



**STATE OF WISCONSIN
Division of Hearings and Appeals**

In the Matter of

[Redacted]
[Redacted]
Redact
[Redacted]

DECISION

MKB/165511

PRELIMINARY RECITALS

Pursuant to a petition filed April 17, 2015, under Wis. Stat. § 49.45(5), and Wis. Admin. Code § HA 3.03(1), to review a decision by the Bureau of Long-Term Support in regard to Medical Assistance, a hearing was held on May 13, 2015, at Medford, Wisconsin.

The issue for determination is whether the petitioner continues to require the level of care needed to remain eligible for medical assistance under the Katie Beckett exception to the program.

There appeared at that time and place the following persons:

PARTIES IN INTEREST:

Petitioner:

[Redacted]
[Redacted]
Redact
[Redacted]

Respondent:

Department of Health Services
1 West Wilson Street, Room 651
Madison, Wisconsin 53703

By: *Redact*, R.N.
Bureau of Long-Term Support
1 West Wilson
Madison, WI

ADMINISTRATIVE LAW JUDGE:

Michael D. O'Brien
Division of Hearings and Appeals

FINDINGS OF FACT

1. The petitioner is a resident of Taylor County.
2. The petitioner was born in October 2000. She is 14 years old.

3. The petitioner is diagnosed with Recessive Dystrophic Epidermylosis Bullosa, a genetic disorder where the skin fails to produce collagen, which causes its three layers to fail to adhere to each other and blisters consisting of blood or other fluid to form. These blisters tear off when friction is applied.
4. The petitioner's blisters are affected by her diet, the temperature, and the humidity.
5. The petitioner's parents and other caregivers must pierce and drain any blister as soon as they see it to prevent it from combining with other blisters to form a larger blister. They must then cover the blister with a special ointment and foam dressing to prevent infection. In addition, when any fluid forms they must identify whether it is an infection and if so take the child to the doctor. At least some of the petitioner's bandages must be changed each day. Whether the bandages on a particular blister must be changed depends upon whether it is an open wound or has the roof of the blister on it. These skills were taught to the petitioner's parents by a dermatologist and neonatal nurse.
6. Since the department found her eligible in August 2013, the petitioner's hands have become more constricted and webbed. She cannot pick up a can of pop.
7. Since the department found her eligible in August 2013, the petitioner has had surgery on her esophagus and her ability to swallow has deteriorated.

DISCUSSION

The petitioner is a 14-year-old girl diagnosed with Recessive Dystrophic Epidermylosis Bullosa, a genetic disorder where the skin fails to produce collagen, which causes its three layers to fail to adhere to each other and leads to the formation of blisters consisting of blood or other fluid. She has received medical assistance under the Katie Beckett waiver on and off for most of her life. This waiver is meant to save government funds by allowing disabled children who would otherwise be in an institution to receive medical assistance while living at home with their parents. 42 U.S.C. §1396a(e)(3)(b)(i); 42 C.F.R. §435.225(b)(1); Wis. Stat. § 49.46(1)(d)4. The household's income and assets are not tested.

In 2007, the Division of Hearings and appeals overturned the department's attempt to end her benefits. *DHA Decision No. MKB-60/81220*. Four years later, the division upheld the department's decision to end her benefits. *DHA Decision No. MKB-60/117270*. The department later reinstated her into the program in August 2013. Now she appeals the department's decision to again end her benefits.

Eligibility depends first upon being found disabled by the Disability Determination Bureau and next upon meeting one of the levels of care: The Hospital and Nursing Home care levels are available for people with physical impairments. The SED (severe emotional disturbance) level is available for those requiring psychiatric hospitalization, and the ICF/DD1 and ICF/DD2 care levels are for individuals who suffer from mental retardation or a developmental disability.

The Disability Determination Bureau has found that the petitioner is physically disabled. She does not have any cognitive impairment or a severe emotional disturbance. The question is whether she meets the hospital or nursing home levels of care.

To meet the hospital level of care she must meet all three of the following criteria:

1. The child needs **Frequent and Complex Medical Care** that require the use of equipment to *prevent life-threatening situations*;
2. The child's complex skilled medical interventions are expected to persist for specific **Duration** of time; and

3. The child's overall health condition must require **Continuous Assessment of an Unstable and Life-Threatening Condition.**

Institutional Levels of Care. Children's Long Term Support Program in Wisconsin. P.29 (emphasis in original)

Frequent and complex care requires skilled medical care multiple times a day and must include one the following items: tracheostomy care, ventilator care, IV access, Oxygen, total parenteral nutrition, or dialysis. *Id.* The petitioner does not require any of this care, so she does not meet the hospital level of care.

