

# **Why WA needs a TEFRA State plan option inspired by Katie Beckett**

Washington Apple Health Medicaid  
coverage for children and youth 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 <sup>1</sup>

1. Quote from speech given at a celebration of the 75<sup>th</sup> 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 law makers to change the law, making the TEFRA 1115 programs and waivers possible.
- Because of the program, 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 if Washington offered a TEFRA or a Katie Beckett waiver demonstration.

# Washington Apple Health Medicaid

# Why is WA Apple Health important for Children with Special Health Care Needs?

- Compared to private insurance, WA Apple Health 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”<sup>2</sup>.

2. Semansky, R. M. & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. *Journal of Behavioral Health Services and Research*, 31(3), 334-342.

# Some Covered WA Apple Health Services for Children

- Dental services
- Doctor office visits
- Durable Medical Equipment
- Home Health services- therapies, aides, nursing
- Hospital- inpatient, outpatient, emergency room
- Medical supplies
- Medicines
- Private Duty Nursing
- Therapies- OT, PT, Speech, ABA
- Behavioral Health
- Vision services
- Well child care

# **How the Gaps in WA Apple Health Affect Washington Families**

“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 <sup>3</sup>

# What is the Problem?

- WA Apple Health 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 WA Apple Health. They also must meet the financial eligibility criteria for their household.
- Families who earn too much to qualify for WA Apple Health have few options for getting it. DDA exclusions like spinal cord injuries, muscular dystrophy, autism with IQ above 84, neurological conditions, and genetic conditions with IQ about 69, etc...
- Medical care for a child with a disability can cost more than most families can afford, even with private insurance coverage and many needed services are not offered.
- We are not allowed to access apple health as a secondary insurance because it makes income limits much lower for people with primary coverage.

# “Options” Parents Have Been Given to Get WA Apple Health For Your Child

Things parents are being told as ways to access needed healthcare in WA:

- Quit your job or taking a lower paying job
- Ask for a lower wages or work less hours to keep or access coverage
- Divorce your spouse and live-in separate households
- Move to another state
- Apply for DDA waiver and wait up to 10 years due to caps and strict eligibility criteria or maybe never get DDA.
- Put your child in an institution or facility, even though you would rather care for them at home with support.
- Give up custody of your child

# 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 and early intervention 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.<sup>5</sup> Some states pay less than 25% of the total health-related costs of children on the program.<sup>6</sup>
- Allowing children to have services at home instead of in an institution or hospital setting 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.<sup>7</sup>

5. Semansky, R. M. & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. *Journal of Behavioral Health Services and Research*, 31(3), 334-342.

6. Minnesota Department of Health, Division of Human Services. (1998). *Caring for our children: A study of TEFRA in Minnesota* <https://mn.gov/mnddc/past/pdf/90s/98/98-DOH-TEFRA.pdf>.

7. Bazelon Center for Mental Health Law. (2002). *Avoiding cruel choices*.

**Who is Affected?**

# Washington's Children with Special Health Care Needs

- No one knows!
- Our government at this point is not even asking the question to determine who is out there and how many are in need

# Options for Washington

# TEFRA Option

- 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 (WA Apple Health) 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 WA Apple Health. Household income is not counted.

## A child may be eligible if:

- They meet the SSI medical criteria for disability
- A doctor says that they need a level of care that is similar to what they would get in an institution. (ICF-IDD level of Care)
- It is safe for them to live at home
- Caring for them at home does not cost more than caring for them in an institution.

# What's the Difference For Your Child?

## HCBS DDA Katie Beckett Waiver

- The waiver can be limited to certain disabilities, geographic area, ages, etc. The state can also limit the number of slots.
- The waiver can offer extra services, specific for children with special health care needs, that are not normally covered under WA Apple Health, such as respite care, home modifications, formula, and diapers.

