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June 4, 2018

Seema Verma
Administrator
US Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Re: CMS Electronic Visit Verification Guidance issued May 2018 – request for a one-year delay of implementation of law

Dear Administrator Verma:

The National Council on Independent Living (NCIL) is writing to express our serious concerns that remain after the May 16, 2018 sub-regulatory guidance issued by CMS on Electronic Visit Verification (EVV). Prior to the release of the guidance NCIL reported to CMS via teleconference the concerns of our national network. These include the serious disregard in numerous states for the law's requirement of stakeholder engagement; the privacy and civil rights violations of consumers of personal care services and their providers in states' EVV implementation; and a "medicalization" of the consumer directed personal care services model that undermines control and choice, which is the bedrock of Independent Living.

NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. NCIL represents thousands of organizations and individuals including: individuals with disabilities, Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

Since our inception in 1982, we have fought for a pathway out of institutions into community life, and consumer-directed Medicaid funded personal care services is the fruit of our labor. EVV may be appropriate for home care agencies but it is antithetical to community personal care services and has the potential to undermine consumer control and choice, which are fundamental to its demonstrated success. Tens of thousands of people with disabilities will be affected by EVV, and the network of community-based long-term services and supports that NCIL has worked so hard to develop with its members over the past 35 years hangs in the balance.

The Cures Act requires EVV to be used for “personal care services or home health care services requiring an in-home visit by a provider in the person’s own home.” We believe that CMS has inappropriately broadened the scope of where EVV must be implemented to include virtually any home and community service if any assistance during a "shift" in the individual’s home is necessary. [NCIL opposed including EVV in the 21st Century Cures Act](#) during the legislative process because we opposed and continue to oppose reporting location in any form, especially GPS, that violates our most private and personal information.

Several states are well underway in implementing EVV in a draconian manner that, at least in one state, has purchased military grade EVV hardware that has been distributed to providers to be used in tracking them using GPS – these devices also include cameras and microphones. The devices are required by the state to be used to track the location of consumers and their providers throughout the community in the course of their daily lives. Thus, the state follows disabled people and their providers as they go shopping, worship, see a therapist, or work. NCIL opposes the use of monitoring in both the home and community, however with regard to the current law and guidance, states should only be allowed to monitor disabled people's activities in their own home as the law intends. *In our opinion, in and of itself that is an egregious privacy rights and civil rights violation.* CMS, to its credit, was correct in its interpretation of the law to assert that GPS is not required, and that states can choose to locate disabled people and providers using other methods available.

With less than eight months left until the January 1, 2019 deadline for EVV implementation, there continues to be significant ambiguity in the CMS guidance released last week and states are scrambling to properly engage stakeholders as required by the law, use that feedback to determine a model that addresses the onerous complexity of what stakeholders want and what the law requires, and seek funding for implementation.

Therefore, NCIL formally requests, minimally, a one year delay in implementation of EVV to allow states to meaningfully engage stakeholders and to design, develop and implement programs that are thoughtful and deliberative. Further, we urge CMS to incorporate into the guidance the insights, questions and feedback from consumers and individual providers of consumer directed programs. Doing so will help ensure that the concerns in this letter and any others identified in that process are addressed in such a way that allows states sufficient time to put EVV systems in place that do not violate the basic tenets of independent living.

If you have any questions or would like to discuss this further, please contact Kelly Buckland, Executive Director, at (202) 207-0334 x 1104 or Kelly@ncil.org.

Sincerely,



Kelly Buckland, Executive Director



Bruce Darling, President

Cc: House Energy & Commerce Chair Walden
House Energy & Commerce Ranking Member Pallone
Speaker Ryan
Minority Leader Pelosi
Senate Finance Chair Hatch
Senate Finance Ranking Member Wyden
Senate Majority Leader McConnell
Senate Minority Leader Schumer
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