Office of Medicaid BOARD OF HEARINGS

Appellant Name and Address:



Rehearing Decision: APPROVED Appeal Number: 2303905

Rehearing Decision 02/28/2025 Rehearing Dates: September 25, 2024

Date: October 28, 2024

Hearing Officer: Macy Lee, Director Record Open to: December 6, 2024

Appearance for Appellant:

Appearance for MassHealth:

Assistant General Counsel Michael D'Angelo Linda Phillips, RN, for Community Care Management



The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Office of Medicaid
Board of Hearings
100 Hancock Street, Quincy, Massachusetts 02171

REHEARING DECISION

Rehearing Decision: APPROVED Issue: PCA Services;

Community Care Management (CCM)

Rehearing Decision 02/28/2025 Rehearing Dates: September 25, 2024

Date:

October 28, 2024

Appellant's Rep.:

MassHealth's Rep.: Michael D'Angelo,

Assistant General

Counsel

Rehearing Location: Board of Hearings, Aid Pending: No

Quincy - Virtual on

Zoom

Authority

This rehearing was conducted pursuant to Massachusetts General Laws Chapter 118E, Chapter 30A, 130 CMR 610.091, and the rules and regulations promulgated thereunder.

Jurisdiction

On March 9, 2023, MassHealth approved appellant¹ for personal care attendant (hereinafter, "PCA") services in addition to continuous skilled nursing (hereinafter, "CSN") hours. See 130 CMR 422.410 and Exhibit 1. The minor appellant, through her attorney, filed a timely appeal on May 10, 2023. See 130 CMR 610.015 and Exhibit 2. A dispute over the amount of assistance is valid grounds for appeal. See 130 CMR 610.032.

Hearing dates were scheduled for June 20, 2023, July 27, 2023, and December 12, 2023, but were rescheduled at the request of appellant's attorney. Hearings were then held on September 5, 2023, October 26, 2023, and January 18, 2024, and were conducted by the hearing officer via video conference. See Exhibit 3. The central dispute "involves the frequency that the appellant

¹ When the request for a fair hearing was received, the appellant was As of the date of this decision, the appellant is now

needs a PCA for assistance with mobility as it relates to her transfers/repositioning every day given her autonomic dysreflexia and spinal precautions." Exhibit 12 at 12-13. The hearing officer left the record open until April 15, 2024, for submission of additional evidence and briefing. On May 22, 2024, the Board of Hearings (hereinafter, "BOH") issued a fair hearing decision upholding MassHealth's action and denying the appeal. Id. Specifically, the decision provided that, "MassHealth's requirement and expectation that one of her parents be her second caregiver along with her nurse at times is consistent with its written policy." *Id.* at 15.

On June 4, 2024, the appellant requested a rehearing. Exhibit 13. On July 16, 2024, pursuant to 130 CMR 610.091, the Medicaid Director notified the parties that there was good cause to order a limited rehearing on the legal issue of parental responsibility for ADLs and IADLs. Exhibit 14. Per the appellant's requests, BOH scheduled the rehearing on September 25, 2024, and October 6, 2024, both of which were held virtually on Zoom and heard by the Director of the Board of Hearings. Exhibit 15.2

Action Taken by MassHealth

In taking into consideration parental responsibility for ADLs, MassHealth Community Case Management ("CCM") approved 93.5 hours per week of PCA services for the appellant when out of school and 81.5 hours per week of PCA services when in school. This is in addition to the appellant's 168 hours per week of continuous skilled nursing (hereinafter, "CSN") hours currently in place. Exhibit 12.

Issues

The limited legal issues for rehearing are whether the determination of parental responsibility is required: (1) for MassHealth's PCA regulations that covered ADL and IADL services under 130 CMR 422.410-412; (2) with regards to ADLs and IADLs under MassHealth's regulation pertaining to medical necessity under 130 CMR 450.204; and (3) under MassHealth's EPSDT regulation at 130 CMR 450.144(A)(1), which covers all medically necessary services listed in 1905(a) of the Social Security Act, 42 USC § 1396d(a) and (r). Exhibit 14.

Summary of Evidence

The rehearing, consisting of nearly two full days, was conducted virtually on Zoom with live transcription for the appellant's mother. The appellant was represented by their attorney.³ MassHealth was represented by an Assistant General Counsel for the General Counsel's Office for the Executive Office of Health and Human Services. Linda Phillips, RN, Associate Director, Appeals

² Per 130 CMR 610.091(A), the BOH Director conducted the rehearing.

³ The appellant did not attend the rehearing.

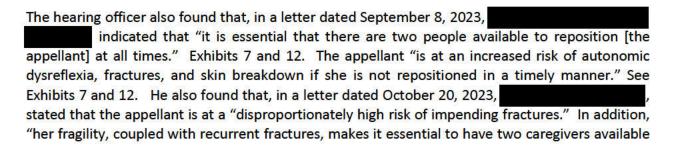
and Regulatory Compliance/Community Case Management at UMass Chan Medical School, also appeared on behalf of MassHealth. Per the Medicaid Director's order for a rehearing, the appellant's mother testified on behalf of the appellant⁴; Director of MassHealth Office of Long Term Services and Supports (hereinafter, "OLTSS"), testified on behalf of MassHealth.⁵ a Clinical Reviewer II at Commonwealth Medicine, UMass Chan Medical School, was subpoenaed by the appellant's attorney to testify at the rehearing.

Exhibits 1 to 11 are a part of the record from the hearing dates of September 5, 2023, October 26, 2023, and January 18, 2024, and are incorporated herein.

Decision Dated May 22, 2024

The Findings of Fact in a decision issued on May 22, 2024, by a Board of Hearings hearing officer are incorporated in this rehearing decision. In his decision, the hearing officer found, *inter alia*, that the appellant "has been a member of CCM since June 4, 2012. Her primary diagnosis is spastic quadriplegia. She also has feeding intolerance, hip dysplasia, aspirations, autonomic dysreflexia, seizure disorder, apnea (central and obstructive), constipation, low bone density, neurogenic bladder, respiratory insufficiency, non-traumatic cerebellar, medullary and spinal cord hemorrhage, chromosomal duplication of unknown clinical significance, bulbar dysfunction, lordosis, and a history of chronic UTI (Exhibit 4)." Exhibit 12 at 10.

