



STATE OF MARYLAND

**DHMH**

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**Maryland Department of Health and Mental Hygiene**  
**201 W. Preston Street • Baltimore, Maryland 21201**

Martin O'Malley, Governor – Anthony G. Brown, Lt. Governor – Laura Herrera Scott, MD, MPH, Acting Secretary

January 8, 2015

The Honorable Edward J. Kasemeyer  
Chair  
Senate Budget & Taxation Committee  
3 West Miller Senate Office Bldg.  
Annapolis, MD 21401-1991

The Honorable Norman H. Conway  
Chair  
House Appropriations Committee  
121 House Office Bldg.  
Annapolis, MD 21401-1991

**Re: 2014 Joint Chairmen's Report, Page 85, M00Q01.01 – Waiver Services to Cover Children with Prader-Willi Syndrome**

Dear Chairmen Kasemeyer and Conway:

In keeping with the requirements of the 2014 Joint Chairmen's Report (p. 85), enclosed is the Department of Health and Mental Hygiene's (the Department) report on whether the Department has made an application for a new waiver or modified an existing waiver to cover children with Prader-Willi syndrome, or why it is not submitting such an application. The language requesting the report withholds a \$100,000 appropriation made for the administration of the Department's Medical Care Programs pending submission of this report.

Thank you for your consideration of this information. If you have questions or need more information on the subjects included in this report, please contact Allison Taylor, Director of Governmental Affairs at (410) 767-6480.

Sincerely,

Laura Herrera Scott, MD, MPH  
Acting Secretary

Enclosure

cc: Chuck Lehman, Deputy Secretary, Health Care Financing  
Tricia Roddy, Director, Office of Planning  
Bernard Simons, Deputy Secretary, Developmental Disabilities Administration  
Allison Taylor, Director, Office of Governmental Affairs

# **Services for Children with Prader-Willi Syndrome**

Submitted by  
The Maryland Department of Health  
and Mental Hygiene

2014 Joint Chairmen's Report, p. 85

## Introduction

The Maryland Department of Health and Mental Hygiene (the Department) submits this report to comply with requirements of the 2014 Joint Chairmen’s Report (p. 85). The language in the Joint Chairmen’s Report requires the Department to provide additional information regarding the Department’s decision to pursue a new waiver—or modify an existing waiver—to cover children with Prader-Willi syndrome, or to discuss its rationale in not doing so. Specifically, the language requested the Department to:

- (1) Review the Medicaid waiver programs in other states that serve children with Prader-Willi Syndrome, including the services provided and the average annual cost per child;
- (2) Identify the number of children in Maryland younger than age 22 with Prader-Willi Syndrome;
- (3) Estimate the number of such children who are likely to meet an Institutional Care Facility for the Developmentally-Disabled- (ICF-DD), hospital- or nursing facility-level of care;
- (4) Approximate the annual cost to Medicaid to provide services for such children under a Medicaid 1915(c) home- and community-based services (HCBS) waiver, based on the actual medical and support needs of those children estimated to be potentially-eligible; and
- (5) Based on the findings under paragraphs (1) through (4), either apply to the Centers for Medicare and Medicaid Services for a new waiver or the modification of an existing waiver to serve children with Prader-Willi Syndrome and report to the budget committees that it is making that application, or report to the committees why it is not seeking a new waiver or waiver modification.

## Background<sup>1</sup>

Prader-Willi Syndrome is a genetic disorder originating in the fifteenth chromosome, causing low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problematic behavior and chronic hunger. This last condition, hyperphagia—the uncontrollable desire to eat driven by the inability to feel satiated—places Prader-Willi Syndrome at the top of the list of known genetic causes of life-threatening obesity in children. The exact prevalence of Prader-Willi Syndrome is unknown, with estimates ranging from one in 8,000 to one in 25,000; the most common figure referenced is one in 15,000.

Prader-Willi Syndrome manifests itself in four phases spanning the life cycle; the uncontrollable appetite exhibited by individuals with Prader-Willi Syndrome does not become apparent in early childhood. After a pregnancy characterized by decreased fetal movement, weight and length, infants with Prader-Willi Syndrome display hypotonia—low muscle tone—combined with poor appetite, difficulty feeding and failure to thrive. Though the end of this first phase is characterized by an increase in appetite and growth, when children with Prader-Willi syndrome enter the second phase between 18 and 36 months of age, weight gain and appetite both begin to increase. The third phase, normally beginning around age eight and lasting into adulthood, brings the full onset of hyperphagia. Most individuals with Prader-Willi

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<sup>1</sup> Prader-Willi Association USA. Available: <http://www.pwsausa.org/>; accessed August 14, 2014.

