



DISABILITY RIGHTS  
PENNSYLVANIA



IMAGINE DIFFERENT  
COALITION

January 25, 2023

VIA EMAIL

Daniel Tsai, Deputy Administrator & Director  
Anne Marie Costello, Deputy Director  
Center for Medicaid and CHIP Services  
Centers for Medicare & Medicaid Services  
7500 Security Boulevard  
Baltimore, MD 21244-1850

**RE: PENNSYLVANIA POLICY & PRACTICE OF PAYING PARENTS OF CHILDREN WITH COMPLEX HEALTH CONDITIONS TO BE HOME HEALTH AIDES**

We write on behalf of a coalition of Medicaid enrollees under age 18, their parents, advocates, and health care professionals throughout Pennsylvania, alarmed about the end of an invaluable policy and practice that has benefited hundreds of children with complex health conditions.

Pennsylvania Medicaid officials recently informed Medicaid stakeholders (e.g., enrollees, advocates, home health providers, managed care organizations) that when the public health emergency (PHE) ends, federal law will no longer allow parents (or other legally responsible adults) to be paid to provide medically necessary home health aide services to their children. State officials reported that Pennsylvania must end its current policy and practice because federal law does not allow it and they specifically cited conversations with federal officials at the Center for Medicaid and CHIP Services. **We would like to meet with relevant CMS staff to discuss CMS' position as soon as possible.**

We have reviewed relevant CMS policies, rules, and regulations and do not agree that they prohibit Pennsylvania's approach (before and during the PHE) for delivering medically necessary home health aide services to children. We request that CMS allow Pennsylvania to continue receiving federal reimbursement to pay parents (or other legally responsible adults) to provide medically necessary home health aide services to children after the end of the PHE.

The situation is urgent bordering on desperate for stressed Pennsylvania families. Some are already receiving verbal communications from their Medicaid managed care organizations that the reimbursement practice they have relied on for months (if not years) will end April 11, 2023. A copy of the written notice state officials have prepared to send affected families is attached. Approximately 400 households across the state—living in rural, suburban, and urban areas—will be affected.

Some of the families already notified about the end of the policy have contacted us and are very distraught. Direct care workers are in short supply across the state. That shortage is extreme in certain areas. If parents cannot be paid for the authorized but non-existent aide services, they are forced to choose between impoverishing their families or placing their children in institutions. Households—especially black households—living near the federal poverty level will likely be disproportionately harmed if the policy and practice of paying parents ends.

We urge CMS to look carefully at Pennsylvania's approach. Pennsylvania parents have in most cases been paid to be providers of home health aide services, **not** providers of personal care services. The distinction is important because these services are separate and distinct. Pennsylvania families should not be harmed because federal and state officials conflate the two.

Personal care services and home health aide services are not the same. At the outset, home health aide services are more regulated than personal care services. Under federal law they must be provided by a home health agency (HHA), while personal care services can be provided by an individual. Compare 42 CFR 440.70(b)(2) (describing home health aides) with 42 CFR 440.167(a)(2) (describing personal care). Federal regulations require at least 75 hours of specific training, supervision, and competency evaluations for home health aides. See 42 CFR 484.80(a) - (h). By contrast, there are no federal regulations governing qualifications, or requiring supervision of, individual (non-agency) providers of personal care services. Nor are there training, competency evaluations, or supervision requirements for agency employed providers of personal care services under federal regulations. See 42 CFR 484.80(i) (stating providers of personal care services employed by home health agencies need only "demonstrate competency in the services the individual is required to furnish").

Prior to the public health emergency (PHE), Pennsylvania paid some parents of minor children to provide home health aide services through Medicare-certified home care agencies. It was done in exceptional circumstances. That practice grew exponentially during the COVID-related PHE after Pennsylvania Medicaid officials submitted and received CMS approval for an 1135 waiver, but services were still requested and approved as home health aide services and provided by parents trained as home health aides and working through Medicare-certified home care agencies. They have **not** been (and should not be) characterized as personal care services.

We urge CMS to review the documentation associated with individual cases. One of our partners, the Pennsylvania Health Law Project (PHLP), reviewed relevant documentation submitted to the state Medicaid agency and its contracting managed care organizations in more than two dozen affected families. In every instance, the medical necessity documentation submitted by the Medicaid enrollee, their treating pediatrician or specialist, and home health agencies consistently use the term “home health aide” rather than personal care. Even the Medicaid MCOs’ billing and authorization codes consistently used home health services as opposed to personal care services.<sup>1</sup> Unlike a prescription for personal care, when a treating physician prescribes home health aide services, they are prescribing a service that requires training and nurse supervision. The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit rules entitle children to actual home health aides when medically necessary, not an untrained and unsupervised substitute in the form of a personal care service worker. When a parent is trained, supervised, and employed by a home health agency, they provide the prescribed and authorized level of care, not merely personal care.

