September 28, 2018

Seema Verma
Administrator
U.S. Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Administrator Verma,

The Consortium for Citizens with Disabilities (CCD) Long-Term Services and Supports (LTSS) Task Force is writing to express extreme concern around the lack of clear guidance and official stakeholder input around the implementation of Electronic Visit Verification (EVV) for personal care and home health services. On July 30, 2018 President Trump signed H.R. 6042 into law, establishing a one-year delay in the implementation of EVV. This delay was necessary, in part, because CMS failed to issue clear and timely guidance around EVV implementation.

CCD is a coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of the approximately 57 million children and adults with disabilities in all aspects of society.

Designing and implementing an effective and carefully considered EVV system requires careful planning by states, and CMS plays a key role in ensuring meaningful stakeholder engagement in that process. Unfortunately, CMS’ subregulatory guidance issued in May 2018 lacked the clarity and specificity states need to successfully implement EVV. Congress’ one-year implementation delay gives CMS new opportunities to 1) directly solicit stakeholder input; 2) ensure states develop effective systems for soliciting stakeholder input; and 3) issue clearer guidance on how states must protect privacy and civil rights of individuals with disabilities when implementing EVV. Below, the Task Force outlines our concerns with EVV implementation and our recommendations for CMS guidance.

Location Tracking and Privacy Concerns

In states already implementing EVV systems, serious consumer and worker privacy concerns have arisen. For example, states have collected data that tracks consumers’ and caregivers’ locations as they go about everyday activities such as shopping, running errands and engaging in recreational activities. This has been a particular concern in consumer-directed programs. In addition, it has been reported that some states are using EVV devices that include cameras, video capabilities, and microphones. We urge CMS to issue guidance that clarifies that states: 1) may only record a location at the beginning or end of a shift that starts or concludes in a person’s home; 2) may not use invasive monitoring devices including, but not limited to, cameras, video-capability, and microphones; 3) may not permit the use of geo-location or GPS tracking devices to meet the requirements of EVV; and 4) must follow clear CMS
guidelines regarding data collection and storage. In establishing these data standards, the guidance should specify the maximum length of time that such data will be stored and how the data will be properly disposed of or scrubbed. To the extent that CMS continues to allow states to use EVV for services provided outside the individual's home, CMS should require states to simply record that the location is "the community" or "outside the home" and not allow the specific location the consumer visits in the community to be tracked or recorded.

**Lack of Stakeholder Input**

States must, by law, seek stakeholder input before implementing EVV. However, many states are nonetheless designing and implementing their EVV systems with little to no stakeholder engagement. As noted above, in states that have begun implementing EVV, significant questions have arisen regarding adequate protection of consumer privacy and civil rights. In addition, providers and caregivers remain concerned about the costs and complications of implementing these systems. In H.R. 6042, Congress directed CMS itself to seek stakeholder input from all parties impacted by EVV, including, but not limited to, consumers, family caregivers, state Medicaid agencies, individuals and agencies providing caregiving services, Medicaid Managed Care Organizations, and state EVV vendors. We encourage CMS to 1) issue clearer guidelines to states about their obligation to seek stakeholder input from all parties affected by EVV implementation; 2) ensure that robust stakeholder engagement has occurred before approving any state’s EVV program; and 3) establish its own process for seeking stakeholder input from affected parties.

**Overly Broad Interpretation of the Statute**

Congress only intended EVV for personal and home care services provided in a person’s home. Yet CMS’ subregulatory guidance, issued in May 2018, greatly expands the requirement beyond the plain language of the statute to apply to any service where assistance with activities of daily living or instrumental activities of daily living are provided. We encourage CMS to reassess their earlier guidance and clarify that EVV should apply exclusively to personal and home care services provided in a person’s home. If states, in bad faith, attempt to change their definition of personal and home care services to avoid compliance with the law, such abuses can be addressed directly by CMS. However, any such action by states should not be justification for an overly broad interpretation of statute.

**Implementation Should be Minimally Burdensome to States and Providers**

Even under CMS’ overly broad application, many ambiguities remain around how EVV applies to a number of services. For example, questions have arisen about whether EVV applies to situations where a provider meets a person at their home to provide services elsewhere in the community. In addition, it is unclear how EVV applies to situations where multiple services are provided at multiple locations during a shift. We urge CMS to issue clarifying guidance that will help states implement EVV in a way that is minimally burdensome to providers and protects the civil and privacy rights of people with disabilities.

**Guidance on How to Deal with the Unfunded Mandate**

The statute requires states to implement EVV or face an FMAP reduction for personal care and other services. Yet Congress failed to appropriate any money to help states and providers implement EVV systems and infrastructure. We would encourage CMS to issue guidance or technical assistance that suggests how states can fund the implementation of effective and safe EVV systems. This is of particular
concern in states where much of the services are participant-directed, and individual enrollees hire their own individual assistants. In such cases, requiring costly technology and burdensome reporting may limit the availability of personal care assistants—particularly assistants who are not employed by a large agency but rather are individual providers. CMS’ guidance should address how states can make EVV “minimally burdensome” for participant-directed services and individual providers.

**Joint Employment Concerns**

The statutory language of the 21st Century Cures Act explicitly states that implementation of EVV does not create an employer-employee relationship between the direct service provider and the agency. However, both DOL guidance and years of case law under the Fair Labor Standards act imply otherwise. We urge CMS to reach out to the Department of Labor and request that the Department issue guidance resolving inconsistencies that may arise around joint-employment between states and providers.

Given the many concerns that states, providers, caregivers and people with disabilities have articulated on EVV, it is imperative that both CMS and state officials reach out and establish official processes to collect stakeholder input from all parties impacted by EVV. In addition, despite earlier guidance issued by CMS, many questions about EVV implementation remain. As a result, CCD LTSS Task Force urges CMS to issue clarifying guidance that can help ensure that states implement EVV in an efficient way that protects the rights of people with disabilities.

Thank you for your time and attention to this important matter. If you have any questions or would like to discuss further, please contact CCD LTSS Task Force Co-Chair Sarah Meek at smeek@ ancor.org.

Sincerely,

Alison Barkoff, Co-Chair  
Center for Public Representation (CPR)

Julia Bascom, Co-Chair  
Autistic Self Advocacy Network (ASAN)

Nicole Jorwic, Co-Chair  
The Arc of the United States

Sarah Meek, Co-Chair  
American Network of Community Options & Resources (ANCOR)

Cc: Calder Lynch, Senior Counselor to the Administrator  
Tim Hill, Acting Director of the Center for Medicaid and Chip Services  
Michael Nardone, Director of the Disabled and Elderly Health Programs Group