

UCSF Health Workforce Research Center on Long-Term Care

Impact of Electronic Visit Verification (EVV) on Personal Care Services Workers and Consumers in the United States

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Executive Summary

Introduction

The 21st Century CURES Act¹, passed by Congress in 2016 and amended in 2018 to extend compliance deadlines, required that all states implement Electronic Visit Verification (EVV) for Medicaid-funded Personal Care Services (PCS) by January 1, 2020 and for Home Health Care Services (HHCS) by January 1, 2023. EVV is a state-implemented telephone and computer-based technology system used to verify electronically that a Medicaid PCS or HHCS worker has arrived on the job and assisted a disabled person with approved PCS tasks. An estimated 4.8 million disabled individuals who are enrolled in various Medicaid PCS programs nationwide are affected by EVV.²

EVV was a response to reports issued by the US Department of Health and Human Services (HHS) Office of the Inspector General (OIG) as early as 2006. The reports raised concerns about fraud, waste, and abuse in Medicaid-funded PCS. These reports culminated in a 2016 HHS OIG investigative advisory recommending that Centers for Medicare and Medicaid (CMS) issue regulations to "more fully and effectively use its authorities to improve oversight and monitoring of PCS programs across all states."

According to CMS, as of September 2017, 10 states had reported implementing some form of EVV for various Medicaid PCS programs. Among these 10 states, several had implemented a version of EVV before the CURES Act was passed. For example, Illinois had implemented EVV in 2014 for its Home Services Program, and Ohio already required EVV for its fee-for-service Medicaid program for both PCS and HHCS. Texas had implemented EVV for most home-based care in 2015. Even though these states had EVV systems in place, they had to make substantial changes to comply with the federal mandate. Other states CMS identified had launched or modified existing EVV systems in an attempt to meet the implementation deadline. However, as the rollout progressed, most states encountered implementation difficulties, including accommodating unique issues related to self-directed programs, responding to stakeholder engagement, funding delays, and technology challenges.⁴ As of March 2020, CMS reported that 49 states, Guam, and the District of Columbia had been granted EVV implementation extensions until January 1, 2021, when funding penalties would be applied if a state failed to implement EVV. Tennessee was the only state that had not applied for a good faith extension.^{5,6} There have

been no further changes in the EVV implementation date since Congress extended it to January 1, 2021. Even though the effective date has passed, some states have not yet fully implemented EVV and, therefore, will receive a reduction in their Federal Medical Assistance Program (FMAP).^{7,8} In an attempt to provide more latitude to states, Congress introduced legislation in 2020 that, if enacted, would extend EVV implementation until six months after the COVID-19 pandemic is declared over.⁹

Neither the CURES Act nor CMS guidance had provided robust direction on how to implement a system that captures EVV reporting requirements, thus allowing states latitude to implement their own designs and technologies, including building on existing systems. At the start of and throughout the rollout, disability rights organizations and other stakeholders, including the Consortium of Citizens with Disabilities, ADAPT, the National Council on Independent Living, the Services Employees International Union, United Domestic Workers (SEIU/UDW), and people with disabilities who use Medicaid PCS,s expressed concerns that EVV could affect privacy, disrupt daily routines, and reduce the time available for care. 10-12

Methods

We investigated if EVV, in representative states, acted as a barrier, facilitator, or a promising practice in terms of supporting and advancing choice, control, community living, and participation for disabled individuals who received Medicaid PCS. We interviewed 12 consumers and eight workers from Ohio, Illinois, and Texas who received Medicaid PCS within the states' Home and Community-Based Services (HCBS) programs. These states were selected because they had either piloted a CURES-compliant EVV program or established one for at least some of their Medicaid PCS programs by late 2017, according to CMS.

Results

Interviews with PCS workers and consumers revealed seven main themes related to EVV use:

- Reduced Quality & Quantity of Services: EVV sometimes harmed the quality of PCS because it limited
 consumer choice and control by requiring pre-approved login and logout locations and preventing workers
 from helping consumers with time-sensitive needs at the beginning of shifts, such as using the restroom.
 Additionally, EVV sometimes reduced available time for services to be provided because workers spent
 extra time at the beginning and end of their shifts ensuring that they complied with EVV requirements.
- Technical & Operational Problems: Burdensome EVV technical problems, such as connectivity issues and the misrecording of login and logout times, was a barrier to timely worker payment. Although resolving these errors was technically workers' responsibility, consumers were also affected. The process for fixing EVV errors was often complicated and took time, and some workers relied on consumers for their help. To avoid frustrations with and spending time on fixing either system or user errors, consumers and workers felt pressured to reduce user errors as much as possible, which resulted in workers and consumers feeling rushed and anxious about logging in and logging out at an exact time.
- Privacy Concerns: Consumer and worker privacy was affected when functionalities of some EVV
 systems, such as the global positioning system (GPS), were activated, and when Social Security numbers
 were required for consumer identification.
- Worker Compensation Concerns: PCS workers did not always receive accurate or timely paychecks for the hours they worked due to EVV system errors. Receiving inaccurate or late paychecks was especially burdensome for PCS workers, whose wages are low.
- Worker Recruitment & Retention Concerns: Many consumers thought that worker issues with
 receiving proper payment, as a result of EVV not functioning properly, acted as a disincentive for workers
 to either join or stay in the PCS workforce.
- Perceived Benefits: EVV's ability to reduce fraud by incentivizing workers to show up on time, especially
 for older consumers with cognitive limitations, was recognized. When properly working, the system
 created more accurate and secure records compared to paper timesheets.

• **User Recommendations**: EVV could be improved in many ways, including: extending the grace period for logging in and out; allowing PCS workers to remain logged in when they accompany consumers to medical appointments and community activities; allowing user errors (e.g., incorrectly typing ID #s) to be corrected more easily; eliminating GPS capabilities; and improving voice verification capabilities.

Conclusions

Congress included EVV for Medicaid-funded PCS and HHCS in the 21st Century CURES Act of 2016 as a response to reported fraud, waste, and abuse in the system. As states rolled out EVV, disability advocacy and rights groups, worker unions, and people with disabilities who use PCS expressed concern that EVV could disrupt daily routines and worker-consumer communications and reduce workers' available time to provide needed care. The majority of interviewees reported a range of difficulties and negative repercussions related to the use of EVV. Interviewees presented numerous examples of the challenges they repeatedly encountered to meet the demands of the systems in use in their states and their efforts to manage the perceived intrusiveness of EVV. Some interviewees thought EVV was useful for worker accountability, especially when older people with cognitive limitations could not monitor their workers effectively. Although consumers and workers acknowledged that EVV will likely continue to be required going forward, the 21st Century CURES Act and CMS guidance governing EVV use could be revised to resolve some of the more persistent problems identified in this report, such as increasing EVV system flexibility, improving system reliability, removing or deactivating GPS tracking capabilities, and discontinuing use of Social Security numbers as identification.

Introduction

The 21st Century CURES Act

The 21st Century CURES Act¹, passed by Congress in 2016 and amended in 2018 to extend compliance deadlines, required that all states implement Electronic Visit Verification (EVV) for Medicaid-funded Personal Care Services (PCS) by January 1, 2020 and for Home Health Care Services (HHCS) by January 1, 2023. EVV is a state-implemented telephone and computer-based technology system used to electronically verify that a Medicaid PCS or HHCS worker has arrived on the job and assisted a disabled person with approved tasks such as dressing, bathing, toileting, meal preparation, eating, and maintaining a household. EVV systems must verify the type of service performed, individual receiving the service, individual providing the service, date of service, location of service delivery, and time the service begins and ends.

