Washington State Health Care Authority

REPORT TO THE LEGISLATURE

Tax Equity and Fiscal Responsibility Act (TEFRA) and Katie Beckett waivers

Options to provide Medicaid to children in need of Medicaid coverage and services in the home

Engrossed Substitute Senate Bill 6168, Chapter 357, Laws of 2020, Section 211(83)

October 15, 2020

Acknowledgments

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Executive summary

Substitute Senate Bill (SSB) 6168, which took effect on April 23, 2020, as Laws of 2020 Chapter 353, directs the Health Care Authority (HCA) to work with the Department of Social and Health Services (DSHS) to assess a Katie Beckett waiver and the Tax Equity and Fiscal Responsibility Act (TEFRA) state plan option. These Medicaid options serve to expand coverage for children with significant disabilities who meet federal requirements for these services, which typically include private duty nursing services in the home.

Legislative report requirements

SSB 6168 directs HCA to complete a legislative report by October 15, 2020, to assess, if this expansion of coverage is approved for implementation:

- The number of children who would be eligible
- The services for which they would be eligible; and
- The potential impact to the state budget

The implementation of a new Medicaid program involves program and systems development that support the promulgation of appropriate Washington Administration Code rules and necessary computer programming to the state's Automated Client Eligibility Services (ACES) and ProviderOne systems to authorize coverage and reimburse the cost of services. This report focuses on the budget impact of providing defined services in the home to children under the age of 19 years, who would qualify for them by meeting financial and functional requirements.

Background

Long-Term Services and Supports (LTSS) in Washington State has a long and demonstrated history of providing an array of services that allow individuals to choose among settings and providers that will best meet their needs. Strong federal and state partnerships to leverage federal funding from the Center for Medicare and Medicaid Services (CMS) is key when developing and implementing successful programs that support less restrictive settings for individuals who otherwise meet level of care requirements in an institutional setting, such as an intermediate care or medical facility.

According to the national LTSS scorecard of states created by the American Association of Retired Persons (AARP), Washington state has sustained the ranking of second in the nation for its high performance while at the same time ranking 34th in cost. LTSS encompasses the broad range of paid and unpaid skilled and personal care assistance that people may need – for several weeks, months or years – when they experience difficulty completing daily-living tasks as a result of aging, chronic illness, cognitive functioning, or disability. LTSS is typically defined as a range of services and supports for individuals who need assistance with daily living tasks such as bathing, dressing, ambulation, transfers, toileting, medication assistance/administration, personal hygiene, transportation, and other health-related tasks.

In addition to the services and supports described, however, the need for services that would allow children under the age of 19 years to live at home, are not available for some whose household income and/or resources is above minimum income standards. If a child does not meet statutory requirements to be a client of the Developmental Disabilities Administration (DDA) and functional requirements for a 1915(c) waiver administered by the DDA, parental income and resources must be counted when determining eligibility. These requirements and the capacity limits of 1915(c) waivers can make Medicaid and LTSS unavailable. This may result in the child being placed in a medical facility, unless a parent or another caretaker can provide 24-hour care and the family can afford the necessary equipment to support the placement.

Program description

An important distinction to make when discussing the Katie Beckett waiver and TEFRA options is to identify the former as a waiver for which authority is made available under Section 1915(c) or Section 1115(a) of the Social Security Act. Authority for TEFRA is made available under Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982, (P.L.97-248). During the course of building this report, the team has begun exploration of Section 1915(i) as an additional option for this population. Each of these authorities allow for counting only a child's income and resources, which likely results in a determination of financial eligibility and approval, since a test of any parental income or resources is waived. Waivers also are typically used to limit enrollment, in addition to providing services not otherwise provided under regular Medicaid programs that provide what is considered comprehensive coverage.

