



Center for Public Representation

NASDDDS

# **Federal Advocacy and Policy Updates: What's New for HCBS and Self-Direction**

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# What Are the Goals for our HCBS System?

- Support people with disabilities to **have lives like people without disabilities**
- Provide opportunities for **true integration, independence, choice, and self-determination** in all aspects of life – where people live, how they spend their days, and real community membership
- Ensure **quality services** that meet people's needs and help them achieve goals they have identified through real person-centered planning

**POLICIES THAT SUPPORT SELF-DIRECTION CAN HELP  
ADVANCE THESE GOALS!**

# **Update on Federal Policies Impacting HCBS & Self-Direction**

- **Electronic Visit Verification**
  - Participant concerns and opportunities for impact
  - State perspectives on opportunities and challenges
- **Home and Community Based Settings Rule**
  - Opportunities for more individualized and integrated services
  - Status of state implementation
- **Employment of People with Disabilities**
  - Legislative and regulatory opportunities and challenges

# **Electronic Visit Verification (EVV)**

# What is EVV?

- Congress passed the 21<sup>st</sup> Century Cures Act in December 2016 requiring states to implement Electronic Visit Verification (EVV) systems
- The EVV section in the Cures Act was supposed to reduce Medicaid fraud, as well as improve the accuracy and quality of service delivery

# What is EVV?

- The law requires states to use an EVV system to verify
  - the type of service provided
  - people receiving and providing the service
  - date
  - location
  - beginning and end time of a service

# How Does it Work?

- Generally, EVV relies on a telephone or web-based device to electronically verify information.
- Options for EVV include telephone timekeeping with caller-ID, web or phone-based applications using Global Positioning System (GPS), or a one-time password generator or other device.
- States have some flexibility in designing the required system.

# What Services are Covered by EVV?

- Cures Act says EVV applies to Medicaid-funded **personal care and home health services “requiring an in-home visit”**
- CMS has interpreted to mean any assistance with **activities of daily living** (bathing, grooming, eating) **or instrumental activities of daily living** (meal preparation, medication management, money management, shopping) **provided in any part in the home**
  - VERY BROAD application - EVV will impact all people with disabilities receiving any type of Medicaid-funded in-home service



# Covered Services (cont'd)

- EVV applies to in-home services provided through HCBS waivers, state plan personal care services, respite, etc.
  - The specific name of the Medicaid service provided in the home does not matter
- States are not required to use EVV for certain services:
  - Services in institutions, in congregate residential settings where 24-hour service is available, and in the Program of All-Inclusive Care for the Elderly (PACE) program
  - But states can *choose* to require EVV for these services

# What is Required for EVV?

- States must have in place EVV systems for certain Medicaid-funded services provided in a consumer's home or will lose some federal Medicaid funding (called federal medical assistance percentage or FMAP)
  - For personal care services by **Jan. 1, 2020**
    - Note that in 2019, Congress passed a bill extending the original deadline of Jan. 1, 2019 by one year
  - For home health care services by **Jan. 1, 2023**

# What is Required for EVV? (cont'd)

- States can apply to get an extra year to implement EVV through a **Good Faith Effort Extension** if they can show:
  - Action taken to carry out EVV requirement
  - Unavoidable system delays/barriers
  - State applications to CMS can be submitted beginning in **July 2019**
  - Good faith guidance is expected soon

# What is Required for EVV? (cont'd)

- Cures Act says states EVV systems must be “minimally burdensome”
- Also requires states must seek stakeholder input in designing their EVV systems

# Why Should You Care?

- Supporters believe that real-time information from EVV will improve billing accuracy, quality of service delivery, and reduce fraud, waste, and abuse in the Medicaid system
  - For example, they have said it will allow providers to know when a service provider doesn't arrive, and the consumer is left without help
- Many people with disabilities and disability organizations worry that EVV will limit autonomy, independence and privacy

# Concerns with EVV – Privacy

- Serious concerns about **invasion of privacy**
  - Tracking of the location of people receiving services (and sharing with the gov't) in their home and potentially throughout the community
  - Most serious concerns with GPS, use of biometrics, cameras, microphones, etc.
- Intrusion of being tracked from location to location throughout daily life in the community

