

Office of Medicaid BOARD OF HEARINGS

Appellant Name and Address:



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| Appeal Decision: | Denied | Appeal Number: | 2409855 |
| Decision Date: | 9/11/2024 | Hearing Date: | 07/30/2024 |
| Hearing Officer: | Alexandra Shube | | |

Appearance for Appellant:



Appearances for MassHealth:

Via telephone:

Alba Beltre – Tewksbury MEC
Eileen Cynamon, BSN, RN – DES
Kathleen Mello, BSN, RN – DES



*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

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| Appeal Decision: | Denied | Issue: | Kaileigh Mulligan Program – Clinical Eligibility |
| Decision Date: | 9/11/2024 | Hearing Date: | 07/30/2024 |
| MassHealth's Reps.: | Alba Beltre; Eileen Cynamon; Kathleen Mello | Appellant's Rep.: | Father |
| Hearing Location: | Tewksbury MassHealth Enrollment Center Remote | Aid Pending: | No |

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 May 31, 2024, MassHealth informed the appellant that he was not eligible for MassHealth Standard or CommonHealth because he did not meet MassHealth's disability requirements for the Kaileigh Mulligan program (Exhibit 1). The appellant filed this appeal in a timely manner on June 25, 2024 (see 130 CMR 610.015(B) and Exhibit 2). Denial of assistance is valid grounds for appeal (see 130 CMR 610.032).

Action Taken by MassHealth

MassHealth denied the appellant's application for MassHealth Standard or CommonHealth because he did not meet MassHealth's disability requirements for the Kaileigh Mulligan program.

Issue

The appeal issue is whether MassHealth correctly determined that the appellant is not clinically eligible for the Kaileigh Mulligan Program.

Summary of Evidence

MassHealth was represented at hearing by a Tewksbury MassHealth Enrollment Center (MEC) eligibility worker from the over-18 unit and two nurses from Disability Evaluation Services (DES). The appellant was represented at hearing by his father. All parties appeared via telephone.

The MassHealth eligibility worker testified that MassHealth reviewed the appellant for the Kaileigh Mulligan Program. The appellant was within the income and asset limits for the program; however, based on a clinical evaluation, DES determined that the appellant was not clinically eligible for the Kaileigh Mulligan Program. The appellant has been deemed disabled for the purposes of MassHealth CommonHealth, but MassHealth needs a CommonHealth application which would be handled by the under-18 unit. Even though the appellant is a minor child under the age of 18 the Kaileigh Mulligan Program, which serves individuals who would be institutionalized, is handled by the over-18 MassHealth unit.

The DES representative testified as follows: MassHealth offers the Kaileigh Mulligan Program to enable certain severely disabled children under the age of 18 to live at home with their parent(s) and to have MassHealth eligibility determined without counting the income and assets of their parent(s). She noted that in March 2020 during the COVID-19 Public Health Emergency (PHE), MassHealth put protections in place that prevented members' MassHealth coverage from ending. Once the protections put in place during the PHE ended on April 1, 2023, MassHealth members had to renew their health coverage to ensure they still qualified for their current benefits.

Pursuant to regulation 130 CMR 519.007(A)(3) and (4), to be clinically eligible for the Kaileigh Mulligan Program, the child must require a level of care equivalent to that provided in a hospital or nursing facility. Relevant to the appellant's situation, for hospital level of care, the child must have a medical need for "ongoing use of invasive medical technologies or techniques to sustain life (such as ventilation, hyperalimentation, gastronomy tube feeding), or dialysis, or both...". For skilled nursing facility level of care, the child must be non-ambulatory.

In the appellant's situation, he was initially determined disabled for MassHealth Child Disability in 2015 (with a review date of 2018) and deemed eligible for the Kaileigh Mulligan Program in 2015 for hospital level of care (with a review date of 2018). A Kaileigh Mulligan redetermination was completed in 2018 and he no longer met the program requirements for hospital or nursing facility level of care because he no longer needed

invasive medical technology and was ambulatory. The appellant's gastrostomy tube (G-tube) was discontinued in [REDACTED]. Another Kaileigh Mulligan redetermination was conducted in [REDACTED] and again, the appellant did not meet the Program requirements. Despite being deemed ineligible for the Program both in [REDACTED] and [REDACTED] his coverage remained active through the Kaileigh Mulligan Program due to the COVID-19 protections.

On April 23, 2024, DES initiated a MassHealth Child Disability review and a Kaileigh Mulligan initial review after receiving the appellant's Child Disability Supplement. The application was missing multiple provider medical records releases which were returned to DES on May 16, 2024. The appellant is a minor child under the age of [REDACTED] diagnosed with Rubinstein-Taybi Syndrome, multiple associated health conditions including right eye vision impairments, dysphagia, low tone, history febrile seizures, and developmental delays including communication delays/non-verbal. DES based its determination on medical documentation from numerous providers and the Individual Education Plan (IEP) from his school. In evaluating the appellant's eligibility for the Kaileigh Mulligan Program, DES used the Level of Care Assessment form and determined, based on provider medical documentation, that the appellant does not require the level of care equivalent to that provided in a hospital or skilled nursing facility.

