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NATIONAL COUNCIL ON INDEPENDENT LIVING ELECTRONIC VISIT VERIFICATION (EVV) TASK FORCE STATEMENT OF PRINCIPLES AND GOALS

Electronic Visit Verification (EVV) requirements were passed into federal law as part of the 21st Century Cures Act ('Cures Act') of 2016. The Cures Act requires the implementation of EVV to monitor all **personal care services (PCS)** and home health care services (HHCS) funded by Medicaid.

States were initially tasked to ensure that all state Medicaid and waiver PCS provided in the home comply with EVV guidelines by January 2019. Recent federal legislation extended this deadline to January 2020. Because many people with disabilities rely on these services to live independently in our homes and communities, **the disability community is negatively impacted in a variety of ways by EVV policies and mandates.**

The National Council on Independent Living (NCIL) believes that people with disabilities have the right to be integrated in society and control our own lives. **EVV systems undermine the intent and integrity of the Independent Living Model** and personal care services, including Consumer-Directed Services (CDS). EVV systems threaten the privacy of countless Americans with disabilities who would otherwise be free of intrusive governmental monitoring.

NCIL advocates for the leadership of people with disabilities in all policy discussions and decisions that impact our lives. The expertise and active engagement of people with disabilities is critical in all EVV development, implementation, and evaluation.

EVV VIOLATES CIVIL RIGHTS

Right to privacy

EVV is based on false stereotypes that people with disabilities and seniors are helpless and homebound, unable to have control over our own lives. EVV was designed to be implemented through a medical model: a one-size-fits-all approach in which individuals are "patients" and which leaves little room for individual consumer choice. **EVV was designed based on outdated, ableist assumptions and is implemented by traditional home care agencies with standardized procedures and routines to which consumers must conform** in order to receive services.

Forcing recipients of personal care services and consumer-directed services into **the EVV "patient model" takes away our ability to live autonomous lives and experience constitutionally guaranteed freedoms that non-disabled individuals take for granted.** EVV forces us and our care workers to have our movements, whereabouts, and very personal activities monitored and data collected by state agencies - solely due to a lived experience with disability that requires personal care assistance.

The punitive proposition that Americans with disabilities and the caring providers who work with us must be surveilled by **EVV is ethically untenable and socially archaic.** It reverses gains of the Independent Living Movement, turning back to the default of unnecessary institutionalization, and strips Americans of their Constitutional rights to personal privacy.

Olmstead decision

The Americans with Disabilities Act (ADA) and the Supreme Court's Olmstead ruling mandate that **Americans with significant disabilities should receive services in a way that enables us to live in the community in the "most integrated setting"**.

There is long history of a critical shortage of personal care providers in the home care industry.¹ With stagnant and, in many states, declining wages over the past decade, independent providers such as personal care assistants (PCAs) are continually expected to do more with less time, less pay and less education than their traditional agency counterparts. **The additional requirements of EVV will further erode the ability of PCAs to do the critical work of providing personal care.**

These workers have voiced concern about their ability to continue to provide a high level of care while also using electronic monitoring systems (EVV), especially in health emergencies or illness. **This will cause many PCAs to leave the field completely.** There are already increasing reports of PCAs abandoning this line of work as EVV is implemented across the nation, leaving the struggling PCA industry, and more importantly, people with disabilities in an even more dire state.

With decreasing availability of PCAs and chronically inadequate wages, **more consumers with disabilities will be pushed into nursing facilities, which take away our dignity, and cost much more in Medicaid dollars. State governments must accept the responsibility of these ramifications** as they knowingly pursue EVV in the face of a provider availability crisis.

