



Department of Health

and Human Services Maine People Living Safe, Healthy and Productive Lives

John E. Baldacci, Governor

Brenda M. Harvey, Commissioner

Department of Health and Human Services 221 State Street # 11 State House Station Augusta, Maine 04333-0011 Tel: (207) 287-3707; Fax (207) 287-3005 TTY: 1-800-606-0215

Katie Beckett Medicaid Coverage Option (KB) Report to the

Joint Standing Committee on Health and Human Services

AND

Joint Standing Committee on Education and Cultural Affairs

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Prepared and Submitted by:

Department of Health and Human Services

Executive Summary

In May 2009, as part of the supplemental budget Part PP, the legislature required the Departments of Health and Human Services (DHHS) and Education (DOE) to report by January, 2010, to the Joint Standing Committee on Health and Human Services and the Joint Standing Committee on Education and Cultural Affairs to determine the feasibility of adopting categories of coverage under the Katie Beckett MaineCare option for psychiatric hospital and Private Non Medical Institutions (PNMI).

The goal of this report is twofold: to respond to the request of the legislature and to gain support to further amend clinical eligibility criteria in MaineCare policy to achieve compliance with Center for Medicare and Medicaid Services (CMS) regulations.

Findings detailed in the report include:

- MaineCare cannot add coverage options to Katie Beckett KB as requested by the legislature because psychiatric hospital is already an existing category and PNMI settings do not meet CMS standards for institutional level of care.
- Implementing strategies to achieve compliance with Federal requirements for institutional level of care determinations and cost "caps" have proved challenging.

Implementation of the following recommendations would enable MaineCare Services to achieve compliance with CMS requirements so that Federal Financial Participation is not jeopardized:

1) Policy changes should be proposed for the Katie Beckett program, so that children qualifying meet eligibility standards equivalent to children clinically requiring an institutional level of care.

The Department requests legislative support to make those changes. (See Appendix A).

2) Guidance should be provided to service providers and families on the manner in which costs of services are counted against costs for each type of institutional care. A proposal has been developed for establishing threshold costs for each KB category of care and a process has been drafted for tracking claims paid and notifying families of service costs. Also, a protocol has been implemented to work with those families in danger of exceeding institutional costs through care management.

For those families actually exceeding institutional costs, we are weighing our options and request the support of the legislature to allow the latitude for the Department to respond as necessary.

Background

Katie Beckett (KB) is an optional Medicaid program that allows states to cover services at home for children with special needs whose families would not otherwise be financially eligible for Medicaid. To qualify for this special category of coverage, the child's special medical needs must reach a level where a clinician would admit the child to an institution to live for an indeterminate period of time. The Katie Beckett coverage option allows Maine to disregard the income of the parent and pay for services at home instead of in an institutional setting.

Maine has five types of Katie Beckett coverage options defined by the institutional setting that a child would otherwise reside in:

- Hospital
- Psychiatric hospital
- Nursing Facility
- Intermediate Care Facilities for Individuals with Mental Retardation (ICF-MR) with 2 subtypes
 - ICF-MR group home
 - ICF-MR nursing facility

Approximately 1700 children have been covered by the KB program in the past year. Some children transition on and off the program during the year. A chart indicating point in time enrollment by month over time follows this section. 2,151 unique children have been covered at some point by the program from January 2007 through September 2009. Including state and federal dollars, Maine spent: 29 million dollars in CY 2007, 25 million in CY 2008 and will likely spend 20 million in CY 2009 on the Katie Beckett program.

Declines in eligibility and costs have resulted from several factors, including, but not limited to:

- Some children transitioned to Supplemental Security Income (SSI)- related Medicaid because they were not living at home;
- Some children changed coverage categories due to a better match with criteria in those categories;
- Some children turned age 19 making them ineligible for the program;
- MaineCare and the Office of Integrated Access and Support (OIAS) transitioned children who turned 18 to SSI-related Medicaid promptly;
- Some children who were previously eligible were found ineligible due to changes in the psychiatric level of care standards effective 7/1/08; and,
- Some children developed needs that were no longer able to be met in a home setting and thus were admitted to institutional settings.

Additional family specific reasons cause children to no longer qualify, such as:

- The family financial situation changed and they became eligible for regular MaineCare;
- The family did not pay KB premiums, especially in circumstances where a family may have determined that the cost of premiums paid by the family exceeded payment of claims or co-pays paid by MaineCare;
- The family decided that the benefit was not needed as most costs were covered by their existing insurance coverage;
- The child's situation improved to the extent that the family determined that the coverage was no longer necessary; or,
- Other personal reasons.