EVV was developed in response to numerous reports released over the course of a decade by the US Department of Health (HHS) and Human Services Office of the Inspector General (OIG) calling attention to weaknesses in the PCS program that were thought to contribute to improper payments, questionable care quality, and significant amounts of fraud. A 2016 OIG investigative advisory reported opening more than 200 investigations from late 2012 through 2016 involving fraud and patient harm or neglect in the PCS program nationwide. The advisory recommended that CMS "more fully and effectively use its authorities to improve oversight and monitoring of PCS programs across all states" by establishing minimum federal qualifications and screening standards for PCS workers. Suggested standards included PCS worker background checks; requiring states to enroll or register all PCS workers and assign them unique numbers; and requiring that PCS payroll claims identify the dates of service and the PCS worker who provided the service. The advisory also recommended that CMS consider whether additional controls were needed.³ In response to the advisory, the EVV mandate was included in the CURES Act. The Congressional Budget Office projected that EVV, when fully implemented, would save \$290 million over a 10-year period.¹³

EVV affects an estimated 4.8 million low-income children, adults, and older people with disabilities who receive Medicaid home and community-based services (HCBS), such as PCS and household management, that enable

them to live independently in the community. Among those potentially affected are people with significant physical disabilities, people with multiple medical conditions, people with mental health conditions, people with intellectual and developmental disabilities, and people who experience autism.²

Implementation

According to CMS, as of September 2017, 10 states had reported implementing some version of EVV for certain Medicaid PCS, and two states, Illinois and Connecticut, had implemented EVV for HHCS. Connecticut was the only state that had implemented EVV for both PCS and HHCS.¹⁴

Some states had required, and thus implemented, a version of EVV for certain Medicaid home care programs before the CURES Act was passed, including Illinois, Texas, and Ohio. Other states had either modified existing systems or begun phasing in EVV in anticipation of the original January 2020 compliance date. However, as rollout progressed, almost every state experienced implementation difficulties, including accommodating unique issues related to self-directed programs, responding to stakeholder engagement, funding delays, and technology challenges, all of which created barriers to fully implementing a CURES-compliant EVV system.⁴ Federal funding was available to states to implement EVV, and the Centers for Medicare and Medicaid Services (CMS) would reduce Medicaid funding if states did not implement EVV by the applicable dates. As of March 2020, according to CMS, 49 states, Guam, and the District of Columbia had applied for and received good faith extensions for January 1, 2021 when funding penalties would be applied if a state failed to implement EVV. Only Tennessee did not apply for the extension.^{5, 6} There have been no further changes in the EVV implementation date since Congress extended it to January 1, 2021. Even though the effective date has passed, some states have not yet fully implemented EVV and, therefore, will receive a reduction in their FMAP.^{7, 8} In an attempt to provide more latitude to states, Congress introduced legislation in 2020 that, if enacted, would extend EVV implementation until six months after the COVID-19 pandemic is declared over.⁹

Neither the CURES Act nor CMS guidance provided robust direction on how to implement a system that captures EVV reporting requirements, thus allowing states latitude to implement their own designs and technologies. This has spurred concerns for PCS workers and disabled people about privacy and personal autonomy. For instance, the CURES Act does not require that EVV systems use the global positioning system (GPS) to identify the whereabouts of PCS workers throughout their shifts, yet CMS acknowledges that GPS is one approach states could use to meet EVV requirements. Disability advocacy and rights groups like the Consortium of Citizens with Disabilities (CCD), a large coalition of national organizations, point out that EVV systems that use GPS could track the location of consumers and their PCS workers as they engage in everyday community activities, like grocery shopping, running errands, and participating in recreational activities, outside of times when workers are logging in and out of EVV.¹⁵

Another component of EVV that has sparked privacy and autonomy concerns is Interactive Voice Response (IVR), often referred to as "voice verification," which requires the PCS worker and/or consumer to login and out using biometric voice authentication on a landline or cellular device. This EVV technology verifies that the approved PCS worker and consumer is the actual person providing and receiving the service(s), respectively. Some PCS workers and consumers have expressed privacy concerns associated with collecting, storing, and using such biometric information. Additionally, workers and consumers have expressed that consumer autonomy can be limited by IVR in situations where consumers experience speech disorders, which can prevent IVR from properly recognizing their voices, thus resulting in non-compliance with EVV.

Since EVV was mandated in the CURES Act and throughout rollout, disability advocacy and rights groups, PCS worker unions, and people with disabilities who use PCS have expressed concern that EVV could disrupt daily routines, disrupt worker-consumer communications, invade consumer and worker privacy, and reduce workers' available time to provide needed care. The National Council on Independent Living, the longest-running national

cross-disability, grassroots organization run by and for people with disabilities, opposed EVV based on privacy and civil rights concerns. 11, 15 Furthermore, The United Domestic Workers (UDW)/American Federation of State, County, and Municipal Employees (AFSCME) Local 3930 and Services Employees International Union (SEIU) Local 2015 observed that EVV's requirement of providing data in real time is "...inherently burdensome and almost certainly would make receiving services in the home and community more difficult." 16 Media reports have also highlighted similar issues. 17 Moreover, CMS noted that states may choose to use EVV to collect more information than the CURES Act mandates as a method to more comprehensively curb fraud, waste, and abuse in the system. The thought of implementing additional reporting requirements and restrictions that were not federally mandated raised concerns about EVV's potential to further encroach on disabled people's autonomy, freedom of choice, and community participation.

Personal Care Services (PCS)

Many people with significant disabilities and functional limitations require home and community-based services (HCBS), which encompasses PCS, to ward off unwanted institutionalization, live independently and safely, and participate as they wish in their communities. In 2013, for the first time, combined state and federal Medicaid spending on HCBS surpassed spending on institutional care, reflecting disabled and older people's preferences to live in the community and state actions to be compliant with the Americans with Disabilities Act (1990), which mandates that public entities administer programs in the most integrated setting appropriate to the needs of disabled individuals. Olmstead v. L.C. (1999) held that a state must allow a person to receive long-term care services in the community if the person does not oppose living in the community, a professional has deemed community living to be appropriate, and provision of such services can be reasonably accommodated by the state. In the community is the person does not oppose living in the community accommodated by the state.

PCS eligibility, number of approved service hours, and community destinations that a consumer may visit while accompanied by their worker are determined by a social worker or other designated representative via a care/service plan. PCS workers, consumers, and home care agencies must strictly follow this care/service plan. There are two models for the provision of PCS. Under the agency provider model, PCS are managed by an authorized agency that is responsible for hiring and firing PCS personnel on behalf of an eligible disabled person, although the disabled individual can supervise and direct agency workers to an extent. The consumer-directed model permits an individual, rather than an agency, to provide PCS and provides the disabled person, or an authorized representative, the autonomy to hire, train, supervise, and fire providers of their choosing. Some, but not all, HCBS programs allow these hired workers to be family members of the consumer. Both the agency provider model and the consumer-directed model of care delivery must comply with state-specific EVV requirements.

Methods

We investigated if EVV, in representative states, acted as a barrier, facilitator, or a promising practice in terms of supporting and advancing choice, control, community living, and participation for disabled people who received Medicaid PCS. We focused on PCS because HHCS agencies were required to comply with EVV at a later date. We set out to answer the following research questions:

- Is EVV a benefit or a burden?
- Does EVV affect personal privacy?
- Does EVV affect workers' ability to perform their jobs?
- Does EVV impact quality of care?