On March 9, 2023, MassHealth approved the appellant for PCA services in addition to CSN hours. Exhibit 1; Exhibit 4 at 90-92. Specifically, MassHealth approved the appellant for 81.5 weekly hours PCA services in school and 93.5 hours out of school in addition to 168 weekly hours of continuous skilled nursing hours (24 hours per day). *Id.* The authorization of 168 nursing hours weekly remains in effect until January 27, 2024, or until the new annual assessment has been completed, whichever is later. *Id.* The total PCA and nursing hours for the appellant are 249.5 when in school and 261.5 hours when out of school. *Id.*



⁴ In his order for a rehearing, the Medicaid Director stated, "The Appellant's mother shall be provided the opportunity to offer additional testimony through a direct examination that Appellant's attorney alleges he did not complete. MassHealth shall have the opportunity to cross-examine Appellant's mother." Exhibit 14.

⁵ The Medicaid Director also ordered that "MassHealth shall produce a witness competent to testify regarding this issue for the purpose of the BOH Director's fact-finding and analysis." Exhibit 14.

24/7 to assist with repositioning and transfers." Exhibits 7 and 12. The hearing officer also found that, in letter dated October 24, 2023, "indicated that the appellant's spine cannot tolerate a Hoyer lift. He stated that to do a transfer for the appellant "requires either one very strong person, or more realistically two individuals to achieve a safe transfer that does not injure the spine and spinal rods." Exhibits 7 and 12.

CCM, which provides CSN and PCA services to medically complex members such as the appellant, determined that the appellant needs "PCA assistance with some ADLs as well as IADLs, notwithstanding her having a nurse on duty for 24 hours, as she needs two caregivers for assistance with some tasks. The appellant was determined to need ADL assistance with mobility and transfers including repositioning, quick wash, shower, grooming, dressing/undressing, passive range of motion exercises, bladder and bowel care, stander time, and menstrual care. She was found to need IADL assistance with laundry, shopping, housekeeping, and transportation to medical appointments." Exhibit 12 at 12.

During the hearing, MassHealth cited *PCA Operating Standards XXVI A. 1. (a-d).* – *Revised 5-28-15, Pages 62-63* as its authority for requiring a parent to be the second caregiver when two persons are required for a PCA task for children. Exhibits 8 and 12. As such, the hearing officer denied the appellant's appeal:

Finally, it must be noted that the appellant's attorney was given several opportunities to submit evidence as to how the appellant's parents were physically unable or prevented in some other way from being the appellant's second caregiver for certain tasks. MassHealth indicated that it would consider raising the appellant's PCA hours only if such information was provided. However, the attorney offered no evidence of a disability or other reason as to why the appellant's parents could not be this second person. Instead, he objected to the request stating that this was not relevant to the appellant's case.

In conclusion, the appellant, by her attorney, has not demonstrated that MassHealth was incorrect in determining her PCA hours to accompany her 24 per day CSN hours given a lack of medical evidence contrary to the findings of her PCA assessment. Moreover, MassHealth's requirement and expectation that one of her parents be her second caregiver along with her nurse at times is consistent with its written policy.

Exhibit 12 at 15.

The hearing officer also noted that, "MassHealth fully acknowledged the appellant's need of two caregivers for many of her PCA tasks. The appellant's attorney, apart from . . . letters, offered no medical evidence to support the contention that the appellant needed greater than 16 repositioning episodes on a daily basis. For instance, the attorney did not cite or submit into

evidence any supportive medical records even though he had full access to all of the appellant's nursing progress notes. While letters from medical providers can provide insight into a case such as this, without corroboration, they cannot on their own be used to establish the appellant's PCA hours." *Id.* at 13.

First Day of Rehearing: September 25, 2024

At the rehearing, the Director reminded the appellant's attorney of the limited scope of the rehearing. The appellant's attorney wanted an entirely new hearing on the merits. His numerous objections to this were noted on the record. Exhibit 27 at 2.

On September 25, 2024, testimony on behalf of MassHealth is as follows: manages OLTSS, which oversees, inter alia, PACE, Home and Community Based Services (hereinafter, "HCBS") waivers, hospice, the PCA program, adult day health, rehabilitation, and adult foster care, cand continuous skilled nursing. As to the PCA program, this program is a selfdirected program that provides personal care attendant services, including dressing, bathing, feeding, shopping, and laundry. The program is governed by state regulations - 130 CMR 422.00 were amended in 2023. Sections 422.410 (Activities of Daily Living and Instrumental Activities of Daily Living) and 422.412 (Non-covered Services) were part of the amendment in 2023. Services are broken down to instrumental activities of daily living (hereinafter, "IADLs") and activities of daily living (hereinafter, "ADLs"). Both activities are defined under the state regulations. Section 422.411 defines covered services while section 422.412 defines uncovered services and precludes the payment of legally responsible relatives. State regulations follow the federal laws that prohibit the state from paying relatives. Under the recently amended state PCA regulations, parental responsibility is a consideration for IADLs but not for ADLs. The state PCA regulations, however, do not "elaborate" on family resources with regards to EPSDT.

also testified that MassHealth issues regulatory guidance through bulletins and operating standards for PCA services. On May 28, 2015, MassHealth issued "PCA Operating Standards." These operating standards have not been updated since 2015. Exhibit 25. testified that there have been discussions at MassHealth about updating the PCA operating standards but that has not yet been done. In interpreting section 26(A)(1) of the PCA Operating Standards, stated that MassHealth requires parents to be the second caregiver when a second person is needed for PCA services, particularly when a second pair of hands are needed for movements and transfers. Exhibit 25 at 62-63.

