

# Office of Medicaid BOARD OF HEARINGS

**Appellant Name and Address:**



<b>Appeal Decision:</b>	Approved-in-part; Dismissed-in-part	<b>Appeal Number:</b>	2176435
<b>Decision Date:</b>	10/26/2021	<b>Hearing Date:</b>	09/30/2021
<b>Hearing Officer:</b>	Casey Groff	<b>Record Open to:</b>	10/06/2021

**Appearance for Appellant:**



**Appearance for MassHealth:**

Mary Jo Elliot, R.N., Optum/MassHealth



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

# APPEAL DECISION

<b>Appeal Decision:</b>	Approved-in-part; Dismissed-in-part	<b>Issue:</b>	Personal Care Attendant Services
<b>Decision Date:</b>	10/26/2021	<b>Hearing Date:</b>	09/30/2021
<b>MassHealth's Rep.:</b>	Mary Jo Elliot	<b>Appellant's Rep.:</b>	██████
<b>Hearing Location:</b>	Telephonic	<b>Aid Pending:</b>	Yes

## Authority

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

## Jurisdiction

Through a notice dated August 4, 2021, MassHealth informed Appellant, a minor, that it was modifying his request for personal care attendant (PCA) services. See 130 CMR 450.204.(A)(1) and Exhibit 1. Appellant's mother filed a timely appeal on behalf of Appellant on August 12, 2021. See 130 CMR 610.015(B); Exhibit 2. Modification of a prior authorization request for PCA services is a valid basis for appeal. See 130 CMR 610.032. A hearing was conducted on September 30, 2021. See Exh. 3. At the conclusion of the hearing, the record was left open until October 6, 2021 for the Appellant to submit additional evidence.

## Action Taken by MassHealth

MassHealth modified Appellant's request for PCA services.

## Issue

The appeal issue is whether MassHealth was correct in modifying Appellant's request for PCA services.

## Summary of Evidence

At the hearing, MassHealth was represented by a registered nurse/clinical appeals reviewer. Appellant was represented by his mother. All parties appeared by telephone.

Through testimony and documentary evidence, the MassHealth R.N. representative presented the following information: Appellant is a minor, under the age of 18, and has diagnoses including: hereditary sensory and autonomic neuropathy type IV, legal blindness, seizure disorder, insomnia, behavioral issues, hyperactive aspiration, anhidrosis, history of lacerated liver due to a fall downstairs, osteomyelitis, hyperactivity, left leg amputation, and lower extremity contractures. See Exh. 4, p. 8. On July 27, 2021, following a re-evaluation by Appellant's personal care management (PCM) agency, Appellant submitted a prior authorization (PA) request seeking approval of personal care attendant (PCA) services for 66 day/evening hours and 2 nighttime hours per night (14 hours per week) for the time period of August 17, 2021 through August 16, 2022.

Through a letter dated August 4, 2021, MassHealth notified Appellant that it approved his request for 14 hours of nighttime PCA services per week; however, it modified his request for PCA day/evening hours by approving 57 hours and 15 minutes per week. See Exh. 1. Specifically, MassHealth modified the times requested for the following activities of daily living (ADLs): (1) bathing & hair wash, (2) bladder care, and (3) "other health-related needs" i.e. assisting into pool to regulate body temperature. See Exh. 1; see also, Exh. 4, p. 19-20.

At the hearing, MassHealth overturned the modifications to bathing and bladder care, thereby approving the requested times as follows: bathing: 45x2x7, plus hair wash: 5x1x7; and bladder care: 15x7x7. The parties were unable to resolve the modification made to time requested for "other health-related needs." See Exh. 4, p. 19.

Appellant, through his PCM agency, requested 10 minutes per day, seven days per week (10x1x7) for a PCA to assist Appellant into a pool to regulate his body temperature. Id. The PCM agency noted in its PA request that due to Appellant's inability to regulate his body temperature and "per PCP's order, [Appellant] is put in a pool with water to help regulate his body temperature.... This task is medically necessary to avoid complications such as increased risk for seizures..." Id.

