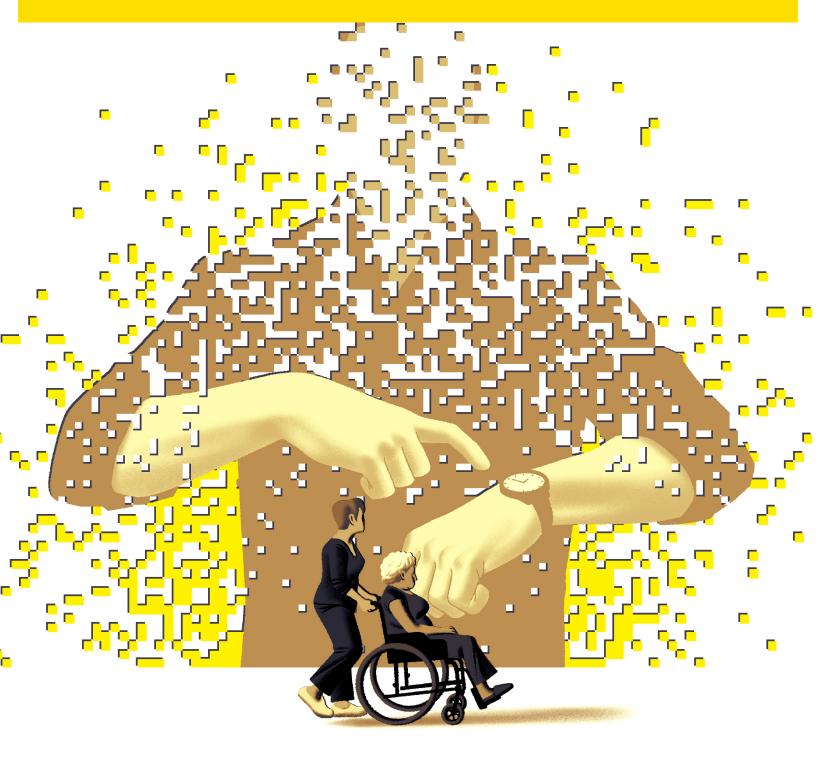
Electronic Visit Verification

A Guide to Intersecting Harms and Policy Consequences

DATA& Society

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Introduction

Public institutions are increasingly turning to technical fixes to solve structural problems, and consequently, sidelining questions of inequality, accountability, and justice. Within public benefits programs, federal and state governments are introducing algorithmic technologies to police vulnerable communities under the guise of rooting out fraud, waste and abuse, rather than passing and implementing policy in consultation with those communities and in response to their needs. These technologies introduce automated, algorithmic processes that lack transparency and mechanisms for appeal, putting the onus on vulnerable 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 the largest single funder of long-term services and supports, the United States government—through programs like Medicaid—plays a significant role in providing necessary care and support services for people with disabilities and older adults. As a result, greater public sector use of technology is impacting both the care workforce and the families they support. Just as the use of automated systems in areas like education, criminal justice, and welfare have already led to deeply inequitable outcomes, the adoption of these technologies in Medicaid home- and community-based programs may perpetuate extractive and punitive approaches towards managing, quantifying, and distributing care across our society.¹

Our report, **Electronic Visit Verification: The Weight of Surveillance and the Fracturing of Care**, explores how the public sector adoption of EVV technology has ignored the needs of marginalized communities and has led to tangible harms. The mandatory rollout of EVV technology has eroded critical supports for people with disabilities and older adults and offloads significant, unacknowledged burdens onto workers and their clients within Medicaid home- and community-based services.

1 Michele Gilman, "Poverty Lawgorithms: A Poverty Lawyer's Guide to Fighting Automated Decision-Making Harms on Low-Income Communities," Data & Society Research Institute, September 14, 2020, <u>https://</u> datasociety.net/library/poverty-lawgorithms The implementation of EVV systems highlights the risks of uncritical adoption of data-centric technologies in the provision of public services. This Policy Brief describes the harms that EVV and—technologies like it—create, and the stakes of continued inaction by federal and state governments. It underscores the importance of the government's commitment to community- and justice-informed uses of algorithmic systems.

