



Stop EVV

Help end invasive electronic visit verification components.

www.stopevv.com

helpstopevv@gmail.com

[f](#) [t](#) [in](#) @StopEVV

The Honorable Seema Verma
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 445-G
200 Independence Avenue, SW
Washington, D.C. 20201

October 26, 2018

Re: November 7 Stakeholder Call Feedback

Dear Administrator Verma:

Stop EVV is a national grassroots campaign led by individuals with disabilities and personal care providers. We raise awareness on the civil rights violations against disabled people through the use of invasive electronic visit verification (EVV) systems. Our national campaign represents a large membership body in all fifty (50) states and Washington, D.C.

We fully support the National Council on Independent Living (NCIL) EVV Principles and Goals statement.

Stop EVV respectfully makes the following requests of CMS:

- 1. Exempt consumer-directed services (CDS) from the EVV requirement.** In May 2018, CMS unilaterally declared congregate residential settings exempt from federal EVV requirements due to the 24-hour nature of service and the “inherent differences in service delivery model”. This same interpretation can and should be applied to CDS.

CDS is significantly inherently different than traditional home care agency services. It is critical that CMS recognize and differentiate between traditional home care agency and consumer-directed services. Not all services under CDS are delivered in a home setting. Consumers under CDS have the right to request their services provided outside of their home or even separate from their physical location at the time services are rendered. Many state CDS programs offer 24-hour services, similar to congregate residential settings. A single care provider under CDS may be working for multiple consumers throughout a shift, those who live together or within close proximity to one another.

Lastly, *the consumer under CDS is considered the direct employer and supervisor.* Only the consumer can sign off on a timesheet to acknowledge services were provided. Unlike agency model care, where the supervisor is off-site and the consumer does not participate in verifying shifts worked or the type of services provided, the CDS consumer hires, trains,

schedules, supervises and terminates their own independent employees. There is no set schedule to match against pre-determined shift records. Any change to management roles within this program, such as EVV's third-party oversight on supervisory rights, will erode CDS programming and independent living civil rights the community has fought to maintain for decades.

- 2. Develop EVV standards that prioritize consumer and personal care provider voices.** Consumers and personal care providers are the end users of all EVV systems. It is critical that their concerns, whether related to privacy, accessibility or other, are taken into consideration and adequately addressed.

Electronic visit verification is a financial giveaway to the technology industry, lobbied for under false pretenses of fraud and patient protection. It is critical that CMS prioritize consumer voices above and beyond those in the technology industry who have financial incentive to push the use of their technologies.

From the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) to the Stop EVV California coalition, communities across the country are overwhelmingly recommending web-based timesheets. Stop EVV is proud to acknowledge the work of our California coalition alongside the California Department of Social Services (CDSS). Stop EVV encourages CMS to develop a framework for implementation like the CDSS model under development. This model prioritizes consumer choice, maintains supervisory roles of consumers in consumer-directed programming, and meets federal laws, including the Americans with Disabilities Act and the Olmstead decision.

Web-based timesheets is the ideal EVV system for most consumers, as it addresses privacy civil right concerns and can be made accessible to individuals with varying disability experiences. A web-based timesheet also protects the supervisory role of consumers in CDS.

Prioritization of consumer EVV system choice is essential to meeting the federal requirement of developing or choosing systems that are 'minimally burdensome'.

- 3. Prohibit the use of invasive components such as geolocation tracking, biometric data collection, cameras, and audio recording capabilities.** Consumers are rightfully outraged at the abhorrent and unnecessary violation of Constitutional privacy rights with the introduction of some EVV components being used or proposed in many states.

The use of tracking devices that unintentionally track disabled consumers as they move about their home and communities creates legal liabilities to the state. The U.S. Supreme Court, in *United States v. Jones* and *Carpenter v. United States*, ruled that GPS tracking devices and cell phone tracking without a warrant violated the 4th Amendment rights guaranteed to citizens under the U.S. Constitution. Further, it is wholly unnecessary to geolocate consumers and/or personal care providers under CDS programs. The very nature of CDS permits consumers to receive care in any setting they deem fit. Many shifts may find the consumer never once in their own home. Geolocation and biometrics are meaningless data in CDS.

Video and audio recording devices, whether used to deliberately or inadvertently capture moments within a consumer's private dwelling, have no place in home care services for any reason. The disability community will not lay idle as state Medicaid programs deny Constitutional rights to privacy or treat disabled Americans as second-class citizens.

4. **States must be held accountable to meet federal requirements related to stakeholder involvement throughout the design and implementation process.** Many states have failed to hold stakeholder meetings until after EVV selection and implementation have occurred. Other states have failed to include consumers or personal care providers as stakeholders. Some states have failed to provide adequate notice or accessibility accommodations for stakeholder events. It is the duty of CMS to oversee that states follow implementation requirements. CMS must develop an EVV oversight committee and create penalties for those states that fail to include the most important stakeholders – consumers.
5. **CMS must continue to engage with key stakeholders, including consumers and personal care providers, on an on-going basis.** While Stop EVV commends CMS for swiftly hosting an Open Door Forum “in keeping with the Sense of Congress language in H.R. 6042” it is not enough. Further meetings must be held. These meetings ought to allow for instant two-way communications. Requesting comments or questions via e-mail and delivered a week prior to the meeting is not acceptable. Engagement is more than talking at an audience. Engagement also includes listening and responding to the audience in real-time.
6. **CMS must develop EVV standards, guidance documents, FAQs and all other communications related to EVV implementation in conjunction with the disability community.** National disability organizations stand ready to immediately work with CMS on this topic. Stop EVV staff welcome an opportunity to work with CMS should an invitation be extended.
7. **A copy of all comments submitted in regard to the November 7 Open Door Forum ought to be made publicly available.**

Stop EVV remains alert regarding how EVV systems violate privacy rights, erode independent living programming, and overall negatively impact the personal care industry. Stop EVV continues to work in partnership with national disability organizations and local advocates on EVV implementation.

We appreciate the opportunity to submit comments and look forward to a response that addresses each item outlined above.

Respectfully,



Kendra Scalia, M.P.P.
Director of Policy, Stop EVV – National