Forcing individuals out of the community and into nursing facilities by not addressing the provider shortage is irresponsible; **further exacerbating this provider crisis via mandatory EVV is discriminatory under federal laws.** The ability to live integrated in the community is a civil right for people with disabilities under the ADA and the Olmstead decision. **Our civil rights are violated by the collateral damage of EVV.**

De facto surcharges - the hidden costs to consumers

Medicaid beneficiaries are among the poorest Americans. To be eligible for Medicaid and personal care services, consumers must meet severe income and resource limits. Income usually cannot exceed nominal amounts, typically around \$1,000 per month total, depending on the state. Consumer resources or assets generally cannot exceed a cumulative value of \$2,000.

Nonetheless, **all proposed EVV systems require the consumer to spend part of our meager resources to regularly access, maintain and pay for secondary services. These may include a smart phone purchase, cellular data plan, Internet connection, landline telephone connection, electric utilities for charging devices,** et cetera.

These EVV mandated costs may seem inconsequential to many, but for Medicaid recipients, usually on a fixed income, **these requirements mean the difference between having enough to eat or going hungry at the end of each month.**

¹ Farrell.

These hidden costs are not acknowledged by proponents of EVV, who seem ignorant to the realities of living on benefits such as Medicaid. When deciding whether to have enough to eat, or to instead pay for a landline to meet EVV requirements, many will opt to spend their dollars on food, resulting in a loss of their personal care services due to “non-compliance” with EVV. This opens yet another avenue toward ***unwanted, unnecessary and costly institutionalization.***

THE FRAUD MYTH

NCIL opposed the passage of Section 207 H.R. 2646 mandating EVV for Personal Care and Consumer-Directed Services and contends that the stated rationale of significant consumer fraud as the basis for EVV is without merit and discriminatory. The legislative history of the Cures Act shows little or no supporting evidence of widespread or even minimal fraud among individual Medicaid consumers or individual providers.

It can often take more than one year to establish Medicaid eligibility. Personal care and CDS consumers are extensively vetted to establish the presence of severe disability and financial need. ***Comprehensive medical history***, documentation, testing and semi-annual renewals are required ***to verify the presence of serious and multiple disabilities which will likely last for life***, and which are serious enough to put those individuals in jeopardy of unnecessary institutionalization.

Where identified, ***fraud appears in agency or industry providers. It is extremely rare in Consumer-Directed Services.*** Negative stereotypes that individuals with disabilities who rely on benefits programs are malingerers is still prevalent in our society, when nothing could be further from the truth. The assertion by some that there is “massive fraud” in personal care services is false and demeaning to both those who rely on and provide these services.

To illustrate, we can look to the incidence of documented fraud in the State of California, which has conducted and made public several years of fraud investigative reporting in their CDS program, known as In-Home Supportive Services (IHSS). These California Department of Social Services statistics are particularly definitive because ***California has more than half of all Medicaid funded CDS consumers and providers in the U.S.***

For example, in Fiscal Year (FY) 2013-14, all counties combined in the state of California convicted only 165 cases of fraud in the IHSS program.² As there were 445,000 consumers and 404,000 providers in the IHSS program, this amounts to ***a fraud rate of 0.04% statewide in the IHSS program.*** The following FY 2014-15 saw a decline in IHSS fraud in California by conviction in just 87 unique cases,³ equating to ***a fraud rate of 0.02% statewide.***

Given that these cases represent more than half of all CDS consumers and providers in the country collectively, it is arguable that ***the presence of fraud in Medicaid CDS in the United States does not even rise to the level of being statistically significant.*** Further, there is nothing in the EVV legislative record to indicate, much less prove, that the elements of EVV would have any impact whatsoever on fraud if it did exist. In any case, the presence of fraud is totally unsubstantiated in the enabling legislation.

These investigations lead NCIL to conclude that the ***real basis for EVV legislation is not fraud, but instead, the coordinated lobbying efforts to advance the interests of technology vendors of EVV systems.***

² California Department of Social Services (CDSS), 2017.

³ Ibid.