The Rollout of Electronic Visit Verification

EVV systems are a form of digital workplace monitoring that tracks homecare workers' time, location, and other data in order to confirm that services were actually delivered. At first glance, EVV systems may seem to be just another digital timekeeping tool and method for ensuring quality of care. However, these systems were federally mandated to serve wider policy ambitions to reduce "fraud, waste, and abuse" in publicly-funded personal care and home health services.² In practice, EVV systems are actually flagging and rooting out non-compliance with program rules in order to control costs. While the federal legislation that mandated EVV required the systems to be "minimally burdensome," in practice their use has negatively impacted both the workforce and Medicaid service recipients.

EVV systems use GPS location tracking, geofencing, and biometric data collection to track workers and, by extension, their clients. Rigid policies and technology requirements that pressure individuals to comply with strict program rules have had a chilling effect on service recipients' lives and has made workers' jobs more difficult. 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.

EVV is yet another example of how government use of algorithmic systems to deliver public services fails to deliver the technologies' purported benefits. The implementation

² Alison Diana, "GPS Cuts Fraud, Costs for Home Healthcare," *InformationWeek,* November 5, 2014, <u>https://www.informationweek.com/healthcare/gps-cuts-fraud-costs-for-home-healthcare/d/d-id/1317202</u>

of EVV systems is actively harming communities, and providing few opportunities for the public to have a say in the way technologies will impact their lives.

The implementation of EVV systems, despite clear, specific, and repeated expressions of tangible harm, demonstrates the consequences of faulty assumptions that data-driven technologies can easily extrapolate measurable truths about care quality through data. These assumptions need to be challenged in order to prevent further harm.

Intersecting Harms and Policy Consequences of EVV

Congress passed the 21st Century CURES Act in 2016. This legislation included a provision that required all Medicaid-funded personal care and home health care services to use EVV systems. The mandate was explained as necessary to reduce "fraud, waste, and abuse," and tech vendors promised significant cost savings by reducing improper billing of Medicaid funds. The Centers for Medicare and Medicaid Services (CMS) did not specify a ceiling to limit what EVV technologies couldn't do, resulting in far more invasive data collection practices and procedures being encoded into state policies and technology design, including GPS location tracking, geofencing, and biometric data collection like facial and voice recognition.

As states sought out stakeholder feedback as part of the implementation process, the outpouring of public complaints conveyed a sense that EVV design and policy decisions reflected regulators' poor understanding of what service provision was actually like on a day-to-day basis. Labor and disability rights groups expressed concerns over the harms EVV would bring about and advocated to delay or prevent its implementation. 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, and issued smartphones to service recipients with little advance notification, training, or information on data collection practices. In some states, exasperated service recipients described placing reminders all over their homes or setting up dozens of phone alarms to keep up with constant electronic check-ins.

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 as everyday activities were flagged as "exceptions," leading to convoluted dealings with healthcare bureaucracies. Requirements in some states that workers must clock in and out at their client's home entrenched ableist assumptions that service recipients are homebound, enforcing a state of de facto house arrest.

In addition to the immediate harms, the rollout of EVV systems and similar data-centric technologies might have further-reaching impacts to U.S. care infrastructures. Some advocates have argued that the EVV mandate undermines many of the gains won by the disability rights and Independent Living movements in their push for the right to live independently in their communities rather than in institutions. Furthermore, growing surveillance and compliance burdens on service recipients may create barriers to accessing critical services in ways that are substantial but not easily measurable in the long-term. It's also possible that data generated by EVV systems could be used in the future in ways that data subjects have not consented to.³

Instead of improving the quality of care, EVV systems expanded and enabled employer policing and worker privacy invasions, exacerbated disparities in health care and tech access, and amplified inequalities at the intersections of racism and ableism. The rollout of these systems was disconnected from the lived experiences of those who need and provide care, turning poverty and lack of internet or smartphone access into a reason to flag care workers as potentially guilty of "fraud, waste, and abuse."