According to provide all services covered by the Center of Medicaid and Medicare Services (hereinafter, "CMS") Early and Periodic Screening, Diagnostic and Treatment (hereinafter, "EPSDT"). See 130 CMR 450.144 As for children, EPSDT is a federal mandate that Medicaid agencies provide medically necessary services to children under the age of 21. EPSDT requires participating states to support screenings, dental, vision, and "catch all" services that includes PCA services. In addition, "medical

necessity," is defined by EPSDT as, "a service needed to correct or ameliorate a physical or mental illness." EPSDT does not distinguish between ADLs and IADLs but discusses "personal care." CMS is responsible for implementing EPSDT and providing guidance to the states. Guidance for implementing EPSDT is provided via commentaries, notes, and guides. In June 2014, CMS issued a guide - "EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents." ⁶ Exhibit 24. Pages 12 to 13 of this guide addresses "Personal Care Services" and that "[t]he determination of whether a child needs personal care services must be based upon the child's individual needs and provided in accordance with a plan of treatment or service plan. See Exhibit 24. Under the state Medicaid plan, Medicaid payments are unavailable for personal care services provided by the child's legally responsible relatives. In addition, "the determination of whether a child needs personal care services must be based upon the child's individual needs and a consideration of family resources that are actually – not hypothetically – available." Exhibit 24 at 12-13. Footnote 16 for this paragraph refers to 42 CFR 440.167, which prohibits legally responsible relatives from being paid for personal care services. CMS does not define "family resources" but EPSDT defines a family member to include a parent. MassHealth interprets "family resources" to be any available parent and is part of the inquiry during an assessment. testified that the distinguishment of ADLs and IADLs with regards to parental responsibility is "a construct" by MassHealth and "is not something we get from the federal government through EPSDT." is unaware as to whether the federal regulations mention family resources but there have been conversations at CMS about EPSDT.

On a lengthy cross-examination, testified, in relevant part, that she did not review the appellant's case file but agreed that the appellant's needs are "well above average." She also stated that she is not a clinician and unaware of the clinical decision-making process, particularly for the appellant. also testified that MassHealth has state authority and multiple different types of authorities to cover services. States have an EPSDT obligation that is an overlay to that "construct" and states are required to follow EPSDT rules. As to ADLs, services by parents are not covered services and they cannot be paid for those services under federal law and state regulations. Under EPSDT, the state must look at the individual needs of a child and determine the appropriateness while considering the resources available to them. Federal law provides an expansion of what is available under state law and states are required to follow federal law. Massachusetts does not have a state regulation that supersedes our federal law regulations and obligations; states must comply with EPSDT but is separate from our state regulations. There is no state regulation that supersedes federal requirements. testified that EPSDT requires MassHealth to consider family resources available to the child but acknowledged that "family resources" are not defined by EPSDT guidance. Both MassHealth regulations and EPSDT require an individual assessment.

⁶ On September 26, 2024, CMS issued a 57-page letter to the states providing best practices for adhering to EPSDT requirements and clarifying policy implementation. This state health official letter neither addresses personal care services nor mentions, "family resources."

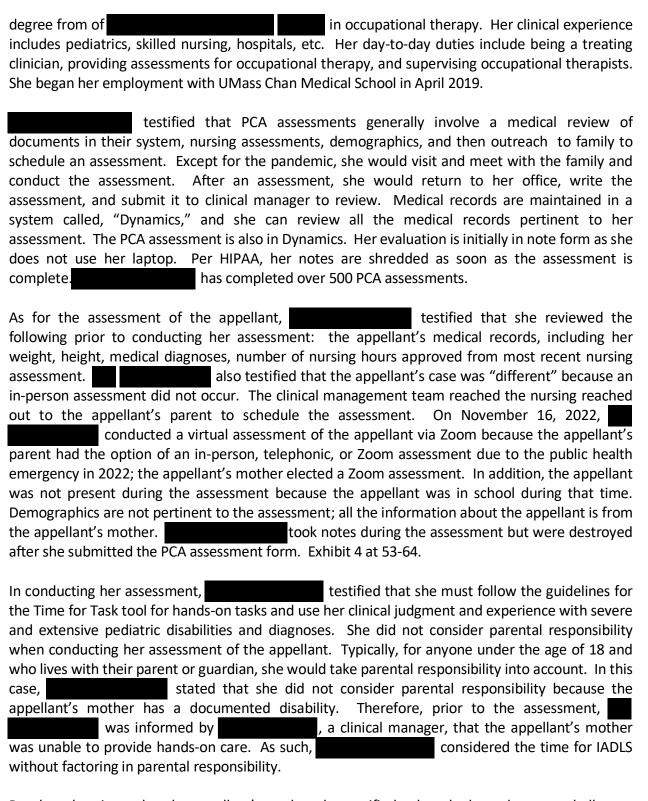
testified that pages 62-63 of the PCA Operating Standards "help parents think about parental responsibility." Exhibit 25 at 62-63. The PCA Operating Standards were last revised on May 28, 2015, and was the most recent version on the date of the hearing. also pointed to subsection A(1)(b) of Section XXVI on page 62 of the PCA Operating Standards as the authority for MassHealth to impose parental responsibility for PCA services. See Exhibit 25 at 62. She opined that this section applies to both ADLs and IADLs. There are no specific criteria provided by the PCA Operating Standards for determining medically necessary PCA services for parental responsibility. Parents are expected to provide evidence of actual available (or unavailable) resources (and not hypothetical) inside the home to the assessing entity. There are no specific criteria that would give further context to reasonable parental resources. Although the term, "family resources," come from the EPSDT guide, it does not define it. An evaluator would apply a reasonable standard and if the family disagrees, they can exercise their appeal rights. believes that the PCA Operating Standards provide very clear criteria that, if a parent is in the home, they are required to be the second person when two people are required to perform an IADL. The PCA Operating Standards is the only guide for assessors. See Exhibit 25; Testimony. The regulations and the PCA Operating Standards are the only materials that govern PCA services in Massachusetts.

also testified that, when CCM is calculating needs and the number of hours, it must consider the resources available. When calculating the number of minutes, CCM must follow the operating standards. also testified that, for example, for transfers, when a parent needs to be the second set of hands, CCM must consider the operating standards when calculating and completing the Time for Task tool. PCM and CCM are required to comply with the PCA Operating Standards. The operating standards are more specific and provide more detail, but the parental resources come from EPSDT guidance for the states and the non-covered services come from our regulations. The operating standards are the most detailed guidance provided and CCM and PCMs are expected to follow these standards. As to transfers and repositioning, and where it is not routine and must be done carefully as in the appellant's case, reiterated that PCAs are unskilled workers with no formal training or education requirements. said that skilled services should be considered and whether PCA is appropriate for such medical needs. Factors are very limiting to parental engagement. In the context of the PCA program, the assessor must consider the task for an unskilled PCA to do, then whether it is appropriate for a parent to perform it if two set of hands are needed.