# Concerns with EVV – Privacy

- CMS has clarified that states are not *required* to include GPS in their EVV systems, but states *may* use GPS if they wish
- States are also not required to track each location as a person moves through the community, just the location at which an in-home service starts or stops. But States may use EVV to track locations beyond where it is required.
- Advocates have raised privacy concerns about GPS and other technology that some states already use

# Concerns with EVV – Privacy

- CMS makes clear that “states may choose to require more information” and “have a good deal of discretion in selecting EVV systems”
  - States can chose to track and record more than the basic requirements
  - It will be hard for provider agencies to create different timekeeping systems for services covered by EVV and those not. This creates worries that EVV will impact the privacy and civil rights of people with disabilities, their family members, and service providers.



# Concerns with EVV – Privacy

- Data security and protection
  - The Cures Act requires EVV systems to meet existing Health Insurance Portability and Accountability Act (HIPAA) requirements
    - What EVV info is covered under HIPAA? For example – is location considered part of “health information”? And even where information is covered under HIPAA, there are access exceptions for law enforcement agencies and many state agencies. Also, though HIPAA creates penalties when information is inappropriately released, that doesn’t get rid of all breaches.
  - How will the state’s EVV system safeguard the privacy of workers and people receiving services?

# Concerns with EVV – Community Integration

- Limits on **independence and community integration**
- Could decrease participation in community activities
  - For example, if an EVV system is physically located in a service recipient's home (like a landline phone or a device installed in the home). People with disabilities may feel trapped at home.
- EVV could be burdensome and time-consuming and interference with daily routines
- Concern with loss of services because providers leave the field

# Concerns with EVV – Community Integration

- **Loss of services**
  - The expense of EVV equipment could create a disincentive for providers to serve Medicaid participants
  - A difficult or expensive system could make the shortage of home care workers worse

# Concerns with EVV – Self-Direction

- Negative impacts on **consumer self-direction**
  - Impact on the consumer control and flexibility of consumer direction
  - It could disrupt routines, with consumers and service providers potentially having to put aside other more immediate tasks or activities to comply with EVV
  - A consumer-directed EVV system must be able to make last-minute changes, including options beyond a few pre-scheduled locations, and allow verification of multiple service delivery locations in a single visit.

# Concerns with EVV – Practical Challenges

- States will need EVV in rural areas with limited or no internet access or cell phone reception, or where the consumer does not have a landline.
- EVV must work with existing Medicaid state data systems, including the systems used for consumer-direction.
- The system must be accessible, including for people with visual, hearing or physical accommodation needs.
- It should be user-friendly
- The system should not have long payment delays when mistakes happen.

# Concerns with EVV – Practical Challenges

- **Outreach and Training**
  - CMS guidance recommends, but doesn't require, that people receiving services, and their families, be educated about EVV and trained on how to use the EVV system.
  - People with disabilities must understand EVV and be trained in how to use their state's EVV system, what to do if they have problems, and how to seek any necessary accommodations.

# Guidance and Legislation Regarding EVV

- Cures Act directed CMS to issue implementation guidance by Jan 2018. Guidance finally came out May 16, 2018
- Many states delayed planning EVV systems and engaging stakeholders (as required by the statute)
  - Serious concerns by states, advocates, and people receiving services that there is not enough time to address the serious concerns w/ EVV
- EVV delay bill passed in late July 2018. It delays required implementation by a year and makes recommendations for stakeholder input

# Guidance and Legislation Regarding EVV (cont'd)

- The delay gave advocates more time to work with Congress, CMS, and states to address the significant concerns with EVV and its potential impact on people with disabilities
- But, it **does not repeal or change the underlying EVV requirements** in the Cures Act or CMS guidance
- CMS has been engaging in a “working group” with representation from states and advocates to identify concerns and solutions



# Requirements for Stakeholder Input

- Stakeholder input requirements
  - CMS guidance noted that the law **requires stakeholder input** and should include outreach to (among others) individuals receiving services and their families
  - The 2018 delay bill encourages CMS to seek stakeholder input and have ongoing communication with stakeholders including beneficiaries, family caregivers, and people who provide personal care services or home health care services