Syndrome remain in this phase; however, a minority does progress to obtain the ability to feel satiated and thereby control their appetite, which is classified as the fourth phase.

Treatment for Prader-Willi Syndrome aligns with its phases of manifestation. Due to the decreased ability to feed in infancy, providers may recommend a high-calorie formula or special feeding methods, with particular attention paid to growth and development monitoring.<sup>2</sup> As a child with Prader-Willi Syndrome passes into the phases characterized by overeating and soon, obesity, treatment with human growth hormones has been shown to increase growth, improve muscle tone and decrease body fat. Individuals with Prader-Willi Syndrome are often referred to endocrinologists upon reaching puberty; sex hormone replacement therapy not only encourages the development of reproductive organs but also reduces the risk of developing osteoporosis. Working with a dietician to develop a healthy, reduced diet should be combined with limiting access to food and strict supervision of food intake. Physical therapy and developmental therapies can help children with Prader-Willi Syndrome to keep up both physically and socially with other children their age. Finally, because individuals with Prader-Willi Syndrome often display behavioral issues, the involvement of a mental health professional—such as a psychiatrist or psychologist—can be beneficial.

## **Medicaid Waiver Programs for Children with Prader-Willi Syndrome**

Across the United States, no state has a waiver that specifically serves individuals with Prader-Willi Syndrome, neither children nor adults.<sup>3</sup> Instead, individuals with Prader-Willi Syndrome may qualify for other waiver options, many times a developmental disabilities waiver, depending on the state's inclusivity of Prader-Willi Syndrome—or its manifestations—as a developmental disability. Also, individuals with Prader-Willi Syndrome may qualify for a waiver due to the presence of co-occurring conditions. A 2008 report on eligibility criteria for HCBS identified 20 states, plus the District of Columbia, that mention Prader-Willi Syndrome as a diagnostic category for admission to state and waiver programs.<sup>4,5</sup> Other states employ broader definitions for waiver eligibility, including eight that utilize the federal definition of developmental disability per the Disabilities Assistance and Bill of Rights Act of 2000. All states include an evaluation of functional ability as part of the assessment process.

In Maryland, children whose household income is under 300 percent of the federal poverty level are eligible for Medicaid or the Maryland Children's Health Program (MCHP);<sup>6</sup> *i.e.*, the family's income is considered when making a determination of the child's eligibility. For Medicaid 1915(c) waivers, on the other hand, only the child's income is taken into account—parental income and assets are considered to be unavailable to the child. In addition to serving a higher-income population, 1915(c) waivers enable participants to receive full Medicaid benefits and additional services not included in the Medicaid State Plan, depending on their needed level of services. Additional services under the waiver could include:

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<sup>2</sup> Mayo Clinic. Prader-Willi Syndrome: Treatments and Drugs. Available: <http://www.mayoclinic.org/diseases-conditions/prader-willi-syndrome/basics/treatment/con-20028982>; accessed August 14, 2014.

<sup>3</sup> Medicaidwaiver.org: Disability Services and Waivers; accessed November 7, 2014.

<sup>4</sup> Zaharia R, Moseley C. (2008). State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants. *Rutgers Center for State Health Policy*: pp 5.

<sup>5</sup> 47 states provided data to this study.

<sup>6</sup> Depending on income level. Benefits packages for Medicaid and MCHP are identical.

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| 1. Assistive technology and adaptive equipment; | 8. Live-in caregiver rent; |
| 2. Behavioral supports;                         | 9. Medical day care;       |
| 3. Community learning services;                 | 10. Personal supports;     |
| 4. Community residential habilitation services; | 11. Respite;               |
| 5. Traditional day habilitation;                | 12. Shared living;         |
| 6. Employment discovery and customization;      | 13. Support brokerage;     |
| 7. Environmental accessibility adaptations;     | 14. Supported employment;  |
|   | 15. Transition services;   |
|   | 16. Transportation; and    |
|   | 17. Vehicle modifications. |

1915(c) waivers require participants to meet certain medical criteria, such as a having developmental disability or meeting institutional level of care. Under such waivers, the cost to provide care in the community must not exceed the cost if the individual were in an institution (nursing facility, ICF-DD, hospital, etc.).

