

1/19/18

Congressman Greg Walden
Chairman, House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC



Congressman Frank Pallone
Ranking Minority Member, House Energy and Commerce Committee
2322 A Rayburn House Office Building
Washington, DC 20515

Dear Congressmen Walden and Pallone:

We are writing to ask your committee to work with the administration to remediate the untenable and surely unintended consequence resulting from **ELECTRONIC VISIT VERIFICATION noted in Section 12006 of the 21st Century Cures Act of 2016**. *We request that you ask the administration to delay the implementation of EVV for disabled citizens that receive personal care through either a consumer directed program or a family caregiver.* There are numerous policy concerns and barriers to implementation. Instead, we ask that you direct states to engage in bipartisan cooperative work with our communities as described in the attachment. A directive requiring engagement with affected citizens will be consistent with CMS directives under every administration since President George H. Bush, and indeed required by Medicaid regulations.

This will give states time to address any issues properly without hurting vulnerable disabled citizens. Without your intervention, people with disabilities are at risk of losing hard fought independence along with other problems outlined in this packet. This letter and the attachments explain the problem, and propose a solution. Action is urgent because this provision is set to go into effect on 1/1/2019 and states are already entering contracts and trying to prepare for this, despite clear evidence of harm and lack of solid appropriate policies.

The undersigned organizations represent people with disabilities throughout the nation, particularly those that rely on personal care to perform everyday activities. The disability community has worked with Congress and our states to create consumer-directed programs that allow us to have the resources we need to live, work, worship, play, and be full citizens in communities throughout the United States.

Each state has flexibility to design their programs but there are certain commonalities. Medicaid was enacted in part to help people with disabilities maintain the maximum possible independence. Since the early 80's people with disabilities have been able to receive home and community based services (HCBS) that enable cost-efficient community based services, in lieu of expensive and undesirable institutional care. The cornerstone of the HCBS model is personal care. Differences between agency and consumer directed programs are outline on the next page.

	Consumer Directed	Agency Directed
Supervision of worker including hiring and firing	Medicaid client or their chosen representative	Agency staff
Funding	Clients must stick within budget, can bill for approved services.	Agencies bill based on rates for approved services.
Location	Home, community, place of employment, anywhere the client needs to go	Usually limited to client home or day center, some agencies allow for services at community sites.
Shift Reporting	Attendant submits time sheets to their employer, who is the client. Clients submit time sheet to independent fiscal oversight agency. There are no systemic discrepancies between client and attendant statements. Because the client is supervisor there is no power imbalance or way attendant can submit sheets after the client signs.	Attendant submits time sheets to agency, some have requirements for client signature but often clients are pressured to sign ahead of time. EVV designed to address conflicts between client and attendant statements.
Type of Service	Clients allowed to blend services to assure efficiency and avoid duplication. (example laundry is done during other personal care). All services from ventilator and complex nursing care to homemaking	Each service type is separate and in some cases requires separate agencies. Medical care done by nursing at nurse rate. Unskilled care done by different people-and rules differ in each state.
Task Reporting	Current regulations allow for outcome based evaluation, not paperwork compliance. Client or representative is responsible to get needs met. There is overall care plan but client does not report on what specific service happens on which visit. Case management oversight assures that client is as healthy as possible.	Attendants report on what tasks are done. Because of EVV limitations, each area of service may require a separate visit (For example a skilled nurse aide may do a morning visit followed by homemaker to make breakfast)
Time Reporting	Attendants do what is needed and the total hours (in ¼ hour increments) are reported on	Most already using some electronic system. Some agencies will not accept

	timesheets. Clients accountable to track who works when including in and out times that may include multiple services.	clients with short visits.
Location Reporting	Not done currently as services follow client to allow for employment and freedom of movement. Clients that are employed can have homemakers clean when the client is at work .	Attendants often report electronically from client home, this system has prevented agencies from allowing for services in the community.
Emergency Needs	Clients are required to have backup plan. If client is sick they are expected to manage this within their budget.	Agencies may or may not be able to cover emergency needs. If client is sick agency provides extra units PRN.
Family Caregiver	Varies by state but many states allow family members to be paid attendants up to 40 hours per week.	Severe limits on allowing family members to be paid caregivers.
Fraud Safeguards	Multiple, case manager visits, independent fiscal agency oversight, strict eligibility to use program, client likely to appear in the Emergency Room or Adult Protection if services not provided.	Retroactive often following up on a complaint or investigation. Case manager visits.
Training of client (or representative)	Usually required, including testing to make sure client understands –includes Medicaid fraud regulations	None
Worker Pool	Family and friends of client or people hired by client –often neighbors. People that are trusted by and care about the client.	Sometimes people with state certification required, anyone that agency can find.
Client Pool	Clients that desire independence, clients that are employed, clients with very complex and severe disabilities that are not accepted by agencies (such as clients using ventilators) Rural	Clients that have less desire for independence, clients with lower needs, clients that are not employed, live in urban areas.