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<sup>1</sup> In May 2022, Pennsylvania Medicaid officials, in direct response to the implementation of Electronic Visit Verification (EVV) in Fee-For-Service and Managed Care Systems, [issued new guidance](#) and created two new billing and authorization codes for home health aide and personal care services. Candidly, this bulletin ([MA Bulletin 05-22-01, 07-22-01](#)), which was only issued so that home health agencies could seek authorization of, and bill for, home health aide services in 15-minute increments, has sown confusion about what is home health aide and personal care services. As noted in the text above, Pennsylvania families should not be harmed by this conflation.

One of the many children that benefits from Pennsylvania's current approach is TD, a four-year-old girl with multiple complex health needs including Rhett syndrome, history of seizures, a vision deficit, and autism. TD's mother has been her paid home health aide since November of 2021. The family lives in Clearfield County, a rural area in central Pennsylvania. TD's treating physician, after meeting TD face-to-face, prescribed home health aide services eight hours each weekday (totaling 40 hours per week). TD's Medicaid managed care plan reviewed and authorized the same. These services can be delivered at TD's home, preschool and other places in the community. But TD's assigned home health agency informed the family that because of staffing shortages, they could only perform half, at best, of the authorized hours. The home health agency suggested TD's mother be her home health aide so TD could obtain all the authorized services she needed without delay. Without the authorized aides, TD could not go to preschool. TD's mother subsequently went through the agency's required training and orientation to become their employee, a certified home health aide. TD is now attending preschool and thriving in her home and community. In addition to the total assistance she requires with her activities of daily living, TD's mother provides 1:1 supervision. She monitors her for seizures, keeps her safe, specifically with ambulation and transferring as she is a fall risk. She also assists TD with her prescribed at-home-therapy regiment, including use of her tobii dynavox communication device. TD's well-being is threatened if federal officials end Pennsylvania's policy and practice of paying parents to be home health aides.

Again, we urge CMS to look carefully at Pennsylvania's approach. Families should not be harmed by a conflation of the home health aide and personal care service definitions.

Finally, we believe CMS itself has confirmed our position regarding parents who are employed by home health agencies and meet all the training, supervision and competency requirements in a February 7, 2022 letter (attached) to the Imagine Different Coalition stating: "With the exception of state plan personal care services authorized under section 1905(a)(24) of the Act, which prohibits services from being provided by a legally responsible family member, and the circumstances detailed below for 1915(c) and 1915(i) HCBS authorities [not at issue here], there is no federal policy that would preclude a family member from providing services they are qualified to provide." Similarly, the National Academy for State Health Policy

(NASHP) has explained that the “Medicaid State Plan Home Health benefit can be used to fund skilled nursing, home health aide, and other therapeutic services that may be provided by family caregivers of [Children with Special Healthcare Needs].” Olivia Randi et al., “[State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid](#),” Issue Brief of National Academy for State Health Policy (January 2021).

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We believe federal reimbursement of Pennsylvania’s current policy and practice of paying parents to be caregivers is essential. CMS’ written clarification and guidance on the issues we have raised above will help us work toward solutions, both short- and long-term, that meet CMS requirements and the needs of these very vulnerable families.

If you require additional information and insight, we can provide it. We also welcome an opportunity to meet with relevant CMS staff to discuss the above. Because the situation is urgent, we ask to meet at your earliest convenience. Please feel free to contact PHLP’s Amy Lowenstein for scheduling and other questions at [alowenstein@phlp.org](mailto:alowenstein@phlp.org) (she can also be reached at (215) 625-9111). On behalf of children with medical complexities and their families, we appreciate your consideration and thank you in advance for your prompt reply.

Sincerely,

**PENNSYLVANIA HEALTH LAW PROJECT (PHLP)**

*Laval Miller-Wilson, Esq.*                      *Amy Lowenstein, Esq.*  
*Kyle Fisher, Esq.*                              *Danna Casserly, Esq.*  
*Marissa LaWall, Esq.*

**IMAGINE DIFFERENT COALITION**

*Rachel Mann, Esq.*                              *Kate Maus, Co-Chair*  
*Liz Healey, Co-Chair*

**PENNSYLVANIA HOMECARE ASSOCIATION (PHA)**

*Teri Henning, Esq.*

**DISABILITY RIGHTS PENNSYLVANIA (DRP)**

*Jennifer Garman, Esq.*                      *Alexandra Hermann, Esq.*

cc (via email):

- Sally Kozak, Deputy Secretary, Office of Medical Assistance Programs, Pennsylvania Department of Human Services

