that when a worker was hired, they often were not reliable, or qualified and several experienced significant problems with potential worker theft. The consumers attribute their inability to find reliable, quality workers due to the low wage.

Even for consumers with steady workers, the low wage and lack of benefits was a concern for their ability to maintain their worker. There was also concern expressed that the number of hours allowed on their service plan were low, leading to workers needing other employment which then conflicted with their job schedules with the consumer.

Based on this feedback, it is clear that wages must be increased as soon as possible to alleviate the hiring crisis for the population that self-directs their Home and Community Based Services. Benefits were important to workers, with paid holiday and paid time off being the most often listed, but these were second place to the need for higher wages.

KACIL's Recommendations

Inadequate Service Plans - All individuals eligible to receive Home and Community Based Services are functionally eligible for long-term care facility placement. Concerns were expressed that the number of hours allowed on consumer's plans were low and therefore did not meet the needs of consumers. Not only does this make it difficult to obtain and retain a worker when sufficient time is not authorized to provide the needed services, but it also forces the worker to obtain other employment to achieve a living wage. Outside employment often interferes with the job schedule for the consumer participant. KACIL recommends that service plans be reviewed for adequacy. KACIL has already provided data to the Kansas Department of Health and Environment which is being reviewed, that clearly demonstrates the decline in service plan hours since the advent of managed care.

Direct Service Work as a "Career" – As the managed care organizations and state agencies express the desire to make direct service work a career choice, it needs to be acknowledged that a career implies full-time work with opportunities. KACIL recommends that in-order for Direct Service Work to be attractive as a long-term career choice, benefits including health, paid time off, holiday pay, mileage reimbursement, paid training and more need to be available. KACIL realizes that Medicaid Expansion may provide health insurance for DSWs that would qualify under its expanded eligibility criteria.

Increased reimbursement rates – KACIL recommends that reimbursement rates be permanently increased to \$4.50 per unit across all waivers so that DSWs can be paid up to \$15.00 per hour. This rate is needed to cover not only the hourly rate but also the employer's share of FICA, unemployment, and worker's compensation coverage. \$15 per hour is needed to compete with jobs that are typically considered entry level, minimum wage jobs such as fast food, discount stores, etc.

Rate Parity – KACIL recommends that there be rate parity for all HCBS waivers, and the reimbursement rates be equal so that all providers should have the same opportunity to offer competitive wages, and/or benefits, to the workers.

Avoid Medicalization – KACIL recommends managed care be structured to meet the needs and support Home and Community Based Services, not the other way around. The current managed care structure is based on a medical model that conflicts with the independent living philosophy. It does not hold true to the self-direction statute that Kansas based their HCBS model on, when consumers had more control over their services.

Community Health Workers – There have been recent discussions regarding moving Care Coordination from the managed care organizations to a Community Health Worker model. There will likely be many advantages to providing consumers with more comprehensive support, KACIL is concerned that yet another service provider “silo” will be added for consumers to navigate.

DSW Targeted Outreach – KACIL recommends that a comprehensive, statewide campaign be coordinated and designed to raise awareness regarding the need and opportunities for employment as a DSW including instruction regarding where to apply. KACIL further recommends that this campaign coincides with the recruitment and retainment bonuses that are being planned utilizing the increased FMAP opportunities.

Paid DSW Training – KACIL recommends that DSW training programs and resources should be developed using the increased FMAP opportunities. KACIL also recommends that the increased FMAP be utilized to compensate DSWs for training time or completion. KACIL would welcome an opportunity to be a part of developing training programs.

Waiver Amendments – KACIL recommends that current pandemic related exceptions (found in Appendix K as approved by CMMS) such as allowing previously excluded family members to provide services and a change background check requirements to allow DSWs to start work pending the return of the background checks be made permanent through waiver amendment. KACIL further recommends required background checks for DSWs be optional based on choice of the self-directing consumer.

In conclusion, KACIL has serious concerns regarding the DSW shortage and the potential related issues validated during this study, that ultimately lead to forced institutionalization when DSWs cannot be found. Centers for Independent Living maintain that access to community-based living should be as equally available as long-term care facility living. Currently this is not the case because of the DSW shortage and the rate disparity between community-based program, home health agencies and institutions. Self-direction of services offers the dignity of choice for Kansans with disabilities. Addressing the DSW shortage will preserve Kansas’ tradition of prioritizing our citizens and their rights to live independently in the setting of their choice.

About Kansas Association of Centers for Independent Living

The Kansas Association of Centers for Independent Living (KACIL) provides a powerful framework so that member Centers excel in advocacy and services ensuring that all Kansans with disabilities have opportunities for independent living and enjoy their civil and human rights. KACIL believes that community living is possible for everyone. Centers for Independent Living assist people who want to live in their own home by providing assistance in locating supports defined by the consumer. Every county in Kansas has a Center for Independent Living designated to provide the Core Services of Independent Living free-of-charge across all ages and disability types including Independent Living Skills training, Individual and Systems Advocacy, Peer Support, Deinstitutionalization, Youth Transition, and Information & Referral plus other services. To find the Center for Independent Living nearest you please visit: www.kcdcinfo.ks.gov/resources/service-maps

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