As a state plan program, TEFRA coverage for a child needing services often provided under a Katie Beckett waiver, enrollment cannot be limited to a defined number of slots that are defined under a

waiver. When made part of the Medicaid state plan, the TEFRA eligibility group becomes an entitlement to all children meeting financial and functional program requirements. This report will outline functional requirements that may be used to limit the number of children who would be or become eligible for enrollment. In fact, it may be possible to target those eligible with specific medical condition(s). As with any eligibility group approved under a waiver or the state plan, working through many potential details with CMS staff can assist states in their effort to provide needed services at a cost that can reasonably be absorbed into their Medicaid budget. In fact, potential savings might be realized over time, if not immediately, given the cost of facility-based services.

Eligibility requirements

To qualify for Medicaid under either the TEFRA state plan option or Katie Beckett waiver, a child must meet all of these criteria:

- Be under 19 years old
- Meet the state's definition of institutional level of care (ILC)
- Have medical care needs that can be safely provided outside of an institutional setting; and
- The cost of care in the community must not exceed the cost of institutional care

The ILC requirement is the most important criteria. This means the child's needs must be intensive enough that the child would typically be expected to receive care in a nursing facility, a hospital, or an intermediate care facility (ICF) for persons with intellectual disabilities. It is important to note that each state has different criteria for defining an ILC, which means the number of children who qualify for either option varies from state to state. Currently 18 states and the District of Columbia have implemented the TEFRA state plan option. A few states have chosen to implement TEFRA look-alike programs using state statutes or other state plan amendments. These programs have the flexibility to extend Medicaid eligibility to a broader group of children with disabilities.

Since its implementation, states have experienced significant increases in TEFRA enrollment, which have created budgetary pressures. Many states have sought alternative approaches to provide Medicaid coverage to children in higher income families who meet an ILC. The most popular alternative to the TEFRA state plan option has been the home and community-based services (HCBS) waiver. Unlike the TEFRA option, HCBS waivers allow states to target specific diagnoses or conditions, cap enrollment in the program, and offer additional Medicaid benefits, including HCBS [services].

The cost of care in the community for HCBS must not exceed the cost of institutional care. A comparison of these costs must be tracked and reported to CMS on an annual basis by DSHS staff who administer them. Their experience and methodology are used to help assess the feasibility and estimate the fiscal impact of implementing a Katie Beckett or TEFRA option.

Understanding the problems policy makers want to solve and the policy goals the state desires to achieve for this population and their families is important in identifying the policies, strategies, and potential funding to achieve those goals. The program and benefit designs employed will affect the

viability of implementing this new eligibility group. The information to help determine the most effective and efficient pathway to providing these services to those who need them most is continuing to be gathered.

Population analysis

Medically fragile children have complex medical and functional support needs. These children may have complex medication regimens, frequent monitoring, or assessment of medical issues and frequent hospitalizations. Children that are hospitalized for thirty days or more can be eligible for Medicaid for up to one year without consideration of family income or resources. When Medicaid coverage ends, this creates a gap in care as children lose access to the Medicaid coverage and in-home services.

The number of children in Washington who would access Medicaid through a Katie Beckett Waiver or TEFRA option is difficult to estimate. The need for these services is known anecdotally, but the ability to waive parental income and resources points to an unknown number of children who would meet functional eligibility requirements, but do not currently meet financial eligibility requirements. A comparison to another state operating the state plan option is helpful when estimating future enrollment. As an example, the State of Oklahoma has a population of just under 4,000,000 as of July 1, 2019[i]. The Oklahoma Health Care Authority reports March 2016 enrollment in the TEFRA State plan option of 611 children[ii]. This amounts to less than one percent of the entire population for the state of Oklahoma. For 2019 the U.S. Census data shows a population of roughly 7,500,000 in Washington. While Washington has a greater population, it also has multiple waiver options for a variety of populations with special needs.