## TEFRA Option

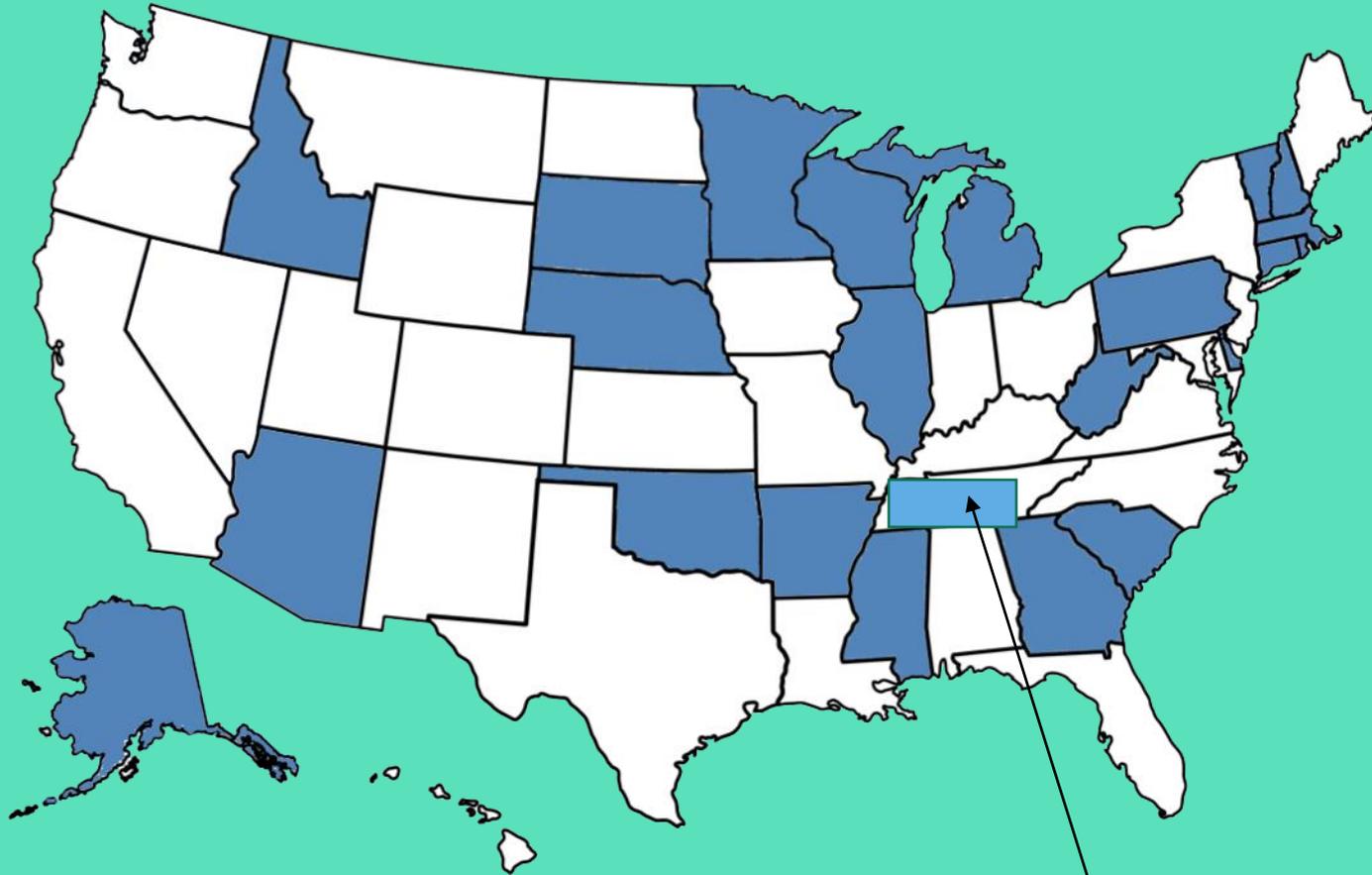
- All children who qualify are eligible regardless of their disability, their age, where they live, etc.
- Provides the same array of Medicaid services as all other Medicaid-eligible children.

# 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 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



TN added in 2019

# What Are Other States Doing?

## Minnesota

- **Target Population:** Children who would otherwise require care in an institution with any type of disability, including medical, developmental, intellectual, or psychiatric conditions.
- **Ages:** 0-18
- **Levels of Care:** Intermediate Care Facility, Nursing Facility, Hospital
- **Income Waiver:** Yes, the program is based on the child's income only. Parent income is not counted. However, a [Parent Fee](#) may apply.
- **Spots:** unlimited
- **Expiration Date:** NA
- **Description:** Provides Medicaid coverage only.
- **Online State Information:** [MN TEFRA](#)
- **Waiting List:** none

## Alaska

- **Target population:** children who would otherwise require care in an institution with any type of disability, including medical, developmental, intellectual, or psychiatric conditions.
- **Ages:** 0-18
- **Levels of care:** intermediate care facility, nursing facility, hospital
- **Income waiver:** yes, the program is based on the child's income only. Parent income is not counted.
- **Waiver type:** tefra
- **Spots:** unlimited
- **Expiration date:** NA
- **Description:** provides medicaid coverage only.
- **Online state information:** this [brochure](#) or [alaska tefra from qualis health](#)
- **Waiting list:** none

# 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.

# Special Services

- A child who is approved for Medicaid through TEFRA is eligible for the full range of Medicaid covered services.
- If the child needs special services, which are available only under a Home and Community Based waiver, they must apply for and be accepted into one of the waiver programs to receive these special services through DDA.

**What's Next?**

# Action Steps

<b>Increase Knowledge</b>	<ul style="list-style-type: none"><li>• Learn about the available options and how they work</li></ul>
<b>Engage in Public Policy Work</b>	<ul style="list-style-type: none"><li>• Know what other states have done</li><li>• Contact your legislators</li></ul>
<b>Organize Other Families</b>	<ul style="list-style-type: none"><li>• Provide information and tools to families to get them to join the effort.</li><li>• Hold regional meetings</li></ul>
<b>Share the Message</b>	<ul style="list-style-type: none"><li>• Share your story!</li></ul>
<b>Connect with Legislators</b>	<ul style="list-style-type: none"><li>• Write letters with personal stories to legislators</li><li>• Develop personal connections with policymakers<ul style="list-style-type: none"><li>• Invite them to programs, schools, homes.</li><li>• Set up meetings in their communities or at their legislative offices</li></ul></li></ul>

Questions

# Join the movement!

Share your story or get involved directly:

<https://www.facebook.com/TEFRAforWA>

email: [TEFRAforWA@gmail.com](mailto:TEFRAforWA@gmail.com)

Thank you,

Doreen VanderVort, Aubri Wing, Amy Miller