Electronic Visit Verification

The Weight of Surveillance and the Fracturing of Care

DATA&SOCIETY

Alexandra Mateescu

EXECUTIVE SUMMARY

In *Electronic Visit Verification: The Weight of Surveillance and the Fracturing of Care,* researcher Alexandra Mateescu argues that the surveillance of home care workers through a mobile app called electronic visit verification erodes the quality of personal care and offloads significant, unacknowledged burdens onto workers and service recipients.

Electronic Visit Verification (EVV) has become a constant presence in the lives of people who provide or receive in-home care services funded by Medicaid. The app, which tracks workers' locations and activities, requires workers to verify their work several times a day. Technologies like EVV have been promoted as a tool for modernizing and improving service delivery, to prevent "fraud, waste, and abuse," and to more fairly and efficiently manage a labor force that is one of the fastest growing occupations in the country. Though the federal legislation that mandated EVV for all Medicaid-funded personal health services required the system to be "minimally burdensome," the reality is that it has been anything but. State-level policies and technology design encoded far more invasive features into EVV systems than were required.

Drawing on interviews with workers and service recipients across the country, Mateescu's report provides evidence about the impacts of EVV implementation on workers and care recipients. Technologies that monitor workers also affect the lives of the people they provide services to, their families, and their social networks. In this respect, **EVV has had far-reaching effects on people's lives; many found themselves moving through invisible walls and re-organizing their daily lives around proving that they were not cheating the system.**

EVV systems made workers' jobs more difficult by placing a greater emphasis on policing compliance than providing care. Pressures to follow EVV system rules often strained employment relationships, as workers struggled to make their work visible to digital systems; **slight missteps in compliance often led to delayed or lost wages.**

A lack of transparency around data collection and its uses had a chilling effect on service recipients' lives, as everyday activities were flagged as "exceptions," leading to convoluted dealings with healthcare bureaucracies. Requirements that workers log their work within geofenced zones entrenched ableist assumptions that service recipients are homebound, enforcing a state of de facto house arrest. Service recipients and workers spoke of feeling criminalized, viewing EVV as an extension of broader legacies of government surveillance over people of color, and poor, disabled, and older adults.

This report shows that EVV has contributed to the **growing landscape of punitive technologies that target and criminalize both low-wage workers and public benefits recipients.** The case of EVV underscores the contradictions inherent in imposing a tech-based solution on the U.S. care crisis. The devastation of COVID-19 has highlighted the consequences of underfunding care provision at every level. Imposing greater surveillance on an already strained and poorly supported workforce cannot remedy pervasive, chronic underinvestment in care, and may ultimately exacerbate the nation's care crisis.

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INTRODUCTION

Ana hates having her photograph taken.[1]

She asks, why are so many pictures needed of her? Who is looking at them? Who wants to see her in her pajamas all the time? Her daughter Rafaela, who has been working as her personal care aide since 2017, is required by Medicaid to use an Electronic Visit Verification mobile app to track her work. To verify that Rafaela is where she says she is, the app asks her to photograph herself and her mother, sometimes multiple times each day, as part of the system's biometric facial verification feature.

Rafaela dreads the times when the app requires her to use this feature because she knows it is frustrating for Ana. Successfully taking a photo sometimes requires multiple takes and phone reboots, re-installing the app, and calling the care coordinator to explain the situation when the system does not recognize their faces. Rafaela and her older son try their best to cajole Ana with playful jokes to convince her to pose for the camera: "So my son tries to make her a little happier; he goes, 'Come on, grandma, let's take a picture!' He goes next to her and goes, 'Come on, you've gotta say cheese!'"

Rafaela is employed through a Medicaid program that pays her to provide essential support to her mother in her home, including cooking, bathing, tracking her medications, and regularly taking her to doctors' appointments. Rafaela has long attended to her mother's needs around the clock as Ana's health declined and she is no longer physically able to do these tasks herself. Rafaela is always busy, whether running errands for herself and her mother, raising her two young children, or volunteering at their school's parent teacher association. Her brother, who lives

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1   Pseudonyms are used for all interviewee names and some details are obscured to preserve their anonymity.

nearby, occasionally helps out with their mother's care, but he works long hours, so she tries limit her requests for help. The part-time wages she receives as her mother's care worker cover only a portion of the time Rafaela spends providing daily support for her mother. But without the pay, she would not have the resources to dedicate the time needed to ensure her mother is living comfortably. Ana would likely have to move into a nursing home.

Many of the details of Rafaela's employment are managed through the app. While she is happy with the app's quick access to her payroll and a messaging interface with her coordinator, the GPS tracking and geofencing features built into the system have tangibly complicated her family's day-to-day life. The tracking is meant to verify to the financial management services agency managing her payroll that Rafaela is indeed where she says she is and not committing Medicaid fraud.

But compliance is more complicated than it seems. Ana's apartment is set as the service location, but in practice she spends much of her time at her daughter's home so that Rafaela can also look after her children when they are not in school. Moving around anywhere can get messy, as it means constantly submitting advance requests to change the designated service location. This presents a dilemma: Rafaela can't clock in or out at her own home, because if she does, the system flags her for additional verification, prompting her, yet again, to photograph her mother on the app's facial verification feature.

Most of the time, Rafaela tries to spare Ana the frustration and travels alone to and from her mother's apartment twice a day to clock in and out in front of her building to avoid getting flagged. On Fridays, taking Ana's photo is mandatory so that Rafaela can submit her weekly timesheet and receive her paycheck. She is not sure what will happen if she gets flagged too many times. Though using this new system is an added hurdle, Rafaela does not consider the constant biometric verifications, the geofencing, or the GPS tracking as much of a choice. As she sees it, her mother needs support, and one way or another, she will do what she has to do to provide it.

For millions of people across the United States, the home is both a workplace and a space where the public-private nature of care infrastructure powerfully implicates many institutions beyond its threshold. Medical institutions, nonprofits, labor unions, federal and state government bureaucracies, and, increasingly, tech companies all shape how care is provided and distributed, down to the most mundane routines of everyday life. For many people with disabilities and older adults, these services are critical for living independently at home and in the community. Medicaid, which is jointly funded by federal and state governments, is the largest single funder of these long-term services and supports in the United States.[2] As a result, the government holds significant power over how—and, critically, whether—people receive the support that they need.

This report is about Electronic Visit Verification (EVV), the mobile app that has become a constant presence in the lives of people like Ana, Rafaela, and many others who are increasingly required to use it on a daily basis. I argue that EVV systems erode quality of care and offload significant, unacknowledged burdens onto workers and service recipients. While these apps have been promoted as a tool for modernizing and improving service delivery, they contribute to the growing landscape of punitive technologies that target and criminalize both low-wage workers and public benefits recipients. The challenges and backlash in response to the technology's rollout across the United States underscores the harms that can result when technologies prioritize promises of efficiency, standardization, and legibility over the lived experiences of those who must intimately live with these technologies.

In 2016, Congress passed the 21st Century Cures Act, a broad piece of legislation that included a provision requiring all Medicaid-funded personal care services and home health care services to implement EVV systems. At a basic level, EVV systems are digital tools through which workers must verify the services that they provide. The most common version is a mobile app that workers or their clients must use on a smartphone or alternatively through a landline phone or other fixed device.

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2   Medicare, the national health insurance program for people over age 65, typically covers only short-term, post-acute home care rather than long-term care, whether in a nursing facility or through in-home assistance. Robin Rudowitz, Elizabeth Williams, Elizabeth Hinton, and Rachel Garfield, "Medicaid Financing: The Basics," The Henry J. Kaiser Family Foundation, May 7, 2021, https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/view/print/.

On its surface, this requirement appears uncontroversial. Many workplaces today use digital timekeeping tools. But the federal government's broader goals were to use these digital check-ins to identify and root out alleged "fraud, waste, and abuse" by digitally surveilling workers and their clients.[3]

Though the legislation required EVV systems to be "minimally burdensome" to their users, in practice, little federal policy guidance was provided on how to adhere to this goal.[4] As a result, state-level policies and technology design encoded far more invasive features into EVV systems than required. While EVV systems track workers, many people are swept into their data collection practices. Technologies that monitor workers also affect the lives of the people to whom they provide services as well as their families and social networks. These decisions have far-reaching effects on people's lives. Many, like Rafaela and Ana, find themselves moving through invisible walls and re-organizing their daily lives around proving that they were not cheating the system.

Drawing on interviews with workers and service recipients across the country, this report provides evidence on the impacts of EVV implementation. The first section describes the challenges of EVV as a tool for measuring and quantifying care labor. As a workplace technology, EVV systems often made workers' jobs more difficult by placing a greater emphasis on policing compliance. Pressures to follow EVV system rules often strained employment relationships as workers struggled to make their work visible to digital systems; slight missteps in compliance often led to delayed or lost wages. The second section discusses how these digital systems both target and exclude workers and their clients. Service recipients and workers spoke of feeling criminalized, viewing EVV as an extension of government surveillance

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3   Alison Diana, "GPS Cuts Fraud, Costs for Home Healthcare," *InformationWeek,* November 5, 2014, https://www.informationweek.com/healthcare/gps-cuts-fraud-costs-for-home-healthcare/d/d-id/1317202; "Leveraging Electronic Visit Verification (EVV) to Enhance Quality Monitoring and Oversight in 1915(c) Waiver Programs," Centers for Medicare and Medicaid Services, accessed October 22, 2021, https://www.medicaid.gov/medicaid/downloads/evv-enhance-quality.pdf.

4   PCS and HHCS, seek stakeholder input, consider existing best practices and EVV systems in use in the state, ensure the opportunity for provider training, and ensure the EVV system is minimally burdensome and that its use is compliant with the privacy and security requirements of the Health Insurance Portability and Accountability Act (HIPAA)." See "CMCS Informational Bulletin: Electronic Visit Verification," Centers for Medicare and Medicaid Services, May 16, 2018. https://www.medicaid.gov/federal-policy-guidance/downloads/cib051618.pdf.

over people of color and poor, disabled, and older adults. A lack of transparency around data collection and its uses had a chilling effect on service recipients' lives as mundane and everyday activities were flagged as "exceptions," leading to convoluted dealings with health care bureaucracies. Rigid policies and technology requirements also served as both coercive and exclusionary. Requirements that workers log their work in real time or within geofenced zones entrenched ableist assumptions that service recipients are homebound, enforcing a state of de facto house arrest. The costs of technology equipment and resources like digital connectivity were offloaded onto service recipients and workers, creating new hurdles for accessing critical public benefits.

Research design and planning for this project began in August 2019.[5] Fieldwork was conducted over the course of 18 months, from October 2019 to April 2021. Qualitative interviews were conducted with 20 workers and service recipients across the United States, in total including four home health aides, nine personal care attendants, and six client/employers. While fieldwork in the first several months of the project was conducted in-person, following March 2020, all interviews were conducted remotely by phone or video conference software. Participants were recruited through a combination of referrals, online forums like local job listings groups for hiring personal care attendants, and in-person events hosted prior to the COVID-19 pandemic. The author also solicited expert opinions from advocates and relevant scholars at all phases of the project, including external peer review of report drafts. Finally, the author conducted participant-observation of webinar-based EVV worker training sessions and information sessions hosted by vendors, state Medicaid agencies, and the Centers for Medicare and Medicaid Services (CMS). This work is further informed by extensive analysis of policy and stakeholder engagement documents, local news reporting, online grassroots mobilizations, and marketing materials from vendors. While issues around EVV implementation continue to evolve, this report draws on the impacts in states that have undergone full or partial rollouts of the technology.

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5   This study was submitted to IRB review and received an exemption under Institutional Review Board Advarra, Inc.

EVV systems are only a small part of a sprawling web of digital bureaucracies, yet they reflect a shift toward increasingly extractive means of managing care across society. Technologies like EVV systems promise to more fairly and efficiently manage a labor force that is one of the fastest growing occupations in the country.[6] But as this report shows, imposing greater time discipline on an already strained workforce cannot remedy pervasive, chronic underinvestment in care. In fact, it may ultimately exacerbate the nation's care crisis. The devastation of the COVID-19 crisis and mass recession have highlighted the consequences of underfunding care provision at every level. Deeply entrenched inequalities across race, class, and ability surfaced during the pandemic as dehumanizing policies and rhetoric treated those who are older and disabled as disposable.[7] However, these consequences also continue beyond moments of crisis. How technologies within the US care system are designed, and whose viewpoints are taken seriously, tells the larger story about these institutions' priorities.

6   "Occupational Outlook Handbook: Home Health and Personal Care Aides," Bureau of Labor Statistics, US Department of Labor, last modified September 8, 2021, https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm.

7   Elliot Kukla, "My Life Is More 'Disposable' During This Pandemic," *The New York Times,* March 19, 2020, https://www.nytimes.com/2020/03/19/opinion/coronavirus-disabled-health-care.html.

BACKGROUND

What Is at Stake in a Digital Timeclock?

Despite promises of efficiency, the national project of rolling out EVV systems in homecare services over the past five years has been fraught from the beginning. This section describes the implementation and subsequent backlash against these technologies across the United States as state Medicaid agencies sought to meet the federal mandate set by the Cures Act.

The emergence of EVV systems reflects a variety of promises to legislators, home health agencies, service recipients, and workers. Technology vendors promised federal and state governments that they would see long-term cost savings by reducing improper billing for services while ensuring worker accountability to protect service recipients from neglect or abuse. Home health agencies were promised an easier compliance process and leaner administrative operations to "squeeze every single cent" from Medicaid reimbursement rates. [8] For budget-strapped state Medicaid agencies, EVV was marketed on the appeal that the technology could significantly decrease fraud and would more than recoup the costs of investment into EVV infrastructures. Service recipients were told that switching to a digital platform would be an upgrade from clunky paper timesheets and keep them safe from neglect or abuse by identifying gaps in service needs. Workers were promised that EVV would enable them to better dedicate time to clients and improve their quality of care.[9]

8   Diana, "GPS Cuts Fraud, Costs For Home Healthcare."

9   See, for example: "Understanding the Full Value of an Electronic Visit Verification System," Sandata Technologies, accessed October 22, 2021, https://www.sandata.com/understanding-the-full-value-of-an-electronic-visit-verification-system/.

However, when the EVV mandate was passed in 2016, labor and disability rights groups foresaw that this new digital infrastructure would likely result in serious harms to their constituencies, so they strove to delay its implementation. The National Council on Independent Living as well as several other advocacy organizations opposed the mandatory implementation of EVV systems.[10] In 2018, in partnership with the American Civil Liberties Union, the Consortium for Citizens with Disabilities and its 30 member organizations published a letter of support for delaying rollouts "to ensure that the privacy and civil rights of consumers are protected; that the administrative and financial burdens on service providers is neither onerous nor duplicative; and that states are able to design and implement their EVV programs in a thoughtful, deliberative manner."[11] In California, a 2018 joint statement from labor unions United Domestic Workers/American Federation of State, County, and Municipal Employees (UDW/AFSCME Local 3930) and Service Employees International Union (SEIU) Local 2015 warned that EVV "would make receiving services in the home and community more difficult and restrictive" and would exacerbate existing labor shortages by eroding job quality.[12] Advocacy groups have particularly focused on banning the use of GPS tracking and biometric data collection on a national level.[13]

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10   "Electronic Visit Verification (EVV) Task Force Statement of Principles and Goals," National Council on Independent Living, accessed October 22, 2021, https://medicaidpub.wpengine.com/wp-content/uploads/2018/05/NCIL-EVV-Principles-and-Goals.pdf; "DREDF Opposes Electronic Visit Verification (EVV) When It Threatens Disabled People's Civil and Privacy Rights and Impedes Personal Choice, Autonomy, and Community Participation," Disability Rights and Education Defense Fund, March 7, 2018, https://dredf.org/2018/03/07/dredf-statement-on-electronic-visit-verification/; "DRC Position on Electronic Visit Verification (EVV)," Disability Rights California, February 2, 2018, https://dredf.org/wp-content/uploads/2018/03/DRC-Electroni-Visit-Verification-System-revB.pdf.

11   "Coalition Letters in Support of Electronic Visit Verification (EVV) Legislation," American Civil Liberties Union, June 1, 2018, https://www.aclu.org/letter/coalition-letters-support-electronic-visit-verification-evv-legislation-house.

12   United Domestic Workers/American Federation of State, County, and Municipal Employees (UDW/AFSCME Local 3930) and Service Employees International Union (SEIU) Local 2015, "Joint Comments in Response to DRAFT Request for Information (RFI) on Electronic Visit Verification (EVV)," October 20, 2017, https://dredf.org/wp-content/uploads/2018/03/SEIU-UDW-Joint-Response-to-Draft-RFI-10-20-17.pdf.

13   Antoinette F. Konski, "Improving 21st Century Cures Act: Personalized Medicine and COVID-19," *The National Law Review,* May 12, 2020. https://www.natlawreview.com/article/improving-21st-century-cures-act-personalized-medicine-and-covid-19.

Even though federal regulators deferred the implementation deadline several times, state governments still struggled over various financial, technical, and programmatic obstacles while facing the impending threat of penalty cuts to federal Medicaid funding if they missed the deadline.[14] Federal Medicaid administrators denied advocates' calls to further delay rollout in response to the COVID-19 pandemic, resulting in pressures to meet the final January 2021 deadline in the midst of a global health crisis.[15]

But even as delays granted state Medicaid agencies with additional time for implementation, stakeholder engagements were often conducted late in the process, after rollouts were already underway. In the years following the 2016 legislation, public backlash emerged as service recipients and workers struggled to adapt to the new requirement. In dozens of town halls across the country, deep confusion surfaced among EVV users over opaque policies and glitchy, inaccessible systems. In Ohio, early rollout in 2018 generated a "firestorm of complaints" after the state awarded a seven-year, $66.5 million contract to vendor Sandata Technologies. The department issued smartphones to service recipients with little advance notification, training, or information on data collection practices.[16] In a 2018 stakeholder call hosted by CMS, officials summarized public input they received from around the country: significant concerns over privacy and financial and administrative burdens as well as fears that EVV would exacerbate labor shortages and push service recipients into institutions or out of Medicaid entirely.[17]

14   Molly Morris, "Examining the Unavoidable Delays to Electronic Visit Verification (EVV) Implementation," Applied Self-Direction, February 2020, https://www.appliedselfdirection.com/sites/default/files/Examining%20Reasons%20for%20EVV%20Delay.pdf; Michelle Diament, "Citing COVID-19, Advocates Want Medicaid Caregiver Check-In Mandate Delayed," *Disability Scoop*, August 20, 2020, https://www.disabilityscoop.com/2020/08/20/citing-covid-19-advocates-want-medicaid-caregiver-check-in-mandate-delayed/28766/; "Electronic Visit Verification FMAP Reduction: Training Call with States," Centers for Medicare and Medicaid Services, April 15, 2021, https://www.medicaid.gov/medicaid/downloads/evv-fmap-reduction-call-with-states-date-april2021.pdf.