To meet the basic nursing home criteria the child must have

a long-term medical or physical condition, which significantly diminishes his/her functional capacity and interferes with the ability to perform age appropriate activities of daily living at home and in the community. This child requires an extraordinary degree of daily assistance from others to meet everyday routines and special medical needs. The special medical needs warrant skilled nursing interventions that require specialized training and monitoring that is significantly beyond that which is routinely provided to children. *The intensity and frequency of required skilled nursing interventions must be so substantial that without direct, daily intervention, the child is at risk for institutionalization within a nursing home.*

Id., p.22. (emphasis in original)

The petitioner has a long-term physical condition that significantly diminishes her functional capacity and interferes with her ability to perform age appropriate activities. As noted, she is diagnosed with Recessive Dystrophic Epidermyolysis Bullosa, a genetic disorder where the skin fails to produce collagen, which causes its three layers to fail to adhere to each other and blisters consisting of blood or other fluid to form. These blisters tear off when friction is applied. The severity of her condition is affected by diet, heat, and humidity. She requires skin care that consists of replacing bandages and anti-itch ointments every day and alternating bleach and vinegar baths at least every other day. She must constantly monitor herself for new blisters, and carries a bandage kit with her everywhere, including at school. She cannot open and squeeze toothpaste or wash her own hair. Her mother pointed out that the care she receives at home is better than she would receive in a nursing home because of its thoroughness. In addition, although her parents are not trained in medicine, they have learned to perform tasks to help their daughter that are usually only performed by someone with at least a nurse's training.

Those seeking benefits generally have the burden of proving that they meet the eligibility criteria, but the petitioner did that less than two years ago, and it appears that, if anything, her condition has declined since then. Her hands have become webbed, and she had surgery on her esophagus in December 2014. It is a well-established principle that a moving party generally has the burden of proof, especially in administrative proceedings. *State v. Hanson*, 295 N.W.2d 209, 98 Wis. 2d 80 (Wis. App. 1980). The court in *Hanson* stated that the policy behind this principle is to assign the burden to the party seeking to change a present state of affairs. The department acknowledged the principle laid down in *Hanson* in *Final Decision ATI-40/87198* where Deputy Secretary Richard Lorang ruled on August 17, 1995, that in any fair hearing concerning the propriety of an agency action, the county or state agency has the burden of proof to establish that the action it took was proper given the facts of the case.

By seeking to discontinue the petitioner's benefits, the department seeks to change the present state of affairs, making it the moving party, especially since there is no evidence that the petitioner's condition has improved since the department last found her eligible. Nothing in the rules guarantees that eligibility will continue for those wrongly found eligible in the first place, but that is not what happened here. The petitioner's condition significantly diminishes her functional capacity and interferes with her ability to

perform age-appropriate activities of daily living such as brushing her teeth, washing her hair, and opening a pop can. Her skin care requires an extraordinary degree of daily assistance from her parents and others to meet daily routines and special medical needs. Her parents have received training that have increased their medical skills well beyond that of the average lay person. This training has allowed them to perform skin care that generally would require the skills of a nurse. There is no question that the skin care the petitioner receives is significantly beyond that which is routinely provided to children. Nor is there any doubt that without this care, the petitioner is at risk for institutionalization within a nursing home. I find that this evidence, which the department found sufficient to find her eligible in August 2013, is sufficient to continue her eligibility.

CONCLUSIONS OF LAW

The petitioner remains eligible for medical assistance through the Katie Beckett waiver because she continues to require care at the nursing home level.

THEREFORE, it is

ORDERED

That this matter is remanded to the Bureau of Long-Term Support with instructions to continue the petitioner's eligibility for medical assistance under the Katie Beckett waiver and to certify within 10 days that it has taken this action. If there was an lapse in the petitioner's benefits, the Bureau must reinstate her retroactive to the date her eligibility ended.

REQUEST FOR A REHEARING

You may request a rehearing if you think this decision is based on a serious mistake in the facts or the law or if you have found new evidence that would change the decision. Your request must be **received within 20 days after the date of this decision**. Late requests cannot be granted.

Send your request for rehearing in writing to the Division of Hearings and Appeals, 5005 University Avenue, Suite 201, Madison, WI 53705-5400 **and** to those identified in this decision as "PARTIES IN INTEREST." Your rehearing request must explain what mistake the Administrative Law Judge made and why it is important or you must describe your new evidence and explain why you did not have it at your first hearing. If your request does not explain these things, it will be denied.

The process for requesting a rehearing may be found at Wis. Stat. § 227.49. A copy of the statutes may be found online or at your local library or courthouse.

APPEAL TO COURT

You may also appeal this decision to Circuit Court in the county where you live. Appeals must be filed with the Court **and** served either personally or by certified mail on the Secretary of the Department of Health Services, 1 West Wilson Street, Room 651, Madison, Wisconsin 53703, **and** on those identified in this decision as "PARTIES IN INTEREST" **no more than 30 days after the date of this decision** or 30 days after a denial of a timely rehearing (if you request one).

The process for Circuit Court Appeals may be found at Wis. Stat. §§ 227.52 and 227.53. A copy of the statutes may be found online or at your local library or courthouse.

Given under my hand at the City of Madison,
Wisconsin, this 15th day of June, 2015

\sMichael D. O'Brien
Administrative Law Judge
Division of Hearings and Appeals



State of Wisconsin\DIVISION OF HEARINGS AND APPEALS

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The preceding decision was sent to the following parties on June 15, 2015.

Bureau of Long-Term Support
Division of Health Care Access and Accountability