Second Day of Rehearing: October 28, 2024

On October 28, 2024, the second day of the rehearing, by way of a subpoena by the appellant's attorney, testified in pertinent part: has a master's

⁷ Time for Task Guidelines for the MassHealth PCA Program provide average times for PCA to perform ADLs and IADLs in Massachusetts. These guidelines are based on the average time it may take a PCA to physically assist a member in performing specific activities. Exhibit 25.



Per the rehearing order, the appellant's mother also testified at length about the many challenges and stresses surrounding the appellant's care. The mother's testimony, in relevant part, is as

follows: The appellant's mother stated that she uses a bi-lateral hearing aid and was unable to hear and follow the hearings on September 5, 2023, and October 26, 2023, which was the reason for her request for a rehearing. See Exhibit 15. She also challenged the scope of the rehearing and claimed that it violates her civil rights. The mother also claimed that the assessment conducted on November 16, 2022, was unreasonable, exhausting, and emotionally taxing for parents to have to quantify minute by minute for each task for the assessment.

The appellant's mother showed a photo of the appellant and testified that the appellant was injured during a C-section delivery. The appellant is a who is quadriplegic and wholly dependent on care. The appellant has siblings and the family members' lives are full of trauma. The mother claimed that the mechanics of the assessment do not apply to the appellant and spoke at length about the appellant's needs. She claims that the assessment is a gross underestimation of the appellant's needs as the appellant requires more than average care. The appellant attends an independent school 10.12% of the academic year. Skilled and professional PCAs are preferred over family help because they can perform these tasks with skilled care and understand the medical risks. The mother stated that skilled care is required for repositioning the appellant to prevent pressure sores, mitigate the risk of fractures, and other lifethreatening conditions.

As to parental responsibility, the mother testified that her day revolves around managing the appellant's care, including scheduling transportation, comprehension coordination of staff, and caring for all three of her children. She is also responsible for staff training, case management, and comprehensive coordination of staff. One great challenge that the mother testified to at length was her countless trips to CVS to pick up her daughter's medications. As of the day of the hearing, the appellant has had 288 appointments, and it takes approximately 30 minutes to get the appellant from school to the appointment. She also finds the case managers to be ineffective in assisting her. She feels "dumped on," "is so busy," and she has no time to handle the administrative work related to the appellant. (Testimony). The mother also testified that her husband is "busy guy." He works in a money management firm and is the full-time, income earning parent in the family while she is the full-time non-income earning parent. She is "shackled to this" and feels that this unfair. She is depressed, angered, and resentful. She feels overwhelmed.

In closing, MassHealth stated that it agreed that there is a medical necessity that the appellant needs two people to lift, carry, and transfer 24 hours per day and seven days per week, and that the issue is whether there is a role of parental responsibility under EPSDT. The issue of medical necessity was already determined in the first hearing by the hearing officer. Exhibit 12 at 13.

Record Open Period

The Director allowed the hearing record to remain open until December 6, 2024, and requested the following from the parties:

Page 9 of Appeal No.: 2303905 REHEARING DECISION

- Affidavit of
 Affidavit of (optional);
- Medical records for the appellant from September 1, 2022, to October 28, 2024, regarding nighttime care; and
- Memorandum of Law addressing 130 CMR 422.410(B) (amended January 1, 2022) and the application of the PCA Operating Standards (Revised on 5-28-2015) and the EPSDT state guidelines June 2014 to section 422.410(B).

On or before December 6, 2024, the parties submitted the following for the Director's consideration:

- Appellee's Memorandum of Law Regarding Controlling Relationship Between Regulations and Sub-Regulatory Guidance (Exhibit 26);
- 2. Memorandum on behalf of the appellant (Exhibit 27);
- Letter from the appellant's mother (Exhibit 28);
- 4. Affidavit from the appellant's father (Exhibit 29); and
- 5. Letter from Marathon Nursing (Exhibit 30).

The appellant's attorney failed to submit medical records for the appellant from September 1, 2022, to October 28, 2024, pertaining to nighttime care. The appellant's mother submitted an 18-page letter containing many statements that were already a part of her testimony. Exhibit 28; Testimony.

In a lengthy and detailed affidavit, the appellant's father stated that he works full-time as a financial planner and the managing director of an investment firm. Exhibit 29. He also stated that, due to the "demands of my professional and personal life, I cannot reasonably provide the level of care [the appellant] requires." *Id.*

, RN, of Marathon Nursing submitted a letter dated December 4, 2024, during the record open period. Exhibit 30. In her letter, she stated that she has cared for the appellant, a "medically complex patient for whom I have provided and supervised nursing care intermittently over the past 12 years." *Id.* opined that, "[w]hile some parents could be trained for this role [necessary PCA duties during the night shift], it would effectively require them to take on this role as a [sic] equivalent of a full-time night shift job. Moreover, the physical demands are considerable, and not all parents are capable of meeting them." *Id.* also believes that, "[b]ased on my extensive experience with [the appellant's] care, my professional background as a physical demands and my understanding of her medical needs, I strongly advocate for the approval of at least 14/7 PCA services, including approval for PCA coverage for an aide to be present and work with the nurse for the entire night shift." *Id.*

Findings of Fact

Based on a preponderance of the evidence, I find the following:

and lives with her parents and two older siblings. The appellant The appellant is is quadriplegic and wholly dependent on care due to a birth related injury. Testimony. 2. The appellant has been a member of CCM since June 4, 2012. Exhibits 4 and 12. Her primary diagnosis is spastic quadriplegia. Id. She also has feeding intolerance, hip dysplasia, aspirations, autonomic dysreflexia, seizure disorder, apnea (central and obstructive), constipation, low bone density, neurogenic bladder, respiratory insufficiency, non-traumatic cerebellar, medullary and spinal cord hemorrhage, chromosomal duplication of unknown clinical significance, bulbar dysfunction, lordosis, and a history of chronic UTI. See id. 3. In a plan dated September 27, 2022, stated that the appellant has "a spinal cord injury that places her at risk for a complication Exhibit 17. An important consideration for this called autonomic dysreflexia (AD)." syndrome is that it is "a medical emergency . . . [t]he sudden onset of severe hypertension has been associated with seizures, intracerebral hemorrhage, and death." Id. conducted a virtual assessment of the appellant 4. On November 16, 2022, via Zoom because the appellant's parents had the option of an in-person, telephonic, or Zoom assessment due to the public health emergency in 2022; the appellant's mother elected a Zoom assessment. Exhibit 4 at 53-64; Testimony. 5. The appellant was not present during the assessment on November 16, 2022, because the appellant was in school during that time. Testimony. Demographics are not pertinent to the assessment; all the information about the appellant was from the appellant's mother. took notes during the assessment but destroyed them after Testimony. she submitted the PCA assessment form. Testimony. did not consider parental responsibility when conducting her assessment of the appellant. Testimony. Typically, for anyone under the age of 18 and who lives with their parent or guardian, she would take parental responsibility into account. Testimony. In stated that she did not consider parental responsibility because the appellant's mother has a documented disability. Testimony. Therefore, prior to the assessment, was informed by Michelle Ingalls, a clinical manager, that the appellant's mother was unable to provide hands-on care. Testimony. As such, considered the time for IADLS without factoring in parental responsibility. Testimony.

