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States select one of the following four choices regarding the provision of waiver services by relatives and/or legal guardians in Appendix C-2-e:

1. **No Payments.** The state does not make payment to relatives and/or legal guardians for the provision of any waiver services.
2. **Yes, but Specific Circumstances.** The state may choose to pay relatives and/or legal guardians for the provision of certain waiver services only in circumstances specified by the state.
3. **Yes, and Specific Circumstances Do Not Apply.** The state may pay relatives and/or legal guardians to provide waiver services, and there are no specific circumstances (if the relative otherwise meets qualifications to provide the service).
4. **Other Policy.** The state may choose another payment policy if not accommodated by the earlier response choices (e.g., if the state wants to restrict payment to specific circumstances for certain types of relatives but not for other types of relatives).



# 1915(c) Waiver Application Appendix C-2-e, Continued

## If state responds “yes” to the provision of services by relatives and/or legal guardians and there are specific circumstances, the state specifies:

- The **types of relatives and/or legal guardians** that may be paid to provide waiver services.
- The **types of waiver services** for which payment may be made to relatives and/or legal guardians.
- The **specific circumstances** when payment may be made to relatives and/or legal guardians **and** the method used to determine when the circumstances apply.
- The **safeguards for ensuring that services are in the best interest of the waiver participant**, especially when legal guardians make decisions on behalf of participant in selecting waiver providers.
- The **procedures established to ensure payment is only made for services rendered**.

## If “yes” and there are *no* specific circumstances, the state specifies:

- Any **limitations on the types of relatives and/or legal guardians** who may provide services.
- The **waiver services** that a relative and/or legal guardian may provide.
- The **procedures established to ensure payment is only made for the services rendered**.

# **Federal Guidance on Legally Responsible Individuals that Provide Waiver Services**

# Federal Guidance on LRIs

## Federal guidance that governs LRIs that provide waiver services:

- The State Medicaid Manual, section 4442.3, B. 1 further explains that Federal Financial Participation is not available for PCS provided to recipients by “legally responsible relatives” (individuals).
- However, section 4442.3 B. 2 allows payment to qualified LRIs for the provision of “extraordinary” services.
- LRIs may provide services when the type of care is considered **“extraordinary.”**

# The 1915(c) HCBS Technical Guide, on LRIs

## **CMS provides additional guidance related to the definitions of LRIs and extraordinary care in the 1915(c) Technical Guide**

- The Technical Guide follows the application document format for a 1915(c) waiver and provides guidance relative to each application appendix (or section).
- Appendix C of the Technical Guide outlines policy expectations for the development of participant services.
  - Appendix C-2 discusses General Services Specifications that apply to multiple services or service types.
  - Item C-2-d provides federal guidance related to LRIs providing PCS.

# 1915(c) Waiver Application Appendix C-2-d

## The state responds to Appendix C-2-d of the waiver application:

Regarding the provision of PCS or similar services by LRIs, states select one:

- **No.** The state does not make payment to legally responsible individuals for furnishing personal care or similar services.
- **Yes.** The state makes payment to legally responsible individuals for furnishing personal care or similar services when they are qualified to provide the services.

## If “yes”, the state specifies:

- The legally responsible individuals who may be paid to furnish such services and the services they may provide.
- State policies that specify the circumstances when payment may be authorized for the provision of **extraordinary care** by a legally responsible individual and how the state ensures that the provision of services by a legally responsible individual is in the best interest of the participant.
- The controls that are employed to ensure that payments are made only for services rendered.

# Distinguishing Extraordinary Care from Family Supports

**LRI can provide PCS and closely related supports through an HCBS waiver when care is “extraordinary”.**

- **Extraordinary Care:** The type and amount of care exceeds what an LRI would ordinarily provide, and the service is necessary to assure the health and welfare of the participant and avoid institutionalization. If the state allows LRIs to provide waiver services, it must establish criteria that defines extraordinary care.
- **Ordinary Care:** Care that is the typical responsibility of a LRI ordinarily provided to individuals, with or without a disability or chronic illness.