Despite repeated calls from labor and disability rights advocates to repeal the EVV mandate, the requirement to use this technology remains in place. This requirement has not only failed to identify widespread "fraud, waste, and abuse" within the care

^{3 &}quot;Electronic Visit Verification (EVV)" Center for Public Representation, n.d., <u>https://medicaid.publicrep.org/</u> feature/electronic-visit-verification-evv/.

system, but it has also endangered the livelihoods and quality of life of care workers and care recipients and their ability to access benefits they're entitled to receive.⁴

The Stakes of Continued Inaction by Governments

Without a reckoning with the government's use of data-centric technologies, marginalized groups will continue to suffer the inequalities these technologies exacerbate. While data-centric technologies are hailed by technology companies and the government as solutions to social problems, EVV demonstrates how the government's use of technology is often guided by punitive aims that reinforce racism, sexism, and classism. The well-being of marginalized communities and the path of society—towards a government use of technology that either promotes or deteriorates care—is at stake.

We provide two policy recommendations that aim to clarify the stakes of continued inaction by federal and state governments around their use of data-centric technologies.

1. Congress must address profound inequalities and chronic underinvestment in the U.S. care system, rather than continuing to introduce technology that further marginalizes and harms the communities who are entitled to benefits and care.

The United States is experiencing a care crisis that has been exacerbated by the COVID-19 pandemic, including a shift away from institutional care settings as occupancy rates in nursing homes and other congregate-living settings dropped

⁴ In states like California, which has the largest direct care workforce in the country, an examination of fraud investigative reporting from 2013-2014 found a fraud rate of 0.04% statewide. National Council on Independent Living, "Electronic Visit Verification (EVV) Task Force Statement of Principles and Goals," October 15, 2018, https://www.ncil.org/wp-content/uploads/2018/10/10-15-18-EVV-Principles-and-Goals.pdf.

sharply across the country.⁵ These institutions had become epicenters of the pandemic, not least due to underfunding and state neglect that reproduced race and class disparities in COVID-19-related deaths across the country.⁶ This rapid de-institutionalization has spurred an even greater need for home- and community-based services, as more people will need to receive services at home. The workforce needed to support it is set to expand by 46 percent over the next decade, requiring more than a million new homecare workers.⁷ Despite soaring demand, this workforce—comprised disproportionately of women of color and immigrants—are devalued both socially and materially through low wages, lack of benefits and training, and long-standing legal exclusions from many standard labor rights and benefits.⁸

Government efforts to invest in and reform the country's care infrastructure have been met with significant contestation over funding. Investment in these programs would include wage increases and better training and benefits for workers, as well as enhanced quality of care and expanded access to services to more people who need them. In mid-2021 the Biden Administration sought \$400 billion in investments into the care industry, but that number has been reduced to \$150 billion and is not yet final.⁹ Advocates have argued this is still not enough to enact substantial reform and meet the growing demand as the U.S. population ages and millions are

⁵ Maggie Flynn, "48 States Saw Nursing Home Occupancy of 80% or Worse as 2021 Dawned—With Census as Low as 56%," Skilled Nursing News, January 25, 2021. <u>https://skillednursingnews.com/2021/01/48-</u> states-saw-nursing-home-occupancy-of-80-or-worse-as-2021-dawned-with-census-as-low-as-56/.; Martha Hostetter, Sarah Klein. "Placing a Higher Value on Direct Care Workers." The Commonwealth Fund, July 1, 2021. https://www.commonwealthfund.org/publications/2021/jul/placing-higher-value-direct-care-workers.

⁶ Katie Reilly, "'It's Getting Worse.' Nursing Home Workers Confront Risks in Facilities Devastated by Coronavirus," *Time*, May 29, 2020. https://time.com/5843893/nursing-homes-workers-coronavirus/; " The Striking Racial Divide in How Covid-19 Has Hit Nursing Homes," *The New York Times*, May 21, 2021. https://www.nytimes.com/2020/05/21/us/coronavirus-nursing-homes-racial-disparity.html.

⁷ National Domestic Workers Alliance. "Care is Essential." April 21, 2021. <u>https://ndwa2020.</u> domesticworkers.org/wp-content/uploads/2021/04/Care_Is_essential_UPDATE_4_02_21-copy.pdf.

