

Department of Legislative Services
 Maryland General Assembly
 2018 Session

FISCAL AND POLICY NOTE
First Reader

House Bill 1113 (Delegates McMillan and Miele)
 Health and Government Operations

Maryland Medical Assistance Program - Services for Children With Prader-Willi Syndrome

This bill requires the Maryland Department of Health (MDH) to apply to the federal Centers for Medicare and Medicaid Services (CMS) for a home- and community-based services waiver in order to receive federal matching funds for services to children with Prader-Willi Syndrome (PWS) who are younger than age 22 and who meet an institutional level of care. Services to be provided may include respite services, family training and education, day treatment services, therapeutic integration services, intensive individual support services, therapeutic living services, intensive in-home intervention services, and specialized case management services. **The bill takes effect July 1, 2018.**

Fiscal Summary

State Effect: Application for the waiver can be handled with existing resources. Medicaid expenditures increase by \$3.5 million (61% federal funds, 39% general funds) in FY 2020, which reflects a one-year delay in implementation, as discussed below. Federal matching funds increase correspondingly. Future years reflect inflation and a slightly lower federal matching rate. **This bill increases the cost of an existing entitlement program.**

(in dollars)	FY 2019	FY 2020	FY 2021	FY 2022	FY 2023
FF Revenue	\$0	\$2,133,500	\$2,167,800	\$2,239,300	\$2,313,200
GF Expenditure	\$0	\$1,364,000	\$1,445,200	\$1,492,900	\$1,542,100
FF Expenditure	\$0	\$2,133,500	\$2,167,800	\$2,239,300	\$2,313,200
Net Effect	\$0	(\$1,364,000)	(\$1,445,200)	(\$1,492,900)	(\$1,542,100)

Note: () = decrease; GF = general funds; FF = federal funds; SF = special funds; - = indeterminate increase; (-) = indeterminate decrease

Local Effect: None.

Small Business Effect: Meaningful.

Analysis

Current Law/Background: The Medicaid Home and Community-Based Services waiver program is authorized in § 1915(c) of the federal Social Security Act. The program permits a state to furnish an array of home- and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization.

The Developmental Disabilities Administration (DDA) administers the Community Pathways waiver. Community Pathways provides services and supports to individuals with developmental disabilities, of any age, living in the community. Services include resource coordination, residential habilitation, day habilitation, supported employment, family and individual support services, community-supported living arrangements, assistive technology and adaptive equipment, employment discovery and customization, community learning services, environmental modifications, respite care, transportation, behavioral support services, live-in caregiver rent, medical day care, and transition services. Individuals can receive one or more of these services depending on their specific needs.

Eligibility for Community Pathways is determined based on the applicant's income and assets only and not the income and assets of the family. Individuals are eligible if they have been determined to have *full eligibility* status based on DDA's supports intensity scale (SIS), which measures support needs in the areas of home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy. Individuals who score lower on the SIS may be eligible for support services only, rather than the full package of waiver services.

According to the Prader-Willi Syndrome Association (USA), PWS is the most common known genetic cause of life-threatening obesity in children. Although the cause is complex, it results from an abnormality on the 15th chromosome. It occurs in males and females equally and in all races. Prevalence estimates range from 1 in 8,000 to 1 in 25,000, with the most likely figure being 1 in 15,000. PWS typically causes low muscle tone, short stature if not treated with growth hormone, incomplete sexual development, and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity.

State Expenditures: Medicaid expenditures increase by an estimated \$3.5 million in fiscal 2020 (61% federal funds, 39% general funds), which reflects a one-year start-up delay. This estimate reflects the cost to establish a new Medicaid home- and community-based services waiver for children with PWS who are younger than age 22 and meet an institutional care facility for the developmentally disabled, a hospital, or a nursing home level of care. This estimate is based on the following information and assumptions.

- MDH applies to CMS for a § 1915(c) Medicaid waiver, and CMS grants the waiver.
- The waiver process takes one year; thus, provision of waiver services does not begin until July 1, 2019 (fiscal 2020).
- Based on analysis of calendar 2015 medical claims data from the All Payer Claims Database, 118 individuals younger than age 22 in Maryland had a PWS diagnosis and received services paid for by Medicaid or a commercial insurance policy.
- Thus, the waiver serves approximately 118 children annually, 44 of whom are already enrolled in Medicaid, and 74 of whom have commercial insurance.
- The annual per-person cost of waiver enrollees is \$18,327 for waiver services only (for those 44 individuals with current Medicaid eligibility) and \$36,367 for Medicaid and waiver services (for those 74 individuals with commercial insurance).
- Total expenditures for waiver services to serve 118 children are \$3,497,546 in fiscal 2020.
- The federal matching rate for waiver services is 61% in fiscal 2020 and 60% in fiscal 2021 and thereafter.

If the waiver process takes less time, costs may increase beginning in fiscal 2019. However, to the extent fewer individuals qualify for and enroll in the waiver, expenditures are reduced. This estimate does not include any additional administrative costs for the new waiver program. Even with a small number of waiver slots, additional personnel is required to perform such functions as provider enrollment, eligibility determination, and payment.

Future years reflect 3.3% inflation in the cost of waiver services.

Small Business Effect: Small business health care providers may serve more individuals under Medicaid due to the waiver.

Additional Information

Prior Introductions: HB 1497 of 2014 received a hearing in the House Health and Government Operations Committee, but no further action was taken on the bill.

Cross File: None.

Information Source(s): Maryland Department of Health; Department of Legislative Services

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nb/ljm

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