MassHealth did not allow any time (0x0) for this activity. The MassHealth representative testified that the requested service was not a reimbursable PCA task as it is considered "anticipatory." Putting someone in a cold pool to prevent a seizure is an emergency measure and not regarded as a first-line treatment within a standard of care – especially given the difficulties transferring the Appellant. There are other more appropriate preventative interventions, such as ensuring that he is drinking enough fluids and that he is dressed appropriately.

In response, Appellant's mother testified that her son has a rare genetic disorder that is not commonly understood. Because of its complexity, the typical first line "standards of care" that are applied in most cases do not apply here. As part of his disorder, Appellant is unable to feel pain, he is unable to sweat (anhidrosis), and he frequently experiences recurring elevations in

body temperature. His epilepsy was progressively getting worse to the point he was having daily seizures and was constantly in and out of the hospital. The seizures typically occurred mid-day when his fever would spike to 104 degrees or higher. Appellant's mother explained that she is a single mother and must work full-time to support her two sons. Having to constantly leave work to respond to the seizures was affecting her ability to maintain her job. Many attempts to reduce his seizures have been made but were without success: The family keeps the house temperature as cool as possible; his neurologist added another anti-seizure medication; they use Tylenol for fevers, but if it is not administered in the right window, the seizure will occur before the medication takes effect; and they have also tried to apply ice packs or a wet cloth. Because the seizures continued despite such efforts, Appellant's neurologist recommended they place Appellant in a kiddie pool of cool water every afternoon when his temperature tends to spike. Appellant's mother testified that once they began the pool, Appellant went from having seizures every other day, to basically having no seizures. This has been the only intervention that consistently and dependably works. Because of its effectiveness, the neurologist has made daily pool sessions a standing order to maintain Appellant's health. Appellant's neurologist wrote a letter in support for PCA assistance with helping Appellant into the pool, which had already been submitted to the PCM agency when conducting the re-evaluation.

During a record-open period following the hearing, Appellant's mother submitted a copy of the letter, written by Appellant's treating neurologist, Sarah Spence, MD, PhD. In the letter, Dr. Spence provided the following additional details about Appellant's condition and the need for increased PCA assistance for getting him in the pool:<sup>1</sup>

[Appellant] is a child followed in my clinic at Boston Children's [Hospital]. [He] has a very complex neurodevelopmental and medical history including congenital insensitivity to pain with self-injury which has resulted in multiple injuries as well as self-mutilation, fractures and severe burns. He also has communication disorder, global developmental delay, vision impairment, epilepsy, eating disorder (G-tube dependent) and significant behavioral dysregulation. He frequently self-injures his limbs resulting in open wounds that do not heal and resistant infections including multiple episodes of osteomyelitis. These injuries ultimately required an amputation of his lower leg, but he still has not allowed the stump to heal so cannot use a prothesis and requires a wheelchair.

....  
I am writing to request an increase in his PCA hours.....He does have hours that happen in the morning where the [PCA] helps [his] mom get him downstairs ***but I am requesting an additional 1-2 hours be added to his PCA allowance for someone to come and help his mother get him up and down the stairs later in the day and assist in carrying him to the pool to keep his temperature down for health.....***

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<sup>1</sup> The letter also detailed how Appellant's home (which was provided by Habitat for Humanity) is not adequately designed to accommodate Appellant's mobility needs, and as a result, Appellant requires assistance being carried up and down the stairs by multiple people at once given his weight and size. There are efforts being made to help Appellant and his family move into a more appropriate housing situation.

See Exh. 5 (emphasis in original).