Of those children found eligible for KB in all institutional levels of care:

- 62 members eligible in SFY '08 did not meet medical eligibility criteria when re-assessed the SFY '09.
- 51 members eligible in SFY '09 did not meet medical eligibility criteria when reassessed during SFY '10.



Katie Beckett enrollment

Response to the Request of the Legislature

The Department of Health and Human Services (DHHS) understands the intent of the legislation in Section PP as a request to add psychiatric hospital level of care as a category of coverage under Katie Beckett. Psychiatric hospital already exists as a category of coverage, however we are out of compliance with CMS regulations around children requiring an institutional level of care, despite policy changes made effective 7/1/08. Therefore, we would like to move forward with further policy changes.

Regarding the legislature's request to add PNMI as a coverage category, Federal regulations state that only children who would otherwise reside in Hospitals, nursing facilities and ICF-MR settings are eligible for Medicaid coverage through KB. PNMI settings are not considered an institutional setting by CMS and therefore do not meet the standard of an institutional level of care. We therefore we cannot add it as a category of coverage under KB.

DHHS' Initiative to Achieve Compliance and Preserve Federal Funding-

At the time that the budget was passed, MaineCare Services had established a Katie Beckett workgroup with representatives from several Offices within the Department as well as advocacy groups including: Maine Equal Justice Partners (MEJP), Maine Parent Federation and Maine Developmental Disabilities Council. The workgroup provided the venue to discuss strategies to address areas of noncompliance in the KB program revealed as a result of an August 2008 State audit. KB findings were determined to be significant and were forwarded to the Center for Medicaid Services (CMS) as result.

Analysis of the program revealed several key areas of concern:

- 1) policy requirements for meeting institutional level of care did not comport with clinical standards for those levels of care and therefore did not comply with Federal intent;
- 2) a "cap" or cost for institutional settings was not established as required by Federal rule, i.e., there was no mechanism to assure that children did not exceed institutional costs;
- 3) some children covered under the Katie Beckett option were not residing at home; and,
- 4) The process for determining eligibility was complex and cumbersome for families.

MaineCare has implemented strategies to shift children living away from home to SSI-related Medicaid and improve the eligibility determination process. However, implementing policy changes to become compliant with Federal institutional level of care requirements and implementing cost "caps" or thresholds to assure costs for services at home do not exceed costs for services in an institution have proved challenging.

Institutional Level of Care Eligibility Standards in Policy are Inconsistent with Clinical Standards

Nursing Facility Level of Care

Background

The policy has several references or standards that are clearly not applicable to children. An example is a provision in the current policy allowing individuals receiving therapies several times per week to qualify for a nursing home level of care. The current policy, because it was written to apply to adults, allows children to qualify for KB when they receive 5 therapies per week. This section of the nursing home policy was meant to reference rehabilitative treatment, not a habilitative therapy for children.

An example of this is where a child may have 2 sessions of speech therapy per week and 3 sessions of occupational therapy per week (or a similar type of scenario). Many children have these types of therapies, often provided in a school setting. A child would not be placed in a nursing facility under those circumstances. In 9 cases in 2008, there were no other qualifying criteria. There have been questionable cases where the services provided at school would likely not be considered medically necessary (a Federal Medicaid requirement) as they were not provided during the summer months. Once this was discovered, in a few instances reported, the assessing nurses denied continuing eligibility for KB. Parents then requested their physician order a therapy for a minimum of five times per week to qualify for the coverage. In order to ensure that children qualifying for coverage genuinely require 5 therapies per week, nurses have had to request additional records to verify medical necessity of the service. In a few cases, parents had reported recreational activities as therapies.

Recommendation

It is recommended that nursing home level of care for children be changed to reflect appropriate clinical standards for admitting a child to a nursing facility.

ICF-MR Level of Care

<u>Background</u>

ICF-MR level of care has traditionally been the Katie Beckett category with the second highest number of members. Qualifying for the coverage has been based on diagnosis and not on level of functioning. The workgroup discussed the criteria due to concern expressed that children currently qualifying for the ICF-MR level of care under the Katie Beckett coverage option would not qualify for adults services provided through the Office of Adults with Cognitive and Physical Disabilities (OACPD). The workgroup consulted with OACPD on the criteria and with internal and external members.

We recommend a standardized assessment for children to determine their level of functioning to qualify for this level of care. An amendment to the rules has been drafted that recommends the Vineland tool as the level of functioning assessment. This tool is a widely-used assessment to determine the degree to which intellectual disabilities adversely affect children.

