



Rhode Island Executive Office of Health and Human Services
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Docket #15-847
Hearing Date: July 23, 2015

Date: July 31, 2015



ADMINISTRATIVE HEARING DECISION

The Administrative Hearing that you requested has been decided in your favor upon a de novo (new and independent) review of the full record of hearing. During the course of the proceeding, the following issue(s) and Agency regulation(s) were the matters before the hearing:

**EXECUTIVE OFFICE OF HEALTH AND HUMAN SERVICES (EOHHS)
MEDICAID CODE OF ADMINISTRATIVE RULES (MCAR)
SECTION: 0394.35 DISABLED CHILD-KATIE BECKETT
SECTION 0394.35.05 SPECIAL ELIGIBILITY CONDITIONS
SECTION 0306.15 ELIGIBILITY BASED ON DISABILITY
SECTION: 0352.15 ELIGIBILITY BASED ON DISABILITY**

The facts of your case, the Agency rules and regulations, and the complete administrative decision made in this matter follow. Your rights to judicial review of this decision are found on the last page.

Copies of this decision have been sent to the following: You (the appellant), and Agency representatives: Caridad Ramos, Michelle Bouchard, and Sharon Kernan.

Present at the hearing were: The Appellant's mother (on behalf of the appellant minor child), Michelle Bouchard, RN (Agency representative), and Margaret Kozel, MD (consultant pediatrician) and Frank Canino, PhD (consultant psychologist).

EOHHS RULES AND REGULATIONS:

Please see the attached APPENDIX for pertinent excerpts from the Executive Office of Health and Human Services Medicaid Code of Administrative Rules (MCAR).

APPEAL RIGHTS:

Please see attached NOTICE OF APPELLATE RIGHTS at the end of this decision.

ISSUE: Does the appellant child continue to meet the level of care (LOC) criteria of the Katie Becket (KB) Medical Assistance (MA) coverage group?

DISCUSSION OF THE EVIDENCE:

The Agency representative, assisted by consulting physicians, testified:

- The Agency initiated a clinical review for redetermination of eligibility in December 2014.
- The child had been receiving KB benefits since January 2012.
- Review of the available information resulted in findings that the minor child continued to meet the disability criteria as defined in Social Security listings, but did not meet the level of care required for eligibility in the KB program.
- The consultant pediatrician had reviewed the case for the last two clinical redeterminations and found that gave continuity to the assessment.
- At the time of the previous review there were some positive indicators of the progress being made, but evidence also revealed that the child still required considerable support.
- At that time she felt another year or two of treatment could be significant.
- In January 2015 a review of conditions associated with CHARGE syndrome, VSD (ventricular septal defect), and problems with aspiration pneumonia, revealed that conditions seemed stable, and did not require extra supports.
- She had previously required hospitalization for aspiration pneumonia.
- She had a mild defect in her eye which has not impaired vision.
- Her hearing loss has been addressed with hearing aids and with speech and language therapies.
- She still has some language deficits.
- At the time of the latest review her conditions appeared to either be stable and not affecting functioning, or were being addressed by the school (such as the therapies for hearing loss).
- A review of behavioral and developmental issues had also been considered.

- A report from Meeting Street OT (occupational therapy) was reviewed and compared with progress notes from her school.
- She was at grade level with respect to reading, and writing was adequate.
- She required a number of one-to-one supports.
- Her IEP identified a number of supports including speech, language, math, health, adaptive physical education, occupational therapy, and some physical therapy, as well as some type of school counseling.
- There was not sufficient information from the school to determine what behavioral issues might exist.
- A psychological report from 2014 which described her cognitive functioning as being in the borderline range with verbal reasoning at 77 and visual performance at 75.
- They did not determine overall IQ because of discrepancies in certain areas.
- That would suggest that she is not at an average level with respect to reasoning and cognition.
- Expressive and receptive language was intact, but she had some articulation difficulties.
- There was no reference to any psychiatric or psychological consultation.
- There was one mention of ADHD, but no conclusive diagnosis.
- A level of care determination would be based on a finding that if a family did not have the financial resources to take care of a disabled child at home, the child would have to be institutionalized.
- Skilled nursing care is an example of the care offered in an institutional setting.
- When establishing level of care, the reviewers look for evidence that there has been an attempt to address problems.
- They did not find information that she would be a candidate for a partial day program.
- She does not need the LOC because of her cognitive level, and her behavioral conditions have not yet been assessed to identify a level of dysfunction.
- There has been no evidence of severe, marked aggression.