## **Findings of Fact**

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

1. Appellant is a minor, under the age of 18, and has diagnoses including: hereditary sensory and autonomic neuropathy type IV, legal blindness, seizure disorder, insomnia, behavioral issues, hyperactive aspiration, anhidrosis, history of lacerated liver due to a fall downstairs, osteomyelitis, hyperactivity, left leg amputation, and lower extremity contractures.
2. On July 27, 2021, following a re-evaluation by his PCM agency, Appellant submitted a PA request seeking approval of PCA services for 66 day/evening hours and 14 nighttime hours per week for the period of August 17, 2021 through August 16, 2022.
3. In the PA request, the PCM agency requested 10 minutes per day (10x1x7) for “other health-related needs” because “per PCP’s order, [Appellant] is put in a pool with water to help regulate his body temperature.... [and this] task is medically necessary to avoid complications such as increased risk for seizures...” and inability to regulate his body temperature.
4. Through a letter dated August 4, 2021, MassHealth notified Appellant that it approved his request for 14 hours of nighttime PCA services per week; however, it modified his request for PCA day/evening hours by approving 57 hours and 15 minutes per week.
5. In making its determination, MassHealth denied the time requested for “other health-related needs” i.e. assisting Appellant into a pool to regulate body temperature; and also reduced the times requested for the ADLs of bathing and bladder care.
6. At the hearing, MassHealth overturned the modifications to bathing and bladder care, but upheld its decision to not approve any time for pool assistance.
7. As part of his rare genetic disorder, Appellant is unable to feel pain, he is unable to sweat (anhidrosis), and he frequently experiences recurring elevations in bodily temperature.
8. Appellant’s seizure activity, which had been getting progressively worse over time, would typically occur mid-day when his temperature would drastically elevate to 104 degrees or higher.
9. To address the increased seizures, Appellant’s neurologist from Boston Children’s Hospital ordered daily episodes for Appellant to be assisted into a small pool of cool water for regulation of body temperature and seizure prevention.

10. The physician order to use the pool was made after trying many other interventions – such as additional anti-seizure medications which had not been totally effective.
11. Use of the pool has been the only effective intervention for reducing the frequency of seizures.
12. In a letter submitted into evidence, Appellant’s treating neurologist wrote to request “an additional 1-2 hours be added to his PCA allowance for someone to come and help his mother get [Appellant] up and down the stairs later in the day and assist in carrying him to the pool to keep his temperature down for health.....” See Exh. 5.

## **Analysis and Conclusions of Law**

MassHealth will pay for personal care attendant (PCA) services to eligible members who can appropriately be cared for in the home, so long as the following conditions are met:<sup>2</sup> First, the services must be “prescribed by a physician or nurse practitioner who is responsible for the member’s...care.” 130 CMR 422.403(C)(1). Additionally, the “member’s disability [must be] permanent or chronic in nature and impair the member’s functional ability to perform [at least two] ADLs ... without physical assistance.” See 130 CMR 422.403(C)(2)-(3). Finally, MassHealth must determine that the requested services are medically necessary. See 130 CMR 422.403(4). A service is “medically necessary” if:

(1) it is reasonably calculated to prevent, diagnose, prevent the worsening of, alleviate, correct, or cure conditions in the member that endanger life, cause suffering or pain, cause physical deformity or malfunction, threaten to cause or to aggravate a handicap, or result in illness or infirmity; and

(2) there is no other medical service or site of service, comparable in effect, available, and suitable for the member requesting the service, that is more conservative or less costly to the MassHealth agency. Services that are less costly to the MassHealth agency include, but are not limited to, health care reasonably known by the provider, or identified by the MassHealth agency pursuant to a prior-authorization request, to be available to the member through sources described in 130 CMR 450.317(C), 503.007, or 517.007.

See 130 CMR 450.204(A).

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<sup>2</sup> PCA services are defined as “physical assistance with ADLs and IADLs provided to a member by a PCA in accordance with the member’s authorized evaluation or reevaluation, service agreement, and 130 CMR 422.410.” See 130 CMR 422.002.

Medically necessary services must also “be of a quality that meets professionally recognized standards of health care and must be substantiated by the record including evidence of such medical necessity and quality.” 130 CMR 450.204(B).