Further, the types of issues in claims identified by the federal government as possible fraud or abuse are often administrative errors or inconsistencies in definition of personal care services across states.⁴ **Electronic visit verification requirements will not address these inconsistencies, administrative errors, or identify fraud where it may exist.**

THE HUMAN AND SOCIAL COST OF EVV

The EVV agency model denies the reality that **people with disabilities and seniors bring to the community a variety of talents, goals and interests that is as deep and wide as that of individuals who do not have disabilities.** Countless seniors and people with disabilities who use personal care services including CDS live active and rewarding lives, contributing to all segments of society. **It is imperative that we continue to be able to hire our own individual providers, and to direct personal care services according to our individual needs.**

Under pressure from for-profit technology and care agencies, **EVV undermines the benefits of Personal Care Services and CDS.** If funds are directed under EVV to the agency for-profit model, **our civil rights and freedoms will be further eroded and starved out of existence.**

The burgeoning cost of EVV will rob public coffers of funds that should be more efficiently utilized to fund adequate living wages and benefits for workers. **Numerous studies have shown institutionalization to be many times more costly in Medicaid funds than the cost of independent personal care providers.** Without the availability of personal care service providers, countless individuals with disabilities needlessly end up in nursing homes for life.

For those who are forced to live out their lives in nursing homes, the cost to human dignity, meaningful participation and contribution to community life, is beyond measure.

EVV AS IMPLEMENTED BY STATES

Some states, including Ohio, have already implemented EVV in advance of the deadline, including draconian GPS surveillance of providers and consumers. Federal legislation requires all states to obtain stakeholder input. Stakeholders must include consumers and community advocates. For-profit EVV vendors are not stakeholders.

EVV must verify: the type of service provided; date and time of service; start and end times; location of service; providers and recipients of service. The EVV system must be “minimally burdensome” and not interrupt or change the services provided. States can request deadline waivers by showing a “good faith effort” if they are having implementation or ramp-up challenges.

CMS guidance specifies that **EVV does not require use of GPS. However,** because of the legislative goal of collecting data to address fraud, **some states interpret EVV to require GPS to capture consumer and provider activities. This misunderstanding has caused the most persistent anxiety and widespread fear among consumers and workers about privacy invasions.** Such privacy violations can include: government and/or criminal archiving of personal information; hacking of cell phones and other devices; collection and illegal use of personal data; photo and video capture of bodily functions and personal care activities; recordings or eavesdropping on personal and private conversation; and other concerns.

Despite significant impact on the lives of people with disabilities, EVV policy development and decisions largely exclude input from the wider disability community. Opportunity for stakeholder involvement has been spotty or

⁴ U.S. Government Accountability Office.

absent. ***A 2017 study noted an overrepresentation of influence from groups that are medical or “patient” model; and an underrepresentation of community-based grassroots disability rights advocates.***⁵

This underlines the medical model of EVV, which holds that the main effects of EVV are on agency providers, and not on consumers. ***Consumers are seen as passive “patients” incapable of full autonomy, while the EVV mandate places new burdens on our lives.***

States host “listening sessions” that are often marketed as an opportunity to provide input into the process, but generally do not offer two-way communication capabilities, leaving consumers and independent providers as inactive participants in the process. Many states continue to move forward with EVV implementation without the input of disabled consumers or independent providers.