15   Diament, "Citing COVID-19."

16   Tim Mullaney, "Report of EVV 'Firestorm' Draws Home Care Industry Pushback," *Home Health Care News*, February 20, 2018, https://homehealthcarenews.com/2018/02/report-of-evv-firestorm-draws-home-care-industry-pushback/.

17   Centers for Medicare and Medicaid Services, Transcript & Audio: "Electronic Visit Verification (EVV) Stakeholder, Open Door Forum," November 7, 2018, https://www.hhs.gov/guidance/document/podcast-and-transcripts-0.

In March 2020, the Virginia Department of Medical Assistance Services solicited feedback on its EVV system and received over a thousand complaints.[18]

The lack of standardization across systems emerged as another challenge as each state developed its own program rules. Since the mandate's passing, technology vendors have competed for contracts, including more than 30 tech companies offering EVV mobile apps and other software.[19] While some state governments contracted with a single, state-mandated vendor, others opted for more open models where agencies and other intermediaries could select from multiple approved vendors.[20] Although some state agencies have sought to develop best practices and revise their policies in response to stakeholder feedback, others have not.[21]

Grassroots efforts sought to limit the data collection practices of EVV systems, but the federal government met them with contradictory guidance. In California, labor union United Domestic Workers, SEIU Local 2015, and organizations like Disability Rights California worked with stakeholders to develop a less invasive, in-house EVV system that would be an expansion of the existing web timesheet portal. With this tool, homecare workers would only be required to manually enter a general location where services were provided, such as "home" or "community." However, in 2019, CMS stated that web-based timesheets alone do not provide auditable confirmation of timesheet data, thus this system was not compliant.[22]

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18   Virginia Department of Medical Assistance Services, Regulatory Town Hall, Public Comment Forum, March 2020, https://townhall.virginia.gov/l/Comments.cfm?stageid=8364.

19   "Directory of Electronic Visit Verification (EVV) Vendors Interested in Serving Self-Direction Programs," Applied Self-Direction, last updated July 27, 2021, https://www.appliedselfdirection.com/sites/default/files/EVV%20Directory_0.pdf.

20   Carlo Calma, "EVV Provision Leaves Home Health in Open vs. Closed Dilemma," *Home Health Care News,* November 28, 2017, https://homehealthcarenews.com/2017/11/evv-provision-leaves-home-health-in-open-vs-closed-dilemma/.

21   See, for example, New Hampshire Department of Health and Human Services, "EVV Market Analysis: Summary of Findings," September 8, 2020, https://www.dhhs.nh.gov/dcbcs/beas/documents/evv-market-analysis-report.pdf.

22   "DRC Position on Electronic Visit Verification (EVV)," Disability Rights California, December 12, 2020, https://www.disabilityrightsca.org/legislation/drc-position-on-electronic-visit-verification-evv; Centers for Medicare and Medicaid Services, "Additional EVV Guidance," *CMCS Informational Bulletin,* August 8, 2019, https://www.medicaid.gov/federal-policy-guidance/downloads/cib080819-2.pdf.

In California alone, the EVV mandate affected the more than 520,000 workers and 600,500 Medicaid service recipients.[23]

While state governments were required to conduct stakeholder engagement, the diffusion of accountability between state and federal officials and technology vendors impeded their efficacy. Even as harms continue to be documented, the sunk costs of implementing this new digital infrastructure has made pushing back against their use challenging.

In Search of "Fraud, Waste, and Abuse"

While some design efforts to improve job or care quality have been a focus for EVV systems, the main purpose advanced by legislators at the federal level did not center on these goals.[24] Instead, the mandate centered on reducing "fraud, waste, and abuse" by tying Medicaid reimbursements to workers' compliance in verifying their hours. A 2016 report from the Congressional Budget Office claimed that EVV use would eventually lead to cost savings via cuts in direct spending by $290 million over a 10-year period.[25] Since the COVID-19 pandemic crisis, vendors also positioned EVV systems as a means for states to "rein in Medicaid costs" due to surging Medicaid enrollment from millions of newly-unemployed and low-income families.[26]

23   "In Home Supportive Services (IHSS) Program," California Department of Social Services, accessed October 22, 2021 https://www.cdss.ca.gov/inforesources/ihss.

24   Emily Tseng, Fabian Okeke, Madeline Sterling, and Nicola Dell, "'We can learn. Why not?' Designing Technologies to Engender Equity for Home Health Aides," in *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems,* 2020, 1–14.

25   "Leveraging Electronic Visit Verification (EVV) to Enhance Quality Monitoring and Oversight in 1915(C) Waiver Programs," Centers for Medicare and Medicaid Services, accessed October 22, 2021, https://www.medicaid.gov/medicaid/downloads/evv-enhance-quality.pdf; "Helping Families in Mental Health Crisis Act of 2015: Direct spending effects of H.R. 2646, as reported by the House Committee on Energy and Commerce on June 15, 2016," Congressional Budget Office, https://www.cbo.gov/publication/51764.

26   Greg Strobel, "HHAeXchange's Homecare Predictions for 2021," *HHAeXchange Blog,* January 18, 2021, https://hhaexchange.com/resources/hhaexchanges-homecare-predictions-for-2021/.

Unlike fraud oversight practices that focus on institutional accountability and liability—such as audits of home health agencies' billing practices—EVV systems conduct digital surveillance on the daily activities of individual workers and their clients. Critics of the EVV mandate have argued that harms to workers are disproportionate relative to the actual extent of fraud at the individual level, pointing to a lack of evidence of widespread fraud within home- and community-based programs. In states like California, which has the largest direct care workforce in the country, an examination of fraud investigative reporting from 2013 to 2014 found a fraud rate of 0.04% statewide.[27] Instead, institutional actors rather than individuals tended to perpetrate high profile cases of Medicaid fraud.

These policy ambitions and public discourses surrounding them cannot be understood outside of the racism, sexism, and deep stigmatization of poverty and disability that have long shaped care infrastructures in the US. Within publicly-funded care services, the presence of digital surveillance is both a condition of low-wage employment and of receiving public welfare benefits.

Nevertheless, the federal government sought to cut down on "fraud, waste, and abuse" by closely scrutinizing workers' time on the job. Prior to the EVV requirement, most workers and service recipients typically submitted paper timesheets or asynchronously logged their times on a web portal, with both parties or a home health agency signing off on the documentation. Technology vendors have claimed that EVV systems make it much more difficult to falsely bill for services because they track work in real time, and are therefore more precise than a fallible paper timesheet.[28] Moreover, EVV systems are designed to identify discrepancies and anomalous patterns, resulting in a flag that requires administrative review to

27   "Electronic Visit Verification (EVV) Task Force Statement of Principles and Goals," National Council on Independent Living.

28   According to CMS, improper payments include any payments "made for treatments or services that were not covered by program rules, that were not medically necessary, or that were billed for but never provided." See "Fact sheet: Preventing Medicaid Improper Payments for Personal Care Services," Centers for Medicare and Medicaid Services, November 2017, https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/pcs-prevent-improperpayment-factsheet.pdf.

approve the hours for payment.[29] If the data does not match—such as a worker clocking out at an unauthorized service location—they may be denied payment or face other penalties.[30]

While homecare workers—usually women—are stereotyped as "natural" caregivers, they are also treated as a threat to both their clients and the institutions that manage them. Digital surveillance of low-wage work is often rooted in racist perceptions of the workforce as unskilled, untrustworthy, or lazy. Extensive surveillance—both subtle and overt—has long been normalized in the context of low-wage work.[31] Increasingly, analog means of tracking workers, like paper timesheets, are viewed as insufficient to protect employers from perceived "time theft," or the assumption that workers are idling on the clock.[32]

In the context of the homecare industry, workers' needs and well-being are often devalued. As legal scholar Lydia Hayes describes in reference to the UK's National Health Service, the trend toward hyper-surveillance of homecare workers can serve to "trivialize the economic needs of home care workers and mark them out collectively as undeserving of public respect and lacking in self-control" while decontextualizing issues of care quality from the wider context of institutional divestment from accountability or support.[33] In settings like nursing facilities, the growing use of privately installed security cameras has shifted responsibility for residents' safety away from the state and employers and onto families and low-wage

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29   "Electronic Visit Verification for Personal Care Services: Status of State Implementation," Medicaid and CHIP Payment and Access Commission (MacPac), March 2019, https://www.macpac.gov/wp-content/uploads/2019/02/Electronic-Visit-Verification-for-Personal-Care-Services-Status-of-State-Implementation.pdf.

30   "Electronic Visit Verification: Implications for States, Providers, and Medicaid Participants," National Association of States United for Aging and Disabilities (NASAUD), May 2018, http://www.advancingstates.org/sites/nasuad/files/2018%20Electronic%20Visit%20Verification%20Report-%20Implications%20for%20States%2C%20Providers%2C%20and%20Medicaid%20Participants_0.pdf.

31   Tracy L. Vargas, "Employees or Suspects? Surveillance and Scrutinization of Low-wage Service Workers in US Dollar Stores," *Journal of Labor and Society 20,* no. 2 (2017): 207–230.

32   Madison Van Oort, "The Emotional Labor of Surveillance: Digital Control in Fast Fashion Retail," *Critical Sociology 45,* no. 7–8 (2019): 1167–1179.

33   Lydia B. Hayes, "Sex, Class and CCTV: The Covert Surveillance of Paid Homecare Workers," in *The Post-Fordist Sexual Contract,* ed. Lisa Adkins and Maryanne Dever (London: Palgrave Macmillan, 2016), 171–193.

workers—primarily Black, Filipina, and Latina women working as certified nursing assistants.[34] These efforts to more closely monitor and discipline the workforce subsume issues around workplace conditions, including poor wages and a lack of benefits and training. The focus on monitoring workers' time as a rubric for care quality can reframe their roles largely through the lens of time consumption, with service recipients framed as "needy (or greedy) time-consumers" and homecare workers as "resource-wasting time-takers."[35]

At the same time, Medicaid service recipients are targets of surveillance specifically because they are low-income individuals and families seeking public assistance. Medicaid's history is rooted within the welfare system, which faces perennial pressures to patch budget deficits by restricting eligibility, slashing benefits, and suppressing its workforce's wages to contain program costs.[36] Although Medicare— the national health insurance program for people over age 65—also covers various short-term homecare services, a corresponding mandate to use EVV systems has not been imposed on beneficiaries of this government program. Similarly, families that can afford to pay for services out-of-pocket are not subjected to these forms of scrutiny. For these reasons, the growing use of fraud-reduction technologies within programs like Medicaid need to be understood in the context of the wealth divides that fuel inequalities across health care access and rights to privacy.

Regulators' assumptions of collusion between workers and service recipients also underlie the imposition of surveillance as a requirement for accessing services. Throughout the history of paid domestic labor, homecare workers' social and emotional investments in their clients' well-being and the intrinsic rewards of caregiving have been used to rationalize low wages and unpaid work.[37] But those

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34   Karen Levy, Lauren Kilgour, and Clara Berridge, "Regulating Privacy in Public/Private Space:
        The Case of Nursing Home Monitoring Laws," *Elder Law Journal* 26 (2018): 323.

35   Lydia B. Hayes and Sian Moore, "Care in a Time of Austerity: The Electronic Monitoring of Homecare
        Workers' Time," *Gender, Work & Organization* 24, no. 4 (2017): 331.

36   Paul Osterman, *Who Will Care for Us?: Long-term Care and the Long-term Workforce* (New York:
        Russell Sage Foundation, 2017), 11.

37   Evelyn Nakano Glenn, *Forced to Care: Coercion and Caregiving in America* (Cambridge: Harvard
        University Press, 2010); Ariel Ducey, "More Than a Job: Meaning, Affect, and Training Health Care
        Workers," in *The Affective Turn,* ed. Patricia Ticineto Clough and Jean Halley, (Durham: Duke University
        Press, 2007), 187–208; Sarah Jaffe, *Work Won't Love You Back: How Devotion to Our Jobs Keeps Us
        Exploited, Exhausted, and Alone* (London: Hachette UK, 2021).

interpersonal commitments can also be regarded as a threat when they are perceived to conflict with institutional imperatives toward efficiency.[38] In 2015, for instance, after the state of Wisconsin started seeing climbing Medicaid costs as a result of program expansions and an aging population, the state administration identified nurses' discretion in determining how much care service recipients needed as a conflict of interest that led to fraud. In response, health officials contracted with a third-party company to conduct independent assessments for personal care as a means for "preventing the unscrupulous provider from exploiting the system," as one Wisconsin Department of Health Services official stated.[39] Political scientist Virginia Eubanks has also described the ways that efforts to automate welfare eligibility processes view interpersonal relationships between caseworkers and clients as "invitations to fraud," with new technology systems designed to break those human ties.[40] In the context of homecare, imposing additional verification requirements onto workers' timesheets has been another strategy toward this end. In 2009, California governor Arnold Schwarzenegger pushed for significant budget cuts to the state's In-Home Supportive Services Program while seeking to mandate that care providers and service recipients submit their fingerprints on each individual timesheet.[41]

38   Kenneth Brown and Marek Korczynski, "When Caring and Surveillance Technology Meet: Organizational Commitment and Discretionary Effort in Home Care Work," *Work and Occupations* 37, no. 3 (2010): 404–432.

39   David Wahlberg, "State Aims to Cut Personal Care Fraud; Providers Say Move Could Harm Patients," *Wisconsin State Journal,* December 21, 2015, https://madison.com/wsj/news/local/health-med-fit/state-aims-to-cut-personal-care-fraud-providers-say-move-could-harm-patients/article_ff5dcbcc-fda5-5782-9399-82d22c01f08c.html.

40   Virginia Eubanks, *Automating Inequality: How High-Tech Tools Profile, Police, and Punish the Poor* (New York: St. Martin's Press, 2018).

41   Clare L. Stacey, *The Caring Self: The Work Experiences of Home Care Aides* (Ithaca: Cornell University Press, 2011), 144.

The assumption that automated systems can be used to reduce fraud and increase efficiency has powerfully affected how public benefits are delivered. In recent years, there has been growing public awareness of the real and potential harms of automated decision-making systems within public benefits programs.[42] Criticism has particularly focused on issues of bias and discrimination based on race, income, and immigrant status.[43] However, as law professor Michele Gilman points out, the kinds of harms perpetuated by automated systems extend beyond bias and raise issues of equity.[44] In understanding what these technologies do, it is important to ask not only whether they are accurate, but also how definitions of fraud themselves are constructed. In the case of EVV systems, the labor required to comply with digital surveillance can itself be unjust.

A Threat to Independent Living

The introduction of EVV systems as a universal solution to verifying care services conflicts with the complexity and diversity of home- and community-based services. In particular, the Cures Act required the expansion of EVV use into self-directed (also known as consumer-directed) programs, where the person receiving services (or another authorized person) is the formal employer and has control over hiring, training, and overseeing their own services.[45] In contrast to an agency model, this employment configuration is overseen by a financial management services company that processes timesheets and Medicaid reimbursements but lets the service

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42   Ryan Calo and Danielle Keats Citron, "The Automated Administrative State: A Crisis of Legitimacy," *Emory Law Journal* 70 (2020): 797.

43   Jon Henley and Robert Booth, "Welfare Surveillance System Violates Human Rights, Dutch Court Rules," *The Guardian,* February 5, 2020, https://www.theguardian.com/technology/2020/feb/05/welfare-surveillance-system-violates-human-rights-dutch-court-rules.

44   Michele Gilman, "Expanding Frameworks: An Economic Justice Approach to Digital Privacy," *Data & Society: Points,* November 6, 2019, https://points.datasociety.net/expanding-frameworks-9e0781ec2037.

45   "Self-Directed Services," Centers for Medicare and Medicaid Services, accessed October 22, 2021, https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html#:~:text=Self%2Ddirected%20Medicaid%20services%20means,a%20system%20of%20available%20supports.

recipient and the worker negotiate other aspects.[46] While some traditional home health agencies used EVV systems prior to the legislation, it was not a commonly used tool within this context.

The deinstitutionalization of long-term care programs was a major outcome of reforms arising from the disability rights and independent living movements. In the 1960s, state governments began to move away from residential facilities and toward the creation of home- and community-based programs. Self-directed programs were later created during the 1990s as an alternative to agency-based models.[47] Federal and state policy makers were receptive to these new programs because they were less costly than agency-based service provision and helped mitigate labor shortages by creating pathways for service recipients to hire family members or other individuals. Self-direction was initially designed by and for people with disabilities, but it is an increasingly popular preference for older adults who overwhelmingly prefer to "age in place" in their homes, according to the American Association of Retired Persons' (AARP) national surveys.[48]

The 1999 Olmstead Supreme Court ruling—which ruled based on the Americans with Disabilities Act (ADA)—affirmed that states are required to provide home- and community-based services for people with disabilities and that these services must be provided in the most integrated setting appropriate to an individual's needs.[49] The ruling also affirmed that policies leading to unnecessary, unwanted institutionalization of Medicaid participants were discriminatory. But while these programs have grown—both agency-based and self-directed—structural preference for institutional settings remains as states are required to provide nursing facility benefits while coverage of the full range of home- and community-based services

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46   "Self-Directed Services," Centers for Medicare and Medicaid Services.