Attachments:

- Pennsylvania Medicaid Official Notice to Affected Families
- CMS' February 7, 2022 Letter to the Imagine Different Coalition

[DATE]

[MEMBER NAME]

[MEMBER ADDRESS]

[MEMBER ADDRESS 2]

[CITY, STATE, ZIP]

Dear Guardian of [Member Name]:

You are receiving this notice because [Member Name] may receive personal care services provided by a parent or other legally responsible relative. A legally responsible relative is a parent or legal guardian. These personal care services are provided through a home health agency and may be called home health aide services. Federal law says that Medicaid (referred to as Medical Assistance or MA in Pennsylvania) cannot pay for personal care services provided by a parent or legally responsible relative. At the beginning of the COVID-19 public health emergency, the federal government waived that rule for Pennsylvania.

The federal public health emergency is expected to end on April 11, 2023. **When the public health emergency ends, [MCO name] will no longer be able to pay for personal care services provided by parents or legally responsible relatives.**

[MCO Name] is prepared to work with your family to make sure that [Member Name's] access to services is maintained.

If [Member Name's] parent or legally responsible relative is currently providing home health aide services, please take these steps:

1. Ask your home health agency to find another home health aide that can cover the shifts currently staffed by the parent or legally responsible relative.
2. Ask whether any other family members who are not legally responsible relatives (for example, a sibling, grandparent, aunt or uncle), family friends or neighbors would be able and willing to provide home health aide services through a home health agency.

3. Contact your case manager, [Case Manager Name], at [phone number] if you and your home health agency are having trouble finding another home health aide to provide services.

If [Member Name's] parent or legally responsible relative is **not** currently providing home health aide services, please tell us immediately so we can plan to continue to pay for services after April 11, 2023. You can do this by contacting the Special Needs Unit at [phone number].

If you have any questions, please contact your [MCO name] case manager, [Case Manager Name], at [phone number], or Special Needs Unit at [phone number]. We will be sending another letter to confirm the end date of the federal public health emergency, and remind you to take the steps outlined above.



February 7, 2022

Ms. Liz Healey and Ms. Kate Maus, Co-Chairs  
Imagine Different...Achieve Different Coalition  
2325 East Carson Street, Suite 100A  
Pittsburgh, PA 15203

Dear Ms. Healey and Ms. Maus:

Thank you for your letter regarding the Imagine Different...Achieve Different Coalition's concerns with Pennsylvania Medicaid's policies restricting authorization of in-home nurses, in which you requested clarification of CMS policies for this service. We appreciate the opportunity to provide information on CMS policy.

Your letter contained three questions; I have provided responses and policy clarification for each question below. Multiple benefit categories are described, given the different options for making services available to children in the Medicaid program.

**To what extent can parent availability be factored into determining medical necessity for skilled nursing care?**

Unless otherwise specified, sections 1902(a)(19) and 1902(a)(30) of the Social Security Act (the Act) and implementing regulations in 42 CFR 440.230(d) establish medical necessity requirements for the Medicaid Program. Although the statute and regulations refer to medical necessity, they do not contain a definition or establish standards for states to follow in determining whether a service is medically necessary. Therefore, states are responsible for developing and implementing medical necessity criteria and making determinations of service provision using the medical necessity criteria. While CMS does not prescribe medical necessity requirements, it is CMS's expectation that a state's medical necessity guidelines are reasonable and allow for appropriate access to services. Services described in section 1905(a) of the Act, such as personal care, home health, and private duty nursing services provided by a registered nurse or licensed practical nurse would be authorized according to medical necessity criteria.

As you identified in your letter, CMS provided its position in a letter dated January 21, 1992 that whether parents are at home or at work is not relevant to the issue of medical necessity. Additionally, it is CMS's position that family members' ability to provide the service should not be a factor for determining if the service is medically necessary for the beneficiary. While the ability and availability to perform the service by family members may be relevant in determining the amount of service hours a beneficiary should receive from the Medicaid program, the presence of a family member in the home should not result in an automatic reduction of services hours for medically necessary services.

Medical necessity is not the criterion used to determine coverage under a Medicaid 1915(c) home and community-based services (HCBS) waiver or a Medicaid 1915(i) HCBS state plan benefit. Rather, the need for an institutional level of care is the criterion for a 1915(c) waiver or meeting the needs-based criteria for the 1915(i) HCBS state plan benefit are necessary to enroll in these HCBS programs. Each state defines its own level of care and needs-based criteria and likewise defines each service, including any limitations as applicable. CMS requires these criteria and service definitions to be codified in the state’s waiver and state plan for these HCBS programs. Approved 1915(c) waivers may be viewed on Medicaid.gov at <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>. Approved 1915(i) state plan amendments may also be viewed on Medicaid.gov at <https://www.medicaid.gov/medicaid/medicaid-state-plan-amendments/index.html>.