**Extraordinary Care is a qualifying waiver service, Ordinary Care is not.**

# CMS Review Criteria for All Family Caregivers

## **States must specify the following when authorizing the provision of waiver services by relatives, legal guardians, and LRIs:**

- The types of family caregivers to whom payment may be made.
- The waiver services for which payment may be made to family caregivers.
- Limitations (if any) on the amount of services that may be furnished by a family caregiver.
- The procedures that are employed to ensure that:
  - payment is made only for services rendered, and
  - services are furnished in the best interest of the individual.

## **For LRIs only:**

- The method of determining that services provided by LRIs is “extraordinary care” exceeding the ordinary care that would be provided to a person without a disability of the same age.

## **For legal guardians and/or relatives only:**

- When relatives or legal guardians are paid to furnish waiver services only in specific circumstances, the state must identify the specific circumstances and method of determining when such circumstances apply.

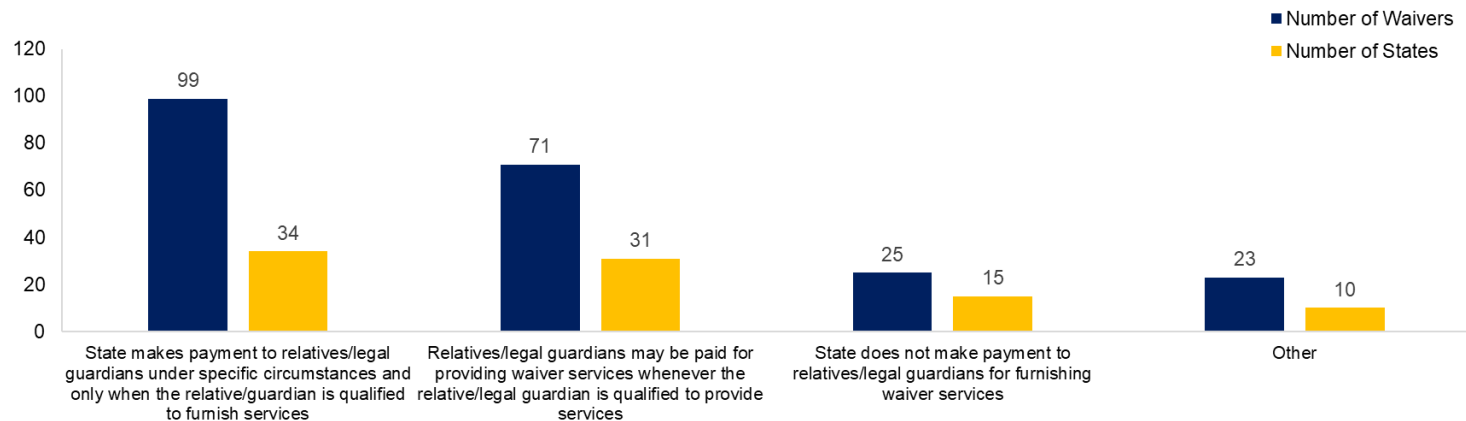
# How States Currently Use Relatives and/or Legal Guardians to Deliver PCS



# Number of States that Use Relatives and/or Legal Guardians to Deliver PCS

## Overview of States that allow Relatives and/or Legal Guardians to provide services:

- Of 253 HCBS waivers active as of June 30, 2020:
  - 218 waivers across 46 states provided PCS.
  - 193 waivers allow for relatives and/or legal guardians to provide waiver services