47   Ibid.

48   Joanne Binette, Kerri Vasold, and AARP Research, "2018 Home and Community Preferences: A National Survey of Adults Ages 18-Plus," *AARP.org,* August 2018, revised July 2019, https://www.aarp.org/research/topics/community/info-2018/2018-home-community-preference.html?CMP=RDRCT-PRI-OTHER-LIVABLECOMMUNITIES-032218.

49   "Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead," US Department of Health & Human Services, last accessed October 22, 2021, https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html.

remains optional.[50] Some disability advocacy groups have argued that if EVV systems impede access to these services and force individuals into institutions, then they violate their rights under Olmstead.[51]

Another major concern has been that EVV systems were built for an agency model, which assumes centralized management where an agency or other health care institution controls most aspects of how and where services are provided.[52] This includes rules such as requiring that services must be provided in the client's home or adhering to rigid schedules. Such requirements run contrary to the intent behind self-directed programs: to give service recipients greater autonomy over their services.

Marketing materials for EVV systems paint a picture of a command center-like station where a home health agency administrator can have a birds-eye view of the workforce. Within the health care industry, EVV systems have been touted as information and communication technologies that allow workers to better observe, communicate, and act on their clients' current health conditions in dialogue with a broader care team.[53] One of the major issues in homecare is that home health aides bear significant responsibility over clients' well-being, but they receive very little professional support.[54] Consequently, some industry efforts to reform homecare jobs have viewed this technology as one promising tool to do so.[55] Within agency-based care, EVV systems were meant to solve the common problems of data entry, oversight, and remote communication with management across field service

50   Erica L. Reaves and MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer,* The Henry J. Kaiser Family Foundation, December 15, 2015, https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/.

51   "Electronic Visit Verification," Center for Public Representation, last accessed October 22, 2021, https://medicaid.publicrep.org/feature/electronic-visit-verification-evv/.

52   "Electronic Visit Verification (EVV) Task Force Statement of Principles and Goals," National Council on Independent Living; Disability Rights and Education Defense Fund to Greg Walden and Frank Pallone, January 19, 2018, https://dredf.org/wp-content/uploads/2018/03/ADAPT-Electronic-Visit-Verification.pdf.

53   Kezia Scales, "Leveraging Technology To Support – Not Supplant – The Home Care Workforce," *Health Affairs,* August 7, 2019, https://www.healthaffairs.org/do/10.1377/hblog20190805.54553/full/.

54   Ariel Ducey, *Never Good Enough: Health Care Workers and the False Promise of Job Training* (Ithaca: Cornell University Press, 2009).

55   Kezia Scales, "Envisioning the Future of Home Care: Trends and Opportunities in Workforce Policy and Practice," *PHI National,* October 15, 2019, https://phinational.org/wp-content/uploads/2019/10/The-Future-of-Home-Care-2019-PHI.pdf.

occupations where employees are constantly on the move. Since the 1990s, various forms of visit verification have been a part of agency-based home health care, first through a client's landline phone and then later via smartphone. In this context, visit verification typically serves to manage complex scheduling logistics across many employees and clients as well as directly communicate with nurses who often oversee the work of home health aides.[56] Their use also coincided with the growing push toward adopting electronic health record systems across the health care system; consequently, they could be integrated into broader efforts to digitize health information.[57]

However, these visions of medically-oriented, centralized management are disconnected from the role of workers in self-directed programs. Although activities overlap, personal care aides and other support workers do not typically perform clinical tasks that home health aides are trained to perform. Instead, they assist with everyday activities like mobility support, bathing, cleaning, or errands like grocery shopping. Specific job titles and responsibilities vary across programs and are tailored to an individual's needs. Direct support professionals, for instance, provide support for people with intellectual and developmental disabilities and teach their clients to perform daily tasks on their own.[58] A crucial dimension of self-directed models is that they move services away from a "medical model" that often treats people with disabilities as passive patients to be managed. The ways that care work itself is socially conceptualized can also be objectifying, disregarding the agency of people with disabilities or pathologizing their bodies and lives.

Introducing EVV systems into this context has been destabilizing. Some efforts have been taken to adapt EVV systems to the particular needs and dynamics of self-directed employment relationships. However, a lack of standardization or best practices that genuinely incorporates workers' and service recipients' perspectives has meant that, in practice, this has often not been the case.

56   Shailendra Jain, "Understanding Electronic Visit Verification," *Homecare Magazine,* June 10, 2019, https://www.homecaremag.com/june-2019/understanding-electronic-visit-verification.

57   Tina Wu, "From Time Sheets to Tablets: Documentation Technology in Frontline Service Sector Managers' Coordination of Home Healthcare Services," *Work and Occupations* 47, no. 3 (2020): 378–405, https://doi.org/10.1177/0730888420922581.

58   "Direct Support Professionals: Overview," *The Arc,* accessed October 23, 2021, https://thearc.org/policy-advocacy/direct-support-professionals/.

THE DIGITAL WITNESS:
QUANTIFYING CARE LABOR

EVV systems function as a form of workplace surveillance, affecting the ways that personal care and other support workers manage their time. Digital and paper-based timekeeping tools are ubiquitous across hourly waged labor, and employers typically have a legal right to monitor their workforces through a variety of methods. But in the context of care and support work, efforts to fit the labor into rigid, predictable time measurements often do not easily capture how work is done on the ground. The ways that EVV systems remove time and location information from their social contexts caused workers and service recipients to worry that the data would tell the wrong story. Particularly, the requirement to track hours spent "on" and "off" the clock in real time posed significant challenges in cases where service recipients' family members are employed as their personal care aides.

Overall, EVV systems police compliance. Under threat of being penalized for continuous flagged activities, workers struggle to prove to the system that they are doing their jobs. Service recipients and their workers tried to work around rigid or glitchy systems, but they often found that EVV systems closed the loop of workarounds that actually sustained working relationships. Generally, workers and service recipients regarded EVV as a blunt instrument that required time-consuming finessing, but doing so raised significant anxieties of scrutiny from state authorities.

Working Against the Clock

Anh-Thi, an Asian American woman who works as a personal care aide for her elderly parents, has her own routine for tracking hours. For years, she has been keeping a notebook where she writes down all of the hours she spends taking care of her elderly mother and father. Toward the end of her pay period, when she must submit her timesheets, she pulls it out again and starts to do some adjusting:

> I have to add to the computer what time [I worked], and then… one more thing, I have to adjust the hours. If I exceed the hours, you know, I always work more than that, I have to reduce the hours, put the hours back.

Anh-Thi provides care for her parents that well exceeds the time for which she is formally compensated by the state. But on her timesheet, she has to be careful not to exceed the time limit that each of her parents have been allocated under Medicaid. While she works a part-time office job, much of the rest of her time is spent going between her parents, who live separately, to help them live comfortably in their homes. She learned about her state's self-directed program through a social worker who approached her in the doctor's office, and they helped her to apply on her parents' behalf. As she is the only one in her family who speaks English, she has long taken charge of her parents' paperwork for all of their health care matters. Since her father's health declined, he has needed round-the-clock care, and Anh-Thi's sisters have also stepped in to do cooking and other household tasks for them.

The transition to an app-based EVV system to track her hours in real time has been a significant challenge for Anh-Thi. For one, splitting her hours between each parent has become a logistically complicated endeavor that her notebook can no longer solve. If one day she is clocked in for 5 hours for her mother and then 6 hours for her father, she exceeds the threshold for overtime, which her financial management services company has strongly discouraged her from claiming. Instead, she has to go into the EVV system's online portal and retroactively cut down her hours. If she has to pick up groceries for her mother en route from a shift at her father's home, she has to remember to switch between them in the system. If she is completing tasks for both of them simultaneously, she has to think ahead about how to split hours between them so she does not use up one parent's allotted care hours too quickly. The location tracking function worries her because many of the tasks she has to do cannot be done at her parents' homes. For one, neither of her parents have internet or home computers so any of their paperwork, like paying medical bills, has to be taken home with her, as do their bed linens for cleaning in her own washing machine. As a result, she expressed feeling deeply stressed over how state Medicaid authorities could infer that she is engaging in approved activities, and not committing Medicaid fraud, simply from her location data.

On top of these complications, the app often glitches, showing Anh-Thi an error reading that does not allow her to log in when she needs to. She often has to take a screenshot of the error message and later manually input her hours online and provide a reason for the adjustment. She worries that all of these constant, daily

manual corrections and varying locations will make her look like she is not fulfilling her responsibilities. While her state's health department granted a temporary grace period for workers to learn how to use the EVV system, she fears what might happen if she is ever audited in the future:

> What are they gonna investigate? If they don't investigate right away in a month, are they gonna wait like a year later and ask you why you entered [an adjustment] that one time? And you're not gonna remember! So even when I submit the hours, and the EVV gave me an error, I capture that [screenshot], and then, if they investigate me, I'm gonna show them this message. I think like, you know, you're not comfortable to work in that situation. I mean, in a normal workplace, you come in, you put up in the system that everybody sees, you are working over there, if the system doesn't record, they will know that you are there. And then right now, who's gonna look at me, who's gonna witness that I am looking after my dad and mom?

Despite EVV recording Anh-Thi's times, the technology was often an unreliable witness. The messy, complicated forethought and administrative work that went into roughly approximating her parents' care to state Medicaid authorities also put a significant setback in Anh-Thi's plans. Her sisters had planned to apply to work as personal care assistants (PCAs) so that Anh-Thi could transfer a share of their parents' allotted hours to them as formal care workers. But while Anh-Thi could have handled assisting them with navigating the old web timesheet, she explained that her sisters were not "tech savvy." The EVV requirement meant that she would need to be constantly present to supervise them. If a tech issue arose, she could not always be there to troubleshoot, which often took hours out of her day. But importantly, the EVV system they had to use did not offer its interface in Vietnamese, or any language other than English.[59] Many EVV models do not offer multi-lingual options, a critical feature for a heavily immigrant workforce that speaks Spanish, Tagalog, French Creole, Yoruba, Russian, Chinese, and dozens of

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59   While some EVV systems on the market offer multiple language options, many do not. For example, an FAQ from EVV vendor Time4Care notes that the app currently does not offer multiple language options, though it may be available in future releases. "Time4Care EVV FAQ," PublicPartnerships.com, accessed October 23, 2021, https://www.publicpartnerships.com/time4care-evv-faq/.

other languages.[60] Altogether, Ahn-Thi felt that adding her sisters as care workers was not worth the risk of getting flagged too many times and potentially losing access to critical financial support that made the current care arrangements for her parents possible.

The struggle to approximate care hours in the data, as in Anh-Thi's experience, was particularly acute for family members who reside with the service recipient. In many cases, they provide support to their client around the clock, regardless of their number of state-funded hours. In some states, this reality has focused stakeholder pushback against EVV policy on exempting live-in caregivers from EVV requirements. In Colorado, for example, the state Medicaid department faced firm opposition from live-in caregivers, primarily parents of children with disabilities for whom the EVV requirement entailed clocking in and out every time a child care task was completed.[61] In some states, exasperated service recipients described placing Post-it Note reminders all over their homes or setting up dozens of phone alarms to keep up with constant electronic check-ins. Colorado Medicaid ultimately opted to exempt live-in caregivers in response to stakeholder feedback, but this has not been the case in other states.[62] For this subset of workers, efforts to cut fraud may merely whittle down what is deemed billable labor from what the state has relegated as a private, family responsibility. As one worker who provides support work to a live-in family member described, "I honestly couldn't tell you when my start or end times are, because in reality there aren't any." In these ways, EVV systems may reinforce the default assumption within US care policy that family time, money, and resources are infinite. As with Anh-Thi and her sisters, these responsibilities often end up falling on women in the family, who must find ways to spread thin resources to sustain sometimes precarious care arrangements.[63]

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60   Robert Espinoza, "Research Brief: Immigrants and the Direct Care Workforce," *PHI National,* June 2017, https://phinational.org/wp-content/uploads/2017/06/immigrants_and_the_direct_care_workforce_-_phi_-_june_2017.pdf.

61   Jennifer Brown, "Medicaid Law Forcing Caregivers to be Tracked by GPS Inspires Privacy Backlash from Colorado's Disabled Community," *The Colorado Sun,* December 23, 2019, https://coloradosun.com/2019/12/23/evv-requirement-for-medicaid/.

62   "Electronic Visit Verification Frequently Asked Questions," Colorado Department of Health Care Policy and Financing, last updated August 27, 2021, https://hcpf.colorado.gov/electronic-visit-verification-frequently-asked-questions#:~:text=Federal%20guidance%20permits%20states%20to,depending%20on%20the%20living%20arrangement.

63   Glenn, *Forced to Care.*

One of the assumptions built into EVV systems is the idea that care work can be divided up into discrete units of time. Within Medicaid home- and community-based programs, a health care professional like a nurse typically performs a needs assessment to ascertain how many care hours a service recipient requires based on estimates of how long particular tasks are supposed to take. These tasks are broken down into numerous service codes falling under either activities of daily living (ADLS)—such as bathing, eating, and mobility support—or as instrumental activities of daily living (IADLs)—such as meal preparation, laundry, or grocery shopping. As the US government's homecare infrastructure expanded in the mid-20th century, the standardization of paid care work emerged as a means to minimize what the state pays out, stripping the work down to timed physical tasks as opposed to "intangibles" like conversing with a client. Historians Eileen Boris and Jennifer Klein note that this change set the stage for rendering much of what workers do invisible to the state, wherein they are expected to complete tasks within budgetary allotments, regardless of whether doing so is possible.[64] As a result, workers often have to negotiate the tensions between "the universalism of bureaucracies and the particularism of caregiving" that characterize institutional management's tendency to try to "expunge uncertainty" from the work, as public health scholar Emily K. Abel and her colleagues describe.[65]

At the same time, the distributed nature of homecare makes it difficult to manage and regulate. Workers thus retain some levels of autonomy in how they do their work, though it also leaves them vulnerable to exploitation.[66] In practice, it means that workers often engage in "surplus care," or unpaid labor for which they are not compensated.[67] As one labor advocate observed, while the industry has standardized tasks into billable units, in reality, it "doesn't always fit neatly into these 15-minute increments, like it's supposed to on paper." For instance, a worker may engage in multiple tasks at the same time. If a task takes longer than anticipated, their time may also slightly overlap with the start of another worker's shift. At a 2019

64   Eileen Boris and Jennifer Klein, *Caring for America: Home Health Workers in the Shadow of the Welfare State* (New York: Oxford University Press, 2015), 9.

65   Emily K. Abel, and Margaret K. Nelson, eds. *Circles of Care: Work and Identity in Women's Lives* (Albany, NY: State University of New York Press, 1990).

66   Brown and Korczynski, "When Caring and Surveillance Technology Meet," 404–432.

67   Stacey, *The Caring Self.*

Colorado stakeholder meeting, several care workers expressed concerns about how the imperative to accurately log their time often directly conflicted with the immediacy of service recipients' needs. Care workers must be responsive to sudden and changing needs that are a part of the unpredictability of human life. As one meeting participant noted, "[t]he last thing I have time for is to stop everything I'm doing to log in."[68]

Overall, workers expressed anxiety that their efforts to translate their activities as data inputs into EVV systems may be misread and potentially penalized. A lack of transparency around what constitutes fraud, or what might get flagged in the system, pressured workers to conform their times in ways that are consistent and predictable. They worried, for instance, that accommodating scheduling flexibilities would make them appear unreliable or untrustworthy. Workers needed to remain hypervigilant to clock out at precise times, even if it meant abruptly stopping in the middle of a task to clock out before resuming and completing their work.

Given the complexities of fitting care work into allotted time constraints, it is important to ask whether time and location data meaningfully measures how or if people are receiving the support that they need. While EVV data can ascertain whether a worker is at a physical location for a defined amount of time, it provides little meaningful information about the quality of care. As these examples show, how workers' time is tracked is laden with power dynamics that shape how workers experience EVV data collection. By design, EVV systems put a significant burden of proof onto workers to show they are not engaging in "time theft." As with many workplace monitoring tools, workers often end up absorbing the costs of labor that cannot easily be quantified, standardized, or made legible to bureaucracies.[69]

Within other contexts, such as the use of ankle monitors in the criminal legal system, scholars and activists have pointed out that location data is not an objective

68   Colorado Department of Health Care Policy & Financing. Electronic Visit Verification (EVV) Stakeholder Meeting Closed Captioning Transcript, July 16, 2019, https://www.colorado.gov/pacific/sites/default/files/EVV_CCTranscript_July2019.pdf.

69   Karen Levy, "The Contexts of Control: Information, Power, and Truck-driving Work," *The Information Society 31,* no. 2 (2015): 160–174.

record of a person's activities or the social contexts in which they take place.[70] Instead, remote monitoring can entrench power dynamics that effectively "require their participants to change or discipline themselves to fit the demands of the system."[71] Given the demographics of the labor force that comprises home health and personal care aides, these burdens are disproportionately imposed on women of color, who may also face other intersecting forms of digital surveillance and control as immigrants, people with disabilities, or low-wage workers, even when such monitoring is presented under a promise of "customization and individualization."[72]

Strained Employment Relationships

The introduction of EVV systems often strained relationships between workers and their clients. Within self-directed programs, service recipients are usually the formal employer and have some control over aspects of employment, but they are also subject to surveillance and supervision. Service recipients are often acutely aware of the precarity of their workers' employment, even as key aspects of wages, administrative rules and regulations, and working conditions are out of their control. Additionally, while workers are overseen by service recipients, they are also at the fulcrum of scrutiny from a home health agency or financial management services company, the EVV company that aggregates their data, and state authorities.

One source of tension emerged around flagged shifts or glitches that led to workers being inadequately paid for their time, or even at all. Along with missed clock-ins, a host of other issues would lead to dozens of shifts rejected or flagged for noncompliance. Karla, a Black woman in the eastern United States, has worked for several years as a personal care aide for two family members who are both

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70   James Kilgore, "Electronic Monitoring is Not the Answer: Critical Reflections on a Flawed Alternative," *Urbana-Champaign Independent Media Center,* October 2015, https://mediajustice.org/wp-content/uploads/2020/01/EM-Report-Kilgore-final-draft-10-4-15.pdf.