### **Prader-Willi Syndrome in Maryland**

In Maryland, children and adults with Prader-Willi Syndrome may be eligible for the Department's 1915(c) waiver for individuals with developmental disabilities, Community Pathways, which is administered by the Developmental Disabilities Administration (DDA). All participants in the Community Pathways Program must meet the criteria for a developmental disability per the Annotated Code of Maryland, Health-General Article, Title VII.<sup>7</sup> Developmental disability is defined as a severe chronic disability of an individual that:

- A. Is attributable to a physical or mental impairment, other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments;
- B. Is likely to continue indefinitely;
- C. Is manifested in an individual younger than 22 years old;
- D. Results in an inability to live independently without external support or continuing and regular assistance; and
- E. Reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services that are individually planned and coordinated for the individual.

If an individual does not meet these criteria for waiver services but does have a severe, chronic disability caused by a physical or mental condition other than a sole diagnosis of mental illness that is likely to continue indefinitely, he may be eligible for State-funded supports-only services.

Upon completing an application and meeting the waiver eligibility criteria, DDA prioritizes each applicant into one of three categories: Crisis Resolution; Crisis Prevention; and Current Request. Individuals are then placed on a waiting list until funding is available to support waiver services.

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<sup>7</sup> <http://medicaidwaiver.org/state/maryland.html>; accessed November 6, 2014.

## Fiscal Considerations

In 2013, there were 87 individuals in Maryland under 22 years of age with a diagnosis of Prader-Willi syndrome.<sup>8</sup> Of the 45 Medicaid-covered individuals, four were enrolled in the Community Pathways Waiver and 41 in traditional, income-based Medicaid.

A comparison of average annual costs per Medicaid enrollee between a primary diagnosis of Prader-Willi Syndrome and other diagnoses show that there are 2,856 diagnosis types with higher average annual costs than Prader-Willi Syndrome (2013). These calculations do not include pharmacy costs, which can cause a devastating financial burden to individuals with Prader-Willi Syndrome. However, even when including pharmacy costs for Prader-Willi diagnoses only, the average annualized cost of a Prader-Willi diagnosis (\$7,076) still ranks 553<sup>rd</sup> behind other diagnoses. If using the median annual pharmacy costs for this population, Prader-Willi Syndrome moves to 1,966<sup>th</sup> on the list, as the mean calculation is more sensitive to outliers (\$611 per enrollee versus \$6,358, respectively). Additionally, despite their high cost, many of the other diagnoses would not meet the level-of-care criteria for a 1915(c) waiver.

These figures comprise the cost of Medicaid services only and do not incorporate the additional cost of waiver services. Data from the Community Pathways Waiver can be used to approximate the annual cost to provide services to children with Prader-Willi Syndrome under a 1915(c) HCBS Waiver, if these children were to meet the level of care criteria detailed above. The Department took into account three considerations:

1. *Children new to Medicaid:* The annual cost per participant in the Community Pathways Waiver for individuals younger than 22 is \$41,799 (2012), which includes both Medicaid and waiver services. Enrolling the 42 currently commercially-covered children with Prader-Willi Syndrome in a 1915(c) waiver would cost approximately \$1,755,558.
2. *Children already enrolled in Medicaid:* For children already covered by Medicaid, the additional annual cost would consist of the difference between the figure above and the cost of Medicaid services only. In 2012, this difference—that is, the cost of waiver services themselves—amounted to \$26,167 per participant. If the 41 Medicaid enrollees with a diagnosis of Prader-Willi Syndrome not already participating were accepted into a 1915(c) waiver, the total additional annual cost for this cohort would be \$1,072,847.
3. *Administrative costs:* In addition to the cost of Medicaid and waiver services themselves, in the case of a new waiver, the Department would need to secure additional human resources to administer the program across DDA, the Office of Health Care Quality and the Division of Eligibility Waiver Services. Needed positions would include waiver eligibility, analytical, quality assurance, finance, information technology and licensing staff, case workers, independent advocates, specialists and contractual vendors.

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<sup>8</sup> Commercial or Medicaid coverage; primary or secondary diagnosis.

## **Departmental Response and Justification**

The 1915(c) Community Pathways Waiver is a currently-available avenue for children with Prader-Willi syndrome who meet eligibility criteria to access needed services. Combined with the estimated fiscal and administrative impact of creating a new waiver specifically for children with Prader-Willi Syndrome, the Department recommends that such children continue to pursue enrollment with the existing Community Pathways Waiver.