Benefit and services analysis

The TEFRA state plan option and Medicaid HCBS waivers - a comparison[iii]

The TEFRA state plan option must be open to all children who qualify. Enrollment cannot be limited by funding only a set number of enrollees. In contrast, a waiver option can be used to limit enrollment based on criteria, such as disability type or enrollment limits. A 1915(c) waiver cannot be used solely to access Medicaid state plan services, however. Criteria based on the need for waiver services is needed to determine the priority population. For those who do not need 1915(c) services on a monthly basis, monthly monitoring would be required.

Table 1: A comparison of the TEFRA state plan option and Medicaid HCBS waivers

	TEFRA state plan option	HCBS Waivers
Who qualifies?	Children, birth to age 18 who: • Meet their state's definition of requiring an institutional level of care • Have medical needs that can safely be provided outside of an institution • Receive care in the community that does not exceed the cost of institutional care[iv, v]	Children (and others as defined by age, diagnosis, or other criteria established by the state) who: • Meet their state's definition of requiring an institutional level of care • Have medical needs that can safely be provided outside of an institution • Receive care in the community that does not exceed the cost of institutional care
What authority do states use to offer these programs?	State plan option (a.k.a. state plan amendment or SPA): • Allows states to change their individualized state plan, which outlines the way their Medicaid program operates. States may use this to add optional services or change eligibility requirements • States must still follow federal Medicaid rules (e.g., a state cannot use a state plan option to cut mandated services) • All services in the state plan option must be available to all children who qualify for Medicaid in the state • No waiting lists are allowed[vi, vii]	Home and Community-Based service waivers: • 1915(c) or 1115 waiver [1915(i) is a state plan HCBS program that is being explored] • Allow states to request that certain Medicaid guidelines be waived. States can use this to provide additional services not usually covered by Medicaid to help individuals remain in the community • With federal approval, states do not have to comply with federal Medicaid rules (i.e., Medicaid regulations are "waived" to make an exception) • Services can be provided to specific groups (e.g., based on diagnosis and/or age and/or other criteria) • Waiting lists are allowed

For a list of state programs that are specifically identified as Katie Beckett/TEFRA program, see information provided in the table below. This information is taken from the Kids' Waivers website. It is maintained by the Complex Child Magazine. Some states may offer services to this population under a waiver that provides services to multiple groups of individuals with a variety of different needs.

- **Level of Care** denotes what type of institution the child would require if not in the program, and can be a Hospital, Nursing Facility, or Intermediate Care Facility.
- **Income Waiver** specifies whether or not the parental income is waived when applying to the program.

Table 2: TEFRA/Katie Beckett state programs

State	Program Name	Program Type	Ages Served	Level of Care	Income Waiver	Populations
Alaska	TEFRA	TEFRA	0 – 18	All	Yes	All
Arkansas	Arkansas TEFRA-like	1115	0 – 18	All	Yes	All
Connecticut	Katie Beckett	1915(c)	0 – 22	All	Yes	PD
District of Columbia	TEFRA/Katie Beckett	TEFRA	0 – 18	All	Yes	All
Georgia	TEFRA/Katie Beckett	TEFRA	0 – 18	All	Yes	All
Idaho	TEFRA/Katie Beckett	TEFRA	0 – 18	All	Yes	All
Maine	Katie Beckett Waiver	TEFRA	0 – 18	All	Yes	All
Massachusetts	Kaileigh Mulligan TEFRA Waiver	TEFRA	0 – 18	All	Yes	All
Michigan	TEFRA	TEFRA	0 – 18	All	Yes	All
Minnesota	MA-TEFRA	TEFRA	0 – 18	All	Yes	All
Nebraska	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
Nevada	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
Oklahoma	TEFRA Children	TEFRA	0 – 18	All	Yes	All
Rhode Island	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
South Carolina	Katie Beckett TEFRA Children	TEFRA	0 – 18	All	Yes	All
Vermont	Disabled Children's Home Care - Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
Wisconsin	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All

LTSS Services

In addition to benefiting from enrollment in Medicaid to supplement private insurance coverage, children with complex medical needs benefit from services to help keep them at home and reduce unnecessary hospitalizations. The primary services to support a person at home are personal care and private duty nursing. If the state were to choose a waiver option, the provision of additional services would be required.