- Have workers experienced any technical problems using EVV?
- Does EVV affect disabled people's choice and autonomy regarding home and community activities?
- How could EVV be improved?

We reviewed peer-reviewed and grey literature, federal and state EVV policies, implementation directives, and reports. We also conducted informal background interviews with selected state officials responsible for EVV implementation. We carried out 60-minute telephone interviews with 12 disabled individuals and eight PCS workers from Texas, Illinois, and Ohio in Medicaid HCBS programs in which EVV for PCS had been piloted or implemented. We received approval from the University of California San Francisco Institutional Review Board to carry out the research.

Recruitment Approach

We recruited participants from Illinois, Texas, and Ohio because, in late 2017, CMS had reported that EVV programs in these states were either piloted or in place for at least some of their Medicaid HCBS programs. To identify possible participants, we conducted email and telephone outreach through state disability advocacy networks, PCS worker unions, home care organizations, and personal networks. Participants with disabilities were selected because they received Medicaid-funded assistance with personal care or other tasks, and their PCS workers were required to use an EVV system. PCS workers were selected because they were employed through a Medicaid-funded HCBS program and were required to use EVV. Individuals who were interested in being interviewed contacted us by phone or email. At that point, we scheduled the telephone interview with the prospective participant, shared information about the project, and emailed a consent form. Two researchers participated in each interview. Interviews were audio-recorded, and one interviewer took extensive notes during each interview. Individuals who participated in an interview received a \$50 gift card.

Interview Protocol & Procedures

We developed semi-structured, open-ended interview protocols for both disabled participants and PCS workers. Disabled participant interview topics fell into two domains: core questions and EVV-specific questions.

Core questions:

- Verified that the consumer was receiving Medicaid-funded PCS
- Determined the number of approved service hours
- Determined the number of workers who provided services for consumers
- Determined whether workers provided services away from home, such as at school or at a job

EVV questions:

- Determined if the person was familiar with EVV and their state's EVV policy
- Determined the type of equipment consumers were required or chose to use
- Determined the frequency and equipment used for EVV reporting
- Determined the types of information reported
- Elicited consumer experiences with and opinions of EVV

Elicited consumer recommendations for improving EVV

PCS worker interview topics fell into the same two domains: core questions and EVV-specific questions.

Core questions:

- Determined whether the person had any licenses or certifications
- Determined worker job responsibilities
- Determined length of time working in the field
- Determined the number of people workers served at the time of the interview
- Determined information about the workers themselves, such as age and functional limitations

EVV questions:

- Determined the type of system that workers were required or chose to use and whether they'd been trained to use it
- Determined the information that workers were required to provide at each shift
- Elicited worker experiences with and opinions of EVV
- Elicited whether workers had benefitted from EVV or had problems or concerns about using the system
- Elicited how EVV affected workers' jobs and the consumers that they worked for
- Elicited worker recommendations for improving EVV

Results

Interviews with PCS workers and consumers provided insight into their backgrounds and history with PCS, their experience with EVV training, and equipment and processes associated with properly complying with EVV. With respect to interviewees' experiences with and opinions of EVV, the interviews revealed six main themes: reduced quality and quantity of services; technical and operational problems; privacy concerns; worker compensation, recruitment, and retention concerns; perceived benefits; and user recommendations for improvement.

PCS Consumer & Worker Profiles

Consumers interviewed reported functional limitations and disabilities that included progressive degenerative neurological disorders, nonprogressive neurological brain disorders (e.g., cerebral palsy, traumatic brain injury, lack of sensory nervous system development), neuromuscular diseases (e.g., muscular dystrophy, spinal muscular atrophy), and other physical conditions, such as scoliosis, compressed chest cavity, vision loss, hearing loss, and balance issues.

Most of the PCS workers interviewed worked for consumers other than those we spoke with for this research. As a group, they had worked in the field for as little as two years and for as long as 50 years. Several were caregivers for family members, and all of them worked for only one consumer at the time of their interview. A few reported that, in the past, they had worked for several consumers at once. Most consumers interviewed reported working with between two and 10 workers. Typically, consumers' PCS worker pools consisted of a mix of

permanent (full-time employees) and part-time, or "backup," workers. Job titles for these individuals included personal assistant, individual provider, personal care services worker, personal care provider, and home or personal care attendant. Throughout this report, we use the terms PCS worker(s) or simply workers.

Some PCS workers held healthcare related certifications, such as a Certified Nursing Assistant (CNA) or Medical Assistant (MA). Others were certified in Cardiopulmonary Resuscitation (CPR), use of Automated External Defibrillator (AED), first aid, habilitation, nutrition, and/or phlebotomy.

PCS Variation

Service Plans & Location of Services

All interviewees spoke about their respective states' limitations on where Medicaid PCS could be provided. They noted that the consumer's care/service plan, which is developed by a consumer's case manager, usually stipulated whether and which services could be provided outside of the home, thus determining if workers could accompany consumers to community locations, sign in and out of EVV at those locations, and/or be paid for services provided at those locations. Typically, locations outside of the home had to be approved and registered with the EVV system ahead of time. However, interviewed consumers with care/service plans that allowed them to receive services outside of their home explained why, in their opinion, this prior approval system did not work well for them. Some reported that their case managers would not approve certain requested service locations, and others feared that additional requests would be rejected if they applied for "too many" locations to be approved. They also noted that it often took a long time for new locations to be approved, which impeded consumers' ability to quickly change plans, if needed. One consumer's case manager expressed that she wished that the consumer would not request so many changes to the care/service plan because it created more administrative work for her; these statements bothered the consumer.

Most interviewees reported that, according to their service plan, workers could provide services away from the consumers' home at some locations in the community. Among this group, several said that they did not have any limitations on where services could be provided. However, despite lack of restrictions about where services could be provided, EVV sometimes required that shifts begin and end at the consumer's home. This was a barrier to receiving care when worker shifts had to start or stop while consumers were already outside of their homes and would remain so for an extended period of time, such as while they were at their job.

Interviewees who reported that workers had the ability to provide at least some services outside of the home said that this ability did not always translate to workers getting paid for all activities conducted outside of the home. For instance, some workers in Ohio and Illinois said that workers in their states were not paid for the time they spent accompanying a consumer to medical appointments or the hospital/emergency department. Additionally, several workers in Illinois reported that they were not allowed to be clocked in during travel or driving time and that the state did not pay for the time they spent driving or traveling. Moreover, the permitted mode of transportation varied from state to state. These differences reflect variations within state Medicaid PCS programs.

The number of approved PCS hours, based on functional need, varied widely among the people interviewed. At minimum, consumers received 10 hours of PCS weekly, and at maximum, 108 hours of PCS weekly. Workers interviewed most frequently provided help with activities of daily living (ADLs), including toileting, feeding, and dressing, and with instrumental activities of daily living (IADLs), including meal preparation, laundry, cleaning, and running errands. They also accompanied consumers to doctor appointments and provided help with tasks such as medication management and scheduling appointments.

Care Models

Among the 12 consumers interviewed, one person reported that their services were provided completely by a home care agency, eight people said they self-directed their care and hired and fired all of their own workers, and three people indicated that a home care agency provided some of their PCS and that they personally recruited, trained, and supervised other workers themselves. One of the interviewees noted several reasons for using a combination of both models. She explained that two of her three agency-provided workers had suddenly quit because they were unhappy with the agency's practices, which then left the agency short-staffed and unable to provide replacement workers. The interviewee needed to recruit workers privately to make up for the additional care that she had previously been receiving from other agency caregivers and to provide a break for the last remaining agency worker. Consumers recruited prospective employees through personal networks, family and friends, worker registries, and social media sites.

