The Katie Beckett Waiver

TennCare coverage for children with special health care needs
Who is Katie Beckett?

"Living at home is where we learn to be a part of the larger picture of life."

– Katie Beckett

1. Quote from speech given at a celebration of the 75th anniversary of the provision of the Social Security Act.
Katie Beckett’s Story

• Katie Beckett’s story brought national attention to a problem within Medicaid law. This led lawmakers to change the law, making the Katie Beckett waiver possible.

• Because of the Katie Beckett waiver, Katie was able to go home and was an advocate for home care until she passed away on May 18, 2012.

• There are many more children and adolescents with disabilities who don’t qualify for Medicaid now but who might qualify if the Katie Beckett waiver were available to them.
Why is TennCare important for Children with Special Health Care Needs?

• Compared to private insurance, TennCare covers more of the services this group needs and in the amounts that they need.
• Better for ongoing medical needs than private insurance.
• No co-pays

“Because of...exclusions on treatment and limitations on coverage and condition, privately insured families of children with special health care needs experience more problems with access to care and lower satisfaction levels than do those with public insurance”2.

Katie Beckett’s Story

“Now, by what sense do we have a regulation in government that says we’ll pay $6,000 a month to keep someone in a hospital that we believe would be better off at home, but the family cannot afford one-sixth that amount to keep them at home?”

- Ronald Reagan

What is the Problem?

• TennCare is mainly for children at lowest income levels, but children with special health care needs are found at all income levels.

• Children with disabilities are not automatically given TennCare. They also have to meet the financial eligibility criteria.

• Families who earn too much to qualify for TennCare have few options for getting it.

• Medical care for a child with a disability can cost more than most families can afford, even with private insurance.
How Might This Affect You and Your Child?

- It makes it difficult for children to get the care they need.

- It makes it harder for caregivers to care for their child because they have to worry about how to pay for care.

- It can force parents to make tough choices
  - A national survey of parents and caregivers of a child with mental illness or serious emotional disturbance found that 20% of those who responded had to relinquish custody of their child to obtain treatment for them.  

“Options” Parents Like You Have Been Given to Get TennCare For Your Child

Some of you may have been told you could:

- Put your child in an institution, even though you would rather care for them at home
- Give up custody of your child
- Quit your job or taking a lower paying job
- Divorce your spouse and live in separate households
- Move to another state
Who is Affected?
There are 255,692 children with special health care needs in Tennessee.

This is over 17% of the state’s child population.

References:
Health Care Coverage for Tennessee’s Children with Special Health Care Needs

• In a given year, about 5% of children with special health care needs in TN do not have insurance

• 26% of these children who are insured in TN have insurance that is inadequate

How Does This Effect Children and Families in Tennessee?

• 18% have unmet needs for specific health care services

• 11% don’t have a usual source of care when sick

• 15% missed 11 or more days of school due to illness

• 20% of parents said child’s condition caused financial problems for their family

• 23% said child’s conditions caused family members to cut back or stop working

Options for Tennessee
The federal government requires that states cover certain individuals under Medicaid. They also offer states optional eligibility categories they can choose to cover.

Under Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA), states have the option to make Medicaid benefits available to children with physical or mental disabilities who would ordinarily not be eligible for SSI benefits because of parent’s income and resources are too high.
The Katie Beckett Waiver

• Federal Medicaid law requires states to cover certain groups and services. It also allows states to apply for a waiver, which gives states the option to extend coverage to additional groups of people or provide extra services.

• The Katie Beckett Waiver allows states to give Medicaid (TennCare) to children with disabilities as a way of preventing institutionalization, even if their parents earn too much for them to qualify.
How Do These Options Work?

• If a child qualifies, only their income is used to decide if they are financially eligible for TennCare. Household income is not counted.

• Could my child qualify? Yes, if:
  • They meet the SSI medical criteria for disability AND…
  • A doctor says that they need a level of care that is similar to what they would get in an institution AND…
  • It is safe for them to live at home AND…
  • Caring for them at home does not cost more than caring for them in an institution.
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<th>Katie Beckett Waiver</th>
<th>TEFRA Option</th>
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<td>• The waiver can be limited to certain disabilities, geographic area, ages, etc. The state can also limit the number of slots.</td>
<td>• All children who qualify are eligible regardless of their disability, their age, where they live, etc.</td>
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<td>• The waiver can offer extra services, specific for children with special health care needs, that are not normally covered under TennCare, such as respite care, home modifications, formula, and diapers.</td>
<td>• Provides the same array of Medicaid services as all other Medicaid-eligible children.</td>
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What’s the Difference For the State?

**Katie Beckett Waiver**

- States must submit an application to the CMS central office.
- To get approval, states must demonstrate that the proposed services will, on average, cost the same or less than institutional care for the targeted population.
- The state has to show that they have the funds to provide services for all the people who will be covered under the waiver.
- The state has to monitor it as a separate program.

**TEFRA Option**

- States don't have to apply but must notify CMS central office that they are choosing to cover this category.
- States can receive federal approval promptly through their CMS regional office.
- The state does not have to show that they have the funds to expand coverage.
- The state does not have to monitor the program.
What’s the Benefit For the State?

• Covering children with significant disabilities is likely to be more cost-effective over the long term because routine preventive care is less expensive than catastrophic acute care.

• The cost of expanding coverage to this group is usually low and most children who qualify also have private insurance. Some states pay less than 25% of the total health-related costs of children on the program.

• Allowing children to have services at home instead of in an institution saves the state money. For example, in Kansas, the average annual per-child cost receiving institutional level services at home is $12,900, compared with institutional costs of $25,600.

Katie Beckett/ TEFRA in Other States
How Are They Working in Other States?

• 22 states offer either the Katie Beckett waiver or the TEFRA option or programs based on those.

• The programs are slightly different in every state, in the services they offer and in eligibility criteria.

• Some states, like Minnesota, charge families a premium based on their income.
States that Offer Katie Beckett or TEFRA
What Are Other States Doing?

Arkansas

• Be age 18 or younger,
• Meet Social Security criteria for disability
• Not have assets above $2000
• Have income less than the current Long Term Care income limit (around $1635 per month)
• Estimated cost of caring for the child can’t exceed the estimated cost of treating the child in an institution

• Note: Families of children determined eligible for TEFRA whose annual income exceeds $25,000 will be required to pay a monthly premium to participate in the program.

Georgia

• Be 18 years old or younger
• Meet Social Security criteria for disability
• Not have assets above $2000
• Requires a level of care provided in a hospital, skilled-nursing facility or intermediate-care facility (including an intermediate-care facility for mental retardation),
• Can appropriately be cared for at home
• Estimated cost of caring for the child will not exceed the estimated cost of treating the child within an institution.
What’s Next?
# Action Steps

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<td>Contact your legislators</td>
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<td>Organize Other Families</td>
<td>Provide information and tools to families to get them to join the effort.</td>
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<td>Hold regional meetings</td>
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<td>Share the Message</td>
<td>Share your story!</td>
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<td>Connect with Legislators</td>
<td>Write letters with personal stories to legislators</td>
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<td>Develop personal connections with policymakers</td>
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<td>• Invite them to programs, schools, homes.</td>
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<td>• Set up meetings in their communities or at their legislative offices</td>
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Questions