Q and A: “Katie Beckett” Category of Eligibility for Medicaid

Question: My client, a ten year-old girl with severe mental retardation and physical disabilities, has been eligible for Medicaid for several years. She is able to live at home with her family because of the services that Medicaid covers, including personal care services, physical therapy and durable medical equipment. She qualifies under the “Katie Beckett” category of eligibility. Thus, she is eligible even though her parents’ income is too high to qualify for Medicaid. Her condition has not improved or changed for several years. Last month, however, when her eligibility was redetermined, her caseworker told her parents that she no longer qualified because she did not meet the level of care requirements.

What does this mean? Is this legal?

Answer: One of the criteria for qualifying for Medicaid eligibility under the “Katie Beckett” category of eligibility is that a child must need the level of care provided in a hospital, nursing facility or intermediate care facility for the mentally retarded. While states have some leeway to establish level of care standards, it raises concerns when they appear to tighten these standards in a way that terminates eligibility. In some cases, these actions may be illegal.

Background

Medicaid is a cooperative state/federal program that covers health care services for people with limited ability to pay for their health care. In order to qualify for Medicaid eligibility, a person must be a resident of the state in which he is applying, a citizen of the U.S. or qualified immigrant, have an income below a certain level, and fit into one of a number of categories of pregnant women and children, caretaker relatives, older individuals and individuals with disabilities.

Participating states are required to cover some of these categories of eligible individuals, such as pregnant women and infants below 133% of the federal poverty level, low income Medicare

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beneficiaries and, in most states, individuals who qualify for Supplemental Security Income (SSI). In addition, states may choose to cover certain other categories of individuals, such as pregnant women and infants below 185% of poverty, poor elderly and disabled individuals and certain women with breast and cervical cancer.

One of the options available to states is coverage of disabled children 18 or younger who are living at home but who do not qualify for SSI or other state supplementary payments for people with disabilities because their family’s income is too high. Generally, a parent’s income and resources will be considered available, or “deemed,” to a child under 21. After one month in an institution, however, there is no more deeming of parental income. When states choose to cover this category, it allows them to waive financial requirements that deem a parent’s income to a child living at home. This option is sometimes known as “TEFRA,” because the statutory provision was added by the Tax Equity and Fiscal Responsibility Act of 1982. It is also referred to as the “Katie Beckett” option, after an institutionalized, ventilator-dependent child who was unable to live at home, not for medical reasons, but because her parents income would have made her ineligible.

In order to qualify for eligibility under this category, a child must be disabled under the standards of the SSI program. In addition, if the child were institutionalized, the child must meet all the standards for eligibility for Medicaid. The statute also provides that the state have determined that the child “requires a level of care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded;” it is appropriate to provide care outside of an institution; and that the estimated amount that will be spent on care provided in the home is equal to or less than the amount that would be spent to keep the child in an institution. When states select the TEFRA option of eligibility, they must cover all individuals who meet the eligibility criteria.

The Centers for Medicare and Medicaid Services (CMS), in its State Medicaid Manual, provides some guidance for determining whether the child “requires” an institutional level of care:

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7This rule comes from the SSI program.


9Id. §1396a(e)(3)(C); 42 C.F.R. § 435.225(b)(2).

10Id. §1396a(e)(3)(B); 42 C.F.R. § 435.225(b)(1).

11States may also apply for home and community based waivers for individuals who would otherwise need the level of care provided by an ICF-MR. 42 U.S.C. § 1396n(c). States have designed these waivers for children who fit the TEFRA criteria and sometimes refer to it as a “Katie Beckett” waiver. When states operate such a waiver program, however, it is important to realize that they are able to limit the numbers of children participating. Thus, it is preferable for states to select the TEFRA option.
In determining whether the child requires a level of care provided in a hospital, skilled nursing facility or intermediate care facility, determine that the child requires the level of care appropriate to these facilities as defined in 42 CFR 440.10 (hospital), 440.40 (skilled nursing facilities) or 440.150 (intermediate care facilities).12

Inpatient hospital services are defined as services ordinarily furnished in a hospital for care and treatment of inpatients and are furnished under the direction of a physician.13 Nursing facility services, by definition, are provided only to individuals aged 21 and older and do not include services in an institution for mental diseases.14 They are services that are needed on a daily basis that must be provided on an inpatient basis and that are ordered by and provided under the direction of a physician.15 Intermediate care facility services are provided “to furnish health or rehabilitation services to persons with mental retardation or related conditions.”16 In addition, individuals in an ICF must receive “active treatment,” which is defined as a continuous program that includes “aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services . . .”17 It must be directed toward acquiring behaviors needed to function with “self determination and independence” and to prevent or slow regression.18 State statutes or regulations may also define these services. In addition, some states may draft policies to provide further details. In some cases, such policies, or application of them, may be problematic.

For example, Delaware recently revamped its eligibility criteria for Medicaid coverage of Katie Beckett children. Prior to the revision, the Delaware state Medicaid regulations tracked the framework set out in the federal regulations, without providing much further detail or guidance.19 In November

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12CMS, State Medicaid Manual, section 3589.
1342 C.F.R. § 440.10.
14Id. § 440.20.
15Id.
16440.150(a). Related conditions consist are severe, chronic disabilities that are attributable to cerebral palsy or epilepsy, or any other condition other than mental illness that is found to be closely related to mental retardation because it results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded person. It must also manifest before age 22 and be likely to continue indefinitely. Finally, it must result in “substantial functional limitations” in three or more designated major life activities: self-care, understanding and use of language, learning, mobility, self-direction and capacity for independent living. 42 C.F.R. § 435.1009.
1742 C.F.R. § 483.440(a).
18Id.
19See Delaware Division of Social Services Manual, § 17200 et seq., repealed by 5 De. Reg.
2001, Delaware finalized new regulations for determining Medicaid eligibility for this category of children, which defined different “levels of care” and set forth factors for consideration by the decision-maker to determine eligibility. The revised provisions include a list of ten “general level of care factors” used to assess “whether a child’s profile is consistent with a qualifying level of care.” These factors include age, environment, availability and characteristics of care giver as well as details about the child’s medical condition. The regulations also contain descriptions and lists of factors for each covered level of care, including hospital, skilled nursing facility, intermediate nursing facility, intermediate care facility for mental disease, and intermediate care facility for mental retardation. They also contain provisions that encourage a broad interpretation of the eligibility criteria for this segment of the population.