EVV Equipment & Processes

Most interviewees reported using EVV for as little as six months and as long as eight years.¹ Consumers and workers reported using four different equipment options to report to the EVV system: a government-issued device (a smartphone with most of its functions deactivated), a worker or consumer cell phone (with an EVV app installed), a landline (referred to as "telephony"), and/or a computer (referred to as "manual entry"). The type of equipment used was determined by their state's laws and regulations, agency policy (if care was delivered through an agency), and at times, consumer and/or worker preference. When either a cellphone or landline was used, the telephone number for that phone had to be verified with the state ahead of time. According to interviewees from Illinois, the state preferred that land lines be used, but other equipment options were also allowed. Many interviewees noted that they used more than one piece of equipment for reporting depending on the day's circumstances. For example, one consumer said they typically used the landline, but would sometimes use their cell phone if their worker needed to log in or out while they were out in the community. Several interviewees from Ohio stated that they originally used the government-issued device, but later switched to the cellphone app after experiencing difficulties with the device.

All interviewees stated that logging in and logging out was only required at the beginning and end of a shift so long as services were being provided at the home of the consumer. However, several interviewees in Illinois stated that workers had to sign out of EVV before departing for a community destination, then sign back in whenever they arrived at the community destination or back at home, depending on what the service plan allowed.

The type of information required for logging in and out was similar across interviewees, albeit with a few minor differences. After calling the appropriate EVV phone number (or logging in via the government-issued device, app, or computer), a worker first entered a number that identified themselves as an approved worker. This ID number was often specific to the EVV system used in their state (e.g., Santrax in Illinois, Sandata in Ohio). Sometimes, a Medicaid ID was used. In other cases, both the EVV system and Medicaid IDs were required. Several interviewees stated that a consumer ID also needed to be entered during the login/out process. Some consumers noted that their Social Security number was required as the ID, which raised privacy and security concerns for them.

After entering the required ID number(s), workers then pressed a single number ("1" or "2") to indicate either log in or log out, respectively. When logging out, they entered another number to indicate the type of services they provided. All interviewees noted that PCS were subsumed under the same "code," so only one number had to be entered for this step in the process (i.e., separate codes were not required for different tasks under the umbrella

¹ Many home health care agencies (HHCAs) used a form of electronic timesheet verification before the CURES Act was signed into law in 2016. The CURES Act required that HHCAs begin collecting additional data electronically using EVV technology by January 1, 2023.

of PCS). At this stage, some interviewees noted that consumers had to provide their signature or voice verification.

EVV Training

The 21st CURES Act requires that "Individuals who furnish personal care services, home health care services, or both...are provided the opportunity for training on the use of such system." HHS issued guidance in 2018 with respect to training PCS workers on the operation of EVV, which lists topics that states were encouraged to consider incorporating, but were not required to incorporate, into training. Topics suggested by HHS included: EVV functional requirements, software training (including details of how to use the system), data capturing, running system reports, use of system hardware, benefits to providers that promote buy-in (e.g., potentially faster payments), and penalties and sanctions for not using the EVV system.²⁰ Training methods, frequency, duration, and delivery (including who delivers training) were left to states to decide because each selected different EVV system models and technologies. Training can be provided by the state, EVV vendors themselves, or other contracted entities. Moreover, while states must offer training, they can determine if it is mandatory or optional.

Half of the interviewed workers commented that trainings had been mandatory. Training content, duration, effectiveness, and satisfaction varied, although generally, interviewees reported that training was helpful.

Workers interviewed reported participating in training offered either in-person or online. Several workers attended in-person, didactic lessons that incorporated slideshow presentations. One of these workers said that the training lasted about two hours and that she thought the training was helpful; she felt that the training used good verbal instruction, embedded video examples, and handouts that walked the worker through the system. Another worker thought that the training was confusing and that EVV was simpler to use compared to how it was depicted at the training.

Other workers attended online rather than in-person trainings. One worker completed a two-hour guided training through a web-based app. This worker said that she found EVV overwhelming from the start and that she had to go back to the training several times to figure out how to use the system. She also relied on the consumer's help from time to time. "There were some things that were unclear once I started using it because the information is very overwhelming and, when you're actually doing it, it's different [compared to the training]." This worker originally used the government-issued device, which had GPS capabilities enabled, and said that one of the overwhelming components of EVV included that she had to log in and out within 100 feet of a very specific location, which the training was not clear about. The worker later switched from the government-issued device to the application on her personal phone, partially for GPS-related issues. However, switching to the app exposed another issue with her initial training; she said that the training did not adequately describe how the web-based version of EVV worked. This was problematic because sometimes the application on her phone did not pick up the sound of the consumer's voice (the consumer experienced a speech impairment) for voice verification, in which case she had to use the web-based system as a backup. The worker commented that because the training did not cover the web-based version well and because it was not user-friendly, it was difficult to navigate, especially in the beginning.

Another worker attended a series of three to four webinar trainings, each lasting about two to three hours. At the time, this worker thought the training was fairly adequate but that actually using EVV was different from how the system was presented in the trainings. She said that one of EVV's flaws, which was not presented at the training, was that the government-issued device would sometimes not clock out in a timely manner. She said, "I would have to go into the maintenance website and go back and correct clock-out times because by the time the device went through its cycle to clock out, it ended up clocking me out 2-3 minutes after my actual clock-out time." She noted that she had to call Sandata, the software company that Ohio used to implement EVV, several times in order to ask questions about the system, such as how to properly input information into the maintenance website.

One consumer recalled that her workers had to attend a webinar presented over the course of two to three days that included a live training and a question-and-answer session. This person commented that she wished that the training materials has also been made available to consumers so they could help their workers understand the system.

Experiences Using EVV

Reduced Quality & Quantity of Services

The majority of interviewees spoke about how EVV negatively affected consumer quality and quantity of care. They explained that EVV:

- Acted as a barrier to receiving services immediately upon worker arrival. Interviewees commented that this was often a problem when consumers needed to use the bathroom at the beginning of workers' shifts. One consumer explained how their needs were sometimes sacrificed in order to stay compliant with EVV: "There have been times when I've needed something immediately upon the caregiver's arrival, you know, for the beginning of the shift. I've needed something immediately, so therefore I'm sacrificing my need so that they can log in in a timely fashion, because if they don't log in at the appropriate time, it throws everything off, because then they're logging out at the incorrect time, and then it throws the whole system off, because it has windows that you have to log in."
- Interrupted workers when in the middle of completing a task. The requirement to logout of EVV at very specific times often interrupted the natural flow of tasks. One worker explained that the lack of fluidity created an anxious environment for the client but was also burdensome to her, as she would usually take the time to complete the interrupted task even after she had logged out: "[EVV] created a level of anxiety that involved the client. The preciseness of when you left was a little disconcerting. If I was in the middle of something, I wasn't going to stop and call in. And sometimes I would, but I would complete my task [after]. With the paper [timesheets], it was more fluid. 'I'm going to write that I left at 4:00, even though it's 4:15, because we're in the middle of cleaning out your refrigerator. I'm not going to walk away.""
- related tasks. Many workers spent extra time focusing on EVV login and logout instead of consumerrelated tasks. Many workers spent extra time focusing on EVV at the beginning and of their shift given
 that mistakes made in the login and out process could lead to incorrect compensation amounts or lack of
 compensation altogether. The extra focus on EVV at the beginning and end of shifts detracted from the
 time that could be spent on consumer-related tasks. Additionally, some EVV systems required that
 passwords be changed every 90 days; on those days, workers had to spend even more time in the
 mornings on EVV. Consumers expressed that a few minutes spent on EVV at the beginning and end of a
 shift might not sound like a lot of time, but that it quickly added up. One consumer explained that her
 workers felt rushed to complete all PCS tasks and properly comply with EVV requirements: "I've heard
 from the providers directly that they feel rushed because now they do have to do this clock-in clock-out,
 and if it's not right, then they worry that again, the check is going to be delayed, so they feel like there is
 never enough time. Especially...if you're someone who conceivably has four clients a day, and you get
 behind on one and it puts your whole day behind, it's definitely a hindrance."
- Required unrealistic scheduling consistency. Although service plans dictate that worker shifts should start and end at specific and consistent times, before EVV, workers and consumers sometimes shifted start/end times slightly to accommodate unanticipated schedule changes. Paper timesheets allowed for workers to report that they began and finished working at the designated times, even if the shift started and ended a little earlier or started and ended a little later in actuality. One worker commented that this reduced scheduling flexibility caused added stress for the consumer as well as herself: "I do know that [EVV has] created a lot of stress with the attendants because [with] my [previous client], we had a set time to put down on the timesheet, but sometimes she would call and say 'I'm still at a church event, can you come an hour later.' And I would say 'yes.' And yet I couldn't reflect that on [EVV] because then it