Here, there is no dispute that Appellant meets all the pre-requisites to qualify for PCA services. This appeal addresses whether MassHealth allotted sufficient time, in accordance with program regulations, for Appellant to receive assistance with his activities of daily living (ADLs) to meet his health care needs. MassHealth regulations provide the following regarding the scope of ADLs within the PCA program:

(A) Activities of Daily Living (ADLs). Activities of daily living include the following:

- (1) mobility: physically assisting a member who has a mobility impairment that prevents unassisted transferring, walking, or use of prescribed durable medical equipment;
- (2) assistance with medications or other health-related needs: physically assisting a member to take medications prescribed by a physician that otherwise would be self-administered;
- (3) bathing or grooming: physically assisting a member with bathing, personal hygiene, or grooming;
- (4) dressing or undressing: physically assisting a member to dress or undress;
- (5) passive range-of-motion exercises: physically assisting a member to perform range-of-motion exercises;
- (6) eating: physically assisting a member to eat. This can include assistance with tube-feeding and special nutritional and dietary needs; and
- (7) toileting: physically assisting a member with bowel and bladder needs.

See 130 CMR 422.410.

MassHealth will reimburse for the “activity time performed by a PCA in providing assistance with the ADL.” 130 CMR 422.411. MassHealth does not, however, pay for “assistance provided in the form of cueing, prompting, supervision, guiding, or coaching.” 130 CMR 422.412(C) Based on the evidence submitted into the record, Appellant has sufficiently demonstrated that he requires the requested time for a PCA to assist him into a pool to regulate his body temperature and accordingly, to assist in preventing seizures. In the PA request, Appellant’s PCM agency requested 10 minutes of assistance once per day, seven days per week (10x1x7) to assist in providing this “health-related need.” See 130 CMR 422.410. In its August 4<sup>th</sup> notice, MassHealth did not approve any time for this intervention based on the reasoning that it is, in part, considered

an emergency measure to curb an oncoming seizure, it is “anticipatory,” and not regarded as a first-line standard of care for preventing seizures.

Appellant’s mother provided credible testimony and submitted persuasive written documentation by Appellant’s treating neurologist which demonstrated that the daily pool episodes are medically necessary and should be a covered PCA service. The evidence indicates that Appellant has rare hereditary disorder known as sensory and autonomic neuropathy type IV. This condition is marked by the inability to feel pain, sweat, or properly regulate internal body temperature. As a result, Appellant is prone to seizures when he has extreme elevations in temperature. Because of his condition, many common interventions, such as “drinking more fluids” to regulate body temperature, are not effective in Appellant’s case. After Appellant’s providers were unable to control the seizures with more traditional measures (i.e. additional anti-seizure medications), Appellant’s treating physician – a neurologist at Boston Children’s Hospital – recommended daily pool submerges to prevent the temperature spikes and corresponding seizures. Appellant’s mother persuasively testified that this intervention has been the only effective treatment and drastically reduced the occurrence of seizures, which prior to the intervention, were occurring approximately every other day. Such evidence demonstrates that the requested service is “reasonably calculated” to help prevent or alleviate the severity of Appellant’s condition (i.e. seizures) and that there is no less-costly service comparable in effectiveness. See 130 CMR 450.204(A). While scheduled pool sessions to regulate body temperature may not be a typical “first-line” treatment to prevent seizures, there is no indication that such a measure is not “of a quality that meets professionally recognized standards of health care” - especially given the unique circumstances presented by Appellant’s condition and where the requested service has been ordered by a treating physician that is familiar with, and responsible for, his care. See 130 CMR 450.204(B).

For these reasons, the appeal is APPROVED-in-part with respect to the modification of “other healthcare needs,” i.e. pool assistance. The appeal is DISMISSED-in-part with respect to the modifications of bathing/hair wash and bladder care, which were resolved by the parties at hearing.

## **Order for MassHealth**

Remove aid pending. For the PA period beginning August 17, 2021 through August 15, 2022, approve the requested time for PCA assistance with “other health-related needs” i.e. pool assistance, at 10x1x7.

In accordance with the agreements made by the parties at hearing, implement the requested time for



bathing at 45x2x7; hair wash at 5x1x7; and bladder care at 15x7x7.

## **Implementation of this Decision**

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

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Casey Groff  
Hearing Officer  
Board of Hearings

cc:

MassHealth Representative: Optum MassHealth LTSS, P.O. Box 159108, Boston, MA 02215