⁸ Margaret K. Nelson, Caring on the Clock: the Complexities and Contradictions of Paid Care Work, (New Brunswick: Rutgers University Press, 2015).

⁹ Dareh Gregorian. "Biden's Build Back Better bill: What made it in and what was stripped out," NBC News, October 28, 2021. https://www.nbcnews.com/politics/joe-biden/biden-s-build-back-betterbill-what-made-it-what-n1282643

experiencing the long-term health effects of COVID-19.¹⁰ Currently, there are more than 800,000 people on waitlists to receive home- and community-based services through Medicaid, with an average wait time of more than three years.¹¹

Labor, disability, and elder rights advocates have warned that the current system is ill-equipped to meet growing demand. Rather than heeding these calls by expanding services and investing directly in the workforce, government actors have often instead deployed new technologies to recalculate the distribution of already thin resources, or to police, surveil, and restrict those who receive them. In multiple states, for instance, government officials introduced automated decision-making tools with the aim of more equitably assessing people's eligibility for Medicaid home- and community-based services.¹² These systems' inability to factor in the subtleties of individuals' care needs led to drastic service cuts with devastating effects to service recipients' health and well-being.¹³ **These measures may serve the interests of controlling costs, but ultimately do not address the underlying state of chronic underinvestment**.

The assumption that automated systems can be used to reduce fraud and increase efficiency is compounding inequality in the way that public benefits are delivered. These attempts to reduce fraud cannot be understood outside the context of racism, sexism, and the deep stigmatization of poverty and disability that have long shaped labor and care infrastructures in the US. **Unlike fraud oversight practices that focus on institutional accountability—such as audits of home health agencies' billing practices—EVV systems direct the digital surveillance**

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

¹¹ Eduardo Porter. "Biden Takes On Sagging Safety Net With Plan to Fix Long-Term Care," New York Times, April 15, 2021. https://www.nytimes.com/2021/04/15/business/economy/home-care-biden.html

¹² Lydia X. Z. Brown, Michelle Richardson, Ridhi Shetty, and Andrew Crawford, "Challenging the Use of Algorithmdriven 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-drivendecision-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.

¹³ Colin Lecher, "What Happens When an Algorithm Cuts Your Healthcare?" *The Verge*, March 21, 2018, <u>https://</u>www.theverge.com/2018/3/21/17144260/healthcare-medicaid-algorithm-arkansas-cerebral-palsy.

spotlight onto individual workers and their clients' daily lives by perpetuating an environment in which the default assumption is that everyone is committing fraud and cannot be trusted.

This is consistent with widespread digital surveillance of low-wage work, which is rooted in racist perceptions of the workforce as unskilled, untrustworthy, or lazy. As a result, extensive surveillance—both subtle and overt—has long been normalized in the context of low wage work.¹⁴ Rather than focusing on improving workplace conditions—including poor wages, lack of benefits and training, lack of access to technology, and overall social devaluation—policy efforts are instead marshalling technology to more closely monitor and discipline the workforce.

The failures of EVV go beyond poor user design and failed implementation and extend to serious questions about whether technology improves job or care quality. Our research indicates it does not. EVV was mandated and implemented following promises from legislators that it would enable long-term cost savings by cutting down on "fraud, waste, and abuse." Because the EVV mandate was never about improving job or care quality, labor and disability rights groups foresaw that this new digital infrastructure would likely result in serious harms to their constituencies, and that it would flatten the complexity and interpersonal nature of care and support work.

2. Federal and State governments must commit to community and justice informed uses of algorithmic systems.

We need to question both the centrality of tech companies in relation to the state provision of services and benefits, and the ability of the companies' technologies to serve vulnerable communities in ways that don't further unjustly criminalize them. Instead of calling for the elimination of all technology in care and labor contexts, our research indicates the need for greater visibility of the harms technologies can create, and a deeper commitment to community-oriented policy approaches that ensure any technology deployed in the provision of public benefits and services is subject to more meaningful democratic deliberation.