Georgia’s Department of Community Health also provides more detailed level of care criteria for hospitals, nursing facilities and ICF-MRs. For example, nursing facility level of care is described as a service that is “so inherently complex that it can be safely and effectively performed only by, or under the supervision of . . . personnel such as registered nurses, LPNs, physical therapists, and speech pathologists or audiologists.” Additional criteria specify that a service must be required five or seven days a week, or must be of a specific type, such as general maintenance care of colostomy or ileostomy.

Specific criteria are not prohibited, unless they conflict with federal law, and are undoubtedly helpful for those trying to determine eligibility. Advocates report, however, that the criteria may be applied in ways that limit eligibility. Moreover, children already determined eligible may face termination of benefits when their case is reviewed under new standards, or when already existing standards are applied more strictly.

1097 (Nov. 21, 2001).

20 Delaware Division of Social Services Manual, § 25000 et seq., published at 5 De. Reg. 1097-1101 (Nov. 21, 2001).

21 Id. at § 25250 (1).

22 Id. at § 25300.

23 Id. For example, the new regulations direct that “any benefit of the doubt concerning program qualification should be resolved in favor of eligibility.”


25 Id.
Advocates have had success challenging terminations of eligibility based on new application of level of care criteria in other contexts. For example, a federal court ordered that Kentucky’s Medicaid agency continue to provide nursing home and home and community based services to plaintiffs when eligibility was terminated based upon an emergency regulation governing level of care determinations.26 The court suggested that eligibility terminations for individuals whose conditions had not changed were suspect.

Advocates facing these issues may want to consider the following points:

**Pre-Hearing Preparation and Investigation.**

Advocates should review of the documentary evidence available about your client’s medical treatment and functional abilities and determine whether additional information would be helpful. For example:

- Gather records and statements of support from your client’s doctors, therapists, and other treatment providers.

- For children, consider school records that may demonstrate the effects of physical, cognitive, or other limitations on your client’s functional abilities and the impact of his or her medical condition on activities of daily living.

- Review the state Medicaid agency and/or managed care organization’s case file to determine what records the decision-maker considered, and whether any important factual information is missing.

- Ask for computer-generated records, including the caseworker’s narrative, which may provide information about the reasoning behind the agency’s decision, or alternatively, evidence its arbitrariness.

- Search for weaknesses in the state’s case. Research the background and credentials of the state agency’s medical witnesses, and be prepared to point out any lack of specialization or expertise in the area relevant to your client’s medical needs. Explore whether the standardized criteria used by the state agency are supported by the literature, consensus statements, and best practices relied upon by the medical community of practitioners who specialize in the treatment of your client’s needs.

**Monitor the State Medicaid Agency’s Adherence to the Administrative Procedures Act When Revising or Implementing New Regulations.**

26Kerr v. Holsinger, C.A. No. 03-68-JMH (E.D. Ky. Mar. 25, 2004) (upholding plaintiffs’ standing to enforce the Medicaid Act under § 1983; denying defendants’ motions for dismissal and summary judgment; and issuing a preliminary injunction ordering the reinstatement of benefits for plaintiffs determined ineligible under the revised regulations, and the provision of adequate notices).
Your state Medicaid agency may be subject to the strictures of your state’s administrative procedures act when issuing new or revised regulations. Typically, before implementing rules and standards of “general applicability,” the APA requires the state Medicaid agency to publish notice of the proposed rules, along with the text of the rule. Notice and text should be published in a government document, such as a state register. Usually, a deadline of submission for public comments should be listed, along with a Medicaid agency contact. Advocates may submit comments on regulatory changes to help ensure that the criteria proposed by the agency meet Medicaid beneficiaries’ interests fairly. They may also file a rulemaking petition if the state does not adhere to the administrative procedures act. Finally, when representing a client at a fair hearing, advocates can review the regulatory criteria applied by the state Medicaid agency to ensure that the standards that the agency is using are current and have been properly enacted.  

Determine Whether State Agency Policies Conflict with Federal or State Statutory or Regulatory Standards.

If your state Medicaid agency promulgates internal policies or sub-regulatory materials, analyze them to determine whether they are more restrictive than the standards contained in the federal Medicaid statute and regulations and corresponding state statutory and regulatory provisions. For example, state policies that contain blanket exclusions or limitations on services often conflict with state regulatory definitions of medical necessity that contain broader language as well as other provisions of federal Medicaid law described earlier in this article. Also, consider whether the state’s policies violate guidance issued by federal government in its State Medicaid Manual or letters to state Medicaid directors.

Advocates should monitor developments related to Katie Beckett eligibility. As states attempt to cut Medicaid costs, they may engage in further attempts to cut eligibility. It is therefore likely that more children will lose eligibility even when their medical needs have not changed.

27See, e.g., In re C.M.L., DCIS No. 8000537285, slip opin. at 4 (DHSS May 16, 2003) (reversing termination of disabled child’s Medicaid benefits on the basis that state agency’s reliance on rules that were not promulgated according to the state Administrative Procedures Act and were more restrictive than the properly enacted version of the regulations was arbitrary).