Medical records from a [REDACTED] gastrointestinal visit state that there is a well-healed gastrostomy scar, indicating that the G-tube is out. Records from an [REDACTED] rehabilitative medicine visit state that the appellant "walks at household and shorter community distances..." His IEP also indicates that he is ambulatory, noting that he can jump, go down 5-6 steps, and accesses certain equipment and structures on the playground.

On May 31, 2024, after reviewing all medical records, DES determined that the appellant does not meet hospital level of care requirements as he does not require ongoing use of invasive medical technology or techniques to sustain life. He does not meet skilled nursing facility level of care requirements as he is ambulatory. A final review and endorsement of the determination was completed by a Pediatric Physician Advisor on May 31, 2024 and the Tewksbury MEC was notified of the decision.

The appellant's father testified that he has already submitted an application for MassHealth CommonHealth and is waiting on that determination. He confirmed that the appellant is ambulatory and does not use a G-tube (and has not for some time now). He inquired whether the appellant's ear tubes are considered permanent medical devices. The DES representative explained that while permanent, the ear tubes are not considered life-sustaining. The appellant's father also explained that the appellant has had recent seizure activity. He's had updated PET and CAT scans which show anomalies in his brain structure. His neurologist has changed his medications recently due to the seizures.

Findings of Fact

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

1. The appellant is a minor child under the age of ■ diagnosed with Rubinstein-Taybi Syndrome, multiple associated health conditions including right eye vision impairments, dysphagia, low tone, history febrile seizures, and developmental delays including communication delays/non-verbal (Testimony and Exhibit 5).
2. On April 23, 2024, DES initiated a MassHealth Child Disability review and a Kaileigh Mulligan initial review after receiving the appellant's Child Disability Supplement (Testimony and Exhibit 5).
3. On May 31, 2024, DES determined that the appellant was not clinically eligible for the Kaileigh Mulligan Program (Testimony and Exhibit 5).
4. On May 31, 2024, MassHealth notified the appellant that he was not eligible for MassHealth Standard or CommonHealth because he did not meet MassHealth's disability requirements for the Kaileigh Mulligan program (Testimony and Exhibit 5).
5. On June 25, 2024, the appellant timely appealed the notice (Exhibit 2).
6. The appellant does not meet hospital level of care requirements as he does not require ongoing use of invasive medical technology or techniques to sustain life (Testimony and Exhibit 5).
7. When the appellant was initially determined clinically eligible for the Kaileigh Mulligan Program in ■ he used a G-tube, which is considered invasive medical technology or a technique to sustain life (Testimony and Exhibit 5).
8. Both medical records and the appellant's father confirmed that the appellant no longer uses a G-tube (Testimony and Exhibit 5).
9. The appellant does not meet skilled nursing facility level of care because he is ambulatory (Testimony and Exhibit 5).
10. Medical records, the appellant's IEP, and his father confirmed that the appellant is ambulatory (Testimony and Exhibit 5).

11. DES has determined that the appellant is disabled and clinically eligible for MassHealth CommonHealth; however, at the time of the May 31, 2024 MassHealth notice, MassHealth had not received the appellant's CommonHealth application.

Analysis and Conclusions of Law

Pursuant to 130 CMR 519.007(A), the Kaileigh Mulligan Program enables severely disabled children under ■ years of age to remain at home. The income and assets of their parents are not considered in the determination of eligibility. The eligibility requirements are as follows:

(1) Eligibility Requirements. Children under ■ years of age may establish eligibility for the Kaileigh Mulligan Program by meeting the following requirements. They must

- (a) 1. meet Title XVI disability standards in accordance with the definition of permanent and total disability for children under ■ years of age in 130 CMR 515.001 or have been receiving SSI on August 22, 1996; and
2. continue to meet Title XVI disability standards that were in effect before August 22, 1996;
- (b) have \$2,000 or less in countable assets;
- (c) 1. have a countable-income amount of \$72.80 or less; or
2. if greater than \$72.80, meet a deductible in accordance with 130 CMR 520.028: *Eligibility for a Deductible* through 520.035: *Conclusion of the Deductible Process*; and
- (d) require a level of care equivalent to that provided in a hospital or nursing facility in accordance with 130 CMR 519.007(A)(3) and (4).