- 7. On March 9, 2023, MassHealth approved the appellant for PCA services in addition to CSN hours. Exhibit 1; Exhibit 4 at 90-92. Specifically, MassHealth approved the appellant for 81.5 weekly hours of PCA services in school and 93.5 hours out of school in addition to 168 weekly hours of continuous skilled nursing hours (24 hours per day). Id. The authorization of 168 nursing hours weekly remains in effect until January 27, 2024, or until the new annual assessment has been completed, whichever is later. The total PCA and nursing hours for the appellant are 249.5 when in school and 261.5 hours when out of school. Id. 8. In a letter dated September 8, 2023, indicated that, "it is essential that there are two people available to reposition [the appellant] at all times." Exhibits 7, 12, 18. 9. In a letter dated on October 20, 2023, stated that the appellant is at a "disproportionately high risk of impending fractures." Exhibits 7, 12, 20. In addition, "her fragility, coupled with recurrent fractures, makes it essential to have two caregivers available 24/7 to assist with repositioning and transfers" Id. 10. In a letter dated October 24, 2023, the appellant's treating physician, , wrote that, "[a]Ithough a Hoyer type lift is usually helpful for transfer of most patients, [the appellant's] spine cannot tolerate the obligatory 'C' shape forced by the sling in the Hoyer lift. [The appellant's] spine must be supported in a straight, sitting posture when she is transferred. To do a transfer for [the appellant] therefore requires either one very strong person, or more realistically two individuals to achieve a safe transfer that does not injure the spine and spinal rods." Exhibit 21. 11. submitted a letter dated December 4, 2024, during the record open period. Exhibit 30. In her letter, she stated that she has cared for the appellant, a "medically complex patient for whom I have provided and supervised nursing care intermittently over the past Id. opined that, "[w]hile some parents could be trained for this role [necessary PCA duties during the night shift], it would effectively require them to take on this role as a [sic] equivalent of a full-time night shift job. Moreover, the physical demands are considerable, and not all parents are capable of meeting them." *Id.* also believes that, "[b]ased on my extensive experience with Harper's care, my professional background as a Nurse Practitioner, and my understanding of her medical needs, I strongly advocate for the approval of at least 14/7 PCA services, including approval for PCA coverage for an aide to be present and work with the nurse for the entire night shift." Id.
- 12. The appellant's parents are very busy people. Testimony. The appellant's mother's day revolves around managing the appellant's care, including scheduling transportation, comprehension coordination of staff, and caring for all three of her children. *Id.* She is also responsible for staff training, case management, and comprehension coordination of staff.

- *Id.* The appellant's father works full time as a financial planner and managing director of an investment firm. Exhibit 29. He also stated in his affidavit dated December 5, 2024, that, due to the "demands of my professional and personal life, I cannot reasonably provide the level of care [the appellant] requires. *Id.*
- 13. The state regulations that govern PCA services 130 CMR 422.000 were amended and promulgated on October 13, 2023. Sections 422.410 (Activities of Daily Living and Instrumental Activities of Daily Living) and 422.412 (Non-covered Services) were part of the 2023 amendment. Under the recently amended state PCA regulations, parental responsibility is a consideration for IADLs but not for ADLs.
- 14. The state PCA Operating Standards PCA Operating Standards XXVI A. 1. (a-d). Revised 5-28-15, Pages 62-63 serve as guidance to the MassHealth regulations pertaining to PCA services and were last revised on May 28, 2015. Exhibit 25.
- 15. The May 28, 2015 version of the PCA Operating Standards is the most detailed guidance provided by MassHealth and CCM and PCM agencies are expected to follow these standards. Testimony. The regulations and the PCA Operating Standards are the only materials that govern PCA services in Massachusetts. Testimony.
- 16. MassHealth cited subsection A(1)(b) of Section XXVI on page 62 of the PCA Operating Standards as the authority for MassHealth to impose parental responsibility for PCA services. Exhibit 25 at 62; Testimony. MassHealth believes that this section applies to both ADLs and IADLs. *Id.*
- 17. In interpreting section XXVI(A)(1) of the PCA Operating Standards, MassHealth requires parents to be the second caregiver when a second person is needed for PCA services, particularly when a second pair of hands are needed for movements and transfers. Exhibit 25 at 62-63; Testimony.
- 18. There are no specific criteria provided by the PCA Operating Standards for determining medically necessary PCA services for parental responsibility. *Id.*; Testimony. Parents are expected to provide evidence of actual available (or unavailable) resources (and not hypothetical) inside the home to the assessing entity. *See id.* There are no specific criteria that would give further context to "reasonable parental resources." *Id.*; Testimony.
- 19. CMS is responsible for implementing EPSDT and providing guidance to the states for Medicaid coverage for children and adolescents. Exhibit 24; Testimony. Guidance for implementing EPSDT is provided via commentaries, notes, and guides. Testimony. In June 2014, CMS issued a guide "EPSDT A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents," which provides some guidance on personal care services. See id.