would look like I wasn't consistent. So a lot of that kind of latitude is taken away from a client in an attendant situation where you almost take some of the freedom away from the client because they have to be at that location at a specific time."

Technical & Operational Problems

Everyone interviewed reported technical and/or operational problems while using EVV. Correcting these problems took time away from providing services to consumers, but was necessary to prevent timekeeping and payroll errors. Several interviewees noted that while they experienced the most severe technical and operation problems when EVV was initially being rolled out many of these problems still had not been completely resolved. Problems included:

- Lack of connectivity. Many interviewees said that calls made to log in and out of EVV often did not go through or were dropped, the EVV number being called would ring continuously, or the EVV line produced a busy signal. These issues sometimes resulted in an inaccurate recording of the login/out time and further burdened workers, as workers were usually responsible for correcting EVV recording errors.
- EVV recording the time incorrectly. Several interviewees reported instances when the worker would log in or out at the correct time, but EVV would record and repeat back a different time. These inaccuracies affected worker pay by creating a discrepancy between the number of hours reported using EVV compared to the (separate) paper timesheets that many workers were still required to submit. Workers, again, were usually responsible for fixing these errors, but the consequences of these errors also affected consumers. One consumer noted that if EVV inaccurately recorded a number of hours that exceeded her approved service hour amount it could jeopardize her receipt of future services. As a result, she spent extra time ensuring that the number of recorded service hours did not exceed the number approved, which caused her added stress: "In my head, I need to calculate how many minutes everything equates to, to make sure that I don't exceed my 10 hours per day...the new governor says that no one can have overtime...which adds to more calculation for me. I just want to pull my hair out. It's just chaos."
- Difficulty in correcting EVV errors. Workers who provided care to consumers under the consumerdirected model were responsible for fixing EVV errors directly, usually via manual entry. Several
 interviewees commented that the manual entry system was not user-friendly and that the process for
 fixing these errors was complicated and laborious. Workers who provided care to consumers under the
 agency provider model had to continually follow up with agency personnel to ensure that corrections had
 been made by administrative staff.

Interviewees also noted less frequent, but nonetheless challenging, issues with regard to logging in and out of EVV, including: the government-issued device breaking, emergency alerts taking precedence over EVV (i.e., preventing login/out at the proper time), lack of Wi-Fi access in certain settings, the system failing to register the login/out time, the system timing out because it took too long to process the login/out time, and the entire system being taken offline for updates.

Privacy Concerns

The CARES Act specifies that EVV systems must comply with Public Health Services Act HIPPA privacy and security requirements; however, EVV privacy concerns have nevertheless arisen in several contexts. One notable example is when PCS is provided in a community location and the government-issued device used for EVV has the capability to transmit the location using GPS. In 2019, CMS provided suggested methods to protect consumer privacy in this situation, but states are left to decide how best to ensure privacy in the context of their individual EVV systems. While GPS is not required, states may elect to use it.²⁰ Other privacy concerns include requiring entry of personal information, such as Social Security numbers, for identification when logging into the EVV system. Even as the EVV enabling legislation and related federal agency clarifications recognize the need for state EVV systems to protect consumer and worker privacy, national disability rights, civil liberties, social justice,

and labor organizations have raised privacy concerns about EVV use. 11, 15, 17 These problems were reflected in the perceptions and experiences of some consumers and workers interviewed.

GPS Capabilities

Several interviewees across all three states were unsure if they were being tracked using GPS. Some consumers in Illinois commented that they were not sure if their EVV system used GPS because they had received very little information about the system when they began using it. Despite not knowing for certain if GPS capabilities were enabled, some workers in Texas and Ohio thought that this might be a possibility. Other consumers in Illinois commented that GPS tracking capabilities had not yet been integrated into the EVV app on their personal cellphone, which was the reporting method they used, and one worker in Ohio stated that GPS tracking was not an issue for her because she used the landline telephony option.

Other interviewees in Ohio, where GPS tracking was required if using the government-issued device, reported that this EVV component was the most objectionable. They noted that they thought GPS systems could potentially track consumers while in the community outside of times when logging in and out of EVV. Both consumers and workers expressed the uncomfortable sensation of possibly being continuously surveilled while they conducted activities outside of the home. Consumers said that the GPS requirement:

- Further reduced their freedoms and privacy. Several consumers said that, as disabled people, they already had fewer freedoms and less privacy than the average person, but that the GPS requirement stripped additional freedoms and further reduced privacy. One consumer said, "Our lives are invaded enough when we're on public assistance and...on a program that is administrated by the government. I understand that I have to share things with the government and with workers about things that we wouldn't normally have to talk about, such as bodily functions. EVV just makes it so that we give up that much more privacy. I feel like big brother is watching me 24 hours a day." Another said, "I feel like I'm being spied on every second of my day, and I didn't have that much freedom to begin with" and, "I don't like the feeling that I'm being tracked that much. The whole concept just makes me uncomfortable."
- Caused safety risks. One consumer, a survivor of sexual assault who was continually being stalked by her assailant, felt that the GPS component of EVV compromised her safety, explaining that "Before EVV, I was able to have a safe address, like a P.O. box, but now I cannot have this. Since EVV, you're not allowed to have a safe address because you need to have a 'real' address [to input into the system]. I feel like this puts me at risk [of being found by my assailant]."

A consumer in Ohio explained that, in general, neither workers nor consumers took issue with the concept of a clock-in and clock-out system such as EVV because it did help to eliminate fraud. However, she took issue with Ohio's decision to implement GPS, as she did not believe that this component of EVV helped achieve its goal of reducing fraud: "No one, and when I say no one, I mean both the providers and the clients, none of us have a problem with a clock-in system...because it covers them as a provider by [proving] that they are not committing fraud. And according to Ohio Medicaid...their main reason other than the federal law that was implemented with the 21st Century CURES Act of putting [GPS] in was to curb fraud. But a GPS system is not going to help you curb fraud, it's going to help you lose good people...and Ohio chose the GPS option. The GPS option is not required by federal law...that was a mandate that Ohio Medicaid chose...There has to be a happy medium, but I don't know if any of us knows what that is. Like I said, the call-in system to say 'Hey, I've arrived at the client's house' or 'My shift is ending and I'm leaving the client's house,' nobody has a problem with that. But to track them...that's where it becomes a problem."