Only one facility in Maine provides ICF-MR level of care for children. Elizabeth Levinson Center is an ICF-MR Nursing Facility (ICF-MR-NF). Children at the Center have extremely high care needs. There have traditionally been very few Katie Beckett children who qualify for the ICF-MR-NF category because the child must meet the requirements for a high level of nursing care and have a diagnosis of mental retardation. Requirements for the ICF-MR-NF level are not well defined in the Katie Beckett section of the policy.

Recommendation

We recommend that ICF-MR group home and nursing facility criteria be changed to reflect clinical standards for admission of a child to those facilities, using a standardized assessment to determine whether the child's level of functioning is adversely affected to the degree where the child would be institutionalized.

Hospital Level of Care

Background

Maine has never had any child classified at the Katie Beckett hospital level of care. Many states do not even offer this option. The workgroup considered recommending its removal as a result. However, a few of the children currently served under the KB nursing facility category could potentially qualify at this level due to their acute needs and the likelihood that a nursing facility would not agree to serve them. This level of care could be determined by a medical doctor or by nurses who assist MaineCare in finding nursing facility resources for children who require discharge from the hospital.

Recommendation

We recommend that additional level of care criteria be added to the Hospital policy for KB members with medical needs that are so acute that it would be difficult to find a nursing facility that would accept them for care.

Psychiatric Hospital Level of Care

Background

This level of care was updated effective 7/1/08. That policy change had been suggested because the Department recognized that children who had been qualifying under the psychiatric hospital level of care criteria did not have a serious emotional disturbance requiring intensive treatment. Tightening the criteria brought Maine into compliance with our state plan and saved a estimated 2.2 million per State Fiscal Year (SFY). Trends in costs attributed to KB appear to validate that estimate, however, many children who were covered under KB have moved to SSI-related Medicaid coverage as a result of streamlining efforts between MaineCare Services and the Office of Integrated Access and Supports (OIAS). Thus, costs paid for services for those children are still paid by MaineCare, but in another Medicaid category.

The following data shows the impact on eligibility of KB psychiatric hospital policy changes:

In SFY 2007-2008 (preceding policy changes effective 7/1/08),

- o 876 children were assessed and met eligibility for KB psych level of care.
- Of those, 507 were reassessed for KB eligibility in SFY 2008-2009, and
- o 51 were denied eligibility.

In SFY 2008-2009 (following policy changes),

- o 514 children were assessed and met eligibility for KB psych level of care.
- Of those, 172 have been reassessed for KB eligibility so far as of the first 6 months of SFY 2009-2010, and
- o 33 have been denied eligibility so far this SFY.

These statistics support the conclusion that denials have increased as a result of KB psychiatric hospital policy changes. However, the contracted assessment provider has reported that an increased review of supporting medical documentation due to quality assurance activities has also affected the number of denials following previous determinations that children were eligible in all KB categories.

Further Policy Changes are needed to Psychiatric Hospital Level of Care criteria

Despite the previous changes to the psychiatric hospital level of care criteria, standards for medical eligibility in the current policy remain inconsistent with clinical standards for care in a psychiatric hospital. Criteria remain diagnosis-based and include descriptions of some behavioral concerns that could be true of many children who do not have a serious emotional disturbance. Also, for some concerns identified, it is difficult to determine that they affect functioning to the degree where the child would require institutionalization.

Because two children with the same diagnosis may be affected very differently in their level of functioning, the workgroup decided that a standardized assessment of functioning for KB psych level of care would be beneficial. The workgroups recommended using the Preschool and Early Childhood Functional Assessment Scale (PECFAS) or Child and Adolescent Functional

Assessment Scale (CAFAS). The PECFAS and CAFAS are instruments that assist clinicians in determining the degree that behavioral health and substance abuse issues affect a child's ability to meet the demands of daily life. The PECFAS is used for younger children and the CAFAS is used for older children. Using the tool would improve consistency through the use of a uniform measure of functioning. Committee members having clinical expertise recommended these tools as they are widely used in behavioral health settings.

In addition to adding a clinically accepted standard for measuring functioning, the group discussed changing the diagnoses and condition criteria to more measurable indicators likely to result in admission to a psychiatric hospital. Additionally, language in the current policy makes it difficult for children who are no longer at an institutional level of care to ever lose eligibility. Current language states that the child "**would** exhibit one of the... [List of] symptoms and/or behaviors without medical intervention (e.g. medication)." This language has resulted in children who have stabilized and are functionally doing well remaining on the program even though they are clinically not at an institutional level of care. Currently, any child who has a diagnosis, a history of behavioral difficulty and takes a psychotropic medication could continue to qualify for KB until they age out of the program. Clearly, that does not meet the Federal requirement for a clinically appropriate determination that a child would reside in a psychiatric hospital without the services provided at home.