71   Irina Shklovski, Janet Vertesi, Emily Troshynski, and Paul Dourish, "The Commodification of Location: Dynamics of Power in Location-based Systems," *Proceedings of the 11th International Conference on Ubiquitous Computing* (New York, N.Y. : Association for Computing Machinery, 2009), 11–20.

72   Ruha Benjamin, *Race After Technology: Abolitionist Tools for the New Jim Code* (Cambridge: Polity, 2019), 296.

developmentally disabled. They moved in with her after her parents passed away, and Karla was able to sign up with a self-directed program to provide support to them in addition to receiving help from two agency home health aides. When either of these workers cannot make their shifts, Karla fills in even though she is not paid for this time.

When Karla received notice that EVV systems were to be rolled out, she could not find the free time to make it to the training sessions that were held in another town a long drive away. Fortunately, her adult daughter, who is the designated employer, was able to download the app on her phone and help her figure it out. But because Karla does not have a home computer and her phone screen is too small, she has to ask her daughter for help when any issue comes up. Often, the system does not let her log in because neither of her family members show up in the drop-down menu to select for the start of a shift. In the moment, she often does not have time to deal with technical issues; she is responsible for preparing her clients' meals, assisting them with eating, bathing, and personal grooming, as well as doing laundry, managing doctors' appointments, ordering supplies, and other necessary tasks.

Sometimes Karla is able to resolve technical issues after significant effort and back-and-forth between herself, her daughter, the EVV company's customer support line, and her case manager at the agency. But a few months into using the system, her paychecks started coming up short, and after sifting through the last few months' pay, she found she was missing over $1,000. It took several months, between herself and her daughter, to figure out where the system had failed to record her time before she was able to prove her case and receive back pay. But during that period, it was a "terrible time" for Karla as her bank account was overdrawn and she fell behind on bills: "My income was ridiculously low, but we live by the grace of God, you know. I'm not the type to check my bank account every day; I just pray that it all goes well."

Since then, Karla has become hypervigilant about checking her pay stubs, as her current wages already make it difficult for her to make ends meet. On top of low wages, personal care jobs also have other hidden costs: Karla's employment does not come with health insurance and she was not able to afford a private plan, which proved very costly after she needed to have surgery to treat an injury she incurred

while physically assisting her client. She expressed frustration that EVV systems had added new responsibilities and obstacles to her job while wages and benefits for homecare workers remained stagnant. "How can we take care of them if we can't take care of ourselves?" she pointed out.

The digital tracking of EVV systems has highlighted the lack of institutional or other human support for personal care workers. Vanessa, a Black woman in her 30s in the eastern United States, works as a personal care aide for her elderly neighbor. She works for him four days a week, but she also picks up hours working on a gig delivery app to make ends meet for herself and her teenage son while she works toward obtaining certification in a better-paying health care occupation. She considers her client a longtime friend, having lived in the same building for many years and often helping him and other elderly neighbors complete household chores and navigate health care bureaucracies. Sometimes, she also helps him get to doctors' appointments on her days off and makes sure to always answer his phone calls no matter the hours in case he has a medical emergency, for he has been in and out of hospitals over the past several years.

While Vanessa takes care to support her neighbor, she herself does not receive the support she needs. She struggles to get in touch with assistance when she has technical issues with the EVV app or needs other urgent assistance. The coordinator at her financial management services company is often unavailable or nonresponsive to Vanessa's messages sent through the EVV system's communication interface, but they seem to immediately check in on her if any of her clock in/out times are slightly off. The discrepancy has been a source of frustration, as she puts significantly more time into helping her client than what she is compensated for. While Vanessa planned to continue to provide personal care services to her neighbor through Medicaid, she felt that between her two jobs, her career ambitions, and her own family, her current arrangement was not sustainable in the long-term.

In the United States, the lack of institutional support for individuals' long-term care needs means that governments and other intermediaries in the care system benefit from the unpaid labor that personal care and home health aides often provide to fill

in the gaps, as well as the unpaid family support that is often taken for granted.[73] As sociologist Evelyn Nakano Glenn notes, these practices are often justified by ideologies that these occupations are more than a job, and which view homecare workers as "quasi-family members rather than as fully autonomous workers."[74] Direct care work is often regarded as "something other than employment," because it is work done overwhelmingly by women, and in particular Black, Asian, and Latina women.[75]

Enforced racial and gendered occupational segregation has been used to devalue these jobs, both socially and materially through low wages and long-standing legal exclusions from many standard labor rights and benefits.[76] Despite soaring demand, low Medicaid reimbursement rates have maintained poverty wages across the industry, and workers are typically not provided standard workplace benefits, such as health insurance, paid sick leave, vacation, or disability insurance. As a result, about one quarter of homecare workers live below the federal poverty line, with average wages falling below $12/hour.[77] While wages in other low-wage sectors like retail have risen, homecare wages have remained stagnant or even fallen after funding cuts.[78] All of these factors have contributed to significant turnover rates in the industry—about 50% to 60% annually—with many workers precariously cycling in and out of the industry.[79] The majority of turnover in the industry is due to staff quitting rather than being fired, and it is increasingly difficult for self-directed

73   Stacey, *The Caring Self,* 144.

74   Glenn, *Forced to Care*, 129.

75   Pierrette Hondagneu-Sotelo, *Doméstica: Immigrant Workers Cleaning and Caring in the Shadows of Affluence, with a New Preface,* (Berkeley: University of California Press, 2007), 9. In the United States, approximately 87% of the homecare workforce are women, 62% are people of color, and more than a quarter are immigrants. "US Homecare Workers: Key Facts," PHI National, September 3, 2019, https://phinational.org/resource/u-s-home-care-workers-key-facts-2019/.

76   Margaret K. Nelson, *Caring on the Clock: The Complexities and Contradictions of Paid Care Work* (New Brunswick: Rutgers University Press, 2015).

77   PHI National, "US Homecare Workers: Key Facts."

78   Dana Gentry, "Home Care Labor Shortage Worsened by COVID, Cuts to Funding," *Nevada Current,* September 14, 2020, https://www.nevadacurrent.com/2020/09/14/home-care-labor-shortage-worsened-by-covid-cuts-to-funding/.

79   "Surveying the Home Care Workforce: Their Challenges and the Positive Impact of Unionization," National Employment Law Project, September 2017, https://www.nelp.org/wp-content/uploads/surveying-home-care-workforce.pdf.

clients and home health agencies to hire and retain workers.[80] In more rural states, the shortage crisis has created a "revolving door" of service availability that often pushes family members to fill in the gaps without public support.[81] In 2021, more than 800,000 people were on waitlists for home- and community-based services throughout the country.[82] Individuals seeking services within self-directed programs may particularly struggle to recruit and retain workers, and the introduction of EVV systems may heighten those challenges.[83]

Service recipients were often acutely aware of the financial strains that made it difficult for personal care workers to remain in the industry, so they sought to ensure that workers received the full hours available. Heather, a white, disabled woman living in the southern United States who manages several support workers that come to assist her throughout the week, expressed frustration about the difficulties of hiring and retaining workers. She pointed out that the wages set by her state for support workers was several dollars lower than what local fast food chains in her area were paying. In addition to trying to ensure that her workers were adequately paid for all their time, Heather often spent hours each week emailing back and forth with the financial services management company that cuts the checks for the workers who come to her home. Their paychecks, which had been consistently the same for years, were suddenly coming up short:

80   *Addressing the Disability Services Workforce Crisis of the 21st Century,* American Network of Community Options and Resources, 2017, https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce%20White%20Paper%20-%20Final%20-%20hyperlinked%20version.pdf.

81   Judith Graham, "The Disabled and the Elderly are Facing a Big Problem: Not Enough Aides," *The Washington Post,* April 23, 2017, https://www.washingtonpost.com/national/health-science/the-disabled-and-the-elderly-are-facing-a-big-problem-not-enough-aides/2017/04/21/5846f576-237f-11e7-a1b3-faff0034e2de_story.html?noredirect=on.

82   Paul Span, "For Older Adults, Home Care Has Become Harder to Find," *The New York Times,* July 24, 2021, https://www.nytimes.com/2021/07/24/health/coronavirus-elderly-home-care.html; MaryBeth Musumeci, Molly O'Malley Watts, and Priya Chidambaram, *Key State Policy Choices About Medicaid Home and Community-Based Services, The Henry J. Kaiser Family Foundation*, February 4, 2020, https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/.

83   "Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers," The Henry J. Kaiser Family Foundation, accessed October 23, 2021, https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/; Naomi Gallopyn and Lisa I. Iezzoni, "Views of Electronic Visit Verification (EVV) among Home-based Personal Assistance Services Consumers and Workers," *Disability and Health Journal* 13, no. 4 (2020): 6.

> And when I questioned [the financial management service agency], they just basically put their hands up like, 'Well, it's not us. We can't help you. You have to call the company that runs the software.' So, they don't know anything, really. They're like, paper pushers, as I like to call the states that do this and so they're just following whatever the state said. They're not truly invested to know how any of it works.

In other instances, delayed wages due to EVV systems led service recipients to develop strategies in response to unreliable Medicaid bureaucracies and other intermediaries, including dipping into personal savings to make up for their care worker's lost wages.[84] The "repair work" done by workers and service recipients when technologies fail is not only time-consuming but also costly. In another workplace context, anthropologists Madeleine Clare Elish and Elizabeth Watkins have described the ways that new technologies disrupted existing workflows and social relationships in hospital nurses' daily routines. However, the gendered labor done by the nurses to improvise and mend those ruptures was rendered invisible in accounts of how those technologies work.[85] Similarly, the invisible costs and logistical burdens taken up by EVV users to keep these technologies functioning may never be included in the narratives of efficiency touted by vendors and government agencies.

In addition to tensions around lost or delayed wages, the added administrative workload that EVV systems put on workers also took away from time providing services to clients. Sometimes, these tasks pitted clients' demands against workers' attempts to comply with EVV systems. Martha, a white woman in the Midwest who works with an elderly client, spoke about how she now needs to arrive 10 to 15 minutes early to park in her client's driveway and clock in:

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84   Virginia Eubanks and Alexandra Mateescu, "'We don't deserve this': New App Places US Caregivers under Digital Surveillance," *The Guardian*, July 28, 2021, https://www.theguardian.com/us-news/2021/jul/28/digital-surveillance-caregivers-artificial-intelligence.

85   Madeleine Elish and Elizabeth Watkins, *Repairing Innovation: A Study of Integrating AI in Clinical Care*, Data & Society, September 2020, https://datasociety.net/library/repairing-innovation/.

The minute I walk through that door of their house, they want my attention; I have things to do. They don't want me looking at my phone. So, you know, sometimes even my client's mom, she'll meet me halfway out the door, you know, to my car, to talk to me so it's like, you know, they don't understand. I have to go through this process; it's required for my billing. And it takes some time, especially if the internet service isn't fantastic that day.

The imperative to clock in and out in real time also placed pressures on personal and professional relationships with family members. For Sharon, who works as a personal attendant to extended family members, the imperative to log time in real time has left her feeling as if all of her interactions with them have become transactional. While acknowledging that the personal attendant work she does is a job and that she has professional commitments to her relatives as clients, she expressed frustration that the requirement to track her hours in real time meant that she could not simply greet her clients when she arrived at their homes; instead, she had to abruptly cut conversation short to pull out her cell phone and begin the process of clocking in. Another personal care aide, who provides support to her elderly mother, spoke about how her mother now frequently complained that she was on her phone all the time, and the EVV system became a point of tension in their relationship.

EVV systems promised to make care provision more efficient and allow workers to dedicate more time to their relationships with clients, but instead, they often strained those relationships. Transparency and due process over worker pay became a significant source of frustration and confusion as these processes were transferred through EVV systems to a third-party company.

DIGITAL HOUSE ARREST:
EVV AS WELFARE SURVEILLANCE
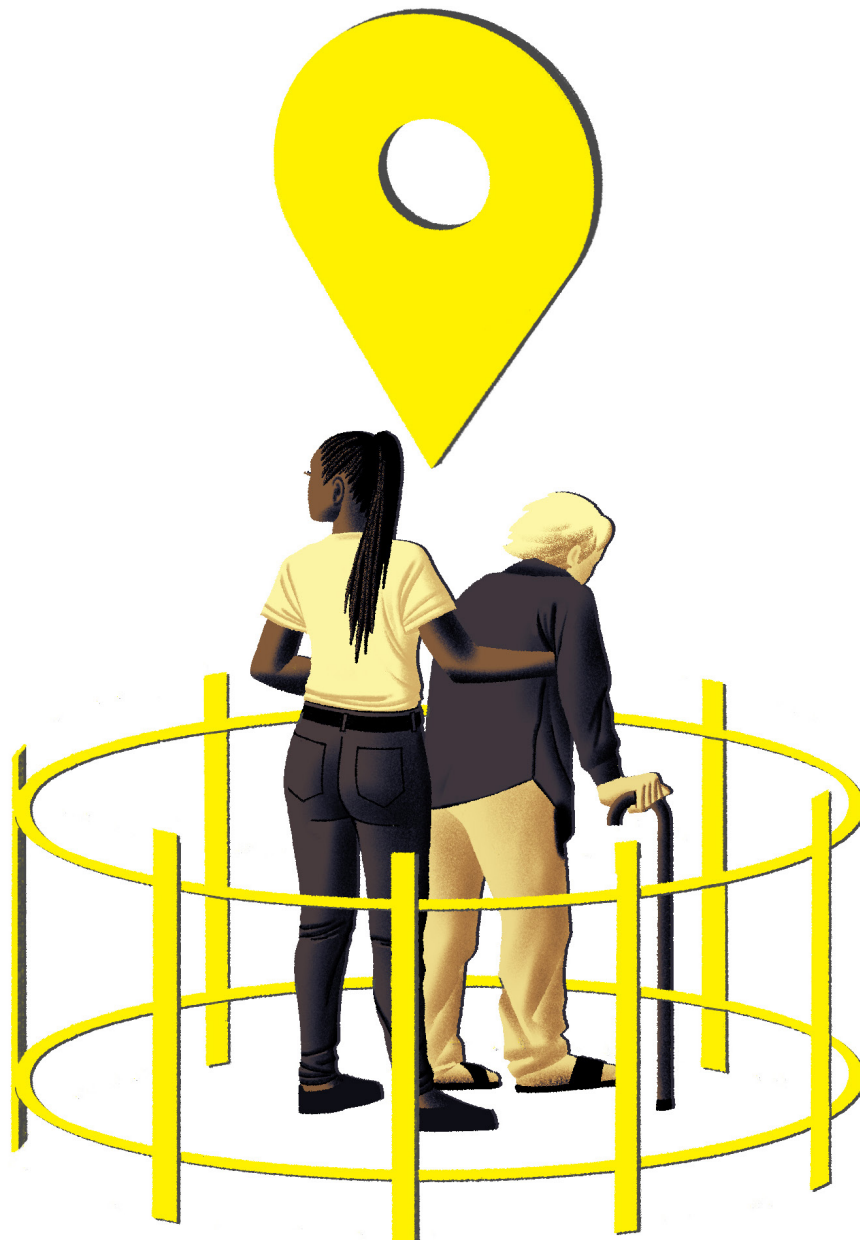
While in principle EVV systems are a workplace management tool, they operate within a service context where electronically monitoring workers also indirectly tracks their clients' activities and movements. The work of personal attendants is generally interwoven into the everyday fabric of service recipients' lives, whether at their homes or at work, during visits to friends or family, or while shopping for groceries. This section argues that monitoring through EVV systems not only evokes abstract privacy concerns for service recipients, but also creates an atmosphere of ambient criminalization that has had a chilling effect on their daily lives. For workers, flagged timesheets could result in halted or missed paychecks, but service recipients experienced pervasive fears that any deviations could invite scrutiny or, in the worst case, be used as grounds to cut hours or disqualify them from receiving services.

Service recipients—primarily within Medicaid self-directed programs—are experiencing EVV systems as both coercive and exclusionary. In the case of EVV, public testimonies from Medicaid service recipients have pointed to the fact that they have no choice but to consent to data collection because, as one blog post put it, many people "absolutely, positively cannot survive" without the long-term services provided by Medicaid.[86] GPS tracking and geofencing features pressure service recipients and their workers to re-orient their lives—including their movements, living arrangements, and routines—to conform with compliance rules. In addition, the financial, logistical, and administrative costs to access technologies fall on workers and service recipients. Exclusion from these technologies can jeopardize their access to services entirely.

Ambient Criminalization

A major concern for advocacy groups has been that EVV systems would de facto confine people with disabilities and older adults in their homes. For instance, the Disability Rights Education and Defense Fund has argued that it "creates the

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86   Kacie Wielgus Buzzard, "Ohio Medicaid Installed a Tracking Device in My Home Because of My Daughter's Disability Services," *The Mighty,* February 4, 2018, https://themighty.com/2018/02/electronic-visit-verification-is-invading-families-privacy/.

potential for an atmosphere of 'house arrest,' limiting community participation, and perpetuating the outmoded stereotype that disabled people cannot or do not leave their homes."[87] Karin Willison, disability editor at the digital health community site The Mighty, has likewise argued that "[e]lectronic visit verification is the equivalent of putting an ankle monitor on people with disabilities and telling us where we can and can't go."[88] Regardless of how or whether state policies or EVV design features penalize noncompliance, they can have a chilling effect on behavior. A survey conducted by the National Council on Independent Living of home care recipients and workers across 36 states found that one-third of respondents reported that they "stay at home more often than prior to EVV use, due to fear that geofencing limitations will flag a visit as fraud or cause delay in or loss of provider wages."[89]

One of the most contested aspects of the EVV mandate has been the widespread use of GPS tracking and geofencing. To date, regulators have taken little action to limit it.[90] The Centers for Medicare and Medicaid Services has clarified that EVV systems are only required for the portion of services provided in the client's home but states can still choose to require more information.[91] While states are not required

87   "DREDF Opposes Electronic Visit Verification (EVV) When It Threatens Disabled People's Civil and Privacy Rights and Impedes Personal Choice, Autonomy, and Community Participation," Disability Rights and Education Defense Fund, March 2018, https://dredf.org/2018/03/07/dredf-statement-on-electronic-visit-verification/.