Social Security Number Use

Identifying a different privacy concern, several consumers who chose to enter daily PCS hours by computer (EVV's manual entry option) objected to being required to use their Social Security numbers as identifying information. Consumers indicated that:

- Social Security numbers were not adequately protected. One consumer explained that EVV forced her to enter her Social Security number on an unencrypted website: "One of my big frustrations with the manual version is that you have to give your Social Security number to a non-encrypted website, and that bothers me. I feel like if we're going to be forced to use something that, [the website] should be encrypted." This consumer reported that she had complained about this to a disability rights organization and to Ohio Medicaid, but at the time of the interview, she was not sure if the requirement had changed.
- Workers felt uncomfortable with knowing consumers' Social Security numbers. Workers had to know or have access to consumer social security numbers in order to input them into the EVV system. One interviewed consumer's worker did not want to be responsible for having her consumer's Social Security number in the event of identity theft (and potentially be considered responsible), and the consumer agreed that providing access to the number created an avenue for identify theft. "One person that worked for me, she said that if she had to put my Social Security number in that she was quitting, and then they were able to get around it just for her, but then she ended up quitting anyway because she got frustrated with the system...the manual [entry option] is time consuming."
- They already had experience with identify theft. One consumer, who had already experienced identity theft (by a former worker), expressed that the Social Security number requirement would create an additional avenue for identify theft. She was further disillusioned with the Social Security number requirement because, in order to receive Medicaid PCS services in general, she was only required to provide her Medicaid ID number, not her Social Security number. "I actually had a provider steal my identity, so that's why it's concerning to me...and I'm still going through court about it, so I'm concerned because of those kinds of things. That's why they took Social Security numbers off of Medicare cards, to try to help you protect your identity. Why should I have to give up my Social Security number to Sandata technologies to use EVV? Here, you want to avoid the GPS and the biometrics, but you should also be able to have the provision to not have to use your Social Security number. There's nothing in the federal law that says that I am required to give them my Social Security number for access to EVV."

Worker Compensation Concerns

Several interviewees said that workers often experienced issues with receiving proper payment, such as being underpaid or experiencing significant delays with receiving payment altogether, usually despite using EVV as instructed. Interviewees explained that these issues were particularly troublesome because workers already received low wages. As of May 2020, the national median wage for PCS workers was \$13.02.²¹ In states where interviews were conducted, the median wage for PCS workers was \$11.41 in Ohio,²² \$13.46 in Illinois,²³ and \$10.11 in Texas.²⁴ Many interviewees explained that, coupled with already low wages, the payment issues caused by EVV acted as a disincentive for workers to remain in the field. Interviewees described that compensation issues occurred because the EVV system:

- Did not properly record the login/out time. As previously mentioned, EVV's technical issues would sometimes prevent it from recording the proper time, even when workers logged in and out on time. Because worker payroll relied on EVV records, workers often received inaccurate payments, usually resulting in pay shortages. One worker explained that this was frustrating, especially after taking the time to properly understand the system and comply with it: "Mostly, [EVV] doesn't keep correct time. It'll tell you what time it is, and you'll write it down, but yet when you get paid, it's never right...we've read [the EVV instructions] in and out, and we're exact, and we even get it down to the minute because we made them send us a chart, like if I clock out one minute over, it's 0.2 of an hour...so we figured out it's very finite. But in the state of Illinois, our pay is never right. We're not getting paid for the hours that we think we worked...a lot of times, they go strictly off the EVV system, and it does not always record things correctly."
- Provided inaccurate GPS data. Consumers indicated that the GPS would sometimes inaccurately
 record the service delivery location, such as recording that services were delivered at the house or
 building next door rather than the exact address listed in the service plan. These issues prevented

workers from being paid on time. One consumer explained that these payment delays discouraged people to join or remain in the PCS workforce: "If the EVV device... is not tracking it properly, [provider] pay is delayed by anywhere from one to three weeks, and everybody in life has bills to pay, so if they're getting delayed on their paychecks and they can't pay their bills on time, they could love the people they work for to death, but you, at some point, you think 'I have to walk away' and say 'I need a steady job where I know my check is going to come in on time, where I'm not calling my bank for my mortgage or my credit card companies and telling them I'm going to be late because the state didn't give me my paycheck'...so yeah, [EVV] is a huge hindrance."

One consumer who volunteered with disability advocacy rights organizations learned from these organizations that, no matter the cause of inaccurate or delayed payments, these issues were pervasive among PCS workers in all states. She explained that at that time, the issue was particularly bad and that the way the system currently functioned was unsustainable for her worker: "Most of the workers who are personal assistants have not been paid proper money or have not been paid at all once since April [2020]. So my caregiver checked back, and they owe her money for the past three or four pay periods, and [the workers] have to wait a month to get their money. So just imagine, someone hasn't been paid since April, this is June, what type of EVV system is this?...[my caregiver] cannot afford to not get paid properly."

Several interviewees indicated that some of these payment issues could be more easily mitigated if EVV records were made accessible. Interviewees explained that once you logged in and out of EVV that there was no way to retrospectively check the dates and times of past logins and logouts, which was especially problematic if EVV recorded an inaccurate login/out time. One worker claimed that this feature of EVV intentionally kept workers from realizing that they received shorted paychecks: "There is no way to call into the system to check what time you clocked in and how many hours you worked. They don't want workers to calculate their hours so that when you get a paycheck, you don't know what you get paid for...because the pay rarely lines up with what you deserve...we [on the bargaining committee] were told that the [payroll] system was so old that it could not provide the number of hours worked on the paycheck...I don't believe this [to be true]."

Worker Recruitment & Retention Concerns

Several interviewees described instances when workers quit because of the EVV requirement. Some consumers explained that several of their previous workers had quit because they could not figure out how to use the EVV system, they thought that the system was too much of a hassle given their pay, and they were uncomfortable having access to the consumer's Social Security number. A consumer in Ohio also reported that one of her workers left because of her own privacy concerns related to the GPS component of EVV: "A provider [of mine], who was a victim of domestic violence, quit because she lived in a battered women's shelter. She didn't feel comfortable having the app on her phone because of her own situation, knowing that the app captures information, including location information, even when not actively in use."

In other instances, workers were fired because of the EVV requirement. A consumer reported that one of her valued workers, who was legally blind and deaf in one ear, could not use EVV effectively because of her own disabilities. The consumer said that EVV officials never attempted to find an accommodation so she could use EVV, and she subsequently lost her job for failing to report her work hours correctly through the system.

Some interviewees reported that EVV and its requirements made attracting new workers more difficult. One consumer said that she had been trying to hire an additional worker through an agency for over three months, and that while it could be difficult to find workers in general, "EVV is not making the job any more attractive." She cited EVV's functionality issues, and resulting payment issues, as an example. Another consumer explained why she felt that EVV contributed to the overall worker shortage, also citing EVV's functionality issues as well as low wages and GPS capabilities: "The providers don't want to be tracked; they have a hard enough time doing what

they need to do. The fact that, on top of doing what we need them to do, they have to take three to four minutes every shift, log in with an ID number for themselves and for their client, and do the same thing when they get out. If you're having a really rough day, whether it's the provider or the client or both, you know, sometimes people forget to log out. It's not intentional. It used to be aides had just a little more freedom; if they were running 15 minutes behind, they would call you and say 'Hey, I'm going to be there, but I'm going to be late.' 'Okay, no problem.' Now, it's like if you're late, it reflects on the EVV system, so yeah, that does cause a problem. It is making it to the point where a majority of the providers, I would say at least 70% that I know of, are getting out between the pay and between the issues with EVV."