# States Define Who is a Relative and/or Legal Guardian

## States may define who is considered a relative and/or legal guardian. Some examples include:

- “A relative is any of the following by blood, marriage or adoption who have not been assigned as legal guardian for the participant: a spouse, a parent of an adult, a stepparent of an adult child, grandparent, brother, sister, aunt, uncle, niece, nephew, adult child or stepchild of a participant or adult grandchild of a participant.”
- “For purposes of this waiver, a relative is defined as a natural or adopted parent, step parent, or sibling who is not also a legal guarding or legally responsible person.”
- “A legal guardian is a person who has legal standing to make decisions on behalf of a minor or adult (e.g., a guardian who has been appointed by the court). The definition of a legal guardian does not apply to agency providers, but does apply to the person actually rendering service to a participant.”
- “A legal guardian is defined as an individual or entity who has obtained a valid court order stating that the individual is the legal guardian of the person of the participant pursuant to State Code”

# States Define Specific Circumstances for Relatives and/or Legal Guardians

**States may choose to only allow relatives and/or legal guardians to render services in specific circumstances. State examples of specific circumstances include:**

- “The state makes payments to relatives but not to legal guardians, spouses or legal representatives for furnishing waiver services when the relative is qualified and either the relative is employed by a provider agency or the participant is self-directing his\her services.”
- “The Department does not pay legally liable relatives or relatives of Conservators of Person (COP) or Conservators of Estate (COE) to provide care.”
- “Family members living under the same roof as the individual being served may not provide services unless there is objective written documentation completed by the case manager as to why there are no other providers available to provide services.”

# States Define Fiscal Policies and Safeguards

**States must specify how payments are made for services rendered. Examples of state approaches to oversight include:**

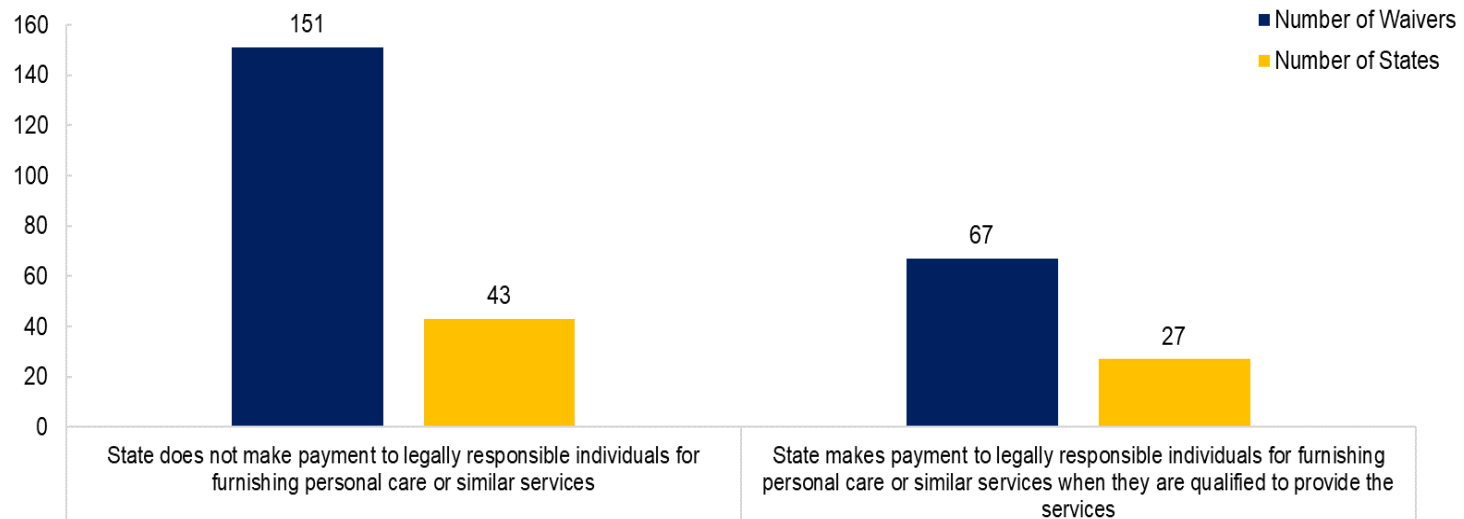
- “The participant or their conservator must **sign timesheets** to confirm the dates and times services were performed. The **fiscal intermediary reviews timesheets** for accuracy and whether they match the allocation in the service plan. Any discrepancy results in the notification to the Department of Social Services prior to the issuance of payment.”
- “On an annual basis a **sampling of waiver participants’ records will be reviewed** by [the state’s developmental services department] to ensure verification that payments are only made for services rendered.”

