

**Department of Legislative Services**  
 Maryland General Assembly  
 2014 Session

**FISCAL AND POLICY NOTE**  
**Revised**

House Bill 1497 (Delegate McMillan)  
 Health and Government Operations

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

This bill requires the Department of Health and Mental Hygiene (DHMH) 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 services, and specialized case management services.

The bill takes effect July 1, 2014.

**Fiscal Summary**

**State Effect:** Medicaid expenditures increase by an estimated \$1.2 million (50% general funds, 50% federal funds) in FY 2016 to provide waiver services to specified individuals, under the assumptions below, including a one-year delay to obtain the required waiver. This estimate does not include administrative costs. Federal matching funds increase correspondingly. Application for the waiver can be handled using existing resources. Future years reflect inflation.

(in dollars)	FY 2015	FY 2016	FY 2017	FY 2018	FY 2019
FF Revenue	\$0	\$575,800	\$590,000	\$604,500	\$619,400
GF Expenditure	\$0	\$575,800	\$590,000	\$604,500	\$619,400
FF Expenditure	\$0	\$575,800	\$590,000	\$604,500	\$619,400
Net Effect	\$0	(\$575,800)	(\$590,000)	(\$604,500)	(\$619,400)

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

**Local Effect:** None.

**Small Business Effect:** Minimal. Small business providers of waiver services may serve additional Medicaid clients.

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## 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. Community Pathways currently serves 9,000 adults and children with developmental disabilities.

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 15<sup>th</sup> 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.

The Prader-Willi Syndrome Association of MD, VA & DC estimates that there are approximately 250 children in Maryland with PWS who are younger than age 22. It is unknown how many of these individuals meet an institutional level of care.

**State Expenditures:** Medicaid expenditures increase by an estimated \$1.2 million in fiscal 2016, 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:

- DHMH 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, 2015.
- The waiver serves 25 children (10% of the estimated number of children in Maryland with PWS).
- Eligibility for the waiver is the same as Community Pathways (financial eligibility based on only the child's income and assets with a maximum monthly income of \$2,130 and assets of up to \$2,000).
- The annual per-person cost of waiver enrollees is \$46,066 in fiscal 2016 (based on the fiscal 2012 cost per individual younger than age 22 served in the Community Pathways waiver of \$41,799 adjusted for 2.46% annual inflation).
- Total expenditures for waiver services for 25 children are \$1,151,657 in fiscal 2016.
- Medicaid expenditures are funded with 50% general funds, 50% federal funds.

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. To the extent that some individuals served by the waiver are already eligible for Medicaid but do not qualify for *full eligibility* status based on DDA's SIS, Medicaid expenditures will be less. The cost of waiver services only (excluding other Medicaid services) is estimated at \$28,838 per enrollee in fiscal 2016. Thus, for every waiver enrollee who is already eligible for Medicaid, total waiver expenditures will be at least \$17,228 less than the estimate annually.

Future years reflect 2.46% inflation in the cost of waiver services.

## Additional Information

**Prior Introductions:** None.

**Cross File:** None.

**Information Source(s):** Prader-Willi Syndrome Association (USA); Prader-Willi Syndrome Association of MD, VA & DC; Department of Health and Mental Hygiene; Department of Legislative Services

**Fiscal Note History:** First Reader - March 13, 2014  
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