Perceived Benefits of EVV

Several consumers and workers noted that EVV had beneficial aspects, including incentivizing workers to show up on time for their scheduled shifts, creating more accurate and secure records than paper timesheets (when properly functioning), reducing fraud, and generally "keeping everyone honest." One consumer felt that these potential benefits only served one particular population, older people with cognitive limitations, well. She explained that "The only benefit that I've really seen is kind of getting these agencies that are scamming the seniors to stop doing that. That is the one benefit that I've seen, but I don't really think it's meant for everyone." She further explained that she used to live in an agency-run home, where she frequently saw agency workers coming in and out, and described how EVV was helpful to an older resident that she knew: "One of my neighbors was 90 years old, and his daughter [would come in] and ask 'Has your aide been here?' and he had Alzheimer's so he couldn't remember if the aide had been there, even if she had been...I kind of feel like it's helped the people that might have Alzheimer's...his daughter said that EVV helps him because at least she knows that someone's been there...but I don't know how much it benefits [people generally], I think it's just an assumption that it probably does."

Despite some of EVV's intended and perceived benefits, some interviewees, mostly consumers, opined that the benefits did not outweigh the negative consequences of the system. Interviewees provided several reasons as to why they felt that this was the case:

- A requirement to use a form of EVV other than manual entry could negatively impact the mental and physical health of some consumers. Interviewees with particular mental or health conditions are unable to consistently provide voice verification and/or signature requirements that forms of EVV other than manual entry demand. Most states allowed the manual entry option to be used full-time (i.e., not just as backup in case one of the other forms of the system failed), although many states did not openly communicate that the manual entry option could be chosen. Furthermore, certain states, such as Illinois, encouraged workers to utilize the government-issued devices. One consumer explained that she would not be able to comply with forms of EVV other than the manual entry option: "Overall, my care is better because of the type of EVV I'm using. [But], if I had to use the call-in on the phone, I would be stressed. I actually limit myself to three phone calls a day because I have autism and it's hard for me to talk on the phone sometimes...there's times I've been on the phone where I've lost it because of sensory overload. And there's times too when I have cognitive problems...I feel like it would be worse if I had to use a different method [of EVV]...I think [the computer/manual entry option] of EVV has actually helped me, but if I were on one of those other methods, I would probably be falling apart."
- While EVV eliminates blatant fraud respective to a few ill-intentioned people, it creates stress and reduces freedoms for the rest. Some interviewees felt that the restrictive measures that EVV required to prevent blatant fraud were too extreme to be applied to day-to-day activities, claiming that EVV hindered consumers' ability to live life freely. One consumer explained that EVV, as implemented at that time, valued cost savings over consumer quality of life: "I can see the benefit in terms of cutting down on really blatant fraud. When you see things on the news about people stealing hundreds of thousands of dollars in services that they are not actually [providing], or they are lying and saying that they are working a shift, meanwhile the [consumer] is laying in their own filth. I'm sure that it's cutting down on the blatant,

blatant fraud and abuse of the system, which is a good thing. I just think that it takes it to an extreme and in the process of that it also cuts down on, it punishes, as so many programs do, people for doing the right thing, or trying to do the right thing, or trying to just live their life. I think too often that people with disabilities, they are not recognized that they have the right to live life like everyone else, and all that that encompasses, including being able to change plans or go to the movies at night or do different kinds of things. I feel like those are the kinds of things that this program forgets in its attempt to cut down on fraud, which is an admirable goal, but it goes too far, and it punishes people for basically living a life the way that everyone else wants to live a life. [EVV] doesn't take that into account at all."

 Despite EVV's requirements, those who want to commit fraud will still find ways to "cheat the system." Other interviewees were confident that people who wanted to commit fraud would be able to find workarounds to the EVV system, thus rendering its strict requirements useless.

User Recommendations

Most interviewees provided suggestions for improving EVV based on their experiences and preferences. Interviewees expressed a desire for EVV to increase system flexibility, eliminate GPS capabilities and biometric measures, improve the login/out process, and streamline documentation of services.

Increase System Flexibility

Most interviewees said that the system would greatly benefit from more flexibility. One consumer said that "EVV has taken away what little bit of flexibility there was in the system and has made everything super rigid," and another said "[EVV] has taken the little bit of freedom that I had to do different things during the day as long it is okay with my caregivers." To improve system flexibility, interviewees said that they wanted:

- A grace period for logging in and out. Several interviewees felt that expanding the window of time in which workers could log in and out by five, 10, or 15 minutes would allow for increased EVV compliance as well as accommodate minor system and user errors.
- A less burdensome way to change the start/end time of shifts. Some consumers expressed that making changes to the start and end time of shifts, such as delaying the start of a shift, created a lot of administrative work for them in order to have the exception approved. One consumer explained, "You have to jump a lot of hoops to delay care by 30 minutes. You need to call the agency, need to make sure that care plans are written in a flexible way. It adds another dimension of hoops that people have to jump through to make simple things happen...it's a lot of work to do simple things, which is caused by having people monitored so closely." Another consumer said, "I see [EVV] as a giant hassle. And an imposition. It's an imposition in the fact that there's no flexibility for life. If I want someone to come at 4:45pm instead of 6:00pm, it's a tough fix to do that."
- Workers to stay logged in while accompanying consumers at appointments and in the community. Interviewees explained that it was confusing for workers to log in and log out every time they accompanied consumers to events, such as medical appointments or funerals, or day-to-day activities, such as grocery shopping or going to work. They noted that it quickly became easy to forget whether workers had actually signed in and out at the beginning and end of a trip outside of the home.
- Workers to be able to login/out at locations other than the consumer's home. Some interviewees said that, despite the fact that workers were able to accompany consumers outside of the home (and login/out when doing so), shifts always had to start and end at consumers' homes. One worker from Illinois explained why she and her consumer had difficulty adhering to that restriction: "My client is very fluid. She is always out in the community. I may be meeting up with her at a conference, to pick her up, to bring her home. As far as being in a certain location when your location has to be consistent, in her case, EVV would not work. If I was talking about improvements, there needs to be more flexibility as far as checking in and checking out about the location of where you are when you check in. It's too dependent on the client being static in a position, in a home, in a living environment, every single time. The flexibility to not have that, to be more flexible about where the attendant is when they make connection with the

client." An Ohioan worker who provided services to her daughter, who required round-the-clock care, explained that restricting login/out to the consumer home was also problematic for her situation given that she often relied on the help of family members to take care of her daughter: "EVV will now have a restriction when you're too far away from the child's home. I go an hour north up to a lake where my brother has a trailer, and we go up there and visit a lot. And it's like, so I take my phone and I log in and log out up there, and I'm just like, well, that's another thing that I have to go in and fix I guess if I'm too far from the home. Medicaid always forgets about my situation, that I stay at home 24 hours and then they load all this stuff on you to do."