Nursing

Nursing Services provided to DSHS clients include assessment, diagnosis, planning, implementation, and evaluation of a client's complex medical needs. Nurses use critical thinking skills to provide direct care services, consultation, and hands on nursing care for nursing tasks. Nurses who provide these services may have additional training/expertise in areas of ventilator care, trach care, feeding pumps, respiratory equipment, seizure management, central line maintenance, and complex care management.

Children who meet medical eligibility for the Private Duty Nursing (PDN) Program are defined as children who require four or more continuous hours of active nursing care that cannot be delegated and require complex skilled nursing tasks such as assessments, complex respiratory treatments, and interventions with IV or parenteral administration of food, fluid, or medication. Medically complex children may have had a history of abuse or neglect, have an illness, congenital disorders, brain injury, developmental delay, multiple chronic conditions, mental health issues, or are socially vulnerable.

There is a group of children who do not meet medical eligibility for PDN, who require intermittent nursing interventions such as seizure management, heart rate monitoring, complex medication regimens, trach care, bowel and bladder interventions, pressure injury care, diabetes monitoring/interventions, dialysis, IV monitoring, traumatic brain injuries, and frequent hospitalizations or emergency room visits. With nursing intervention/oversight, these children could safely remain in their homes with care planning and tasks being monitored by a nurse.

For PDN services, which may be a primary service needed by children qualifying for one of these programs, scrutiny must be given when comparing costs, for example, in a hospital and at home. The payment for PDN services in a hospital in the state is based on a diagnosis-related group (DRG) rate, which is considerably less that what is paid per hour in the home. Costs for PDN services at home for this age group is $12.46 per every 15 minutes of attendance, or $49.84 per hour, or $797.44 per day at the regular rate for the highest paid professional. For comparison, the benchmark cost of care in an ICF is $1,083 per day. Additional costs paid at the DRG rate in other settings and those for additional services needed in the home, such as equipment, which is otherwise available in a hospital setting, is used to enhance information provided in this report.

Personal care

Personal care services means hands-on assistance, supervision, and/or cueing with activities of daily living (ADL), instrumental activities of daily living (IADL), and health-related tasks due to functional limitations. ADLs include bathing, bed mobility, body care, dressing, eating, locomotion, medication management, toilet use, transfers, and personal hygiene. IADL assistance is incidental to the provision of ADL assistance and includes meal preparation, ordinary housework, essential shopping, ensuring wood supply when wood is the primary source of heat, and travel to medical services. Health-related tasks are related to the needs of an individual, which can be delegated or assigned by licensed health care professionals to be performed by an attendant.

Fiscal impact

Waiver services options

Services that may be purchased under a 1915(c) waiver are limited to services not already covered under the Medicaid state plan benefit. Therefore, nursing services, personal care, and other medically necessary service, such as medical equipment and therapies are not available under the waiver and cannot be a consideration for approval of the waiver. This means that for a youth to be eligible for a 1915(c) waiver, that person must have needs beyond nursing or medical necessity to prevent institutionalization that could be met only by the receipt of a specific waiver service each month. If DDA were to operate a 1915(c) waiver for medically fragile youth, the services that would be available under that waiver would be specialized equipment and supplies for non-medically necessary equipment and environmental adaptations. While helping to meet medical needs, equipment and supplies do not meet the requirement of providing a monthly waiver service, which can include monthly monitoring. To meet the minimum requirement, each client assigned to a 1915(c) waiver must have a case manager to provide monthly monitoring support.

Costs could be limited to an annual budget similar to the Individual and Family Services (IFS) waiver.

