



National Council on Independent Living

## CALL TO ACTION

### THE NEED FOR FEDERAL PROTECTIONS IN ELECTRONIC VISIT VERIFICATION

Electronic Visit Verification (EVV) systems undermine the intent and integrity of the Independent Living Model and personal care services. The disability community demands Congress address these issues immediately through **a federal bill that reverses the EVV mandate**; or, **minimally, with a federal bill that ensures Americans' right to privacy by prohibiting the invasive and unnecessary use of GPS, biometrics and geofencing** in electronic visit verification systems for Medicaid-funded personal care services and home health care services.

The 21st Century Cures Act, which mandates EVV use for all Medicaid-funded personal care services (PCS) or home health care services (HHCS), does not require a specific type of system. Vendors are selling states expensive technologies that **invade privacy, disrupt care, and jeopardize the foundation of home care services** in the country.

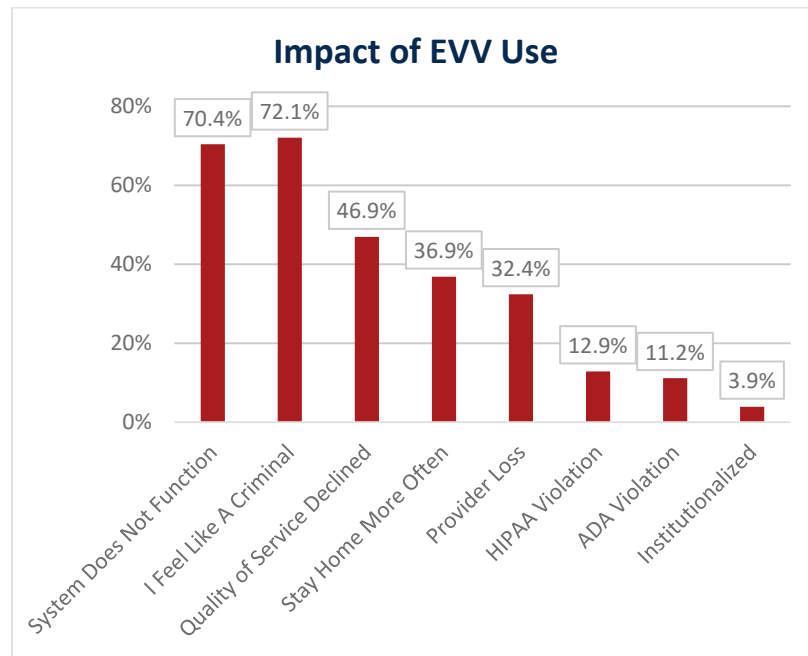
- **GPS and geofencing force disabled people and their care providers to have their movements, whereabouts, and very personal activities monitored** only due to disability status. This wholly violates our Constitutional right to privacy.
- The **draconian use of GPS and biometrics** in EVV causes providers to leave jobs. Individuals with disabilities across the country are facing **severe provider shortage and unnecessary institutionalization**.
- The burgeoning cost of **EVV robs public coffers of funds that should be more efficiently utilized to adequately fund living wages and benefits for workers**. For recipients who are forced to live out their lives in nursing homes and other institutional settings, the **cost to human dignity and loss of meaningful participation in community life is beyond measure**.
- The rationale that EVV protects against fraud and abuse is **without merit and discriminatory**. It is based on **prejudice and stereotypes**. In California, home to half of all program recipients and providers in the country, **a FY 2014-15 fraud study found a rate of just 0.02%**.

**EVV violates the pursuit of dignity and the constitutionally protected right to privacy of individuals with disabilities.** Disabled recipients are required to tolerate such privacy invasions and indignities to get care we need to avoid **being forced into institutional settings**. EVV systems threaten the privacy of countless Americans with disabilities who would otherwise be able to remain safely in their own homes and communities free of intrusive governmental monitoring.

Most states have begun to implement EVV in some form, gearing up for a January 1, 2021 deadline. Many of these states have only rolled out EVV requirements to a portion of Medicaid recipients. To

better understand the impact, if any, of EVV use, the National Council on Independent Living (NCIL) conducted a survey of home care recipients and their care providers. These figures capture just three months of EVV use across the nation.

- Seven in 10 report that EVV systems do not work as intended on a regular basis.
- Seven in 10 individuals report that EVV systems that include one of the three invasive components make them feel like a criminal, causing a loss of providers.
- Almost half of respondents say EVV implementation has lowered the quality of services provided.
- One-third of respondents 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.
- One-third of individuals have experienced provider loss due to EVV.
- More than 10% of individuals have already experienced violations of their HIPAA and ADA rights.
- Almost 4% of respondents have become unnecessarily institutionalized because EVV directly impacted their ability to hire or retain workers.



The bar graph above shows the impact of EVV Use on System. Does Not Work: 70.4%, I Feel Like A Criminal: 72.1%, Quality of Service Declined: 46.9%, Stay Home More Often: 36.9%, Provider Loss: 32.4%, HIPAA Violation: 12.9%, ADA Violation: 11.2%, and Institutionalization: 3.9%.

### Survey Summary

- Conducted 8/14 – 11/13/2019
- 468 Responses

- 36 States Represented
- 52% EVV Use Rate
- Invasive EVV Component Use:
  - 56.6% GPS Tracking
  - 17.3% Biometric Use
  - 15% Geofencing

### **Survey Respondents Say:**

*“Tracking of any human who has not committed a crime is wrong. Tracking of people due to their disabilities is discrimination.”*

*“Privacy matters. Dignity matters. State agencies will not discuss this during stakeholder meetings.”*

*“My care suffers because [caregivers] spend too much time figuring out EVV.”*

*“My whereabouts are being watched by people I don’t even know!”*

*“The device recorded my conversation without me knowing it and [the vendor] sent it to my agency.”*

### **Glossary of Terms:**

- GPS Tracking - A navigation system that uses satellite signals to identify the location of an object on Earth.
- Biometrics - A technology used for identification, including fingerprinting, facial recognition software, eye or retina scans, voice verification and others.
- Geofencing - Using GPS technology to create a boundary around a fixed location, geofencing prevents community access, as payment for services is stopped when the recipient or provider crosses the virtual boundary.