

Submitted electronically to CMS 10/20/18 to EVV@cms.hhs.gov
Re: Nov 7 Stakeholder Call feedback on EVV

We are submitting the following comments regarding the implementation of EVV:

California is home to a huge number of people affected by the EVV mandate, vastly more than any other state. We are proud to be known as the birthplace of the Independent Living Movement. Over the decades, Californians have built a robust network of social, economic, legal and institutional resources to advance and protect the rights of people with disabilities. Section 12006 of the CURES Act gives wide latitude to states regarding implementation. However, disability activists nationwide report serious concerns that some state programs are in conflict with the hard fought principles of independent living.

The California Department of Social Services (CDSS) is developing a framework for implementation that we believe meets the requirements of federal law while also promises to respect our rights under the Americans with Disabilities Act, the Olmstead decision and California state law. We hope they are successful. We are impressed that CDSS has made a commitment to an inclusive and democratic stakeholder process. However, this is not the case in many other states, which have either systematically excluded grass roots consumers and workers as stakeholders, or held a sham process. This has resulted in poorly conceived and designed EVV programs.

The current CMS process meets the requirement to hold “at least one stakeholder meeting” as mandated by HR 6042. While meeting minimal legal requirements, this does not seem to us to be a good faith effort to listen to our concerns and learn from our insight. **We hope you find ways to do better, and insist that you conduct more than one meeting.**

In addition, we propose the following:

- 1. We would like the following “best practices” for consumer directed programs be included in CMS guidelines:**
 - a) Because of the complex technological challenges of meeting the needs of people with a variety of disabilities who live in poverty, which includes the workers who assist them, states should provide an on-going appeals process for stakeholder groups and individuals who feel their rights have been abrogated. This would involve the appointment of a statewide ombudsman or advocate who would be readily available in person by phone and videophone (for the Deaf community) to identify and solve accessibility issues and technological shortcomings.
 - b) States must not fall into the mental trap that assumes any drop in program use is due to “fraud reduction”. Robust quality assurance practices will be

- needed in order to ensure that drop in program use is NOT the result of accessibility barriers due to disability or poverty.
- c) Consumers, under consumer directed programs, (as they are the direct employer), must have the final authority to correct timesheets.
2. Some states have decided, on their own initiative, to employ geo-tracking and biometric identification in their EVV programs. These are not requirements of federal EVV law. We feel this violates not only the rights of people with disabilities to privacy and control over personal data collection, but is not consistent with the intent of Sec 12006 of the CURES act. The law is very clear: that EVV programs SHALL be “minimally burdensome” and should not “impede the manner in which care is delivered”. **CMS should not fund EVV programs that employ onerous and often completely impractical requirements, as they do not meet these legal standards.** Around the clock live in family caregivers, electrically sensitive individuals, people with disabilities who need assistance but are active in their community---all find these EVV models inconsistent with their needs. For example, family caregivers work many more hours than they are paid for, and resent having to conform to an industrial model of work reporting that not only interferes with service delivery, but also does not accurately reflect the actual amount of work they perform. In a program that’s designed to reduce fraud they are required to underreport work hours!
3. **We insist that CMS require accountability from states regarding their stakeholder participation.** In order to qualify for federal approval, states must provide documentation of a genuine stakeholder process that includes the voice of grass roots consumers, family members and workers. This is mandated by the CURES Act.

Finally, we request access to all of the comments submitted to you on this issue in the public comment period. How may we obtain that?

Signed,

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The StopEVV Coalition is a grass roots partnership effort of people with disabilities and their attendants. Our consumer/worker coalition includes individuals who have been disability rights activists for decades.