# How States Currently Use Legally Responsible Individuals (LRIs) to Deliver PCS

# Number of States that Use LRIs to Deliver PCS

## Overview of states that allow LRIs to provide services:

- Of 253 HCBS waivers active as of June 30, 2020:
  - 218 waivers across 46 states provided PCS.
  - 67 waivers across 27 states\* allowed LRIs to provide PCS as a waiver service.



\*Note: States may have some waivers that allow legally responsible individuals to furnish PCS and other waivers that do not. State counts are not mutually exclusive and therefore do not sum to 46 states.

# States Can Define LRIs

## Define a Legally Responsible Individual:

- Identify state law, regulation, or policy that may inform the definition of an LRI.
- Assure the definition provided in the waiver application does not conflict with any other state definitions.
  - If there are conflicts with other state definitions, clearly explain the differences.
- Determine if the definition is specific enough to reduce misinterpretation.

# States Define Who is an LRI

**LRIs are frequently the parent of a minor child, or a spouse; however, CMS asks states to define LRIs. State examples defining *legally responsible individuals include:***

- “May be a **parent, stepparent, foster parent** of the participant, a spouse, or legal guardian of the participant **ONLY** under the following circumstances: there are no other available providers”.
- “A legally responsible individual is any person who has a duty under State law to care for another person and typically includes: (a) **the parent (biological, adoptive, foster, or step)** or guardian of a minor child or (b) **a spouse** of a waiver participant.”
  - The services must be extraordinary, exceeding the range of activities that a LRI would ordinarily provide in the household on behalf of a person without a disability of the same age



# States Establish Criteria for Extraordinary Care Provided by LRIs

**For LRIs, states develop criteria for extraordinary care that explains how the care exceeds that of a person without a disability or chronic condition of the same age:**

- Define ordinary care that the state considers customary for LRIs to provide to an individual who does not have a disability for all age ranges served by the waiver.
- Develop criteria for extraordinary care that contrasts with the definition for ordinary care.
  - Specify elements of a daily routine or other activities of daily living that qualify as extraordinary care, such as specialized care required which exceeds care ordinarily provided to participants of similar age without a disability
  - The requirement of specific qualifications to address participant needs, such as training or certifications, that would elevate care to extraordinary status.
- Determine other criteria specific to a waiver population or other challenges within the state (access to a qualified provider, for example).

# States Define Extraordinary Care

## **Services rendered by an LRI must be deemed extraordinary care. States examples of extraordinary care when PCS is rendered by LRIs:**

- “When [a PCS waiver service] is provided by a relative to a participant who is younger than 18 years of age, this service may only be used to provide extraordinary care. A relative is responsible to meet the needs of a participant who is younger than 18 years of age, including the need for assistance and supervision typically required for children at various stages of growth and development.”
- “Extraordinary care is described as providing general and specialized supports such as Hoyer lift/mechanized bath chairs, indwelling catheter, medical gases, prosthetic orthotics, and suppository/bowel program.”

# States Define Fiscal Policies & Safeguards

## States must specify how payments are made for services rendered. State examples of oversight include:

- "The [state agency] will conduct a **randomly selected, statistically valid sample of services** provided by legally responsible persons to ensure payment is made only for services rendered and the services rendered are in the best interest of the participant."
- "The [Medicaid information system] **compares the submitted claims to the services authorized in the plan of care prior to payment**. The claim will not be paid if there is a discrepancy between the amount billed and the rate of pay authorized in the plan. MCOs must ensure payments are made only for services rendered through the development and implementation of a contractually required program integrity plan. The [state agency] maintains oversight of the MCO program integrity plans and responsibility for overall quality monitoring and oversight."
- One state's waiver reports **cross referencing** the personal care assistant's billing with IRS information to verify that the PCA was not employed at another setting at the time they recorded providing PCS.