# What You Can Do

- Get involved in the stakeholder input process in your state
  - States MUST engage stakeholders and now there is more time to do it in a thoughtful way
    - Advocate that service recipients and their families be part of the planning
  - Encourage practices that minimize privacy intrusions, do not limit community participation, and accommodate self-direction
  - Participate in public forums
  - Advocate for training and outreach to service recipients and their families (not just providers)

# What You Can Do (cont'd)

- Possible questions to raise:
  - What kind of privacy protections are in place, particularly for web-based services? How will your state's planned EVV system address security issues and safeguard the privacy of users?
  - Is the proposed system accessible?
  - What kind of training will be available for people receiving services?
  - How will the EVV system take into account the unique nature of self-direction, including the needed flexibility in scheduling workers?

# What You Can Do (cont'd)

- Applied Self Direction has developed a “Blueprint” for issues to systems to consider in implementing EVV in self-direction – you can use this to help you comment
  - <http://www.appliedselfdirection.com/sites/default/files/EVV%20Blueprint%20for%20Self-Direction.pdf>
- Other issues to keep in mind:
  - Consumers & direct-care workers shouldn't have to bear the direct and indirect costs of EVV, including costs for EVV equipment
  - States can not assume that all consumers or direct-care workers have or can afford to purchase a cell phone, cellular data or internet service plan, or a landline

# Medicaid HCBS Settings Rule

# What is the HCBS Settings Rule?

- Federal rule issued in 2014 by the Centers for Medicare & Medicaid Services (CMS) to clearly define the requirements for all settings that receive Medicaid funding as Home and Community-Based Services (HCBS) settings
  - Applies to all HCBS funding streams (1915c waivers, 1915i state plan HCBS, 1915k community choice, and HCBS in 1115s)
  - Applies to all types of HCBS settings, both residential and day service settings

# Goal and Scope of HCBS Rule

- To “ensure that individuals receiving services through HCBS programs have **full access to the benefits of community living**”
- To “further expand the opportunities for meaningful community integration in support of the **goals of the ADA and the Supreme Court decision in *Olmstead***”

# Development of the HCBS Settings Rule

- Started because concerns about segregation, isolation and institutional practices in “community” settings funded by HCBS
  - HCBS is meant to be an alternative to institutions
- Changing disability service models and desires by people with disabilities and their families leading to a need for more clarity about standards
  - Including self-direction
- ADA and *Olmstead* enforcement challenging settings that segregated people with disabilities yet were funded by HCBS



# Opportunities Created by the HCBS Settings Rule

- The HCBS settings rule provides an opportunity to:
  - Expand the capacity of more integrated and individualized services
  - Move state systems away from outdated, segregated service models
  - Ensure basic rights in all HCBS settings
  - Expand control by HCBS participants, including opportunities for self-direction

# Characteristics of Home and Community Based Settings

An outcome oriented definition that focuses on the nature and quality of individuals' experiences, including that the setting:

1. Is **integrated in and supports access to the greater community**;
2. Provides **opportunities to seek employment and work in competitive integrated settings**, engage in community life, and control personal resources
3. Is selected by the individual from among setting options, **including non-disability specific settings**

# HCBS Setting Characteristics (cont'd)

4. Ensures the individual receives services in the community to the **same degree of access** as individuals not receiving Medicaid HCBS
5. Ensures an individual's rights of **privacy, dignity, respect, and freedom from coercion and restraint**
6. Optimizes **individual initiative, autonomy, and independence** in making life choices
7. Facilitates **individual choice** regarding services and supports, and who provides them

Additional requirements for provider-owned residential settings

# States Must Assess and Categorize All Settings

- 1) Meets all requirements of the rules (or can with modifications)
- 2) Can never meet requirements of the rules because it is an institution (nursing home, ICF, hospital or IMD)
- 3) Is presumed institutional
  - Setting is unallowable unless a state can prove through a “heightened scrutiny” process that the setting overcomes the institutional presumption and meets the rule’s requirements