- 20. The federal EPSDT guidance on personal care services does not distinguish between ADLs and IADLs but discusses "personal care services." Exhibit 24 at 12-13. The distinguishment of ADLs and IADLs is a "state construct" by MassHealth and "is not something [MassHealth] get[s] from the federal government through EPSDT." Testimony.
- 21. The federal EPSDT guidance refers to "family resources" for personal care services but does not define it. Exhibit 24 at 12-13; Testimony. The "determination of whether a child needs personal care services must be based upon the child's individual needs and a consideration of family resources that are actually not hypothetically available." Exhibit 24 at 12-13; Testimony. Footnote 16 for this paragraph refers to 42 CFR 440.167, which prohibits legally responsible relatives from being paid for personal care services. CMS, however, does not define "family resources" but EPSDT defines a family member to include a parent. MassHealth interprets "family resources" to be any available parent and is part of the inquiry during an assessment. Testimony.
- 22. The state PCA regulations do not "elaborate" on family resources as provided in the federal EPSDT guidance. Testimony. In addition, the term, "family resources," is not used in the state PCA regulations. Testimony.

Analysis and Conclusions of Law

Legal Issues for Rehearing

The Medicaid Director ordered a rehearing before the Director on the following legal issues: whether the determination of parental responsibility is required: (1) for MassHealth's PCA regulations that covered ADL and IADL services under 130 CMR 422.410-412; (2) with regards to ADLs and IADLs under MassHealth's regulation pertaining to medical necessity under 130 CMR 450.204; and (3) under MassHealth's EPSDT regulation at 130 CMR 450.144(A)(1), which covers all medically necessary services listed in 1905(a) of the Social Security Act, 42 USC § 1396d(a) and (r). Exhibit 14. The rehearing order also stated that the "BOH Director shall also make findings of fact and analysis on this issue using the relevant CMS guidance, which shall be provided as evidence by MassHealth at the rehearing." *Id*.

The Medicaid Program and Federal and State Mandates

The Medicaid program is authorized by Title XIX of the Social Security Act. See generally 42 U.S.C. § 1396, et seq. Medicaid is a cooperative federal and state program where federal funding is provided to participating states to assist them in providing medical care to low-income individuals and families. See Needham v, Dir. Of Office of Medicaid, 88 Mass. App. Ct. 558, 561 (2015). A state may voluntarily choose to participate in the Medicaid program. See Beal v. Doe, 432 U.S.

Page 14 of Appeal No.: 2303905 REHEARING DECISION

438, 440-41 (1977). "Although a state's participation in Medicaid is voluntary, if it chooses to adopt a plan it must do so consonant with the requirements imposed by the Medicaid Act." *Needham*, 88 Mass. App. Ct. at 561. To receive federal funding, a state program must meet all the federal requirements and regulations. *See id.* at 561 (*citing Haley v. Comm'r of Pub. Welfare*, 394 Mass. 466, 467 (1985)). The Secretary of Health and Human Services must approve a state plan for medical assistance to participate in the Medicaid program. *See* 42 U.S.C. §§ 1396d(a), (r) and 42 CFR 440.345. A state must also provide EPSDT services if it participates in the Medicaid program. See 42 U.S.C. §§ 1396d(a), (r) and 42 CFR 440.345. EPSDET is a federally mandated Medicaid benefit aimed at ensuring that children under the age of 21 receive necessary health services, including those not covered under the state's Medicaid plan for adults. Exhibit 24 at 1.

CMS is the federal agency of the Department of Health and Human Services tasked with administering the Medicaid Act. *Moore ex. Re. Moore v. Reese*, 637 F.3d 1220, 1235 (11th Cir. 2011). This duty includes supervising the administration of state plans to ensure compliance with the Medicaid Act. *See* 42 U.S.C. § 1396c. CMS also has the authority to withhold funding to states that fail to comply with federal statutes and regulations. *See id.* As to EPSDT, federal supervision requires participating states to annually report information pertaining to EPSDT services and programming to CMS. *See* 42 U.S.C. §§ 1396a(D), 1396d(r)(5), 1397h(h). CMS is tasked to review state implementation of EPSDT requirements, identify any gaps and deficiencies, and provide technical assistance. *See* Bipartisan Safer Communities Act, Pub. L. No. 117-159, 136 Stat. 1313, § 11004(1) (2022).

The Commonwealth of Massachusetts is a voluntary participant in the Medicaid program. The Executive Office of Health and Human Services is the state secretariat that operates MassHealth, the Massachusetts Medicaid program statutorily known as the Division of Medical Assistance. G.L. c. 118E, §1, et seq. Section 11 requires MassHealth to "cooperate with the appropriate federal authorities in the administration of Title XIX, under which federal funds are available to the commonwealth for Medicaid, and accept for the commonwealth any benefits thereof." G.L. c. 118E, § 11. As such, MassHealth is required to comply with federal mandates involving Medicaid and including EPSDT.

The EPSDT guide for the states that was issued in June 2014 provides that,

[t]he determination of whether a child needs personal care services must be based upon the child's individual needs and provided in accordance with a plan of treatment or service plan. Under regular State Plan Medicaid, no Medicaid payments are available for personal care services provided by the child's legally responsible relatives[]. In addition, the determination of whether a child needs personal care services must be based upon the child's individual needs and a consideration of family resources that actually – not hypothetically – available.

Page 15 of Appeal No.: 2303905 REHEARING DECISION

Exhibit 24 at 13 (emphasis added). Nowhere in the EPSDT guidance is the broad term, "family resources," defined. *See* Exhibit 24. This term could include financial resources, physical and mental abilities, or the availability of family members other than parents. In its post rehearing memorandum of law, MassHealth conceded that the "CMS guidance issued on September 26, 2024, does not address the concept of 'family resources' in the context of EPSDT services. Additionally, the guidance does not address or discuss differences between ADL[s] and IADL[s]." *See* Exhibit 26 at 2, 8-9. Therefore, the only CMS guidance in place for personal care services is the one issued in June 2014.

Similarly, the PCA Operating Standards issued by MassHealth on May 25, 2015, provide that,

[w]hen a PCM Agency initiates a pediatric PCA evaluation request, the PCM Agency must consider the following as part of the evaluation and documentation process:

- 1) Parent(s), legal guardian(s) or designee(s) are responsible for providing oversight and care for children and directing the PCA services (see MassHealth Regulations 130 CMR 422.412(A) and 130 CMR 422.412(F)).
 - a. The MassHealth Regulations address non-covered services (130 CMR 422.412(C)) which include assistance provided in the form of cueing, prompting, supervision, guiding, and/or coaching.
 - b. A parent or "designee" (i.e. sibling, aunt, uncle, etc.) is required to be the second person when two people are required to perform a task (i.e. if a child has spastic tone due to cerebral palsy, a second person may be required for transfers).