Table 3: IFS costs based on level of services

Level	Level Rate
1	$1,200
2	$1,800
3	$2,400
4	$3,600

Case management and other staffing considerations

Expansion of LTSS services, regardless of the authority used will also require an increase in staff, to include program and quality assurance staff, case managers, customer service, in addition to associated costs for facilities and equipment. Two additional FTEs for DDA program operations are estimated to cost $488,000 ($284,000 GFS) over a biennium. Other staff costs would become part of the mandatory workload model. Because of the complexity of the cases, a lower caseload ratio would be preferred. We anticipate the caseload ratio mix of a 1:40.

HCA caseload costs

It is difficult to determine how many enrollees would not already be approved for Medicaid coverage under another program that does not include access to these additional services. For each enrollee who is new to the Medicaid program, the costs of providing managed care would be approximately $1,230 per member per month. Each participant approved for receiving services under one of the TEFRA/Katie Beckett options would automatically be eligible for comprehensive coverage provided by HCA.

HCA assumes that the requirements of this bill would be eligible for Federal Medical Assistance

Percentage (FMAP) of 50 percent. Using the number of people enrolled in the example cited of a state plan program in Oklahoma in March 2016, the cost estimate is based on a ramp-up 611 new clients over five years; that number is rounded to 600 for simplification. A five-year ramp-up of 600 new clients for fiscal years (FY) 2022 through FY 2026 assumes a fiscal impact of $20,964,243 ($10,482,121 GF-S).

Table 4: Estimated HCA costs over five years

PMPM costs		FY 2022	FY 2023	FY 2024	FY 2025	FY 2026
	GF-State	886,010	1,722,020	2,608,030	3,494,040	4,380,050
	GF-Federal Medicaid Title XIX	886,010	1,722,020	2,608,030	3,494,040	4,380,050
Total		1,722,020	3,544,041	5,266,061	6,988,081	8,710,101
Biennial Total			5,266,061		12,254,142	

Conclusion

Gaining knowledge through an 1115 demonstration waiver is recommended. Following the example of other states establishing an 1115 demonstration waiver for medically fragile children would permit the state to gain experience and understand the numbers of children needing access to Medicaid. After gaining experience through a demonstration option, a determination could then be made as to whether to implement a TEFRA state plan option or one of the waiver options available. For the program evaluation component of an 1115 demonstration waiver, ensuring that enrollment in the demonstration increases beneficiaries' access to health care services and satisfaction in the quality of this specialized care received in the home would likely provide a meaningful purpose for the program design.

Adding a 1915(c) option is not recommended at this time, as it would increase the complexity of the service system for children with intellectual or developmental disabilities. Children who are DDA eligible have a path to a waiver program with expansion of waiver capacity on DDA's current five waivers. A 1915(c) waiver will also require either a monthly service or monthly monitoring and many children will have their needs met with access to Medicaid and state plan services. Stakeholders have expressed a desire to have access to the Medicaid program as their priority and access to personal care and nursing will be sufficient to close the existing gap in HCBS services.

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[i] "U.S. Census Bureau QuickFacts: Oklahoma." Census Bureau QuickFacts, 1 July 2019, www.census.gov/quickfacts/OK.

[ii] TEFRA Fast Facts, State of Oklahoma Health Care Authority, 13 Apr. 2016, www.okhca.org/WorkArea/DownloadAsset.aspx?id=18991.

[iii] Expanding Access to Medicaid Coverage: The TEFRA Option and Children with Disabilities, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, June, 2015

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[v] Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., Williams, L. (2000). Understanding Medicaid home and community services: A primer. Retrieved from http://aspe.hhs.gov/daltcp/reports/primer.htm#noteC1-25

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[vii] Ghandour, R. M., Comeau, M., Tobias, C., Dworetzky, B., Hamershock, R., Honberg, L., Mann, M. Y., & Bachman, S. S. (In press). Assuring adequate health insurance for children with special health care needs: Progress from 2001 to 20092010. Academic Pediatrics, 1-10.