¹⁴ Aiha Nguyen, The Constant Boss: Labor Under Digital Surveillance, Data & Society Research Institute, May 19 2021, https://datasociety.net/library/the-constant-boss/

In the years following the 2016 legislation mandating EVV, public backlash emerged as service recipients and workers struggled to adapt to the new requirement. Dozens of town halls across the country surfaced deep confusion among EVV users over opaque policies and glitchy, inaccessible systems. In a 2018 stakeholder call hosted by CMS, officials summarized the public input they had received from around the country: this included significant concerns over privacy, financial and administrative burdens, and fears that EVV would exacerbate labor shortages and push service recipients into institutions or out of Medicaid entirely.¹⁵

Public input and participation in an accountability process is not synonymous with accountability to the public. The timing and nature of the public engagement, who represents "the public," and the response to that input by the institution controlling the technology all matter deeply.

These questions come at a time when tech companies are looking to enhance the scope and predictive power of their products. Despite significant implementation failures involving more rudimentary technologies, multiple state governments have already adopted powerful, automated-decision making tools to assess disable people's eligibility for Medicaid and home and community based services, often with little public debate or transparency over how decisions are made. While it is unclear whether EVV-generated data has yet been used to cut services, it is one potential trajectory for future use of the technology.

The denial of these services and benefits without sufficient notice, explanation, and opportunity to appeal constitutes a possible due process violation.¹⁶ EVV systems were designed to passively track time and location data to verify services, but in reality they are actively changing service recipients' ability to live freely in their communities and to access the services they're entitled to receive.

¹⁵ Centers for Medicare and Medicaid Services, "Electronic Visit Verification (EVV) Stakeholder, Open Door Forum," November 7, 2018, https://www.hhs.gov/guidance/document/podcast-and-transcripts-0.

¹⁶ Danielle Keats Citron, "Technological Due Process," *Washington University Law Review* 85, no. 6 (2008): 1249–1313, https://openscholarship.wustl.edu/law_lawreview/vol85/iss6/2

Moving forward, we need federal and state governments to think expansively and creatively about whether and in which ways existing regulatory tools can be applied to mitigate algorithmic-driven harms. In instances where those tools are not sufficient, we need to collaborate closely with labor and disability rights coalitions to imagine and implement alternatives that are responsive to the needs of communities.

This includes banning and prohibiting the use of such technologies in certain contexts absent effective oversight. Leaving this set of governance concerns up to companies through self-regulation, company principles, and other "responsible Al" initiatives is not going to result in meaningful checks on harms, particularly to historically marginalized groups who are already radically under-represented in the design of predictive systems.

Resources and Further Reading

Our research outlines many instances in which labor and disability rights advocates foresaw the harms that EVV systems would bring. Advocates actively participated in public engagement and consultative processes around both the passage of the 21st Century Cures Act in 2016 and subsequent town halls. Many groups have continued to advocate for alternative policies, including a ban on the use of geolocation (GPS) and biometrics by EVV systems. The following resources significantly informed our work and provide a detailed path forward for implementing care policy that respects the rights of care workers and recipients.

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

The Center for Public Representation, Concerns with EVV

Disability Rights Education and Defense Fund (DREDF), <u>Statement on</u> Electronic Visit Verification

Disability Rights California, <u>DRC</u> <u>Position on Electronic Visit</u> Verification (EVV)

Kendra Scalia, Disability Visibility Project, <u>"Electronic Visit</u> <u>Verification (EVV) Is Here:</u> What you need to know and how to get involved" s.e. smith, Rooted in Rights, <u>Electronic</u> <u>Visit Verification: a Threat to</u> <u>Independence for Disabled People</u>

Georgia Council on Developmental Disabilities and the Center for Public Representation, <u>Electronic</u> <u>Visit Verification: New to Medicaid</u> <u>In-Home Services</u>

United Domestic Workers, <u>Electronic</u> <u>Visit Verification (EVV): What you</u> need to know right now

Alicia Hopkins, The Mighty, <u>How Electronic Visit Verification Is</u> Harming People With Disabilities

ACLU Letter, <u>Coalition Letters in</u> <u>Support of Electronic Visit</u> Verification (EVV) Legislation

If you'd like to learn more about the intersecting harms of Electronic Visit Verification and the government's use of data-centric technologies, please contact Serena Oduro, Policy Research Analyst, at <u>policy@datasociety.net</u>.

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