Eliminate GPS Capabilities & Biometric Measures

Several interviewees said that EVV could be improved if it no longer required and enabled GPS tracking and biometric measures. Interviewees were concerned that GPS capabilities and the capture of biometric measures:

- Were too limiting for consumers who lived active lives. Several consumers wanted the GPS requirement removed or changed drastically (e.g., make it easier to add approved locations) to allow for more flexibility in terms of when and where they were allowed to go, and thus lead more active lives. One consumer expressed that the GPS component of EVV was the "greatest obstacle and imposition in being able to live life in an authentic way" because "the system needs to recognize that people with disabilities live active lives. It's not a one-size-fits-all approach, which is what has been taken here. I think that there can still be some flexibility while also allowing for accountability."
- Lacked regulation. Some interviewees felt that, beyond the fact that GPS and biometric data collection was problematic to begin with, the lack of regulation of this information could lead to even more invasive forms of the system in the future. One consumer opined that if the system were to become even more invasive that it would further contribute to the worker shortage: "I feel like there's no control over the biometrics, geofencing, algorithms, GPS tracking stuff, and the only way to make this better is to put some types of restrictions and control around it, [like putting] some kind of laws or legislation in place, because if not, [these EVV systems are] just going to be picked up by tech companies who have this idea or that [idea] and that's what's making our providers leave because...if we have to do biometric facial recognition or scanning our finger, I'm gonna tell you, even more people are going to leave the state, leave the provider pool, and that's scary because we're already in a national provider crisis."

Interviewees in Ohio who expressed that they did not want GPS capabilities recognized that these capabilities were not mandated in the original legislation but were rather an optional component that the state chose. One consumer stated that she felt like she could still remain compliant with the CURES Act using the manual entry option and workers should be able to provide information about shift start/end times when they arrived home at the end of the day, similar to how medical charting is sometimes completed.

Improve the Login and Out Process

Several interviewees reported that minor changes to the login/out process would make the system easier to work with, such as creating capacity in the system to repeat back the worker and consumer ID number, allowing for errors to be corrected when typing in EVV codes on the spot, and adding AM and PM time distinctions in the system. Some interviewees also indicated that improving voice verification software to allow it to pick up and understand more voices would make the logout process easier and faster.

Streamline Documentation of Services

Some consumers called for the elimination of paper timesheets and suggested that EVV's electronic documentation of hours worked should be considered adequate documentation by itself. Others said that if paper timesheets continued to be required that they should be converted to an online entry system. Several consumers preferred that EVV be tied to the billing system. In order to be compliant in documenting services, one consumer stated that she had to ensure that data was correctly entered into EVV, help her worker fill out the paper

timesheet, and complete separate documentation for the billing company. She said these steps were cumbersome and time-consuming but that the processes would be improved if they could be combined.

Conclusions

Congress included EVV for Medicaid-funded PCS and HHCS in the 21st Century CURES Act of 2016 as a response to fraud, waste, and abuse in the system reported by the HHS OIG. The Centers for Medicare and Medicaid Services required EVV implementation for Medicaid PCS programs by January 1, 2021. As states rolled out EVV, disability advocacy and rights groups, worker unions, and people with disabilities who use PCS expressed concern that EVV could disrupt daily routines and worker-consumer communications as well as reduce the time available for care.

A majority of consumers and workers interviewed for this qualitative study said they thought that EVV interfered with daily caregiving routines and reduced available time for care and other services. These disruptions created barriers to consumer control over their daily lives and activities and burdened workers whose jobs were made more difficult by EVV's technical flaws and stringent reporting requirements.

Complicating matters, EVV also intersects with various Medicaid HCBS program rules that already place limits on PCS hours and, in some cases, locations where services can be delivered. For instance, some programs do not pay workers for travel time while accompanying a consumer to a medical appointment. These limitations already challenge consumers to manage their care needs within approved service hours and tasks. When EVV is also required, both workers and consumers reported additional hurdles to meet reporting requirements, and consumers said they had fewer daily life choices and opportunities for community participation. Interviewees presented numerous examples of how they attempted to manage the intrusion of EVV into their lives and the difficulties they repeatedly encountered in effort to meet the demands of the systems in use in their states. In some instances, they reported raising their concerns to state policymakers with little effect. While a few interviewees thought EVV was useful for worker accountability, especially when older people with cognitive limitations could not monitor their workers effectively, the majority reported a range of difficulties and repercussions. Congress could amend the 21st Century CURES Act and CMS could issue regulations that resolve some of the more persistent problems identified in this report.

Policy Implications & Recommendations

Increased Medicaid HCBS, including PCS, has made it possible for disabled people who require help with ADLs and IADLs to live independently and participate in their communities rather than being forced to live in restrictive institutional settings. Even though PCS enables choice and control for beneficiaries, Medicaid rules determine service hours, and consumers therefore must carefully manage the time that has been allocated to them. This study aimed to understand how EVV affected workers and consumers as they navigated compliance and accountability in the context of publicly funded PCS.

Congress passed legislation requiring EVV in response to federal reports of fraud and abuse in the Medicaid PCS and HHCA systems. However well intended, the law lacks implementation details that acknowledge and protect consumers and workers from unnecessary compliance burdens, safeguard choice and autonomy in self-directed programs, and ensure privacy. Interviewees identified many ways in which EVV has created new hurdles to completing ADLs and IADLs, affected how service hours are used, and raised security concerns. These burdens should be addressed before states lock systems into place that will be difficult and expensive to change going forward.

Consumers and workers acknowledge that EVV is likely here to stay. However, the 21st Century Cures Act as written provides states with considerable latitude in implementing EVV. Eliminating some of this latitude could

reduce day-to-day reporting burdens, preserve consistent PCS quality, and allow for more efficient implementation of the system overall. Congress should amend the 21st Century Cures Act to take into account consumers' and workers' most pervasive concerns. Specifically, the Cures Act should spell out in greater detail that EVV systems must not interfere with the basic elements and goals of consumer self-direction. It should explicitly prohibit use of GPS tracking in EVV systems to take into account privacy concerns for both workers and consumers rather than allowing it as an optional component. Use of Social Security numbers as identification should also expressly be prohibited.

Moreover, CMS has provided scant guidance regarding EVV implementation. The agency should amend and revise its EVV guidance to resolve other persistent problems identified in this report. For instance, it should require states to implement a grace period for logging in and out of EVV, create user-friendly methods to correct system and user errors during login/out, and permit workers to stay logged in while accompanying consumers in the community. These changes, taken together with legislative amendments to the CURES Act, would reduce some of EVV's most pervasive functional problems and allow care to be delivered without creating additional barriers.

Limitations

The findings of the report may not be representative of all EVV users (workers and consumers) given the small number of interviews conducted across three states. We originally planned to conduct more interviews in Texas but struggled to a) find people in Texas who had experience with EVV (at the time that interviews were conducted, EVV was still optional for many programs) and b) attract interviewees to participate in the study during the height of the COVID-19 pandemic. As a result, we secured only one interview in the state. Recruiting interviewees in Ohio and Illinois was easier, but still challenging at times given the constraints imparted by the pandemic.

Acronyms Used in this Report

ADLs: Activities of Daily Living

AFSCME: American Federation of State, County, and Municipal Employees

CCD: Consortium of Citizens with Disabilities
CMS: Centers for Medicare and Medicaid Services

EVV: Electronic Visit Verification

FMAP: Federal Medical Assistance Program

GPS: Global Positioning System

HCBS: Home and Community-Based Services

HHCA: Home Health Care Agency HHCS: Home Health Care Services

HHS: US Department of Health and Human Services

IADLs: Instrumental Activities of Daily Living

IVR: Interactive Voice Response (i.e., voice verification)

OIG: Office of the Inspector General

PCS: Personal Care Services

SEIU: Services Employees International Union

UDW: United Domestic Workers

Twitter: @ucsfhwrc

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