88   Karin Willison, "How Electronic Visit Verification (EVV) Invades the Privacy of People With Disabilities," *The Mighty,* January 19, 2018, https://themighty.com/2018/01/electronic-visit-verification-gps-tracking-disabled-people/.

89   "Call to Action: The Need for Federal Protections In Electronic Visit Verification," National Council on Independent Living, accessed October 23, 2021, https://secureservercdn.net/198.71.233.129/bzd.3bc.myftpupload.com/wp-content/uploads/2020/08/8-2-20-CALL-TO-ACTION.pdf.

90   For instance, a report published by the Consumer-Directed Personal Assistance Association of New York State discussing stakeholder reception to EVV systems found that "[s]ervices based on global positioning system (GPS) monitoring or biometrics were met with staunch resistance." See "Electronic Visit Verification and Self-Direction: A Consumer Perspective," CDPAANYS, May 2018, https://cdpaanys.org/wp-content/uploads/2018/09/EVV-Self-Direction-Consumer-Advocates-report.pdf.

91   CMS published a policy guidance document in August 2019 that reminded states that "EVV is only required for the portion of the service rendered in the home," offering states the option to simply use the terms "home" and/or "community" to designate location in EVV system for location, instead of recording GPS coordinates. Calder Lynch, "Additional EVV Guidance," *Centers for Medicare and Medicaid Services,* August 8, 2019, https://www.medicaid.gov/federal-policy-guidance/downloads/cib080819-2.pdf; "Frequently Asked Questions: Section 12006 of the 21st Century Cures Act, Electronic Visit Verification (EVV) Systems for Personal Care Services (PCS) and Home HealthCare Services (HHCS)," Department of Health and Human Services, Center for Medicare and Medicaid Services, May 16, 2018, https://www.medicaid.gov/federal-policy-guidance/downloads/faq051618.pdf.

to use GPS tracking or geofencing, CMS has noted that they "cannot prohibit states from using GPS," and that legislation from Congress would be needed to implement a federal ban.[92] Consequently, states have typically imposed more restrictive policies, with most opting in to GPS location tracking and geofencing.[93]

At the same time, advocates have argued that state officials have not been transparent with service recipients about the range of EVV options, giving the appearance that GPS tracking devices are the only option.[94] Because no clear guidelines exist for the states on how to implement geofencing, geographic parameters are arbitrarily set. For instance, one company, Axxess, has set their geofenced perimeters to 1,500 feet from the service recipient's home while allGeo, another vendor, sets a perimeter at 100 feet.[95] Although some states have sought more flexible options for allowing multiple locations, in states like Arkansas, the Department of Human Services has required workers to clock in and out only inside the client's home for ARChoices, the state's home- and community-based waiver program. Consequently, service recipients within this program have limited their movements and activities outside the home to avoid triggering an "unauthorized location" error, creating living situations that one worker described as "an invisible dog fence for humans."[96]

In interviews with service recipients, the GPS requirement tangibly impacted their day-to-day lives. EVV systems typically check a worker's visits against a pre-set schedule, but within self-directed programs, services are not always scheduled in advance and may change on short notice. One service recipient, Angela, a Black

92   Centers for Medicare and Medicaid Services, Electronic Visit Verification (EVV) Stakeholder Open Door Forum, Wednesday, November 7, 2018, https://www.cms.gov/Outreach-and-Education/Outreach/OpenDoorForums/PodcastAndTranscripts.

93   Michelle Diament, "Feds Weigh In On Medicaid Caregiver Check-In Mandate," *Disability Scoop,* August 22, 2019, https://www.disabilityscoop.com/2019/08/22/feds-weigh-in-on-medicaid-caregiver-check-in-mandate/27053/.

94   Alicia Hopkins, "How Electronic Visit Verification Is Harming People With Disabilities," *Yahoo News,* August 19, 2019, https://www.yahoo.com/now/electronic-visit-verification-harming-people-183015414.html.

95   "EVV Geofence Update," Axxess, September 13, 2019, https://www.axxess.com/help/axxess-homecare/software-updates/evv-geofence-update/; "What is Geofencing Time Clock?," AllGeo, accessed October 23, 2021, https://www.allgeo.com/what-is-geofence-time-clock-app.

96   Eubanks and Mateescu, "'We don't deserve this.'"

woman living in the Midwest, compared the ways in which this added work of explaining her movements left her feeling like she was under perpetual probation:

> Well, I can't actually go anywhere these days because of the coronavirus, but if I do... well it's hard for me to get places regardless. But if I do, if I'm meeting my worker somewhere and they clock in, I don't want to constantly be getting a call or a flag or whatever for them to say 'why were you at such-and-such location?' My case manager is not my parole officer.

The requirement to record location nevertheless demands "constant justificatory labor" from service recipients and workers in order to move about freely.[97] Sharon, a white woman in the Midwest who prides herself in being a meticulous planner ("If I didn't plan, I wouldn't be able to juggle it all") when it comes to providing support services for two of her extended family members, describes the additional work she must do to avoid getting flagged:

> And so you have your primary location, which is [the client's] home. And then, like, I basically put in all the places that we normally go, and like, if I know we're going to go somewhere else, then, you know, add that location in, like we have that option. So, I've never had anything be flagged yet because all of my locations were in... I basically had to put all of it in, like we go to the same grocery store, we go to their house, their parent's house, my house, all the families' houses, their doctors... basically anywhere that we frequented, the library, I put those in right when they, when we basically were forced to start using the thing in order to kind of get ahead of that.

If Sharon and the family members she provides services to travel to a new location, she has to remember to enter it into the system in advance, though she is not sure if the system allows for changes on short notice. She worries that one of the consequences of the tracking will be the creation of an extensive digital map of all of her family members' homes and physical movements. "Being managed by a third-

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97   Jacob Metcalf, "When Verification Is Also Surveillance," *Points: Data & Society,* February 27, 2018, https://points.datasociety.net/when-verification-is-also-surveillance-21edb6c12cc9.

party company, who in that company is viewing where we've been, you know?" she asks. "Who is that data being shared with? Is it just being shared with the state? Is it being shared with a different organization? I don't know, and they've never been clear."

Conscious of these dynamics, some design efforts have been made to create or modify EVV systems specifically for self-directed programs. A 2018 presentation from CMS provided recommendations to ensure that EVV systems are "both flexible and reliable" when verifying locations outside the home, noting that they should be designed to "avoid rigid scheduling rules."[98] The recommendations suggest populating the EVV system with a service recipient's "anticipated and preferred community locations" through their case manager or through the EVV system's web portal. At the same time, the document warns about the need to monitor for outliers, or "exceptions," noting that "multiple location edit requests in a same day, or every day for a month might flag a further review by the case manager or the provider."[99]

The decision to require more specific location data can pose different harms for different individuals. One disability advocate noted concerns about where data is collected and stored and the risk of data breach or mishandling. Sharon had tried to "put [EVV] off as long as possible" in part because one of her clients worried that her location data could be accessed by a potentially dangerous ex-spouse. A University of California San Francisco study on EVV users' experiences reported that domestic abuse and sexual assault survivors in particular felt their safety compromised because EVV systems required service recipients to enter a home address rather than a post office box, which such individuals often use for their personal safety.[100] States that have allowed individuals to request an exemption

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98 "CMS acknowledges that EVV in self-direction should avoid rigid scheduling rules and be able to accommodate services at multiple locations in order to preserve the flexibility of self-directed services." Centers for Medicare and Medicaid Services, Electronic Visit Verification (EVV) Stakeholder Open Door Forum, November 7, 2018, https://www.cms.gov/Outreach-and-Education/Outreach/OpenDoorForums/PodcastAndTranscripts.

99 "EVV Requirements in the 21st Century Cures Act," Centers for Medicare and Medicaid Services, August 2018, https://www.appliedselfdirection.com/sites/default/files/EVV%20Requirements%20in%20the%2021st%20Century%20Cures%20Act%20Intensive.pdf.

100 Jacqueline Miller, Mary Lou Breslin, and Susan Chapman, *Impact of Electronic Visit Verification (EVV) on Personal Care Services Workers and Consumers in the United States,* University of California San Francisco Health Workforce Research Center on Long-Term Care, July 22, 2021, https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/EVV_Report_210722.pdf.

from GPS location tracking still place the onus on the individual to provide proof of a "documented safety risk."[101] Digital location tracking can also pose specific risks for immigrant workers and service recipients, who many have undocumented family members. In 2015, nearly one quarter of US direct care workers were immigrants, comprising half or more of the workforce in states like New York and California.[102] A 2017 national survey of privacy and security concerns found that people living in low-income households were considerably more likely to be concerned about what personal information is being collected about them and how it is used.[103]

Some service recipients and their workers sought out strategies to shield themselves or each other from EVV data collection. Christine, a Black woman living in the Southwest who works as a personal care aide for her elderly mother, described obtaining a second phone to use solely for EVV check-ins:

> I just got a second phone set up for that because I don't feel comfortable with any type of tracking device, me being a PCA, no! If I was maybe a driver for UPS or something like that, okay, but I've been a PCA since 2012. And I'm not comfortable with being tracked; I'm just one of those people; I really wouldn't want a job like that. If I was to, like, have clients [other than my mother], if I did, I would be looking for another job. It's an extra hassle that I wouldn't want to deal with.

Although Christine works through a home health agency, her employer did not provide her with a cell phone for using EVV; they only offered a training session to onboard her on how to use the app and directed her to the EVV company's third-party customer service line for all technical issues.

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101 "Developmental Disabilities Worker's Guide: EVV Exceptions for Agency Community Living Services providers employing DSPs," Oregon Office of Developmental Disabilities Services, March 13, 2020, https://www.oregon.gov/dhs/SENIORS-DISABILITIES/DD/PROVIDERS-PARTNERS/Documents/EVV-Agency-Exceptions.pdf.

102 Espinoza, "Immigrants and the Direct Care Workforce."

103 Mary Madden, *Privacy, Security, and Digital Inequality: How Technology Experiences and Resources Vary by Socioeconomic Status, Race, and Ethnicity*, Data & Society, September 27, 2017, https://datasociety.net/wp-content/uploads/2017/09/DataAndSociety_PrivacySecurityandDigitalInequality.pdf, 2

In addition to location tracking, logging hours and tasks in real time can create significant logistical challenges in coordinating workers. Together, Ruth and her daughter Melanie manage schedules for Melanie's personal attendants. In a given month, Melanie's support workers complete hundreds of log-ins to record their time. Because her workers' hours are funded through more than one Medicaid program, they also must sometimes remember to clock in and out more than once within a single shift. Small missteps, like workers swapping shifts on short notice, or one worker clocking in a little before the other has clocked out during a shift change, raises a flag and ushers in a phone call from the financial management services company demanding an explanation. The family worries that constantly keeping tabs on and rebuking the support workers for minor timekeeping errors may be damaging their relationships with the workers. Ruth worries that, because the hourly pay is so low, these additional pressures may drive them away.

To the family, the EVV system's digital tracking has felt, as Ruth put it, like an escalation of the "low-level, constant state of fear" of continually proving and re-proving Melanie's disability to the nurses and social workers who come in every 6 months to reassess her for service eligibility. Navigating the complicated paperwork, bureaucratic jargon, and eligibility requirements in order to be approved —and regularly re-approved—for these services has been a huge learning curve for the family over the years. Ruth says that social workers and nurses often ask "inappropriate" or probing questions that feel "designed to catch us," which has underscored the precarity of state support for Melanie's services:

> I'm actually, I'm always in terror of these nurses and social workers coming every six months because I'm constantly afraid that they're going to take away what they gave her. She has a lot of hours of care, which is, you know, very expensive for [my state's] Medicaid. And I'm always afraid every time someone comes in and reassesses, you know, it's kind of a low-level, constant state of fear that what, you know, what they gave her is going to be taken away.

In state-funded homecare, differences across race, class, gender, and immigrant status also shape the ways that state authorities, such as social workers, exert power over the lives of people who receive services. Service recipients' feelings of

distrust or cynicism toward these institutions are often shaped by lived experiences of being disbelieved or dismissed.[104]

Access to public benefits for people with disabilities is often contingent upon their acceptance of state scrutiny into their lives, usually for the purpose to justify denying benefits.[105] In 2019, for example, the Trump administration aimed to roll out a plan to surveil people who claim social security disability benefits by scrutinizing their social media activities in order to identify alleged fraud.[106] Although the plan was ultimately dropped, it is emblematic of distrust toward people seeking public assistance as illicit or unworthy beneficiaries, and people with disabilities in particular as burdens on state governments' budgets. This context has shaped the reception of EVV systems, as service recipients worry about how data about their activities and movements may be used or interpreted. Moreover, disability scholars have critiqued the ways in which monitoring technologies can often amplify inequalities at the intersections of racism and ableism. By design, digital tracking may invite intrusive or violent involvement of law enforcement or other state institutions into the lives of disabled people of color, as well as the care workforce.[107] For instance, partnerships with law enforcement that implement location tracking are often justified in the name of safety, such as the use of GPS electronic bracelets that some states have deployed to monitor autistic children and older adults with dementia.[108] The time and location tracking through EVV systems may potentially compound and intersect with other various forms of state surveillance and coercion.

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104   Cynthia J. Cranford, *Home Care Fault Lines: Understanding Tensions and Creating Alliances* (Ithaca: Cornell University Press, 2020).

105   Karen Reilly, "A Primer on Surveillance Issues in the Disability Community," *Team CommUNITY Blog*, April 22, 2021, https://www.digitalrights.community/blog/primer-surveillance-in-disability-community.

106   Robert Pear, "On Disability and on Facebook? Uncle Sam Wants to Watch What You Post," *The New York Times,* March 10, 2019, https://www.nytimes.com/2019/03/10/us/politics/social-security-disability-trump-facebook.html.

107   Leon J. Hilton, "Avonte's Law: Autism, Wandering, and the Racial Surveillance of Neurological Difference," *African American Review* 50, no. 2 (2017): 221–235.

108   Alison Marie Kenner, "Securing the Elderly Body: Dementia, Surveillance, and the Politics of 'Aging in Place,'" *Surveillance & Society* 5, no. 3 (2008): 252–269.

Both service recipients and workers also expressed uncertainty over what data was actually collected by EVV systems, where it would be sent, and how it would be used or interpreted. Although most EVV systems allow for service recipients or workers to go into a web portal to manually correct any errors before submitting their data for payroll, the number of times they could do so without repercussions was often not clear. For instance, one worker felt frustrated at not getting a clear answer from her state's health department, despite her efforts: "When do they decide how many times, once, twice, what is your criteria? I have no idea. What if you just have an old, raggedy phone that messes up sometimes? Do they get punished because they haven't upgraded their phone?" Another service recipient spoke about her fears of being penalized for making too many manual corrections on her worker's timesheet data:

> When it is time for turning in the timesheet to make sure everything's okay, I can go in and correct any mistakes. But they have told us, we're only allowed so many corrections before we get penalized. No one's told us exactly how many corrections or what the penalty is. So, you know, and we've asked [the case manager] and they just ignore it. They just, like, brush right over.

Public confusion about data collection has been an issue in several states since the start of EVV rollouts. In 2018, for example, when the state of Ohio contracted to EVV vendor Sandata Technologies to administer the state's EVV system, backlash emerged when service recipients expressed concerns over the devices' built-in camera and microphone capabilities. The Ohio Department of Medicaid had to issue clarifications that these features were not activated on the state-issued cell phones that had been mailed to service recipients.[109]

The concerns of service recipients over how their workers are monitored highlights the potential for function creep. Workplace data collection practices can be used to engage in "refractive surveillance," wherein data collected about one actor is

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109   Katie Wedell, "State's New Anti-fraud Devices Have the Disabled Worried about Snooping," *Dayton Daily News*, February 6, 2018, https://www.daytondailynews.com/news/state--regional-govt--politics/state-new-anti-fraud-devices-have-the-disabled-worried-about-snooping/alGiZrghAYWNfDzdjjkQZL/.

used to make decisions about another.[110] While some service recipients expressed fears about more indirect risks, such as data breaches, a more pervasive concern, as Ruth expressed, was how data could potentially be used by state authorities to justify decisions like service cuts. A 2019 report by the New York State Department of Health summarizing feedback from listening sessions reported that service recipients have asked for assurance "that location data will not be used to make invasive inferences about their lifestyle choices or to justify denial of service."[111]

Their concerns may be justified, considering that tech companies are looking to enhance the scope and predictive power of their products.[112] In 2020, for example, an Alphabet-backed startup called Carebridge announced plans to combine EVV systems with predictive models for determining and allocating care hours for people receiving long-term services and supports.[113] An industry white paper similarly promotes the use of predictive analytics to identify patterns that are "dependable predictors of improper billing" in Medicaid services.[114] Multiple state governments have already adopted automated decision-making tools to assess people's eligibility for Medicaid home- and community-based services, often with little public debate or transparency over how decisions are made.[115] Arkansas's Department of Human Services introduced such a system in 2018, which made

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110   Karen Levy and Solon Barocas, "Refractive Surveillance: Monitoring Customers to Manage Workers," *International Journal of Communication* 12 (2018): 23.

111   "Electronic Visit Verification: Stakeholder Convening Report," New York State Department of Health Office of Health Insurance Programs, 2019, https://www.health.ny.gov/health_care/medicaid/redesign/evv/repository/docs/2019-stakeholder_conven_rpt.pdf.

112   "COVID-19: Predictive Analytics for the Next Wave," CellTrak, August 7, 2019, https://www.celltrak.com/white-paper-covid-big-data.

113   "CareBridge Launches to Improve Care for Individuals Receiving Long-Term Support Services," *BusinessWire,* January 13, 2020, https://www.businesswire.com/news/home/20200113005935/en/CareBridge-Launches-Improve-Care-Individuals-Receiving-Long-Term.