# Presumptively Institutional Settings

- Settings in facilities providing inpatient institutional services
- Settings on the grounds of, or adjacent to, a public institution
- Settings that **have the effect of isolating HCBS recipients from the broader community.**

# State Transition Plan Process

- States must submit statewide transition plans (STP) to CMS
  - Final plans approved by March 2019
  - States have until March 2022 to fully implement their STP
- **Step 1: Initial STP approval**
  - Approval of the state's systemic assessment of all relevant rules, regulations, licensing, etc. for compliance with & support of the rule, with needed changes suggested.
  - Description of the process for site assessment, validation and identifying presumptively institutional settings

# State Plan Approval Steps (cont'd)

- **Step 2: Final STP approval**
  - Approves the settings assessment process, including methodology, validation and compliance determinations for specific sites
  - Approves the process for identifying presumptively institutional settings and for determining whether the presumption is overcome
  - Includes detail on remediation process, ongoing monitoring, and relocation process for individuals who move to new settings

# State Plan Approval Steps (cont'd)

- **Step 3: Heightened scrutiny review process**
  - State identifies and evaluates settings presumed institutional
  - State submits to CMS for review those settings it believes overcome the presumption after public comment
  - Public can also identify settings directly to CMS if state does not respond
  - Can occur at any point



# STP Public Input

- Public input on STPs is required – minimum 30-day public notice and comment period before plans (both initial and then final) are submitted to CMS
- The State must consider and modify the plan to account for public comment
- States are encouraged to improve transparency, outreach and create ongoing opportunities for stakeholder input
- **THIS IS A CRITICAL OPPORTUNITY FOR ENGAGEMENT**
  - The state must get feedback from the public

# Status of State Plan Approvals

- 44 states have received initial approval
- States that have received initial approval got a letter describing the additional steps it must take to get final approval
  - This is an important document for stakeholders to use for comment and input
- 13 states have also received final approval:
  - AK, AR, DE, DC, ID, KY, MN, ND, OK, OR, TN, WA, & WY

\* As of March 31, 2019

# Positive State Examples

- Some states are moving towards more individualized and integrated services through the HCBS transition process:
  - Moving from facility-based to all community-based day services
  - Transforming models for facility-based day habilitation
  - Phasing out sheltered workshops
  - Setting size limits on residential settings
  - Requiring housing subsidies to be used in scattered site apartments
  - Expanding the capacity of competitive, integrated employment
  - Funding help bring providers into compliance through model changes
  - Aligning with *Olmstead* activities

# Implications for Self-Direction

- The Rule requires people be given more autonomy and control over decisions in their own lives
  - Self-direction can help further these goals
- The Rule requires people have a choice of receiving services in “non-disability specific-settings”
  - Often times self-direction allows people to receive services in their own home or in mainstream community settings
- The Rule requires people to have a choice of providers
  - This is an opportunity to push for more self-direction in your state

# What You Can Do

- Continue to learn about the HCBS Settings Rule and why it is important; help educate other people with disabilities and families
- Ensure that self-direction is a part of the conversation and considered in the STP
- Keep updated on your state's implementation
- Submit comments when your state's plan is out for public comment

# **Employment of People with Disabilities**

# Employment is Key To Community Inclusion

- Competitive integrated employment helps people with disabilities:
  - Access the greater community;
  - Build relationships with people without disabilities;
  - Develop new skills and self-esteem;
  - Earn money to get out of poverty;
  - Use less Medicaid services; and
  - Have meaningful ways to spend their days

# Disability Employment and Self-Direction

- Most people with disabilities say they want to work, yet the majority are still in congregate day programs
- Federal policies to increase opportunities for competitive integrated employment mean more people will need individualized employment supports
  - Self-directed support can help fill this important support need



# Community Participation and Self-Direction

## Community Participation:

- Is an outcome, not a service
- Is individualized, allows flexibility and consumer choice, and leads to community membership and contribution
- Relies on community partnerships and leverages natural supports
- Includes any activities that people with and without disabilities do in their spare time: volunteer work; postsecondary, adult, or continuing education; accessing community facilities such as the library, gym, or recreation center;