In closing, we feel strongly that consumer directed programs and family caregivers must be exempted or at least delayed until the myriad problems are addressed. EVV is an expensive, complex and bureaucratic technology designed to address problems with agency driven services that do not apply to consumer directed or those provided by family caregivers.

We are eager talk to you or meet with you as soon as possible if you have any hesitation about working quickly to solve this problem. If needed some of us can come to DC to meet with you in person. We can arrange a call at any time. Because states are moving forward now to adhere to the 1/1/19 timeframe we hope that your committee can discuss this and meet with the administration forthwith.

Thank you for your cooperation.

Signature page attached:

CC: Congresswoman Diana DeGette (Bill Sponsor)

Attachments:

- 1) Proposal for alternative
- 2) Known problems with EVV
- 3) Guiding principles to be in place before EVV can be used

Proposed Alternative:

CMS requires each state to work with stakeholders that must include Medicaid clients that use consumer-directed care, family caregivers, paid attendants, and Fiscal Management Entities to address the following:

- 1) Is there a concern that clients are not getting the necessary visits or that the services on the care plan are not being delivered?
- 2) Do clients have a backup system in the event that a personal care worker cannot perform their tasks on any given day (planned and unplanned)?
- 3) Are clients proficient in supervision and trained on how to manage a worker that does not report timely for work and/or does not complete tasks as directed?
- 4) What are the safeguards in place to assure the clients are receiving the proper care?
- 5) What are the safeguards in place to assure that no one is paid for services not performed?
- 6) Are the safeguards in place adequate?
- 7) If not, what does the state suggest?

If the state determines that EVV is appropriate, they should explain how they will assure that the guiding principles and known problems are addressed. States should not be allowed to implement EVV for consumer direction or family caregivers until there is a plan to address the known issues. States also must have a resolution process for problems.

The state should either convene a specific workgroup to address this issue or may use an existing group that works on consumer direction issues. The state should be allowed to claim a 75% match for expenses related to this work. The state should have a group convened by 7/1/19 with a preliminary report by 1/1/21 and final report by 9/30/24. Annual interim reports should be posted on a public website on 10/1 of each year.

Known Problems with EVV/FVV and Consumer Direction

- 1) **GPS RELATED:** These systems often require GPS and are linked to the client home. Consumer direction clients are allowed to receive services anywhere—such as when we travel for our employment or volunteer work. –
 - a. Consumer directed clients can control how we handle our services. For example we do not have to sit at home while someone cleans our house or does our groceries and laundry
 - b. At times, a consumer directed client might need a worker to meet them somewhere. The worker might drive taking 20 minutes but client takes the bus taking an hour. During this time the worker must remain on the clock per labor laws, but the client will be in a different place. How will a system figure out when this is OK and when it is not?
- 2) **DIGITAL DIVIDE:**
 - a. Some older citizens are not proficient with electronic gadgets. It is likely that both clients and workers will not know how to do this, will forget, will make errors, etc. This will result in workers already living paycheck to paycheck not being paid on time.
 - b. Many low-income people have neither landlines nor WIFI. Some rural areas have no access to WIFI.
- 3) Some of our citizens (both clients and employees) with mental health issues will have serious problems with having GPS devices tracking their movements for evaluation by the government.
- 4) Increasingly people with disabilities are pairing up to afford housing. It is more common to have a situation where two disabled people share an attendant. This saves the state some money (only pay for shopping and housework once) but this is impossible to do with an EVV model.

GUIDING PRINCIPLES OF THE USE OF EVV/FVV

- 1) EVV/FVV must not interfere with the autonomy of the recipient of the home and community based services/personal attendant services/ and or home health services.
- 2) System must allow the consumer the flexibility to receive their services where and when needed. The system must be mobile so as to not impede activities of integration within the community. This means it cannot be linked to the home and must allow for times when the client and worker are separated (see other list of known problems).
- 3) System must allow for continued trust that has been established between the consumer and their personal attendant. Clients are the supervisor of the attendants, but also must trust attendants at a very deep level due to the intimacy of the work. Requiring attendants to report to the government whether a client took a bath or not is overkill and will lead to friction, particularly if this leads to billing problems where attendants are docked if they do not report specific client activities that may be on a care plan. Moreover, this is an invasion of privacy that is absolutely unacceptable. Does the government really need to know the intimate details of our personal hygiene?
- 4) The EVV technology used must be user friendly for the workforce and meet accessibility standards for people with disabilities. Federal implementation must take into account end user accommodation and individualized training needs. This means voice recognition must accommodate speech impairments and accents. Systems must have screen reader capabilities. Individualized training for workers and clients with learning disabilities must be available. Moreover, clients with coordination problems should not be penalized when they break the devices. .
- 5) The federal government must cover all costs of EVV. Otherwise this is an unfunded mandate. Clients that need assistance with using EVV will need additional time on their care plans. Extensive instruction and replacement devices must be considered.
- 6) There must be independent oversight of EVV providers, including investigations of complaints. If there is a dispute regarding payment, these must be addressed quickly to avoid violation of labor laws. The system must allow editing by the client at a later time or date when someone forgets to sign in or out. If the aide does the work the aide must be paid.