Exhibit 25 at 62. In addition, "family resources" are not defined in the PCA Operating Standards. *Id.* The PCA Operating Standards do not distinguish between ADLs and IADLs.

The applicable PCA regulations, which were promulgated on October 13, 2023, define ADLs as "[s]uch activities [] performed by a personal care attendant (PCA) to physically assistant a member with mobility, taking medications, bathing or grooming, dressing, passive range of motion exercises, eating, and toileting." 130 CMR 422.402; see also 130 CMR 422.410(A). The PCA regulations mention parental responsibility only with respect to IADLs and not ADLs. Section 130 CMR 422.410(C), which addresses the determination of the number of hours for physical assistance, states:

In determining the number of hours of physical assistance that a member requires under 130 CMR 422.410(B) for **IADLs**, the PCM agency must assume the following.

Page 16 of Appeal No.: 2303905 REHEARING DECISION

- (1) When a member is living with family members, the family members will provide assistance with most IADLs. For example, routine laundry, housekeeping, shopping, and meal preparation and clean-up should include those needs of the member.
- (2) When a member is living with one or more other members who are authorized for MassHealth personal care services, PCA time for homemaking tasks (such as shopping, housekeeping, laundry, and meal preparation and cleanup) must be calculated on a shared basis.
- (3) The MassHealth agency will consider individual circumstances when determining the number of hours of physical assistance that a member requires for IADLs.

Section 422.410(C) plainly and specifically refers to IADLs and not to ADLs. Nothing in 130 CMR 422.000 connects assistance from family members to ADLs. *See* 130 CMR 422.410(A). "Family members" are defined as "the spouse of the member, the parent of a minor member, including an adoptive parent, or any legally responsible relative." 130 CMR 422.402. Services provided by family members are considered "non-covered services." 130 CMR 422.412(F).

Legal Analysis and Conclusion

In all appeals stemming from MassHealth action, the appellant bears the burden of proof at fair hearings "to demonstrate the invalidity of the administrative determination." *Andrews v. Division of Medical Assistance*, 68 Mass. App. Ct. 228, 231 (2006); *Merisme v. Board of Appeals of Motor Vehicle Liability Policies and Bonds*, 27 Mass. App. Ct. 470, 474 (1989). The fair hearing decision, established by a preponderance of evidence, is based upon "evidence, testimony, materials, and legal rules, presented at hearing, including the MassHealth agency's interpretation of its rules, policies and regulations." 130 CMR 610.085(A). In reaching a decision, the "hearing officer must give due consideration to Policy Memoranda and any other MassHealth agency representations and materials containing legal rules, standards, policies, procedures, or interpretations as a source of guidance in applying a law or regulation." *Id.* at 610.085(C)(3). Furthermore, the MassHealth Fair Hearing Rules provide that a hearing officer must render a decision in accordance with the law, including specifically:

... [T]he hearing officer must not render a decision regarding the legality of federal or state law including, but not limited to, the MassHealth regulations. If the legality of such law or regulations is raised by the appellant, the hearing officer must render a decision based on the applicable law or regulation as interpreted by the MassHealth agency. Such decision must include a statement that the hearing officer cannot rule on the legality of such law or regulation and must be subject to judicial review in accordance with 130 CMR 610.092.

Page 17 of Appeal No.: 2303905 REHEARING DECISION

Id. at 610.085(C)(2).

The fair hearing regulations are also clear about the hearing officer's responsibility to apply MassHealth written policies as well as its regulations in rendering a decision. Section 610.082, which pertains to the basis of fair hearing decisions states that, "[t]he hearing officer's decision is based upon evidence, testimony, materials, and legal rules, presented at the hearing, including the MassHealth agency's interpretation of its rules, policies, and regulation. (C)(3) The hearing officer must give due consideration to Policy Memoranda and any other MassHealth agency representations and materials containing legal rules, standards, policies, procedures, or interpretations as a source of guidance in applying a law or regulation." 130 CMR 610.082(A).

Regulations are legally binding rules that have the force of law, while regulatory guidance provides interpretations, clarifications, and recommendations without the same legal weight. Borden, Inc. v. Commissioner of Pub. Health, 388 Mass. 707, 723 (1983). Properly promulgated regulations have "the force of law . . . and must be accorded all the deference due to a statute." Id. Guidelines issued by an agency, on the other hand, do not have the same status as regulations adopted pursuant to the Massachusetts Administrative Procedure Act at G.L. c. 30A § 1(5). "Ordinarily an agency's interpretation of its own rule [or regulation] is entitled to great weight. . . However, this principle is one of deference, not abdication, and courts will not hesitate to overrule agency interpretations . . . when those interpretations are arbitrary, unreasonable or inconsistent with the plain terms of the rule [or regulation] itself." Finkelstein v. Board of Registration in Optometry, 370 Mass. 476, 478 (1976).

In a case directly related to MassHealth, the Court stated that, while courts give deference to the agency's interpretation of its own regulations, courts will not hesitate to overrule agency interpretations when those interpretations are arbitrary, unreasonable, or inconsistent with the plain terms of the regulation itself. *Shaw v. Sec. of Exec. Off. of Health and Human Services*, 881 N.E.2d 165 (Mass. App. 2008). In this case, MassHealth's interpretation of 130 CMR 433.408(A)(1) and (2) was that MassHealth was not responsible for the payment of services requiring prior authorization unless the provider obtained authorization *before* providing services, even if the services were later deemed medically necessary. The court rejected MassHealth's interpretation. The court reasoned, the plain meaning of 130 CMR § 433.408(A)(1) & (2) was principally concerned with the medical necessity of a request as the controlling prerequisite for payment, not that the provision of services came before authorization by MassHealth.