For Medicaid 1915(c) HCBS waiver and 1915(i) HCBS state plan benefits, person-centered service planning is the process by which services and supports are established and made available to the Medicaid HCBS beneficiary. This process includes planning for both paid and unpaid supports (commonly referred to as “formal” and “informal” supports) and would include parent availability. HCBS may include skilled nursing services and cannot duplicate a state plan home health or personal care benefit, but can extend it by providing additional services. Most states have Nurse Practice Acts that define who may provide skilled nursing care and when it can be delegated to another individual such as a parent.

### **What compensatory benefits can accrue to children and families for authorized but unstaffed nursing hours?**

States are required to assure the sufficiency of providers to meet the needs of Medicaid beneficiaries to access the services authorized in the Medicaid state plan and 1915(c) HCBS waivers. There is no defined compensatory benefit to children and families for unstaffed hours, but the state would be responsible to monitor and take corrective action where a provider shortage exists and authorized service needs are not being met.

### **What services can parents be paid to provide, and under what circumstances?**

With the exception of state plan personal care services authorized under section 1905(a)(24) of the Act, which prohibits services from being provided by a *legally responsible family member*, and the circumstances detailed below for 1915(c) and 1915(i) HCBS authorities, there is no federal policy that would preclude a family member from providing services they are qualified to provide. For example, under the Medicaid home health benefit, there is no federal policy that would preclude a family member employed by a home health agency from providing nursing services to another family member if the conditions of 42 CFR 440.70 are met. The required nursing services under the home health benefit are those defined in the state’s Nurse Practice Act and are covered on a part-time or intermittent basis. It is important to note, that while the federal definition of home health nursing services contains no general preclusion on services furnished by a family member, a state may have a reasonable provider standard that may include consideration for beneficiary/provider relationship.

For both 1915(c) and 1915(i) HCBS authorities, a state may allow *legally responsible relatives* (including parents) to be paid to provide HCBS services in extraordinary circumstances such as when another provider is unavailable. Each state defines the extraordinary circumstances in which legally responsible individuals may become paid workers. This provision is usually used

with individuals who require a provider with particular skills, such as behavioral interventions. It is also used in rural areas that have provider shortages or during emergencies such as the COVID-19 pandemic or a natural disaster. Even in extraordinary circumstances, for children, the parent or legally responsible relative may be paid to provide only those services in addition to what a child of the same age without a disability requires and which are necessary to assure the health and welfare of the child.

When qualified providers outside of legally responsible relatives are available to implement services as identified in the person-centered service plan, extraordinary circumstances are generally not present. In these scenarios, legally responsible relatives would not be authorized as providers, but other family members could be, at state option.

Although your letter did not include specific questions regarding managed care policies, you included several managed care policy documents with your letter and many children in Pennsylvania Medicaid are enrolled in managed care organizations. Therefore, I contacted the Pennsylvania Medicaid agency for a response. They acknowledged that the Imagine Different...Achieve Different Coalition had brought the issue of paying parents as home health aides to their attention, but they were unfamiliar with the first two issues in your letter. The Pennsylvania Medicaid agency informed me that they had contacted CMS for policy clarification on paying parents as home health aides earlier this month. I have sent them a copy of this response to assist in responding to their inquiry.

Additionally, the Pennsylvania Medicaid agency confirmed that that all of their managed care organizations are compliant with Pennsylvania Medicaid policy related to the authorization of pediatric shift nursing, and that they work directly with specific managed care organizations to address isolated incidents when they arise. Please continue to raise specific concerns to the Pennsylvania Medicaid agency so that it can ensure that enrollees are receiving covered services in an appropriate manner as well as monitor and address any issues with their managed care plans' performance.

I hope the information in this letter is responsive to your concerns. If you have additional questions about state plan services, please contact Kirsten Jensen, Director of our Division of Benefits and Coverage at [kirsten.jensen@cms.hhs.gov](mailto:kirsten.jensen@cms.hhs.gov). For questions related to 1915(c) or 1915(i) HCBS programs, please contact Ralph Lollar, Director of our Division of Long-Term Services and Supports at [ralph.lollar@cms.hhs.gov](mailto:ralph.lollar@cms.hhs.gov). For managed care questions, please contact John Giles, Director of our Division of Managed Care Policy at [john.giles1@cms.hhs.gov](mailto:john.giles1@cms.hhs.gov).

Sincerely,

Alissa Mooney DeBoy  
Director  
Disabled and Elderly Health Programs Group

cc: Sally A. Kozak, MHA, RN  
Deputy Secretary Office of Medical Assistance Programs