# State Policy Considerations for the Use of Family Caregivers in an HCBS Waiver

# Policy Considerations for Family Caregivers

## **States have the flexibility to develop policy specific to family caregivers in the following areas:**

- Whether the state will allow payment to family caregivers.
- Identifying the services family caregivers can provide.
- Defining limitations on the amount of care or services for which payment may be made.
- Determining whether provision of care by the family caregiver is in the best interest of the participant.
- Establishing procedures to ensure payment is made only for services rendered.

## **For LRIs specifically, states have the flexibility to develop policy that:**

- Defines an LRI.
- Creates criteria for extraordinary care that explains how the care exceeds that of a person without a disability or chronic condition of the same age.

# Why and How States Currently Use Family Caregivers to Deliver PCS

- The challenges of rural or remote locations, workforce limitations, and family and recipient needs/preferences were frequently cited as reasons states allow family caregivers for personal care or similar services.
- When the waiver program allows payment to family caregivers for furnishing personal care or similar services:
  - The family caregiver must meet all provider qualifications.
  - Services rendered must be equivalent to services supplied by other types of providers.
  - There must be procedures in place:
    - To verify that services for which payment is made have been rendered in accordance with the participant's service plan.
    - To ensure services rendered meet the conditions that the state has established for the provision of such services.

# Reasons States May Choose Family Caregivers

## As states consider the use of family caregivers for 1915(c) waiver PCS, they should:

- Solicit stakeholder input on participant preferences and needs in the state.
- Assess the provider network in the state.
- Identify if the provider network can deliver services that:
  - Reach geographic areas in which eligible recipients reside.
  - Adhere to cultural considerations such as religious beliefs and practices, dietary preferences, language, and customs for the provision of care.
  - Provide services without disruption due to weather, terrain, or distance from a provider location.
  - Follow person centered service plans, as developed by the participant and their supports.

# States Determine Applicable Services Rendered by Family Caregivers

## Identify the services family caregivers can provide:

- Determine the specific PCS and/or closely related services, if any, that a family caregiver may provide.
- Provide and describe the qualifications required to deliver those services in a format easily accessible and a manner easily understood by one unfamiliar with Medicaid policy or medical terminology.
  - Examples of accessible formats include case manager interactions, website publications, etc.



# States Confirm Use of Family Caregivers is in the Best Interest of the Participant

## Determine how the provision of care by the family caregiver is in the best interest of the participant.

- Develop criteria that define the best interests of a participant when a family caregiver may provide services:
  - Use of a family caregiver does not create a conflict of interest.
    - For example, a state may consider safeguards or restrictions for family members who assist with or are responsible for budget management and service planning.
  - Concerns regarding community integration/isolation are addressed.
    - State service plan monitoring should include review activities that verify that participant services and supports are rendered in the type, scope, frequency, and amount identified in the participant's service plan and that participant needs and social and community integration goals are addressed.
  - Safeguards related to abuse, neglect, and exploitation are in place.
- Additional considerations for when a family caregiver may provide services:
  - Respite is required when the family caregiver is temporarily unavailable or no longer able to provide care to the participant.
  - Respite may also be provided for routine, regularly scheduled absences to help prevent caregiver burnout.

# States Set Limits on Use of Family Caregivers

**Define limitations on the PCS for which payment may be made when there are limitations for family caregivers, such as:**

- The number of hours per week or month a family caregiver can provide care.
- Specific circumstances, such as inclement weather, or as in the case of an emergency or disaster, the inability to bring providers into the home, that trigger when a family caregiver can provide care.
- Settings in which a family caregiver can provide care.