- It is imperative that her conditions be addressed by a treating source that is very familiar with her challenges.
- Receptive and expressive speech is within normal range, but articulation is well below normal.
- They are looking for information which tells them what the level of intervention should be.
- It may require several visits to establish what interventions are needed.
- Clinical evaluations are done at different intervals depending upon the individual circumstances.
- The agency typically sends information regarding the next clinical review in the acceptance letter, as subsequent review dates are determined on a case by case basis.

The appellant minor's mother testified:

- The minor child is currently 8 years of age.
- She is still unable to eat by herself.
- She continues to require special food preparation and utensils.
- At the age of six, she had fourteen or fifteen hearing tests.
- A CT scan revealed malformations which resulted in hearing loss.
- Several genetic tests were performed before they were able to confirm CHARGE syndrome.
- Although she is currently using hearing aids, her articulation is still very difficult to understand.
- Generally, she is probably understood about 40% of the time.
- The hearing/speech problem does lead to some behavioral issues.
- They have an appointment with a new therapist that they will meet next week.
- The child is having a number of outbursts and becoming more physical.

- She has difficulty making friends.
- When others try to talk to her, she does not know how to interact with them.
- She definitely requires more speech therapy.
- Because of the aspiration problem, she stills requires monitoring when eating, and drinks from a closed cup.
- She needs assistance with toileting both at home and at school.
- There is increasing concern about her behavior, especially pushing and other expressions of frustration.
- They have had some difficulty finding an appropriate therapist because her poor articulation has been a barrier to communication with treatment providers.
- She still requires a significant amount of speech therapy, physical therapy and occupational therapy.
- She has difficulty sitting still, and often gets up and runs.
- She has been hospitalized in the past, and has had several endoscopies to evaluate her condition.
- The parents are very worried about her mental state at this time.
- She frequently talks to herself, and has outbursts.
- The behavioral challenges are more noticeable as she ages.
- It is difficult for her to function independently when she cannot be understood.
- The last psychologist that they sought help from, dismissed her because of her language.
- She is able to use a little sign language, and can read lips.
- There is no evidence of improvement when considering the services she receives from her school as they have not taken any of the supports away.
- She needs much more than the school has to offer.
- Katie Beckett has been providing some of those additional therapies such as speech, PT, OT and therapeutic riding.

- Meeting Street School has shut down their program, which is why they are looking for new treating sources.
- They are trying to get speech therapy at Hasbro, but there is a long waiting period.
- They are going to meet with a new speech therapist to get a sense of whether or not she is the best resource to work with the child.
- She had believed that she had another year to obtain evaluation for the clinical review.

FINDINGS OF FACT:

- The appellant minor's case was prepared for redetermination of eligibility for Medical Assistance (MA) through the Katie Beckett (KB) coverage group in December 2014.
- Following a clinical review of the evidence submitted, the Agency issued a letter of denial dated April 1, 2015 indicating that the child met the disability requirements according to applicable Social Security regulations, but that she did not meet the requisite level of care (LOC) criteria for KB Medical Assistance (MA).
- The appellant's mother filed a timely request for hearing on her behalf, which was received by the Agency on April 8, 2015.
- The appellant's mother has established that she requires substantial monitoring, interventions, and supportive therapies secondary to her combination of physical impairments, and is pending evaluation for behavioral health.
- The agency has not supported their findings relative to the evaluation of level of care criteria resulting in a decision to terminate eligibility for the Katie Beckett Medical Assistance coverage group.
- A de novo review of the available records and testimony reveals that the minor child's conditions may have changed, but the impact of the combination of her impairments has not been reduced.
- The minor child continues to require help with all activities of daily living, an individualized education program, safety awareness, occupational therapy, speech and language therapy, and physical therapy.
- Impact of the child's needs on the family is a factor in this case.
- The appellant continues to meet the requirements of eligibility for Medical Assistance through the Katie Beckett coverage group.

THE EVIDENCE RECORD:

- ✓ A Physician Evaluation for Katie Beckett coverage group dated January 5, 2015 and signed by a pediatrician, [REDACTED]
- ✓ A Parent/Guardian Questionnaire dated December 12, 2014 signed by the mother of the appellant minor.
- ✓ Records of Boston Children's Hospital for August 12, 2013 to July 8, 2014.
- ✓ An Occupational Therapy Evaluation from Meeting Street dated January 15, 2013.
- ✓ IEPs from [REDACTED] for June 5, 2013 through June 4 2015.
- ✓ A school progress report for IEP dated June 4, 2014 to June 4, 2015.
- ✓ A Psychological report dated March 24, 2014 and signed by school psychologist, [REDACTED].
- ✓ An educational evaluation dated April 29, 2014 to May 2, 2014 and signed by special education diagnostician, [REDACTED].
- ✓ A social history re-evaluation completed on March 20, 2014 and signed by a licensed clinical social worker, [REDACTED].
- ✓ An occupational therapy evaluation dated April 2, 2014 to May 1, 2014, and signed by occupational therapist, [REDACTED].
- ✓ A speech and language evaluation dated April 17, 2014 and signed by speech therapist, [REDACTED].
- ✓ A West Bay Collaborative physical therapy evaluation dated April 15, 2015 and signed by physical therapist, [REDACTED].
- ✓ Hearing Testimony.

The mother of the minor child has been in the process of seeking new treating sources and entering on waiting lists for evaluations and services that could improve the understanding of her daughter's impairments and identify more intensive therapies. She explained that she was unaware that a clinical assessment of the child's progress would be required in January 2015, as she anticipated that she would have another year to obtain medical evidence. The agency representative stated that they typically notify clients at the time of approval, when the next clinical redetermination will be conducted. Although the agency representative assumed that action had been taken, the 2014 letter communicating the actual date of the next medical review was not provided as evidence. The appellant's mother was clearly taking steps to prepare her documentation of the case facts for a two year redetermination as she had done in the past. The agency did not arrange an adjustment conference to clarify the procedure and regulations after the appeal was filed according to agency policy 0110.20.05.

The Katie Beckett Unit is considered a non-examining source when evaluating impairments of disabled children. In other words, greater weight of opinion is given to the physicians, and therapists (treating and examining sources) who are actually working with and/or treating the child. In this matter, the agency representative did not present information about the process used to evaluate the facts of this case, and did not identify the regulatory standard used to decide that the child the agency previously found qualified for KB benefits (on two separate occasions) had improved to the degree that she no longer met the requirements. There was no claim that prior decisions were erroneous or flawed in any way. The agency had a responsibility to compare the

medical findings from the last favorable decision to the current information and complete the Social Security Administration's three-step evaluation for medical improvement in accordance with 20 CFR 416.994a at the time of redetermination. That process was not described at hearing, but the documented outcome was that the child had not medically or functionally improved, and that she continued to meet the disability criteria according to the federal regulations. The denial resulted at a subsequent step, which was the determination of level of care.

The parameters of the program indicate that the child must require a level of care that would ordinarily be available at a hospital or skilled nursing facility, which the reviewers determined had been the case in the past. The agency found that based on the information submitted at the time of the second redetermination, it was not proven that the minor child continues to require the skilled services necessary for continuation of KB MA. The mother representing the appellant child did not agree with the agency's findings, and was seeking a more specific explanation regarding the evaluation criteria. She alleged that the impact of her daughter's conditions was not fully considered, and explained that she is continuing to seek additional assessment of her daughter's impairments.

The agency testimony was primarily devoted to statements about the content of the records submitted. Although some definition of the level of care was mentioned in the denial notice, presenters did not clearly identify the standard of review used when determining that the minor child's status had changed, nor did they make any distinction between an initial finding and a redetermination.

According to pediatrician, [REDACTED] (a treating source of the appellant deserving of great weight of opinion in accordance with the regulations), the appellant minor has primary diagnoses requiring specialized care and support beyond those of a typically developing child of similar age including developmental delays, CHARGE syndrome, VSD with cardiomyopathy, and a hearing deficit. The existence of those impairments have been supported by acceptable clinical and diagnostic testing and evaluations. In addition, the child has been treated for eosinophilic esophagitis (a chronic immune system disease) impacting her ability to swallow when eating or drinking, food allergies, and colobomas (an eye abnormality). The mother of the appellant minor has also described in detail the speech and language challenges she faces, and the extraordinary impact that her communication deficits has on her safety, participation in treatment sessions and educational activities, and ability to make friends and mature socially.

The appellant minor's mother testified regarding her daughter's developmental delays. Her conditions impair her ability to carry out activities of daily living (ADLs) independently. The pediatrician affirmed that motor, speech, and social delays, and a swallowing disorder result in her need for assistance with all ADLs, such as dressing, bathing, toileting, and eating, as well as needing help with homework, and socialization. Parallel supports are arranged during school hours. She is currently age eight, and is significantly delayed in refining speech articulation because of her hearing impairment. Recent use of hearing aids may help in the long term, but she essentially has to unlearn some of her current habits and relearn more precise articulation techniques.