Work group members expressed concern that removing the "would" language and adding the PECFAS/CAFAS assessment might create a situation where children with complex and acute needs experiencing a period of stability could lose coverage. To address this issue, the workgroup concluded that some children with a "carefully constructed set of supports" may function well for a period of time but that the careful consideration of medical documentation by an experienced clinician could determine that without those supports that child would require a psychiatric hospitalization. Workgroup members did not want the removal of the "would" language to result in children who are stable (but have significant history) losing KB and then requiring hospitalization. As a result, the workgroup incorporated language allowing for an exception process.

Recommendation

We recommend removal of diagnosis-based criteria and the use of a standardized assessment to determine whether a child's functioning is significantly adversely affected by behavioral health needs to the extent that they would meet criteria for institutionalization in a psychiatric hospital.

Passage of the Recovery Act Complicates Efforts to Address Non-Compliance in Policy

Due to the passage of the <u>American Recovery and Reinvestment Act of 2009</u> (ARRA), in order for states to receive an enhanced federal match, they are not permitted to tighten eligibility standards or change the process of eligibility determinations in any way that would restrict eligibility beyond the standards that were in place on July 1, 2008. MaineCare was poised to propose changes to the KB ICF-MR level of care in August 2009. It was unclear, however, whether those changes could be implemented due to the "Maintenance of Effort" (MOE) requirements connected to Maine accepting the enhanced Medicaid Federal match.

Medicaid policy guidance provided to the states from CMS in July 2009, indicated that the recommended changes will not create non-compliance with the temporary, new Federal standards. However, MaineCare sent a letter to CMS requesting approval to move forward with

policy changes for ICF-MR standards relating to KB. Repressentatives of MaineCare also had a discussion with CMS policy staff regarding all the current KB policy initiatives under consideration to improve compliance with institutional level of care decisions. <u>CMS' decision states that MaineCare will not violate Federal MOE requirements</u> by continuing efforts to improve compliance with standards for institutional level of care. Thus, MaineCare will not jeopardize receipt of enhanced Federal Financial Participation due to ARRA by making recommended policy changes. (Appendix B)

No Mechanism Exists to Assure that Costs do not Exceed Institutional Costs

The internal and external workgroups met throughout 2009 to address this audit finding. The final recommendation of the workgroup, including advocates, was to implement a "threshold" amount instead of a "cap," representing the amount that the state would pay for an institutional setting and offering care management services for any child whose costs exceed 75% of the threshold at any time during the year. Advocates expressed that families are not always aware of the costs of services, especially when those services are provided at school and that providing a letter notifying the family when they reach 75% of the threshold and then offering a report of claims paid will allow the family to make decisions about efficiencies that may be implemented for the medical care of the child. Advocates noted that schools often bill Medicaid for services and that parents must give permission for schools to do so. Some advocates stated that if a parent becomes aware that services provided at school will cause their child to potentially exceed institutional costs, the parent could refuse to allow the school to bill Medicaid.

There are a small percentage of very ill children in Maine (less than 1% of the Katie Beckett population) for whom it appears that care could be covered by Medicaid more inexpensively in an institutional setting. State staff and advocates have agreed that potentially terminating eligibility of children whose costs exceed institutional costs runs counter to the concept of covering the medically neediest children. However, the intent of the Federal rule is clear that providing the Katie Beckett coverage cannot be more costly to the Federal government than the cost of institutionalization. For those families exceeding costs, we are weighing our options and request the latitude to respond as necessary.

Conclusions

The Department is unable to include PNMI as a new category of level of care for KB. Psychiatric hospital is already an existing option.

Recommendations

- 1) The Department respectfully requests legislative support for implementing policy changes to achieve compliance with Federal requirements, so that children qualifying for the Katie Beckett program meet medical eligibility standards for children requiring an institutional level of care. (See policy change summary, Appendix A).
- 2) To address the lack of cost "caps," a proposal has been developed to track claims, notify families of service costs and work with those families in danger of exceeding costs through care management. For those families exceeding costs, we are weighing our options and request the support of the legislature in allowing the latitude to respond as necessary.

We appreciate the opportunity to provide information on the Katie Beckett program and look forward to the response of the legislature regarding proposed recommendations to improve compliance.