# States Establish Payment Safeguards

## **Develop procedures to confirm payment is made only for services rendered.**

- Determine methods to document time worked, such as a daily time and activity log or use of electronic visit verification (EVV).
- Verify service delivery does not exceed limits, if any, placed on family caregivers.
- Establish methods to effectively monitor the family caregiver service provision.
  - For example, case managers can conduct in-home assessments to verify that services are being rendered.
- Evaluate options for integrating family caregiver service delivery verification with other 1915(c) waiver service post-payment review activities.

# Electronic Visit Verification

**The 21<sup>st</sup> Century Cures Act requires that states implement EVV for all Medicaid PCS (and Home Healthcare Services) requiring an in-home visit by a provider.**

- PCS provided by family caregivers who live in the same home with the participant do not require EVV.
- When services are provided by a family caregiver who does not live in the same home as the participant, EVV is required.
- The state may choose to expand beyond the requirements of the 21st Century Cures Act and implement EVV for all family caregivers.
- Potential benefits of EVV include:
  - Decreased reliance on maintaining and retaining paper records due to electronic service records.
  - Automation of service verification, electronic service records, and assurance that payment is based on actual service delivery at recorded check-in and check-out times and locations.
  - Assurance that payment for waiver services is based on assessed participant need as identified on the individual's person-centered service plan.

# States Expanded Role of Family Caregivers During COVID-19 Public Health Emergency (PHE)

## States used Appendix K flexibilities to change how providers deliver waiver services during the COVID-19 PHE.

- Appendix K allows states to change policies related to the operation of 1915(c) waivers to respond to emergencies such as natural disasters, pandemics, or other large-scale events declared as emergencies.
- Some states used Appendix K flexibilities to expand the scope or use of family caregivers that provide waiver services. Examples are:
  - Increased duration of service provision: One state paid relatives/legal guardians for greater than 40-hours per week for services (payment for hours must be within federal overtime guidelines).
  - Accepted substitutions for regular caregivers: One state modified PCS for participants infected with COVID-19, when the regular provider is unable or unwilling to provide services.
  - “In situations when regular staffing for services approved in a support plan cannot be assured, the state may allow providers to hire family caregivers as direct service workers for the following services: Chore, Respite, the following types of Residential Habilitation: Supported Living Services, In Home Supports.”
- Several states also cited safeguards to ensure individuals receive necessary services authorized through the care plan, such as case management monitoring and post payment review of claims paid.

# How States Can Expand Use of Family Caregivers to Deliver PCS

**States may choose to expand the role and scope of family caregivers for emergencies.**

- Federal and state-declared emergencies may create circumstances where family caregivers can enhance the provider network:
  - Inadequate workforce due to transmission (or potential transmission) of a communicable disease, such as COVID-19.
  - Transportation and access issues due to natural disasters such as hurricanes, mud slides, or wildfires.
  - Challenges in identification of available workforce with cultural competencies (such as language skills) due to displacement by the declared emergency.
- CMS requires emergency back-up plans for all waiver participants. States may wish to incorporate how family caregivers can support backup plans in the event of workforce disruptions or emergencies in related documentation.

**More broadly, states may leverage family caregivers into the waiver service delivery model to address non-emergency considerations, such as family schedules, needs and preferences of the participant, and access to care.**

# Use of Family Caregivers During and After the COVID-19 PHE

**As states evaluate disaster relief waivers or Appendix K flexibilities implemented in response to COVID-19, they should carefully consider the use of family caregivers during and after the PHE.**

- States should look at the benefits realized from the use of family caregivers during the PHE.
- States should consider whether extending the waiver or Appendix K policies beyond disaster relief and within normal operations of the state's delivery system would be beneficial.