(2) Additional Requirements. The MassHealth agency must have determined

- (a) that care provided outside an institution is appropriate; and
- (b) that the estimated cost paid by the MassHealth agency would not be more than the estimated cost paid if the child were institutionalized.

(3) Level of Care that Must be Required in a Hospital. To require the level of care provided in a hospital, **the child must have a medical need for:**

- (a) direct administration of at least two discrete skilled-nursing services (as defined in 130 CMR 515.001: *Definition of Terms*) on a daily basis, each of which requires complex nursing procedures, such as administration of intravenous hyperalimentation, changing tracheotomy tubes, assessment or monitoring related to an uncontrolled seizure disorder, assessment or monitoring related to an unstable cardiopulmonary status, or other unstable medical condition;
- (b) direct management of the child's medical care by a physician or under the supervision of a physician on at least a weekly basis;

(c) ongoing use of invasive medical technologies or techniques to sustain life (such as ventilation, hyperalimentation, gastrostomy tube feeding), or dialysis, or both; and

(d) at least one of the following:

1. assistance in one or more activities of daily living (ADLs), as defined in 130 CMR 515.001: *Definition of Terms*, beyond what is required at an age-appropriate activity level; or
2. one or more skilled therapeutic services (occupational therapy, physical therapy, or speech and language therapy), provided directly by or under the supervision of a licensed therapist at least five times a week.

(4) Level of Care That Must Be Required in a Skilled-nursing Facility. To require the level of care provided in a skilled-nursing facility, **the child must be nonambulatory and meet the following requirements.**

(a) A child [REDACTED] of age or older must have global developmental skills (as defined in 130 CMR 515.001: *Definition of Terms*) not exceeding those of a [REDACTED] child as indicated by a developmental assessment performed by the child's physician or by another certified professional. In addition, the child's developmental skills level must not be expected to improve.

(b) A child less than [REDACTED] of age must have global developmental skills significantly below an age-appropriate level and such skills must not be expected to progress at an age-appropriate rate as indicated by a developmental assessment performed by the child's physician or by another certified professional.

(c) Regardless of age, the child must also require all of the following:

1. direct administration of a least two discrete skilled-nursing services on a daily basis, each of which requires complex nursing procedures as described at 130 CMR 519.007(A)(3);
2. direct management of the child's medical care by a physician or under the supervision of a physician on a monthly basis;
3. assistance in one or more ADLs beyond what is required at an age-appropriate activity level; and
4. any combination of skilled therapeutic services (physical therapy, occupational therapy, speech and language therapy) provided directly by or under the supervision of a licensed therapist at least five times a week.

(Emphasis added).

At issue in this appeal is MassHealth's determination that the appellant does not meet the clinical requirements for the Kaileigh Mulligan Program. As set forth in the regulations above, to qualify for the program there must be a showing that the child requires either hospital or skilled

nursing facility level of care. To demonstrate a need for hospital level of care, the child **must** require (among a number of other things), ongoing use of invasive medical technologies or techniques to sustain life. To demonstrate a need for skilled nursing facility level of care, the child **must** (among a number of other things) be non-ambulatory.

While the appellant has been deemed disabled and has complex medical needs, he does not meet the requirements necessary to qualify for the Kaileigh Mulligan Program. He does not require ongoing use of invasive medical technology or techniques to sustain life to demonstrate the need for hospital level of care. At hearing, his father mentioned the use of ear tubes which are permanent medical devices. MassHealth explained that the ear tubes are not considered qualifying for the Kaileigh Mulligan Program because they are not life-sustaining. The appellant's father confirmed that the appellant does not use a g-tube anymore and has not for some time. Additionally, both the appellant's medical and school records and his father confirmed that the appellant is ambulatory. As he is ambulatory, he does not meet the requirements to demonstrate the need for skilled nursing facility level of care.

For these reasons, the appellant does not meet the regulatory criteria for the Kaileigh Mulligan Program and the appeal is denied.¹

Order for MassHealth

None.

¹ The appellant has already filed an application for MassHealth CommonHealth benefits and will receive a determination from MassHealth on that application from the under-█ unit. The appellant's representative can contact MassHealth Customer Service at 800-841-2900 if he has questions regarding MassHealth CommonHealth.

Notification of Your Right to Appeal to Court

If you disagree with this decision, you have the right to appeal to Court in accordance with Chapter 30A of the Massachusetts General Laws. To appeal, you must file a complaint with the Superior Court for the county where you reside, or Suffolk County Superior Court, within 30 days of your receipt of this decision.

Alexandra Shube
Hearing Officer
Board of Hearings

MassHealth Representative: Sylvia Tiar, Tewksbury MassHealth Enrollment Center, 367 East Street, Tewksbury, MA 01876-1957
UMass/Disability Evaluation Services, Attn: DES Appeals Unit, 333 South Street, Shrewsbury, MA 01545