Additionally, the supports in place from physical therapy, occupational therapy and speech pathology have not been eliminated or reduced. She still requires considerable instruction, practice, and supervision to master everyday functions, and to protect her safety.

As the child ages, some of her challenges have actually increased, as she requires more intensive therapies to compensate for the loss of time she has experienced. The speech delay alone, stands in the way of her progress toward gaining independence. The mother of the appellant minor has also testified that concerns relative to behavioral changes can now be added to the physical impairments they are working to manage. She has observed more outbursts, physical pushing, and other expressions of frustration at an age when acquiring an understanding of acceptable and unacceptable behavior is essential. Additional behavioral health intervention and treatment is being sought at this time.

CONCLUSION:

The issue to be decided is whether the available clinical evidence establishes that the appellant minor, who continues to meet the disability criteria, has also proven that the requisite LOC standards have been met to justify continuing eligibility for the Katie Becket (KB) Medical Assistance (MA) coverage group. According to 42 CFR 435.225 the child must, in absence of home and community supports be at risk for institutional placement.

A review of the Agency's policies regarding MA finds that the KB coverage group consists of certain disabled children under the age of eighteen (18) who are living at home but who require the level of care provided in a Hospital, a Nursing Facility, or an ICF/MR (Intermediate Care Facility/Mentally Retarded). The letter of denial issued in this case indicated that KB used the Social Security Administration's definition of disability. They were mandated to redetermine disability for Medical Assistance in accordance with the applicable law, including the Social Security Act and regulations (20 CFR 416.901-416.998). Federal regulations define a disabled child as a minor child who has a medically determinable physical or mental impairment or combination of impairments that could be expected to cause marked and severe functional limitations for at least twelve months. In this matter, the Agency medical improvement review resulted in a finding that the appellant minor's impairments continued to meet or equal the requirements as in previous years. Consequently, eligibility for KB MA benefits at the time of the latest redetermination depended upon whether or not the available evidence and testimony could establish that the child continues to meet the LOC characteristics. The LOC is evaluated by determining if, in the absence of appropriate home and community interventions and supports, the child would either reside in an institutional facility or be at immediate risk for such placement. The reviewers typically look for types of therapies carried out in such situations.

There is no dispute that the appellant child is under the age of 18, living in her parents' home, and has been diagnosed with a combination of severe conditions which rise to a level of impairment as defined by the Social Security listings. At the current time, evidence indicates that she is challenged physically and mentally, and that her impairments impact her functioning affecting major life activities including self-care hygiene, eating and drinking. Learning and cognition has been slowed by hearing loss and language delays. Although she is now using hearing aids that should enable her progress, she has a significant amount of catching up to do, and the progression is slow. Socially, she is also affected by deficits in articulation limiting communication with friends, and even with treatment providers. Her parents worry about her safety secondary to communication issues, as well as physical limitations and fragility, and emerging behavioral changes. The family is beginning to take steps to help her take control of her behavior. Clearly, expressions of frustration and outbursts are believable, and understandable in the context of her restrictions.

Evidence and testimony has established that the minor child requires extensive monitoring throughout the day. Observations and assessments of her capabilities continue to be essential to actively manage her care. While some of her conditions have stabilized, others are becoming more complex with age. The child's impairments

significantly interfere with ADLs, and she requires help daily with bathing, dressing, toileting, feeding, getting on and off of the school bus, and changing locations within the school setting. All of the special accommodations are time consuming, and have a substantial impact on the family as well as education and therapy providers. She still needs a significant amount of occupational therapy, physical therapy, and speech and language therapy. The needs of the family when caring for the child at home even with use of community services must be considered. The special needs of the child's care clearly impact the family, and specialized interventions and therapies continue to be used to manage daily living, safety, and health.

After a careful review of the Agency's policies, as well as the evidence and testimony given, this Appeals Officer finds that based on the available evidence, the Agency has not supported the findings relative to the evaluation of LOC criteria discontinuing eligibility for the Katie Becket Medical Assistance coverage group. The appellant remains disabled according to 20 CFR 416.901-416.998 of the Social Security Act and, the agency has not met the burden to provide proof of progress that would justify closure of the KB case according to LOC characteristics outlined in 42 CFR 435.225. The appellant's request for relief is therefore granted. The Agency has authority to set a new redetermination date as deemed appropriate for a case of this type, and to inform the appellant of the timeframe for review to allow opportunity to access documentation of updated information relative to her impairments and/or new diagnoses.

Pursuant to DHS Policy General Provisions section 0110.60.05, action required by this decision, if any, completed by the Agency representative must be confirmed in writing to this Hearing Officer.