# American Rescue Plan (ARP) FMAP Increase

- CMS published a letter to State Medicaid Directors with guidance on implementing Section 9817 of the American Rescue Plan Act.
  - Section 9817 provides qualifying states with a temporary 10 percentage point increase to the federal medical assistance percentage (FMAP) for certain Medicaid HCBS expenditures.
  - The letter contains guidance and considerations for states expanding or implementing supports for family caregivers such as reimbursement for PPE expenses and payment as a service provider.
  - The letter also contains guidance for states to assist individuals and caregivers with the scheduling, transportation, education and outreach for the COVID-19 vaccine.



# American Rescue Plan (ARP) FMAP Increase, ctnd.

States must adhere to the following criteria to receive the ARP FMAP increase:

- Additional funding must be used to supplement, not supplant state level HCBS funding.
- The state shall implement one or more activities which enhance, expand, or strengthen HCBS programs.
- Total FMAP is capped at 95% inclusive of the increase available under section 9817.
- States cannot impose stricter eligibility standards, methodologies, or procedures for HCBS programs and services than those in place April 1, 2021.
- States must preserve covered HCBS, including the amount, duration, and scope of services, in effect as of April 1, 2021.
- States must maintain HCBS provider payments at a rate no less than those in place as of April 1, 2021.

# Summary, Q+A, Resources and References

# Benefits of Developing and Documenting Robust State Policies for Family Caregivers Delivering PCS

## When opting for family PCS caregivers:

- **States can leverage family caregivers to meet a variety of program needs.**
  - Needs will range from challenges of public health emergencies, to natural disasters, to workforce limitations, and participant and family needs.
- **States must evaluate and ensure compliance** with documented monitoring and oversight measures.
- **States can reduce administrative burden** by incorporating clearly-defined policies when including relatives, legal guardians, and LRIs as part of the provider pool.

# Summary

- At the state's choice, waiver services, including PCS in 1915(c) HCBS waiver programs may be provided by family caregivers, including LRIs.
- Each state has unique policy considerations when determining whether family caregivers are a viable service delivery method.
- With guidance provided by CMS, states define the terms of the PCS provided by family caregivers.
- Participants and states may benefit from robust policies when LRIs provide PCS.
- With proper safeguards, states can confidently maximize the use of family caregivers in delivering PCS in their waiver programs.

# Questions?

*For further information, contact:*

[HCBS@cms.hhs.gov](mailto:HCBS@cms.hhs.gov)

***Please complete the feedback survey to help inform future trainings. A link to the survey is posted in the chat box.***

# Additional Resources and References

- **Copies of the HCBS Training Series** – Webinars presented during Medicaid Monthly Update calls are located at the link below: <https://www.medicaid.gov/medicaid/hcbs/training/index.html>
- **The 1915(c) Technical Guide to the waiver application** is located here: [https://wms-mmdl.cms.gov/WMS/help/35/Instructions\\_TechnicalGuide\\_V3.6.pdf](https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf)
- The **State Medicaid Director Letter on the American Rescue Plan Act** is located here: <https://www.medicaid.gov/federal-policy-guidance/downloads/smd21003.pdf>

Refer to CMS guidance for additional information regarding **Electronic Visit Verification**:

- [CMCS Informational Bulletin](#) from August 2019.
- [Frequently Asked Questions](#) from May 2018.

Refer to the following for additional information regarding **PCS**:

- [Combating Waste, Fraud, and Abuse in Medicaid's Personal Care Services Program](#) before the House Subcommittee on Energy and Commerce in May 2017.
- [Preventing Medicaid Improper Payments for Personal Care Services](#) from CMS in November 2017.
- [Medicaid Fraud Control Units: Investigation and Prosecution of Fraud and Beneficiary Abuse in Medicaid Personal Care Services](#) from the Health and Human Services Office of Inspector General in December 2017.
- [Electronic Visit Verification Implications for States, Providers, and Medicaid Participants](#) from the National Association of States United for Aging and Disabilities (now ADvancing States) in May 2018.