NCIL PRINCIPLES ON EVV

- EVV threatens decades of advocacy work that created a true Independent Living Model for people with disabilities who wish to live and work in our own communities. ***EVV has no place in Personal Care Services or Consumer-Directed Services***, or in waiver programs that offer CDS-like options. While some states refer to their programs by differing names, CDS programs provide the consumer with: ***choice of service provider; location of service (home or community); scheduling responsibilities; and consumer control. EVV in all forms erodes these rights*** and eliminates consumers’ ability to direct care at their own volition.
- Stakeholder groups must include and empower people with disabilities, independent of providers, to be drivers and experts in ***the development of policies that uphold the freedoms, rights, dignity, privacy, and independence of people with disabilities.***
- ***The federal EVV mandate, not created because of the need to eliminate fraud in Medicaid personal care services, is instead, a massive financial giveaway to technology vendors of EVV systems.***
- ***Global Positioning Systems (GPS) and biometrics are a direct and excessive violation of the privacy and potential safety of individuals living with disabilities.*** Given the growing frequency and size of private data breaches, consumers are or will be required to tolerate additional intrusions and burdens under EVV, just to receive the life-sustaining care on which we rely to live independently and avoid institutionalization. Americans are guaranteed Constitutional protection from these types of privacy intrusions, and ***disabled Americans demand equal protection under the law.***
- ***GPS / biometrics have a chilling effect on the independent provider / personal care assistant network and further shrinks the chronically inadequate pool of available employees.*** Often working at minimum wage, PCAs are reluctant to be geo-located during their work day, to be biometrically identified, or to take a job requiring technology skills without increased compensation and at the risk of providing quality care. Some employees are cautioning consumers they will leave once subjected to EVV. Potential workers are going elsewhere when they learn that GPS or biometrics are required. ***Individuals with disabilities across the country are facing increased provider shortage because states are not prohibited from utilizing GPS and biometric features under EVV.***

⁵ Hwang, et al.

- People with disabilities have a right to transparency and access to any private data that is collected from our lived experiences. ***The burgeoning EVV industry is not forthcoming about the type of data it collects and stores.*** Data compromise and loss prevention plans must include immediate notification of any breaches to consumers and providers. Threats to identity protection and digital privacy should be given the highest accountability priority.
- ***NCIL believes that people with disabilities have the right to control our own destinies.*** If individuals are to make informed decisions, it's imperative that CMS and states create and implement comprehensive outreach and education to consumers and providers about EVV choice options, such as web portals, telephony, mobile apps, etc.

NCIL EVV TASK FORCE GOALS

- Seek and support federal legislation to ***remove EVV from the 21st Century Cures Act.***
- ***Advocate at the federal level*** with key players, including the Centers for Medicare and Medicaid Services (CMS) and Congressional leaders and staff members, to ensure disability rights and needs are heard, taken into consideration and provided priority in guidance documents, legislation and other communications.
- ***Support direct action and/or legislative pursuits*** through education and resource networking.
- ***Build a national grassroots network of advocates*** to create and disseminate educational resources regarding EVV, its impact on disability communities, and how to eliminate and/or advocate for a minimally burdensome EVV system.
- Collaborate with advocacy organizations, such as Stop EVV, to ***build a clearinghouse of EVV information.***
- ***Develop a “minimally burdensome” EVV standard*** while actively pursuing options to reverse EVV compliance requirements. See the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) Consumer Advocates Workgroup report.⁶ See also California Department of Social Services proposed EVV framework.⁷ Any standard developed must include EVV systems without GPS; offer delayed reporting; and availability of EVV systems that focus on consumer choice.
- ***Support legal action by advocacy communities*** as appropriate where EVV impacts the ability of individuals to continue ***to live independently*** in their own homes and/or move freely throughout the community.
- ***Support legal action by advocacy communities*** as appropriate where EVV implementation infringes upon consumers' ***rights to privacy or data protection.***

⁶ Consumer Directed Personal Assistance Association of New York State (CDPAANYS).

⁷ California Department of Social Services (CDSS), 2018.

CONCLUSION

EVV threatens to violate the privacy and individual pursuit of liberty for people with disabilities who are federally mandated to comply. ***EVV threatens the independent living movement and erodes Consumer-Directed Service*** rights and responsibilities of consumers as sole employers. EVV was a late addition to the 21st Century Cures Act with serious underrepresentation of the disability community input throughout the policy process.

For these reasons, ***NCIL opposes EVV and is actively pursuing options to reverse compliance requirements.*** While this mandate remains, NCIL invites other advocacy groups and the disability community at-large to unite in the preservation of the rights to live, work, and play in the community free from excessive monitoring and invasions of privacy.

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