A hearing officer, however, does have the authority to overrule MassHealth's interpretation of its regulations if they are "arbitrary, unreasonable, or inconsistent with the plain terms of the regulation itself." Warcewicz v. Department of Environmental Protection, 410 Mass. 548, 550 (1991), see also Theophilopoulos v. Board of Health of Salem, 85 Mass. App. Ct. 90, 100 (2013) ("An agency's interpretation of its own regulations is entitled to 'considerable deference' and must be

upheld unless it is inconsistent with the plain language of the regulation or otherwise arbitrary or unreasonable."). However, *Warcewicz* and *Theophilpoulos* both discuss the authority of the court over a governmental agency, not that of an administrative law body such as the Board of Hearings. The MassHealth Fair Hearing rules are clear that, even in the instance where the legality of a law or regulation is raised by the appellant, a hearing officer's decision must still be based on the "regulation *as interpreted by the MassHealth agency.*" 130 CMR 610.082(C)(2). Here, however, the Medicaid Director has ordered the Director to determine whether parental responsibility is required: (1) for MassHealth's PCA regulations that covered ADL and IADL services under 130 CMR 422.410-412; (2) with regards to ADLs and IADLs under MassHealth's regulation pertaining to medical necessity under 130 CMR 450.204; and (3) under MassHealth's EPSDT regulation at 130 CMR 450.144(A)(1), which covers all medically necessary services listed in 1905(a) of the Social Security Act, 42 USC § 1396d(a) and (r). Exhibit 14. Indeed, the directive was "the BOH Director shall also make findings of fact and analysis on this issue using the relevant CMS guidance, which shall be provided as evidence by MassHealth at the rehearing." *Id.*

In the present appeal, I am faced with outdated federal and state guidance that predate the amended MassHealth PCA regulations. The EPSDT guidance to the states was issued in June 2014. A 57-page letter to the states was released by CMS on September 26, 2024, providing best practices for adhering to EPSDT requirements and clarifying policy implementation. This letter, however, neither addresses personal care services nor defines "family resources." The 2014 federal EPSDT guidance refers to "family resources" for personal care services but does not define it. Exhibit 24 at 12-13; Testimony. The "determination of whether a child needs personal care services must be based upon the child's individual needs and a consideration of family resources that are actually - not hypothetically - available." Exhibit 24 at 12-13 (emphasis added); Testimony. Footnote 16 for this paragraph refers to 42 CFR 440.167, which prohibits legally responsible relatives from being paid for personal care services. CMS, however, does not define "family resources" but EPSDT defines a family member to include a parent. MassHealth interprets "family resources" to be any available parent and is part of the inquiry during an assessment. Testimony. Moreover, the federal EPSDT guidance on personal care services does not distinguish between ADLs and IADLs but discusses "personal care services." Exhibit 24 at 12-13. The distinguishment of ADLs and IADLs is a "state construct" by MassHealth and "is not something [MassHealth] get[s] from the federal government through EPSDT." Testimony. Consequently, the June 2014 EPSDT guide is the only guidance available to the states for personal care services.

Similarly, the PCA Operating Standards are outdated and preceded the promulgation of 130 CMR 422.400. The state PCA Operating Standards - PCA Operating Standards XXVI A. 1. (a-d). – Revised 5-28-15, Pages 62-63 - serve as guidance to the MassHealth regulations pertaining to PCA services but were last revised on May 28, 2015. Exhibit 25. The May 28, 2015 version of the PCA Operating Standards is the most detailed guidance provided by MassHealth and CCM and PCMs and they are expected to follow these standards. Testimony. The regulations and the PCA Operating Standards are the only materials that govern PCA services in Massachusetts. Testimony.

During the rehearing, MassHealth cited subsection A(1)(b) of Section XXVI on page 62 of the PCA Operating Standards as the authority for MassHealth to impose parental responsibility for PCA services. Exhibit 25 at 62; Testimony. MassHealth believes that this section applies to both ADLs In interpreting section XXVI(A)(1) of the PCA Operating Standards, MassHealth requires parents to be the second caregiver when a second person is needed for PCA services, particularly when a second pair of hands are needed for movements and transfers. Exhibit 25 at 62-63; Testimony. There are also no specific criteria provided by the PCA Operating Standards for determining medically necessary PCA services for parental responsibility. Id.; Testimony. The MassHealth PCA regulations which do not "elaborate" on family resources as provided in the federal EPSDT guidance. Testimony. In addition, the term, "family resources," is not used in the state PCA regulations. Testimony. Parents are expected to provide evidence of actual available (or unavailable) resources (and not hypothetical) inside the home to the assessing entity. See id. There are no specific criteria that would give further context to "reasonable parental resources." Id.; Testimony. Meanwhile, "family resources" was not incorporated in the 2023 amendment of the MassHealth PCA regulations and "family members [providing] assistance" is referenced only in the section (C) pertaining to IADLs. 130 CMR 450.410(C).

Given the above, it would be erroneous of me to give "due consideration" to the PCA Operating Standards when they were issued seven to eight years prior to the 2023 amendments and are therefore superseded by the recently amended PCA regulations. As such, I find that these operating standards are outdated and no longer provide the interpretive guidance needed for the current PCA regulations. Moreover, I also find that the EPSDT guidance for the states, which was issued in June 2014, and requires the consideration of "family resources," is superseded by the 130 CMR 422.410-412. I must render a decision in accordance with the PCA regulations - 130 CMR 422.000 - which are silent as to family assistance for medically necessary PCA services for ADLs. In contrast, the plain terms of the PCA regulations provide that family assistance must be considered for IADLs only. See 130 CMR 422.410(C). Therefore, I find that the appellant has met her burden in demonstrating that, under the PCA regulations, parental responsibility is not required for medically necessary PCA services for ADL under 130 CMR 422.410-412. I find that MassHealth erred in considering parental responsibility as the second caregiver for the repositioning and transfer of the appellant, of which both tasks that are considered ADLs under the State PCA regulations.

After rehearing this appeal, and for the foregoing reasons, the appeal is hereby APPROVED.

Order for MassHealth

Complete a new and in-person assessment of the appellant and her need for PCA hours for transfers and repositioning without considering parental responsibility and family resources. This new assessment must be completed within 30 days of this decision.

Page 20 of Appeal No.: 2303905 REHEARING DECISION

Implementation of this Decision

If this decision is not implemented within 30 days after the date of this decision, or if you experience problems with the implementation of this decision, you should report this in writing to the undersigned Director of the Board of Hearings at the address on the first page of this decision.

Macy Lee Director of the Board of Hearings

cc:

Michael D'Angelo Assistant General Counsel

Linda Phillips, RN Associate Director, Appeals and Regulatory Compliance Commonwealth Medicine UMass Chan Medical School