



Thank you for this opportunity to address Budget Amendments for the upcoming  
2024-2026 BIENNIAL STATE BUDGET

I am Teresa L. Champion with the Virginia Autism Project, the parent/legal guardian of a  
30 y.o. with Autism Spectrum Disorder (ASD) and PANS/PANDAS. I am also his paid attendant  
and caregiver. When I am not at home, my husband is his unpaid caregiver.

I would like to address two important items for the Disability community for you to  
consider in the Budget: 1) paying family caregivers and 2) removing income penalties for  
recipients of Medicaid Waivers.

### **1. Paying family caregivers.**

As many of you know, before the COVID-19 Pandemic, only parents of adults could be  
paid caregivers/attendants under Virginia's Medicaid Waiver ("Waiver"). During the pandemic,  
(when everything shut down, no one was working and the disabled still needed care) Appendix K  
was filed and gave parents of minor children the ability to be paid caregivers.

The flexibility provided by Appendix K needs to be preserved and permanently  
formalized under Consumer Directed ("CD") Services. Instead, the Department of Medical  
Assistance Services ("DMAS") and the Medicaid Provider Lobby are attempting to gut CD  
services in favor of paying agency providers. This is both dangerous for the disabled individual  
and a disservice to the families attempting to care for their loved ones.

Paying a parent to be a caregiver:

- Seeks to address issues raised by the COVID-19 pandemic including the crisis of  
caregiver workforce shortages,
- Promotes equity and access to services in underserved communities across Virginia,
- Addresses the long-standing LTSS direct care workforce shortages which have now  
become a crisis nationwide,
- Confronts increasing demand for home-based care,
- Addresses gaps in meeting the needs of communities of color and English Language  
learners,
- Recognizes increasing interest in and preference for home-and-community-based care  
over institutional care through consumer directed programs,
- Gives older adults and people with disabilities an alternative to institutionalization, and
- Keeps vulnerable children safe with parent caregivers.

It would cost Virginia more to pay for agency-directed care rather than paying family  
caregivers under consumer-directed services. For example, one hour of personal care provided  
through an agency would cost \$5.34 more in Northern Virginia and \$5.81 more in the rest of the



state than care provided by a paid family member. The annualized cost increase per individual is more than \$11,000 in Northern Virginia and over \$12,000 for the rest of the state. This data is according to the hourly rates listed by Virginia Medicaid.<sup>1</sup>

Family caregivers are an important source of home health services nationwide, though they are often not compensated for the skilled and non-skilled care that they provide. Nationally, family caregivers provide about 1.5 billion hours of health care annually to 5.6 million to children and youth with special health care needs (CYSHCN). If these services were instead provided by an agency-employed home health aide, they would cost an estimated \$11.6B to \$35.7B per year, well more than double the current cost of paying family caregivers.<sup>2</sup>

## **2. Removing Income Penalties for Recipients of a Medicaid Waiver**

Our system of social service support is based on the long-held belief that people with disabilities (“PWD”) would not be able to work. Limits on income in these federal and state programs continue to assume this to be true. With technology and medical advances, PWD can have meaningful work experiences but our policies place antiquated income restrictions that put these individuals at risk of losing their life-saving Waiver benefits.

A child or an adult who is disabled may apply for a Waiver. Virginia has three (3) Developmental Disability (DD) Waivers under the federal Home and Community-Based Services (“HCBS”) program. The person who receives a Waiver (“Recipient”) may have daily support like attendant care and transportation. They may live in a group home or other housing that allows them to live as independently as possible.

The Recipient receives services under a Waiver. They do not receive income or money from that Waiver. Income to the Recipient can be “earned” from employment or “unearned” from benefits through the Social Security Administration (“SSA”). These individuals need both services and income to live independently. Once they reach a certain income level through either earned or unearned income, the Recipient pays the state a “Personal Maintenance Allowance” or a Patient Pay Amount (“PPA”) to the state based on their income as a contribution to the cost of their Waiver Services.

### **The Penalty Issue:**

An *unearned income* issue arises when a parent retires or dies. The Recipient who may have been receiving Social Security Income (“SSI”) is moved to Social Security Disability Income (“SSDI”). This benefit is based on the past work record of the parent. An *earned income* issue arises when the individual is able to work at a full or part-time job.

Because it is based on the work record of the parent, SSDI benefits are substantially greater, sometimes up to three times SSI. The total cost of care for the individual is more than

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<sup>1</sup> <https://vamedicaid.dmas.virginia.gov/bulletin/personal-care-rate-update-effective-july-1-2022>

<sup>2</sup> <https://www.nashp.org/wp-content/uploads/2021/01/Family-Caregivers-for-CYSHCN-PDF-1-15-2021.pdf>



this larger amount. This increased SSDI amount can push the Recipient up to and over and over the Waiver Services income level limit, thus terminating their Waiver Services. These SSDI benefits become a substantial **penalty** for them because these lost Medicaid Waiver service costs are much greater than SSDI income could provide.

The Centers for Medicare and Medicaid Services (CMS) has addressed this problem with updated policies and have instructed state Medicaid Directors about these policy changes.<sup>3</sup>

DMAS has thus far refused to adopt the CMS changes but Delegate Shin has introduced a bill that would disregard the SSDI income penalty above the maximum monthly SSI amount.

Please be aware that a better fix for this issue may be a budget amendment.

Respectfully submitted,  
Teresa L. Champion  
Virginia Autism Project

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<sup>3</sup> [https://www.medicaid.gov/sites/default/files/2021-12/smd21004\\_0.pdf](https://www.medicaid.gov/sites/default/files/2021-12/smd21004_0.pdf)