114   *Identify, Predict, Prevent, Recover: A Handbook for Medicaid Program Integrity,* The Governing Institute and Optum (n.d.), http://sealbeachfamilymedicalgroup.com/content/dam/optum3/optum/en/resources/ebooks/574564-identify-predi.pdf, 7.

115   Lydia X. Z. Brown, Michelle Richardson, Ridhi Shetty, and Andrew Crawford, "Challenging the Use of Algorithm-driven Decision-making in Benefits Determinations Affecting People with Disabilities," Center for Democracy and Technology, October 2020, https://cdt.org/insights/report-challenging-the-use-of-algorithm-driven-decision-making-in-benefits-determinations-affecting-people-with-disabilities/; Erin McCormick, "What Happened When a 'Wildly Irrational' Algorithm Made Crucial Healthcare Decisions," *The Guardian,* July 2, 2021, https://www.theguardian.com/us-news/2021/jul/02/algorithm-crucial-healthcare-decisions.

drastic cuts with devastating effects to service recipients' health and well-being.[116] While it is unclear whether data generated by EVV systems have been used to make decisions about service eligibility or levels of care, it is one potential trajectory for uses of the technology. One concern is that, as labor shortages create obstacles for self-directed clients to fill their allotted care hours, state administrators could interpret data on "underutilization" of services as evidence that Medicaid recipients do not need those hours.

While EVV systems were designed to passively track time and location data to verify services, they actively changed service recipients' ability to live freely in their communities. Service recipients had to implement new tactics to shield themselves and workers from data collection while preserving their right to services. The introduction of EVV systems into self-directed programs also serves in some ways to re-institutionalize services by imposing more rigid, centralized control that assumes by default that service recipients are homebound.

Digital Exclusion

While advocates have opposed EVV's privacy incursions, the ability to comply at all with being monitored excludes many workers and service recipients. The default requirement to adopt and regularly use new technologies like EVV systems assumes ready access to infrastructures and resources: at minimum, an up-to-date and well-functioning smartphone with a consistently active data plan or an installed landline for workers to call in and out as well as a computer and home internet connection.

These resources are often out of reach for Medicaid service recipients and the workforce that supports them, many of whom face precarious economic conditions. Many people with disabilities are pushed into poverty, and at the same time may not be able to build up income or savings without risking their eligibility to programs like Supplemental Security Income or Social Security Disability Insurance that impose strict income or asset limits and require constant reporting on finances

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116   Colin Lecher, "What Happens When an Algorithm Cuts Your Healthcare?" *The Verge,* March 21, 2018, https://www.theverge.com/2018/3/21/17144260/healthcare-medicaid-algorithm-arkansas-cerebral-palsy.

as a form of means testing.[117] Consequently, the financial resources necessary to set up workplace equipment to fulfill the EVV mandate is out of reach for many people. According to a 2019 Pew Research Center survey, roughly 29% of adults with household incomes less than $30,000 a year did not own a smartphone while 44% did not have home broadband services and 46% did not own a traditional computer.[118] As one disability advocate pointed out, "EVV is now an economic barrier to enter this industry."

Workers and service recipients were told that EVV incurred no additional costs as states have contracted with vendors to offer free EVV mobile app access. Within an agency-based model, some home health agency companies may take on the costs of purchasing and issuing smartphones with the pre-loaded EVV app to their employees. Nevertheless, the costs of smartphone ownership, maintenance, and phone/internet bills typically falls on EVV users. For example, the EVV program developed by the North Carolina Department of Health and Human Services is a "bring your own device (BYOD) program."[119] Similarly, Alabama Medicaid has stated that ownership and associated costs of a mobile device for EVV is "the responsibility of the provider's in-home service workers."[120]

Some states are seeking to implement workarounds and accommodations for individuals who do not have access to cell phones or computers.[121] In some states, for example, service recipients or workers without access to a smartphone were directed to apply for support from Lifeline, the Federal Communications Commission assistance program where low-income Americans (including Medicaid beneficiaries) may qualify for a cell or landline phone and other free or discounted

117   Azza Altiraifi, "A Deadly Poverty Trap: Asset Limits in the Time of the Coronavirus," *American Progress,* April 7, 2020, https://www.americanprogress.org/issues/disability/news/2020/04/07/482736/deadly-poverty-trap-asset-limits-time-coronavirus/.

118   Emily A. Vogels, "Digital Divide Persists Even as Lower-income Americans Make Gains in Tech Adoption," Pew Research Center, June 22, 2021, https://www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/.

119   "Frequently Asked Electronic Visit Verification (EVV) Questions," North Carolina Department of Health and Human Services, February 18, 2021, https://files.nc.gov/ncdma/documents/Providers/Programs_Services/EVV/NC-Medicaid-EVV-FAQs-02182021.pdf.

120   "Alabama Medicaid's Electronic Visit Verification and Monitoring System (EVVM) Frequently Asked Questions," Alabama Medicaid, accessed October 23, 2021, https://medicaid.alabama.gov/documents/6.0_LTC_Waivers/6.1_HCBS_Waivers/6.1.10_LTC_Meetings/6.1.10_EVVM_Provider_FAQs_6-23-17.pdf.

121   Morris, "Examining the Unavoidable Delays."

communications services.[122] But while this assistance provides some support, it does not fully address many of the practical obstacles to maintaining the constant connectivity necessary to sustain frequent electronic check-ins. For years, criticism from activists and researchers has pointed out that Lifeline is not widely marketed, and under-resourcing limits the program's usefulness to its low-income users, who are disproportionately people of color, including many older adults and people with disabilities.[123] The COVID-19 pandemic also highlighted many of the program's severe limitations: the mass transition to telehealth and other remote services put significant strains on individuals to ration their minutes and phone data. Journalistic accounts throughout 2020 described stories of individuals having to choose between talking to their doctors, employers, and loved ones.[124]

Both service recipients and workers spoke about struggles to keep up with phone bills to maintain EVV, as well as struggles to ensure that their phone was fully charged at all times. One service recipient was frustrated that her older smartphone's weakened battery life meant that she and her attendant had to rush any activities conducted outside of her home out of fear that the battery might suddenly die in the middle of a shift and the worker would not be able to clock out in time. While the installation of a landline or physical device is another available alternative, it would functionally limit a service recipient's movements, as they would have to always be at home in time for a worker to clock in or out.[125]

122   For example, as advocacy organization Disability Rights Pennsylvania has noted, "One concern is the cost for the community. In Pennsylvania, the Department of Human Services and the provider are not providing devices for the community for EVV. If someone can't afford the device, they can contact a Lifeline program to obtain a telephone." See "Electronic Visit Verification Update – Good Faith Exemption Request," Disability Rights Pennsylvania, December 3, 2019, https://www.disabilityrightspa.org/newsroom/electronic-visit-verification-update-good-faith-exemption-request/.

123   Emmanuel Martinez, "Is the US Government's Lifeline Service Really a Lifeline?" *The Markup,* May 14, 2020, https://themarkup.org/ask-the-markup/2020/05/14/is-the-u-s-governments-lifeline-phone-service-really-a-lifeline.

124   Tony Romm, "Lacking a Lifeline: How a Federal Effort to Help Low-income Americans Pay Their Phone Bills Failed Amid the Pandemic," *The Washington Post,* February 9, 2021, https://www.washingtonpost.com/technology/2021/02/09/lifeline-broadband-internet-fcc-coronavirus/.

125   A joint statement from the Georgia Council on Developmental Disabilities and the Center for Public Representation points out: "For example, if an EVV system requires a device to be physically located in a service recipient's home (like a landline phone or a device installed in the home), people with disabilities may feel trapped at home and limited in their ability to move around the community." See "Electronic Visit Verification: New to Medicaid In-Home Services," Georgia Council on Developmental Disabilities and the Center for Public Representation, May 2018, https://medicaidpub.wpengine.com/wp-content/uploads/2018/05/2018-EVV-Resource-1.pdf.

Aside from equipment costs, sporadic cell service access and limited internet services have destabilized service recipients in rural areas.[126] Service recipients and advocates have been vocal about these barriers in rural states like Vermont, where stakeholder feedback solicited by Vermont's Agency of Human Services urged that EVV system design "must be prepared for the potential lack of internet access, no landline, or insufficient cell phone signal."[127] In addition to connectivity problems, stakeholder feedback in several states included complaints that the GPS functionality would frequently record the wrong location, which led to delayed or lost wages. One anonymous commenter in an EVV town hall forum sarcastically joked, "I knew I should have bought a house that had a kitchen 27 miles closer to my home. GPS says I am 27 miles away from my kitchen when I am in my kitchen!"[128]

Some EVV systems have included an off-line mode that allows the app to capture information, store it locally, and then transmit when connection is re-established.[129] The state of New Mexico, for instance, issued tablets to workers with a system that would only require them to access internet connectivity once a week to upload visit data.[130] However, this does not fully resolve the problem. Michael, who is disabled, lives in a rural part of the eastern United States with his mother, Carol. While she is able to fill in the gaps when his worker is not on shift or calls in sick, they would not be able to manage without the additional support since Carol works full-time outside the home. Because their home does not have a landline installed, Michael had to

126   A report from the National Association of States United for Aging and Disabilities (NASUAD) cited "challenges in rural and frontier areas where landlines may not be available and cellular service may be limited or not reliable." See "Electronic Visit Verification: Implications for States, Providers, and Medicaid Participants," NASUAD, May 2018, https://medicaid.utah.gov/Documents/pdfs/evv/2018%20NASUAD%20Report.pdf.

127   "Public Comments Received for GCR 18-007: Personal Care Electronic Visit Verification," State of Vermont Agency of Human Services, August 7, 2018, https://humanservices.vermont.gov/sites/ahsnew/files/documents/MedicaidPolicy/GCRProposedPolicies/gcr-18-007-evv-comment-compilation.pdf.

128   Virginia Department of Medical Assistance Services, Regulatory Town Hall, Public Comment Forum, March 2020, https://townhall.virginia.gov/l/Comments.cfm?stageid=8364.

129   For example, see "Understanding Electronic Visit Verification Mobile Caregiver+ Quick Reference Guide Completing a Visit in the Mobile App While in Offline Mode," Kentucky Cabinet for Health and Family Services, last updated October 18, 2021, https://chfs.ky.gov/agencies/dms/dca/Documents/evvqrgofflinevisits.pdf.

130   "CMCS Informational Bulletin: Electronic Visit Verification," Centers for Medicare and Medicaid Services, May 16, 2018, https://www.medicaid.gov/federal-policy-guidance/downloads/cib051618.pdf.

purchase a smartphone to replace his slow, "banged up" older phone and download the app. In addition to dealing with poor reception and incorrectly recorded GPS locations, figuring out how to regularly transmit off-line EVV data has been a major point of tension with his attendant. Without home internet, the worker on several occasions has driven out in search of public Wi-Fi connection in order to regularly transmit the timesheet data to get paid in time. Worried about potentially getting exposed to the COVID-19 virus, the worker has often pulled into the parking lots of the nearest fast food chains in order to try to connect to the businesses' Wi-Fi.

Checking the time entries before the worker submits the timesheet is also challenging. While Michael feels he has a good relationship and routine with his attendant, who has worked with him for three years, he worries that these added burdens of unpaid time and gas costs will eventually push the attendant to quit and seek other employment. Michael has had an especially difficult time attracting workers in the past because of the low pay and lack of benefits offered by his state, but also because he lives in a remote area. "It's hard to convince someone to drive for hours, to come out here, when some days all I need are two or three hours of help here and there," he said. "With the driving, that could, that's easily half or more of someone's day. And for what? Maybe $30?"

The design of EVV systems themselves also lacked accessibility features that are essential for people with disabilities. For instance, a request for information from EVV tech vendors conducted by the New York Department of Health found that systems came with widely varying accessibility features and that "[l]ess than half of the vendors who responded stated their solution was ADA compliant," let alone met additional accessibility requirements.[131] Many design features are exclusionary, such as requiring service recipients who may be paralyzed or lack physical dexterity to use their fingers to write their signatures on a phone screen to sign off on services, or to use voice verification features if they are non-verbal.[132]

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131   "Electronic Visit Verification: Request for Information (RFI) Summary of Responses and Path for Implementing EVV," New York State Department of Health, Office of Health Insurance Programs, accessed October 23, 2021, https://health.ny.gov/funding/rfi/evv/docs/summary_of_responses.pdf.

132   Wedell, "State's New Anti-fraud Devices."

Voice verification features, for instance, may require the service recipient to state their names over the phone, which has been disruptive for some individuals. One worker found it difficult to clock in when a voice verification prompt appeared:

> So, not on the mobile devices, but if you call, like let's say that system's down, you're supposed to call. And I don't, because my individual does not like talking on the phone with people; just even saying his name is enough to induce anxiety. He just doesn't like it. But yeah, they have, the individual has to get on the phone then, after you put in all the time data, and say their name and confirm that you gave them services.

Although it was a new requirement of her job, she did not feel comfortable pressuring her client into interacting with the EVV system. An alternative to voice verification is facial recognition. Some EVV vendors, such as Direct Care Innovations and FreedomCare, offer facial recognition options to confirm the worker's presence at the start and end of a shift. If the system fails to verify their face, the worker can't clock in.[133] Yet facial recognition can impose its own barriers; the technology was widely criticized after research revealed that these systems have embedded racial and gender biases, showing lower accuracy rates for identifying people of color, particularly Black women.[134]

In addition to issues of bias, the physical act of collecting facial recognition data can be coercive. Tara, a white woman in the southern United States, supervises two workers who provide support to her teenage son, Kevin, who is autistic. Sometimes, the EVV system fails to clock one of the attendants in, and as a result, the system prompts them to photograph themselves and Kevin to verify their presence. However, Kevin is often unable to hold still to be photographed and being pressured to do so can be very emotionally distressing for him. Tara worries that her son's workers are incentivized to be more concerned with clocking in correctly than with her son's well-being, especially as she and her husband work long hours and are not always able to directly oversee the workers.

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133   "High Tech and Low Tech Options for EVV," Direct Care Innovations, March 24, 2019, https://www.dcisoftware.com/blog/dci-evv-options/.

134   Joy Buolamwini and Timnit Gebru, "Gender Shades: Intersectional Accuracy Disparities in Commercial Gender Classification," *Proceedings of Machine Learning Research,* 81 (2018): 1–15.

While policymakers and technology vendors promised that EVV systems would optimize the delivery of homecare services, who benefits from those efficiencies is not evenly distributed. Interactions with technical systems to access public benefits are experienced as a form of what tech policy scholar Chris Gilliard calls "imposed surveillance," that is involuntary, overt, clunky, and meant to stand out.[135] In contrast to luxury consumer technologies that prioritize users' convenience, EVV systems impose the material costs and exhaustive psychological stress of glitchy, cumbersome, and inaccessible design. While some workers and service recipients are able to adapt, others are excluded entirely.

Surveillance, Equity, and the Future of the US Care System

This report has examined the ways in which legislators, technology designers, and state officials have sought to implement EVV systems and the subsequent challenges workers and service recipients faced as they struggled to make a glitchy and restrictive system work. Efforts to quantify care and support work were largely motivated by ambitions to root out fraud and focused on enforcing compliance in ways that revealed a poor understanding of how services are provided. The implementation of EVV eroded the social dimensions that underpin this work. Workers face many challenges in trying to make their work legible to digital tracking, and this work undermines regulators' and technologists' assumption that data-driven technologies can easily extrapolate measurable truths about care quality. For service recipients, the reporting requirements built into EVV systems functionally impeded their ability to live freely in their own communities. As anthropologist Khiara Bridges has argued, the conditions imposed on people seeking state support from programs like Medicaid often enable "informal disenfranchisement," where individuals may formally bear a right but in practice are stripped of the ability to exercise it.[136] People with disabilities have a legal right to receive services within their communities rather than in more restrictive institutional settings. EVV requirements have added hurdles that, for some, make accessing those services

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135   Chris Gilliard, "Caught in the Spotlight," Urban Omnibus, January 9, 2020, https://urbanomnibus.net/2020/01/caught-in-the-spotlight/.

136   Khiara M. Bridges, *The Poverty of Privacy Rights* (Stanford: Stanford University Press, 2017).

difficult or impossible. Even where they are able to access services, these services come at a growing financial and personal cost.

The issue of EVV goes beyond a story of poor user design and implementation. In the absence of substantive institutional change, technology is portrayed as an appealing means for governments to exert greater control and squeeze effort from its public sector workforces. Government actors increasingly turn to algorithmic technologies to recalculate the distribution of already thin resources, or to police, surveil, and restrict those who already receive them. But while these measures may serve the interest of controlling costs, they ultimately do not address the underlying state of chronic underinvestment. In fact, they can be used to render invisible much of the actual labor that goes into sustaining care systems, as can be seen in the lengths taken by individuals to make often-dysfunctional EVV systems work.

Data-centric technologies are increasingly embedded into public life through everyday interactions with state infrastructures, but these technologies can obscure the true dynamics of social support. While providing a veneer of efficiency, technologies like EVV systems may defer institutional accountability and distract from the profound inequalities foundational to the US care system. In doing so, they end up taking "political issues out of public process and framing them instead as procurement processes."[137] In the case of EVV, the federal mandate left disability and labor advocates out of decision-making, reducing their role to one of harm reduction over design technicalities with unaccountable third-party vendors. This lack of transparency and mechanisms for appeal placed the onus on individuals with scarce resources to not only push back, but to advocate for services and benefits they have a right to expect from the state. As an accountability measure, solicitations for ex post facto stakeholder input cannot remedy harms that have already occurred and will not fully capture the long-term impacts, which may themselves be hard to measure. Employment relations scholar Adam Seth Litwin has argued that technologies within the homecare industry have potential to take a "high-road" trajectory that benefits health care workers and their clients. However, without significant policy intervention, they are more likely to take the default path where these tools are "deployed primarily to increase returns for atomized

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137   Sean MacDonald, *"Technology Theater," Centre for International Governance Innovation*, July 13, 2020, https://www.cigionline.org/articles/technology-theatre.

actors, and to reduce staffing and increase micromanagement of workers."[138]
While technology may serve to help build a more equitable care system, it is not a
certain prospect.