# Community Participation and Employment

- *Leads to employment* through career exploration & networking
- *Wraps around employment* to fill gaps in time, experience, social connection

# Time of Opportunities and Challenges Around Disability Employment

- Protect and advance recent progress:
  - Passage of WIOA, HCBS Settings Rule, Employment First initiatives in states, etc.
- Advocate against efforts to roll-back key federal statutes, regulations and guidance that advance Competitive Integrated Employment (CIE)

# Workforce Innovation and Opportunity Act (WIOA)

- Prioritizes and increases employment of people with disabilities in **competitive integrated employment (CIE)**
  - Defines CIE as work at or above minimum wage, with wages & benefits comparable to, & fully integrated with, co-workers w/o disabilities
- Clear statutory goal to **limit significantly the use of 14(c) sub-minimum wage**
  - Anyone under 24 must explore and try CIE before they can be placed in a sub-minimum wage setting; prohibits schools from contracting with sub-minimum wage providers; and requires at least annual engagement of anyone in sub-minimum wage setting
- Statute recognizes the importance of and requires **cross-agency collaboration** (including VR, Medicaid and IDD)

# Challenges: WIOA's CIE Definition

- Regulations issued in 2016 by the Dept. of Education define competitive integrated employment in detail
- Push back in the new Administration on WIOA's CIE regs:
  - Focus of “integration” on interaction with co-workers
  - Whether AbilityOne jobs are CIE -- longstanding VR policy to evaluate individual settings but guidance acknowledges many A1 programs may not meet the definition
  - “Typically in the community,” meaning not a job just created for people with disabilities

# WIOA's CIE Regulations: What You Can Do

- We expect that a Notice of Proposed Rulemaking (NRPM) will be out imminently
  - NPRMs must be put out for public comment and the agency must respond to the comments when finalizing a rule
  - IT WILL BE CRITICAL FOR PEOPLE WHO SUPPORT COMPETITIVE INTEGRATED EMPLOYMENT TO COMMENT
- A coalition of national advocacy organizations will be providing information about the NPRM and how to comment once the rule is out.
  - Resources will be at <https://integratedemploymentnow.org/>

# Opportunities: Sub-minimum Wage & CIE Legislation

- **Transformation to Competitive Employment (H.R. 873/S. 260)**
  - First bill to combine funding for capacity building of CIE with a phase out of sub-minimum wage under Section 14(c)
  - Would create a grant program to states (and to providers if in states that don't get a grant) for provider transformation
  - 6 year phase out of Section 14(c); immediate prohibition on new certificates
  - Disability community is working to educate members of Congress and seek co-sponsors

# Sub-minimum Wage & CIE Legislation (cont'd)

- **Raise the Wage Act (S. 150/H.R. 582)**
  - Bill to raise the federal minimum wage (to \$15/hour)
  - Includes people with disabilities; has a 6 year phase out of sub-minimum wage under Section 14(c)
  - Disability community has supported inclusion of 14(c) phase out
- **Other 14c/CIE bills in the last Congress**
  - TIME Act, a standalone bill phasing out Section 14(c)
  - Transitions to Independence Act
    - Funding for states to transition segregated day settings to integrated day settings including CIE



# Resources

## Electronic Visit Verification

- CMS EVV page: <https://www.medicaid.gov/medicaid/hcbs/guidance/electronic-visit-verification/index.html>
- Applied Self-Direction EVV Resources: <http://www.appliedselfdirection.com/evv-resources>
- CPR EVV page: <https://medicaid.publicrep.org/feature/electronic-visit-verification-evv/>

# Resources (cont'd)

## HCBS Settings Rule

- CMS website: [www.medicaid.gov/hcbs](http://www.medicaid.gov/hcbs)
- HCBS Advocacy coalition: [www.hcbsadvocacy.org](http://www.hcbsadvocacy.org)

## Disability Employment

- Coalition to Advance Competitive Integrated Employment: [www.integratedemploymentnow.org](http://www.integratedemploymentnow.org)
- Collaboration to Promote Self Determination: [www.thecpsd.org](http://www.thecpsd.org)

Questions?