Carol J. Ouellette
Appeals Officer

APPENDIX

MEDICAL ASSISTANCE**0394.35 DISABLED CHILD-KATIE BECKETT**

REV:08/2006

This coverage group consists of certain disabled children under the age of nineteen (19) who are living at home and who would qualify for Medical Assistance if in a medical institution.

"Katie Beckett" coverage requires that the child meet special eligibility conditions in addition to financial eligibility.

A child under 19 years of age who is living at home but who is in need of the level of care provided in a hospital, Nursing Facility, or Intermediate Care Facility for Mental Retardation, has his/her Medical Assistance financial eligibility determined as if s/he were actually institutionalized. ONLY THE CHILD'S OWN INCOME AND RESOURCES ARE USED IN THE DETERMINATION OF FINANCIAL ELIGIBILITY. THE INCOME AND RESOURCES OF THE CHILD'S PARENTS ARE NOT DEEMED TO BE AVAILABLE TO THE CHILD. A "Katie Beckett" child is deemed Categorically Needy for the full scope of medical services. The purpose of "Katie Beckett" coverage is to make Medical Assistance for home care available to children who might otherwise be disqualified due to the parents' income.

0394.35.05 Special Elig Conditions

REV:08/2006

To be eligible for Katie Beckett coverage, it must be determined that:

- o **The child requires the level of care provided in a hospital, a Nursing Facility, or an ICF-MR.** The DHS worker must assure that a completed assessment of the child's needs is sent to the Center for Child and Family Health (CCFH). This unit has the responsibility of determining the level of care and disability status for the child and the specific time frame for re-evaluation.
- o The level of care provided at home is appropriate for the child;
- o The estimated cost to Medical Assistance for providing the appropriate level of care at home does not exceed the cost to Medical Assistance for providing care in an institutional setting.

If the child meets these special eligibility conditions and is otherwise eligible, the DHS worker authorizes medical coverage.

Children eligible for Medical Assistance under this coverage group may be enrolled in a Rite Care Health Plan in accordance with provisions contained in Section 0348, if they are not otherwise covered by a third party health insurance plan.

0306.15 Eligibility Based on Disability

REV:06/1994

To be eligible for Medical Assistance because of permanent or total disability, a person (adult or child) must have a permanent physical or mental impairment, disease or loss, other than blindness, that substantially precludes engagement in useful occupations within his/her competence.

A physical or mental impairment is an impairment which results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable, clinical and laboratory diagnostic techniques.

For purposes of eligibility, an individual is disabled if s/he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or which has lasted, or can be expected to last for a continuous period of not less than twelve (12) months or, **in the case of a child, if s/he suffers from any medically determinable physical or mental impairment of comparable severity.**

Statements of the applicant, including the individual's own description of the impairment (symptoms) are, alone, insufficient to establish the presence of a physical or mental impairment.

0352.15 ELIGIBILITY BASED ON DISABILITY

REV:07/2010

- A. To qualify for Medical Assistance, an individual or member of a couple must be age 65 years or older, blind or disabled.
- B. The Department evaluates disability for Medical Assistance in accordance with applicable law including the Social Security Act and regulations (20 C.F.R sec. 416.901-416.998).**
1. For any adult to be eligible for Medical Assistance because of a disability, he/she must be unable to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or which has lasted, or can be expected to last for a continuous period of not less than twelve (12) months (20 C.F.R. sec. 416.905).
 2. The medical impairment must make the individual unable to do his/her past relevant work (which is defined as "work that you have done within the past 15 years, that was substantial gainful activity, and that lasted long enough for you to learn to do it" (20 C.F.R. sec. 416.960(b)) or any other substantial gainful employment that exists in the national economy (20 C.F.R. sec. 416.905).
 3. The physical or mental impairment must result from anatomical, physiological, or psychological abnormalities which can be shown by medically acceptable clinical and laboratory diagnostic techniques. The individual's statements alone are not enough to show the existence of impairments (20 C.F.R. sec. 416.908).

NOTICE OF APPELLATE RIGHTS

This Final Order constitutes a final order of the Department of Human Services pursuant to RI General Laws §42-35-12. Pursuant to RI General Laws §42-35-15, a final order may be appealed to the Superior Court sitting in and for the County of Providence within thirty (30) days of the mailing date of this decision. Such appeal, if taken, must be completed by filing a petition for review in Superior Court. The filing of the complaint does not itself stay enforcement of this order. The agency may grant, or the reviewing court may order, a stay upon the appropriate terms.