From a labor perspective, more attention must also be paid to the growth of
worker surveillance beyond the spaces of the office or the warehouse. The mass
shift to remote work during the COVID-19 pandemic sparked public debate over
the workplace's digital spill-over into the intimate spaces of the home. These
conversations have largely taken the experiences of professional, white-collar
workers as the default.[139] However, these concerns are hardly new for homecare
workers—predominantly women of color—who both labor invisibly in private
homes and are hypervisible under the lens of an increasing array of surveillance
technologies. Additionally, for low-income families who must regularly interact with
government agencies for social support, the home has never been a fully secure
refuge from various forms of surveillance.[140] Efforts to strengthen worker data
rights must center these experiences rather than perpetuate legacies that treat
domestic work as outside the realm of "real" work.

While the pandemic has caused a collapse of an already precarious care system,
the care crisis in the United States will deepen in the coming years. The rapid de-
institutionalization of nursing homes in the wake of COVID-19, the long-lasting
health effects of the pandemic, and an aging population will spur an even greater
need for home- and community-based services. The workforce needed to meet this
demand is set to expand by 46% over the next decade, which will require more
than a million new homecare workers.[141] Current political debates over whether the
millions of care workers across the country count as "infrastructure" are ultimately

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138   Adam Seth Litwin, *Technological Change in Health Care Delivery,* UC Berkeley Labor Center (June 23,
        2020): 8, https://laborcenter.berkeley.edu/wp-content/uploads/2020/07/Technological-Change-in-
        Health-Care-Delivery.pdf.

139   Bobby Allyn, "Your Boss Is Watching You: Work-From-Home Boom Leads To More Surveillance," *The
        Guardian,* September 5, 2021, https://www.npr.org/2020/05/13/854014403/your-boss-is-watching-
        you-work-from-home-boom-leads-to-more-surveillance.

140   Gilman, "Expanding Frameworks."

141   Monée Fields-White and Cassandra Lyn Robertson, "What the Caregiver Workforce Shortage Means
        for the Future of Care," *The American Prospect,* July 23, 2021, https://prospect.org/health/what-
        caregiver-workforce-shortage-means-for-future-of-care/.

about who deserves support and who does not. In mid-2021, Congress sought to pass legislation that would introduce $400 billion in investment into the industry, including wage increases and better training and benefits for workers. In subsequent legislation, this number has since been reduced by more than half. National Domestic Workers Alliance co-founder Ai-jen Poo has called the measure "one of the single most impactful plans to address racial and gender inequity in our economy."[142] Despite this progress, advocates have pointed out that it is still not enough to enact substantial reform and meet the growing demand.[143] And greater investment may not be not enough if those investments do not center workers and the people they assist. As communications scholar and designer Sasha Costanza-Chock has noted, the design of new technologies "requires full inclusion of, accountability to, and ultimately control" by people with direct lived experience.[144] The work that remains is to listen to the people most affected to create a care system built on mutuality and support rather than one that is extractive and carceral.

142   Lauren Gambino, "How Biden's $2tn Infrastructure Plan Seeks to Achieve Racial Justice," *The Guardian,* April 5, 2021, https://www.theguardian.com/us-news/2021/apr/05/joe-biden-2tn-infrastructure-plan-racial-justice.

143   Leigh Ann Caldwell. "Biden wants billions for elder care. So far, Democrats are giving less than half," *NBC News,* September 10, 2021. https://www.nbcnews.com/politics/congress/biden-wants-billions-elder-care-far-democrats-are-giving-less-half-rcna1975.

144   Sasha Costanza-Chock, *Design Justice: Community-Led Practices to Build the Worlds We Need* (Cambridge: The MIT Press, 2020).

LIST OF KEY TERMS

Home- and community-based services

This term encompasses an array of programs available to Medicaid members that provide services at a person's home or community rather than in institutional settings.

Home care agency

Home care agencies are licensed businesses that provide a range of in-home services, such as home care and home health services, either through private pay or reimbursed by Medicaid. The size and business model of agencies varies, ranging from small, local agencies to major companies that may employ up to thousands of workers at multiple locations.

Home health aide

Home health aides provide assistance with activities of daily living and/or instrumental activities of daily living in addition to performing basic medical procedures. They may work under the supervision of a nurse or other medical professional, and are employed by home health agencies. Home health aides require more training and additional certification compared to personal care aides.

Financial management services company

Within self-directed programs, they are third-party organizations that are contracted by state governments to process timesheets, provide payroll and benefits administration services, and issue paychecks to workers with funding disbursed through Medicaid.

Long-term services and supports

This term encompasses both institutional and home- and community-based services that are provided long-term, as opposed to temporary, short-term services. In the United States, more than 14 million people needed long-term services and supports in 2018, according to AARP surveys.[145]

Medicaid

Medicaid is the public health insurance program for low-income families that is administered by states under federal guidance and jointly funded by federal and state governments. It is the largest single funder of long-term services and supports, including both home- and community-based services and services provided in institutional settings like nursing homes. Medicaid provides health coverage to more than 75 million individuals in the United States.[146]

Personal care aide

Also known as personal attendants/assistants, support workers, or other job titles depending on the state and program under which they are employed. This workforce provides assistance to service recipients with activities of daily living and/or instrumental activities of daily living. Personal care aides may be employed by a homecare agency or by the service recipient through self-directed programs.

Self-directed services

In contrast to an agency-based model of home- and community-based service provision, self-directed services provide greater flexibility and choice to the service recipient, including authority over hiring, scheduling, and how and where services are provided. In this model, the service recipient is typically the employer.

Service recipient/client

Individuals who receive paid support through publicly-funded home- and community-based programs or other long-term services and supports are variously referred to as clients, consumers, or service recipients. In this report, they are referred to as service recipients, or clients in relation to their workers.

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145   Edem Hado and Harriet Komisar. "Fact Sheet: Long-Term Services and Supports," AARP Public Policy Institute, August 2019 : 1, https://www.aarp.org/content/dam/aarp/ppi/2019/08/long-term-services-and-supports.doi.10.26419-2Fppi.00079.001.pdf.

146   This number reflects enrollment as of April 2021. See "April 2021 Medicaid and CHIP Enrollment Data Highlights," Medicaid.gov, accessed October 23, 2021, https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html.

ACKNOWLEDGMENTS

REFERENCES

Abel, Emily K. and Margaret K. Nelson, eds. *Circles of Care: Work and Identity in Women's Lives.* Albany, NY: State University of New York Press, 1990.

Alabama Medicaid. "Alabama Medicaid's Electronic Visit Verification and Monitoring System (EVVM) Frequently Asked Questions." Accessed October 23, 2021. https://medicaid.alabama.gov/documents/6.0_LTC_Waivers/6.1_HCBS_Waivers/6.1.10_LTC_Meetings/6.1.10_EVVM_Provider_FAQs_6-23-17.pdf.

Allyn, Bobby. "Your Boss Is Watching You: Work-From-Home Boom Leads To More Surveillance." *NPR.org*, May 13, 2020. https://www.theguardian.com/us-news/2021/sep/05/covid-coronavirus-work-home-office-surveillance.

AllGeo. "What is Geofencing time clock?" Accessed October 23, 2021. https://www.allgeo.com/what-is-geofence-time-clock-app.

Altiraifi, Azza. "A Deadly Poverty Trap: Asset Limits in the Time of the Coronavirus." *American Progress*, April 7, 2020. https://www.americanprogress.org/issues/disability/news/2020/04/07/482736/deadly-poverty-trap-asset-limits-time-coronavirus/.

American Civil Liberties Union. "Coalition Letters in Support of Electronic Visit Verification (EVV) Legislation." June 1, 2018. https://www.aclu.org/letter/coalition-letters-support-electronic-visit-verification-evv-legislation-house.

American Network of Community Options and Resources. *Addressing the Disability Services Workforce Crisis of the 21st Century.* 2017. https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce%20White%20Paper%20-%20Final%20-%20hyperlinked%20version.pdf.

Applied Self Direction. "Directory of Electronic Visit Verification (EVV) Vendors Interested in Serving Self-Direction Programs." Last updated July 27, 2021. https://www.appliedselfdirection.com/sites/default/files/EVV%20Directory_0.pdf.

Axxess. "EVV Geofence Update." September 13, 2019. https://www.axxess.com/help/axxess-homecare/software-updates/evv-geofence-update/.

Benjamin, Ruha. *Race After Technology: Abolitionist Tools for the New Jim Code.* Cambridge: Polity, 2019.

Binette, Joanne, Kerri Vasold, and AARP Research. "2018 Home and Community Preferences: A National Survey of Adults Ages 18-Plus." *AARP.org.* August 2018, revised July 2019. https://www.aarp.org/research/topics/community/info-2018/2018-home-community-preference.html?CMP=RDRCT-PRI-OTHER-LIVABLECOMMUNITIES-032218.

Boris, Eileen and Jennifer Klein. *Caring for America: Home Health Workers in the Shadow of the Welfare State.* New York: Oxford University Press, 2015.

Bridges, Khiara M. *The Poverty of Privacy Rights.* Stanford: Stanford University Press, 2017.

Brown, Jennifer. "Medicaid Law Forcing Caregivers to be Tracked by GPS Inspires Privacy Backlash from Colorado's Disabled Community." *The Colorado Sun,* December 23, 2019. https://coloradosun.com/2019/12/23/evv-requirement-for-medicaid/.

Brown, Kenneth and Marek Korczynski. "When Caring and Surveillance Technology Meet: Organizational Commitment and Discretionary Effort in Home Care Work." *Work and Occupations* 37, no. 3 (2010): 404–432.

Brown, Lydia X. Z., Michelle Richardson, Ridhi Shetty, and Andrew Crawford. "Challenging the Use of Algorithm-driven Decision-making in Benefits Determinations Affecting People with Disabilities." *Center for Democracy and Technology,* October 2020. https://cdt.org/insights/report-challenging-the-use-of-algorithm-driven-decision-making-in-benefits-determinations-affecting-people-with-disabilities/.

Buolamwini, Joy and Timnit Gebru. "Gender Shades: Intersectional Accuracy Disparities in Commercial Gender Classification." *Proceedings of Machine Learning Research* 81 (2018): 1–15.

Bureau of Labor Statistics, US Department of Labor. "Occupational Outlook Handbook: Home Health and Personal Care Aides." n.d. https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm.

Burnett, Jen. "Electronic Visit Verification: Implications for States, Providers, and Medicaid Participants." *HMA Insights Blog.* May 10, 2018. https://www.healthmanagement.com/blog/electronic-visit-verification-implications-states-providers-medicaid-participants/.

BusinessWire. "CareBridge Launches to Improve Care for Individuals Receiving Long-Term Support Services." January 13, 2020. https://www.businesswire.com/news/home/20200113005935/en/CareBridge-Launches-Improve-Care-Individuals-Receiving-Long-Term.

Buzzard, Kacie Wielgus. "Ohio Medicaid Installed a Tracking Device in My Home Because of My Daughter's Disability Services." *The Mighty,* February 4, 2018. https://themighty.com/2018/02/electronic-visit-verification-is-invading-families-privacy/.

California Department of Social Services. "In Home Supportive Services (IHSS) Program." Accessed October 22, 2021. https://www.cdss.ca.gov/inforesources/ihss.

Calma, Carlo. "EVV Provision Leaves Home Health in Open vs. Closed Dilemma." *Home Health Care News,* November 28, 2017. https://homehealthcarenews.com/2017/11/evv-provision-leaves-home-health-in-open-vs-closed-dilemma/.

Calo, Ryan, and Danielle Keats Citron. "The Automated Administrative State: A Crisis of Legitimacy." *Emory Law Journal* 70 (2020): 797. Page range?

CellTrak. "COVID-19: Predictive Analytics for the Next Wave." August 7, 2019. https://www.celltrak.com/white-paper-covid-big-data.

Center for Public Representation. "Electronic Visit Verification." Accessed October 22, 2021. https://medicaid.publicrep.org/feature/electronic-visit-verification-evv/.

Centers for Medicare and Medicaid Services. "CMCS Informational Bulletin: Electronic Visit Verification." May 16, 2018. https://www.medicaid.gov/federal-policy-guidance/downloads/cib051618.pdf.

----------"Electronic Visit Verification FMAP Reduction." April 15, 2021. https://www.medicaid.gov/medicaid/downloads/evv-fmap-reduction-call-with-states-date-april2021.pdf.

----------"Self-Directed Services." Accessed October 22, 2021. https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html.
----------"Frequently Asked Questions: Section 12006 of the 21st Century Cures Act, Electronic Visit Verification (EVV) Systems for Personal Care Services (PCS) and Home HealthCare Services (HHCS)." May 16, 2018. https://www.medicaid.gov/federal-policy-guidance/downloads/faq051618.pdf.

----------"Electronic Visit Verification (EVV) Stakeholder Open Door Forum." November 7, 2018. https://www.cms.gov/Outreach-and-Education/Outreach/OpenDoorForums/PodcastAndTranscripts.

----------"Leveraging Electronic Visit Verification (EVV) to Enhance Quality Monitoring and Oversight in 1915(C) Waiver Programs." Accessed October 22, 2021. https://www.medicaid.gov/medicaid/downloads/evv-enhance-quality.pdf.

----------"Fact sheet: Preventing Medicaid Improper Payments for Personal Care Services." November 2017. https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/pcs-prevent-improperpayment-factsheet.pdf.

----------"EVV Requirements in the 21st Century Cures Act." August 2018. https://www.appliedselfdirection.com/sites/default/files/EVV%20Requirements%20in%20the%2021st%20Century%20Cures%20Act%20Intensive.pdf.

----------"Additional EVV Guidance." *CMCS Informational Bulletin,* August 8, 2019. https://www.medicaid.gov/federal-policy-guidance/downloads/cib080819-2.pdf.

Colorado Department of Health Care Policy & Financing. Electronic Visit Verification (EVV) Stakeholder Meeting Closed Captioning Transcript. July 16, 2019. https://www.colorado.gov/pacific/sites/default/files/EVV_CCTranscript_July2019.pdf.

----------"Electronic Visit Verification Frequently Asked Questions." August 13, 2021. https://hcpf.colorado.gov/electronic-visit-verification-frequently-asked-questions#:~:text=Federal%20guidance%20permits%20states%20to,depending%20on%20the%20living%20arrangement.

Congressional Budget Office, "Helping Families in Mental Health Crisis Act of 2015: Direct spending effects of H.R. 2646, as reported by the House Committee on Energy and Commerce on June 15, 2016." https://www.cbo.gov/publication/51764.

Consumer Directed Personal Assistance Association of New York State. "Electronic Visit Verification and Self-Direction: A Consumer Perspective." May 2018, https://cdpaanys.org/wp-content/uploads/2018/09/EVV-Self-Direction-Consumer-Advocates-report.pdf.

Costanza-Chock, Sasha. *Design Justice: Community-Led Practices to Build the Worlds We Need.* Cambridge: The MIT Press, 2020.

Cranford, Cynthia J. Home Care Fault Lines: *Understanding Tensions and Creating Alliances.* Ithaca: Cornell University Press, 2020.

Diament, Michelle. "Citing COVID-19, Advocates Want Medicaid Caregiver Check-In Mandate Delayed." *Disability Scoop,* August 20, 2020. https://www.disabilityscoop.com/2020/08/20/citing-covid-19-advocates-want-medicaid-caregiver-check-in-mandate-delayed/28766/.

----------. "Feds Weigh In On Medicaid Caregiver Check-In Mandate." *Disability Scoop,* August 22, 2019. https://www.disabilityscoop.com/2019/08/22/feds-weigh-in-on-medicaid-caregiver-check-in-mandate/27053/.

Diana, Alison. "GPS Cuts Fraud, Costs for Home Healthcare." *InformationWeek,* November 5, 2014. https://www.informationweek.com/healthcare/gps-cuts-fraud-costs-for-home-healthcare/d/d-id/1317202.

Direct Care Innovations. "High Tech and Low Tech Options for EVV." *Direct Care Innovations,* March 24, 2019. https://www.dcisoftware.com/blog/dci-evv-options/.

Disability Rights and Education Defense Fund. "DREDF Opposes Electronic Visit Verification (EVV) When It Threatens Disabled People's Civil and Privacy Rights and Impedes Personal Choice, Autonomy, and Community Participation." March 2018, https://dredf.org/2018/03/07/dredf-statement-on-electronic-visit-verification/.

---------- to Greg Walden and Frank Pallone. January 19, 2018. https://dredf.org/wp-content/uploads/2018/03/ADAPT-Electronic-Visit-Verification.pdf.

Disability Rights California. "DRC Position on Electronic Visit Verification (EVV)." *Disability Rights California,* February 2, 2018. https://dredf.org/wp-content/uploads/2018/03/DRC-Electroni-Visit-Verification-System-revB.pdf.

Disability Rights Pennsylvania. "Electronic Visit Verification Update – Good Faith Exemption Request." December 3, 2019. https://www.disabilityrightspa.org/newsroom/electronic-visit-verification-update-good-faith-exemption-request/.

Ducey, Ariel. *Never Good Enough: Health Care Workers and the False Promise of Job Training.* Ithaca: Cornell University Press, 2009.

---------- "More Than a Job: Meaning, Affect, and Training Health Care Workers." In *The Affective Turn,* edited by Patricia Ticineto Clough and Jean Halley, 187–208. Durham: Duke University Press, 2007.

Elish, Madeleine, and Elizabeth Watkins. *Repairing Innovation: A Study of Integrating AI in Clinical Care.* Data & Society, September 2020. https://datasociety.net/library/repairing-innovation/.

Espinoza, Robert. "Research Brief: Immigrants and the Direct Care Workforce." *PHI National,* June 2017. https://phinational.org/wp-content/uploads/2017/06/immigrants_and_the_direct_care_workforce_-_phi_-_june_2017.pdf.

Eubanks, Virginia. *Automating Inequality: How High-Tech Tools Profile, Police, and Punish the Poor,* New York: St. Martin's Press, 2018.

Eubanks, Virginia, and Alexandra Mateescu, "'We don't deserve this': New App Places US Caregivers Under Digital Surveillance." *The Guardian,* July 28, 2021. https://www.theguardian.com/us-news/2021/jul/28/digital-surveillance-caregivers-artificial-intelligence.

