

HB1445: Maryland Protecting People with Disabilities Act
House Health & Social Services Subcommittee, 3/10/26
Jeneva Stone, Family Caregiver
FAVORABLE WITH AMENDMENTS

Dear Chair Bagnall and Vice Chair Cullison,

Insofar as this bill protects DDA 1915(c/i/k) waiver participants from procedural disenrollment, I am wholeheartedly in favor.

However, as a family caregiver for a young man enrolled in both the DDA waiver (HCBS under 1915(c)) and the Rare and Expensive Case Management (REM) program (HCBS under 1115 plan), I cannot determine how HB1445 would protect my son Rob's civil rights to community access under the 1999 SCOTUS Olmstead Decision during an appeals process.

While Section I (A)(3) defines Home and Community-Based Services as those authorized under both 1115 and 1915(c), (i), or (k), the subsequent discussion of civil rights protections under the bill addresses only participants under 1915(c/i/k) provisions, and does not address the ongoing risk of service loss and subsequent institutionalization that those waiver participants who are dually enrolled in the REM program face, especially those who receive REM private duty nursing services (PDN).

There is a profound lack of clarity at the Department of Health on the very concept of ongoing "eligibility" for persons such as Rob Stone in either or both the DDA waiver and the REM program, and, therefore, on what constitutes "ineligibility" for either or both programs, and, as follows, a lack of clarity on what constitutes "procedural disenrollment" in such cases where disabled Marylanders rely on multiple state Medicaid programs for community integration.

For example, if the REM program determines that Rob is no longer eligible for PDN after having received it for years (despite its continuing to be medically necessary for him), **that would effectively disenfranchise him from DDA waiver services, that is, have the same effect as procedural disenrollment.** That's because a waiver participant who is assessed as needing PDN services may not utilize either Personal or Community Development Supports under the DDA waiver without a PDN present—unless a gratuitous family caregiver is able to give up both work and sleep, and, frankly, all other normal life activities.

Furthermore, REM "eligibility" determinations for PDN are not clearly defined in statute or in any communications from the Maryland Department of Health. Please see the attached 2025 memo: to receive PDN, a REM participant must demonstrate "medical necessity," yet the PDN is not ultimately allocated on the Medicaid recipient's needs—it is allocated on the family caregiver's needs to work, sleep and attend school. Furthermore, if a REM participant does not

have a “willing and able” caregiver, they may not receive services for which they are otherwise eligible. If you read “Sulerzyski v. MDH,” you will note that the position of MDH on PDN is **not**, in fact, necessarily aligned with federal case law.

I am concerned that if this bill is enacted as written, it might actually undermine Olmstead protections for disabled people with complex needs who are dually enrolled in the DDA waiver and other 1115 HCBS programs, stripping them of necessary HCBS supports as they attempt to appeal questionable ineligibility decisions or effective procedural disenrollments.

I would request the following amendment to the bill:

Section I (b)(1-4): Strike all references to “Administration,” as that refers solely to the DDA, and replace with “Home- and Community-Based Services as defined in 15-103.9.(A)(3) of this act.” That would enable all Maryland Medicaid HCBS participants to continue to receive services while appealing their determination, regardless of whether these are DDA services, REM services, or CFC services.

Alternatively, insert a statement that clearly states that “no part of this bill shall override or replace community integration protections for people with disabilities under the 1999 SCOTUS Olmstead Decision, Sec. 504 of the 1973 Rehabilitation Act, or Title II of the ADA.”

I am not an attorney, and if I have misunderstood the bill, I will, of course, be happy to receive clarification on it. As I stated throughout, my concern is that the bill could unintentionally undermine Olmstead protections for Maryland Medicaid recipients who rely on multiple HCBS programs for community integration.