Fields-White, Monée, and Cassandra Lyn Robertson. "What the Caregiver Workforce Shortage Means for the Future of Care." *The American Prospect,* July 23, 2021. https://prospect.org/health/what-caregiver-workforce-shortage-means-for-future-of-care/.

Gallopyn, Naomi, and Lisa I. Iezzoni. "Views of Electronic Visit Verification (EVV) among Home-based Personal Assistance Services Consumers and Workers." *Disability and Health Journal* 13, no. 4 (2020): 6.

Gambino, Lauren. "How Biden's $2tn Infrastructure Plan Seeks to Achieve Racial Justice." *The Guardian,* April 5, 2021. https://www.theguardian.com/us-news/2021/apr/05/joe-biden-2tn-infrastructure-plan-racial-justice.

Gentry, Dana. "Home Care Labor Shortage Worsened by COVID, Cuts to Funding." *Nevada Current,* September 14, 2020. https://www.nevadacurrent.com/2020/09/14/home-care-labor-shortage-worsened-by-covid-cuts-to-funding/.

Georgia Council on Developmental Disabilities and the Center for Public Representation. "Electronic Visit Verification: New to Medicaid In-Home Services." May 2018. https://medicaidpub.wpengine.com/wp-content/uploads/2018/05/2018-EVV-Resource-1.pdf.

Gilliard, Chris. "Caught in the Spotlight." *Urban Omnibus,* January 9, 2020. https://urbanomnibus.net/2020/01/caught-in-the-spotlight/.

Gilman, Michele. "Expanding Frameworks: An Economic Justice Approach to Digital Privacy." *Data & Society: Points,* November 6, 2019. https://points.datasociety.net/expanding-frameworks-9e0781ec2037.

Graham, Judith. "The Disabled and the Elderly are Facing a Big Problem: Not Enough Aides." *The Washington Post,* April 23, 2017. https://www.washingtonpost.com/national/health-science/the-disabled-and-the-elderly-are-facing-a-big-problem-not-enough-aides/2017/04/21/5846f576-237f-11e7-a1b3-faff0034e2de_story.html.

Hado, Edem, and Harriet Komisar. "Fact Sheet: Long-Term Services and Supports." *AARP Public Policy Institute,* August 2019. https://www.aarp.org/content/dam/aarp/ppi/2019/08/long-term-services-and-supports.doi.10.26419-2Fppi.00079.001.pdf.

Hayes, Lydia B. "Sex, Class and CCTV: The Covert Surveillance of Paid Homecare Workers." In *The Post-Fordist Sexual Contract,* edited by Lisa Adkins and Maryanne Dever, 171–193. London: Palgrave Macmillan, 2016.

Hayes, Lydia B., and Sian Moore. "Care in a Time of Austerity: The Electronic Monitoring of Homecare Workers' Time." *Gender, Work & Organization* 24, no. 4 (2017).

Henley, Jon, and Robert Booth. "Welfare Surveillance System Violates Human Rights, Dutch Court Rules." *The Guardian,* February 5, 2020. https://www.theguardian.com/technology/2020/feb/05/welfare-surveillance-system-violates-human-rights-dutch-court-rules.

Hilton, Leon J. "Avonte's Law: Autism, Wandering, and the Racial Surveillance of Neurological Difference." *African American Review* 50, no. 2 (2017): 221–235.

Hondagneu-Sotelo, Pierrette. *Doméstica: Immigrant Workers Cleaning and Caring in the Shadows of Affluence, with a New Preface.* Berkeley: University of California Press, 2007.

Hopkins, Alicia. "How Electronic Visit Verification Is Harming People with Disabilities." *Yahoo News,* August 19, 2019. https://www.yahoo.com/now/electronic-visit-verification-harming-people-183015414.html.

Jaffe, Sarah. *Work Won't Love You Back: How Devotion to Our Jobs Keeps Us Exploited, Exhausted, and Alone.* London: Hachette UK, 2021.

Jain, Shailendra. "Understanding Electronic Visit Verification." *Homecare Magazine,* June 10, 2019. https://www.homecaremag.com/june-2019/understanding-electronic-visit-verification.

Kenner, Alison Marie. "Securing the Elderly Body: Dementia, Surveillance, and the Politics of 'Aging in Place.'" *Surveillance & Society* 5, no (2008): 252–269.

Kentucky Cabinet for Health and Family Services. "Understanding Electronic Visit Verification Mobile Caregiver+ Quick Reference Guide Completing a Visit in the Mobile App while in Offline Mode." July 19, 2021. https://chfs.ky.gov/agencies/dms/dca/Documents/evvqrgofflinevisits.pdf.

Kilgore, James. "Electronic Monitoring is Not the Answer: Critical Reflections on a Flawed Alternative." Urbana-Champaign Independent Media Center, October 2015. https://mediajustice.org/wp-content/uploads/2020/01/EM-Report-Kilgore-final-draft-10-4-15.pdf.

Konski, Antoinette F. "Improving 21st Century Cures Act: Personalized Medicine and COVID-19." The National Law Review, May 12, 2020. https://www.natlawreview.com/article/improving-21st-century-cures-act-personalized-medicine-and-covid-19.

Kukla, Elliot. "My Life Is More 'Disposable' During This Pandemic." *The New York Times*, March 19, 2020. https://www.nytimes.com/2020/03/19/opinion/coronavirus-disabled-health-care.html.

Lecher, Colin. "What Happens When an Algorithm Cuts Your Healthcare?" *The Verge,* March 21, 2018. https://www.theverge.com/2018/3/21/17144260/healthcare-medicaid-algorithm-arkansas-cerebral-palsy.

Levy, Karen. "The Contexts of Control: Information, Power, and Truck-driving Work." *The Information Society* 31, no. 2 (2015): 160–174.

Levy, Karen, Lauren Kilgour, and Clara Berridge. "Regulating Privacy in Public/Private Space: The Case of Nursing Home Monitoring Laws." *Elder Law Journal* 26 (2018): 323.

Levy, Karen, and Solon Barocas. "Refractive Surveillance: Monitoring Customers to Manage Workers." *International Journal of Communication* 12 (2018): 23.

Litwin, Adam Seth. *Technological Change in Health Care Delivery.* UC Berkeley Labor Center, June 23, 2020. https://laborcenter.berkeley.edu/wp-content/uploads/2020/07/Technological-Change-in-Health-Care-Delivery.pdf.

Lynch, Calder. "Additional EVV Guidance." *Centers for Medicare and Medicaid Services,* August 8, 2019. https://www.medicaid.gov/federal-policy-guidance/downloads/cib080819-2.pdf.

MacDonald, Sean. "Technology Theater." Centre for International Governance Innovation, July 13, 2020. https://www.cigionline.org/articles/technology-theatre.

Madden, Mary. "Privacy, Security, and Digital Inequality: How Technology Experiences and Resources Vary by Socioeconomic Status, Race, and Ethnicity." *Data & Society,* 2017. https://datasociety.net/wp-content/uploads/2017/09/DataAndSociety_PrivacySecurityandDigitalInequality.pdf.

Martinez, Emmanuel. "Is the US Government's Lifeline Service Really a Lifeline?" *The Markup,* May 14, 2020. https://themarkup.org/ask-the-markup/2020/05/14/is-the-u-s-governments-lifeline-phone-service-really-a-lifeline.

Medicaid and CHIP Payment and Access Commission (MacPac). "Electronic Visit Verification for Personal Care Services: Status of State Implementation." March 2019. https://www.macpac.gov/publication/electronic-visit-verification-for-personal-care-services-status-of-state-implementation/.

Metcalf, Jacob. "When Verification Is Also Surveillance," *Points: Data & Society,* February 27, 2018. https://points.datasociety.net/when-verification-is-also-surveillance-21edb6c12cc9.

McCormick, Erin. "What Happened When a 'Wildly Irrational' Algorithm Made Crucial Healthcare Decisions." *The Guardian,* July 2, 2021. https://www.theguardian.com/us-news/2021/jul/02/algorithm-crucial-healthcare-decisions.

Miller, Jacqueline, Mary Lou Breslin, and Susan Chapman. *Impact of Electronic Visit Verification (EVV) on Personal Care Services Workers and Consumers in the United States.* University of California San Francisco Health Workforce Research Center on Long-Term Care, July 22, 2021. https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/EVV_Report_210722.pdf.

Morris, Molly. "Examining the Unavoidable Delays to Electronic Visit Verification (EVV) Implementation." Applied Self-Direction, February 2020. https://www.appliedselfdirection.com/sites/default/files/Examining%20Reasons%20for%20EVV%20Delay.pdf

Mullaney, Tim. "Report of EVV 'Firestorm' Draws Home Care Industry Pushback." *Home Health Care News,* February 20, 2018. https://homehealthcarenews.com/2018/02/report-of-evv-firestorm-draws-home-care-industry-pushback/.

Musumeci, MaryBeth, Molly O'Malley Watts, and Priya Chidambaram. *Key State Policy Choices About Medicaid Home and Community-Based Services.* THe Henry J. Kaiser Family Foundation, February 4, 2020, https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/.

Nakano Glenn, Evelyn. *Forced to Care: Coercion and Caregiving in America.* Cambridge: Harvard University Press, 2010.

National Employment Law Project, "Surveying the Home Care Workforce: Their Challenges and the Positive Impact of Unionization." September 2017. https://www.nelp.org/wp-content/uploads/surveying-home-care-workforce.pdf.

Nelson, Margaret K. *Caring on the Clock: The Complexities and Contradictions of Paid Care Work.* New Brunswick: Rutgers University Press, 2015.

National Council on Independent Living. "Call to Action: The Need for Federal Protections In Electronic Visit Verification." Accessed October 23, 2021. https://secureservercdn.net/198.71.233.129/bzd.3bc.myftpupload.com/wp-content/uploads/2020/08/8-2-20-CALL-TO-ACTION.pdf.

-----------"Electronic Visit Verification (EVV) Task Force Statement of Principles and Goals." Accessed October 22, 2021. https://www.ncil.org/wp-content/uploads/2018/10/10-15-18-EVV-Principles-and-Goals.pdf.

New Hampshire Department of Health and Human Services. "EVV Market Analysis: Summary of Findings." September 8, 2020. https://www.dhhs.nh.gov/dcbcs/beas/documents/evv-market-analysis-report.pdf.

New York State Department of Health, Office of Health Insurance Programs. "Electronic Visit Verification: Request for Information (RFI) Summary of Responses and Path for Implementing EVV." Accessed October 23, 2021. https://health.ny.gov/funding/rfi/evv/docs/summary_of_responses.pdf.

----------"Electronic Visit Verification: Stakeholder Convening Report." 2019. https://www.health.ny.gov/health_care/medicaid/redesign/evv/repository/docs/2019-stakeholder_conven_rpt.pdf.

North Carolina Department of Health and Human Services. "Frequently Asked Electronic Visit Verification (EVV) Questions." February 18, 2021. https://files.nc.gov/ncdma/documents/Providers/Programs_Services/EVV/NC-Medicaid-EVV-FAQs-02182021.pdf.

Oregon Office of Developmental Disabilities Services. "Developmental Disabilities Worker's Guide: EVV Exceptions for Agency Community Living Services providers employing DSPs." March 13, 2020. https://www.oregon.gov/dhs/SENIORS-DISABILITIES/DD/PROVIDERS-PARTNERS/Documents/EVV-Agency-Exceptions.pdf.

Osterman, Paul. *Who Will Care for Us?: Long-term Care and the Long-term Workforce.* New York: Russell Sage Foundation, 2017.

Pear, Robert. "On Disability and on Facebook? Uncle Sam Wants to Watch What You Post." *The New York Times,* March 10, 2019. https://www.nytimes.com/2019/03/10/us/politics/social-security-disability-trump-facebook.html.

Vogels, Emily A. "Digital Divide Persists Even as Lower-income Americans Make Gains in Tech Adoption." Pew Research Center, June 22, 2021. https://www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/.

PHI National. "US Homecare Workers: Key Facts." September 3, 2019. https://phinational.org/resource/u-s-home-care-workers-key-facts-2019/.

Reaves, Erica L. and MaryBeth Musumeci. *Medicaid and Long-Term Services and Supports: A Primer.* THe Henry J. Kaiser Family Foundation, December 15, 2015. https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/.

Reilly, Karen. "A Primer on Surveillance Issues in the Disability Community." Team CommUNITY Blog, April 22, 2021. https://www.digitalrights.community/blog/primer-surveillance-in-disability-community.

Romm, Tony. "Lacking a Lifeline: How a Federal Effort to Help Low-income Americans Pay Their Phone Bills Failed Amid the Pandemic." *The Washington Post,* February 9, 2021, https://www.washingtonpost.com/technology/2021/02/09/lifeline-broadband-internet-fcc-coronavirus/.

Rudowitz, Robin, Elizabeth Williams, Elizabeth Hinton, and Rachel Garfield. "Medicaid Financing: The Basics." THe Henry J. Kaiser Family Foundation, May 7, 2021. https://www.kff.org/medicaid/issue-brief/medicaid-financing-the-basics/view/print/.

Sandata Technologies. "Understanding the Full Value of an Electronic Visit Verification System." Accessed October 22, 2021. https://www.sandata.com/understanding-the-full-value-of-an-electronic-visit-verification-system/.

Scales, Kezia. "Leveraging Technology To Support – Not Supplant – The Home Care Workforce." *Health Affairs,* August 7, 2019. https://www.healthaffairs.org/do/10.1377/hblog20190805.54553/full/.

----------"Envisioning the Future of Home Care: Trends and Opportunities in Workforce Policy and Practice." *PHI National,* October 15, 2019, https://phinational.org/wp-content/uploads/2019/10/The-Future-of-Home-Care-2019-PHI.pdf.

Shklovski, Irina, Janet Vertesi, Emily Troshynski, and Paul Dourish. "The Commodification of Location: Dynamics of Power in Location-based Systems." In *Proceedings of the 11th International Conference on Ubiquitous Computing* (New York, NY: Association for Computing Machinery, 2009), 11–20.

Span, Paul. "For Older Adults, Home Care Has Become Harder to Find." *The New York Times,* July 24, 2021. https://www.nytimes.com/2021/07/24/health/coronavirus-elderly-home-care.html.

Stacey, Clare L. *The Caring Self: The Work Experiences of Home Care Aides.* Ithaca: Cornell University Press, 2011.

State of Vermont Agency of Human Services. "Public comments received for GCR 18-007: Personal Care Electronic Visit Verification." August 7, 2018. https://humanservices.vermont.gov/sites/ahsnew/files/documents/MedicaidPolicy/GCRProposedPolicies/gcr-18-007-evv-comment-compilation.pdf.

Strobol, Greg. "HHAeXchange's Homecare Predictions for 2021." *HHAeXchange Blog,* January 18, 2021. https://hhaexchange.com/resources/hhaexchanges-homecare-predictions-for-2021/.

The Arc. "Direct Support Professionals: Overview."Accessed October 23, 2021. https://thearc.org/policy-advocacy/direct-support-professionals/.

The Governing Institute and Optum. *Identify, Predict, Prevent, Recover: A Handbook for Medicaid Program Integrity,* n.d. http://sealbeachfamilymedicalgroup.com/content/dam/optum3/optum/en/resources/ebooks/574564-identify-predi.pdf.

The Henry J. Kaiser Family Foundation "Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers." Accessed October 23, 2021. https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/.

Tseng, Emily, Fabian Okeke, Madeline Sterling, and Nicola Dell. "'We can learn. Why not?' Designing Technologies to Engender Equity for Home Health Aides." In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems,* 2020, 1–14.

United Domestic Workers/American Federation of State, County, and Municipal Employees (UDW/AFSCME Local 3930) and Service Employees International Union (SEIU) Local 2015. "Joint comments in response to DRAFT Request for Information (RFI) on Electronic Visit Verification (EVV)." October 20, 2017. https://dredf.org/wp-content/uploads/2018/03/SEIU-UDW-Joint-Response-to-Draft-RFI-10-20-17.pdf.

US Department of Health and Human Services, "Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead." https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html.

----------"Transcript and Audio: Electronic Visit Verification (EVV) Stakeholder, Open Door Forum." November 7, 2018. https://www.hhs.gov/guidance/document/podcast-and-transcripts-0.

Van Oort, Madison. "The Emotional Labor of Surveillance: Digital Control in Fast Fashion Retail." *Critical Sociology* 45, no. 7–8 (2019): 1167–1179.

Virginia Department of Medical Assistance Services, Regulatory Town Hall Public Comment Forum. March 2020. https://townhall.virginia.gov/l/Comments.cfm?stageid=8364.

Vargas, Tracy L. "Employees or Suspects? Surveillance and Scrutinization of Low-wage Service Workers in US Dollar Stores." *Journal of Labor and Society* 20, no. 2 (2017): 207–230.

Wahlberg, David. "State Aims to Cut Personal Care Fraud; Providers Say Move Could Harm Patients." *Wisconsin State Journal,* December 21, 2015. https://madison.com/wsj/news/local/health-med-fit/state-aims-to-cut-personal-care-fraud-providers-say-move-could-harm-patients/article_ff5dcbcc-fda5-5782-9399-82d22c01f08c.html.

Willison, Karin. "How Electronic Visit Verification (EVV) Invades the Privacy of People With Disabilities." *The Mighty,* January 19, 2018. https://themighty.com/2018/01/electronic-visit-verification-gps-tracking-disabled-people/.

Wedell, Katie. "State's New Anti-fraud Devices Have the Disabled Worried about Snooping." *Dayton Daily News,* February 6, 2018. https://www.daytondailynews.com/news/state--regional-govt--politics/state-new-anti-fraud-devices-have-the-disabled-worried-about-snooping/alGiZrghAYWNfDzdjjkQZL/.

Wu, Tina. "From Time Sheets to Tablets: Documentation Technology in Frontline Service Sector Managers' Coordination of Home Healthcare Services." *Work and Occupations* 47, no. 3 (2020): 378–405. https://doi.org/10.1177/0730888420922581.

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