

**SB 0721 Testimony - Ralph's Act**  
**March - Finance Committee**

Dear Committee Members,

Thank you for the opportunity to share my family's experience and support for SB 0721 - Ralph's Act. I am here because no Maryland family should have to endure what we have simply to secure services for a loved one with developmental disabilities. While MDH argues otherwise, nothing in this bill will compromise the integrity of DDA's waiting list, which already utilizes priority categories, and where the universe of people who may fall within the bill's provisions is exceedingly narrow. Nor will it subject MDH to legal risks around Medicaid eligibility because the bill does not mandate granting a Medicaid waiver – just the timely ability to apply for one. Finally, the bill advances the established policy of prioritizing continuity of services for individuals with disabilities.

**Ralph had a long road to the Crisis Resolution priority category.**

My brother, Ralph, is 41 years old. For most of his life, Ralph lived in Connecticut with our mother as his primary caregiver, attending appropriate educational and day habilitation programs. But, in November 2023, our mother died unexpectedly. At the same time, our father began experiencing serious medical issues that led to a car accident he did not remember causing. Overnight, Ralph lost his lifelong caregiver and was left in the care of an elderly father with cardiac and neurological problems, severe hearing loss, and declining health.

As I grieved my mother and managed my father's health crisis, I prepared to apply for Maryland DDA services so Ralph could safely transition to live with me in Maryland – the state I have called home since 2008. What followed was more than a year and a half of delay, shifting explanations, and moving goalposts.

I gathered decades-old psychological reports, documented why school records no longer existed, obtained updated evaluations, submitted medical documentation showing my father was no longer capable of safely caring for Ralph. On the application, I cited the regulation establishing Ralph's Maryland residency through me, his guardian, and proof of my Maryland residence.

But, after filing the application, I heard nothing for three months. When I followed up, I was told Ralph had to be a Maryland resident to qualify, despite the regulation I cited. Only after legal intervention did the eligibility interview proceed.

The interviewer recommended placement in the Crisis Resolution category due to the risks posed by Ralph's caregiver's health. Yet DDA placed him in "Current Request," a

category that never leads to receiving services if the applicant is not transitioning from school.

From there, the process became more troubling. Despite extensive documentation of my father's inability to care for Ralph, including physician letters and evidence of hospitalization, DDA stated that Crisis Resolution could not apply because the caregiver in crisis lived in Connecticut. Yet the governing regulation states that Crisis Resolution applies when an applicant is "living with a caregiver who is unable to provide adequate care due to the caregiver's impaired health." It does not limit that caregiver to Maryland.

Over the next year, I submitted multiple Priority Category Assessments (PCAs), with physician letters, day program reports documenting Ralph's self-injurious and dangerous behaviors, videos of escalating episodes, and proof that I cannot telework or provide full-time daytime supervision due to my employment. It was never enough. At one point, I was asked whether Ralph had already been harmed in a car accident caused by my father's unsafe driving. Apparently, imminent risk was not sufficient.

Throughout this process, I sought help from elected officials, who facilitated meetings with DDA representatives. I was told I did not need to move Ralph to obtain the crisis resolution priority category. Later, I was told I should submit a new PCA after he moved. Meanwhile, my father was hospitalized twice for cardiac-related emergencies. Each time, I traveled to Connecticut to care for Ralph.

Ultimately, after my father's repeated hospitalizations, filing a Medicaid appeal, and retaining counsel, I moved Ralph to Maryland without services in place. Only then did DDA finally place him in Crisis Resolution.

Ralph is here now and my husband and I are taking leave from work to supervise him. We are relying on friends for help. But this instability could have been avoided. If Ralph had been appropriately placed in Crisis Resolution when the evidence first demonstrated it was warranted, I could have minimized his time without day programming. I could have developed a person-centered plan and secured a provider before relocating him. Instead, we were forced to choose between leaving Ralph in an unsafe situation or chaotically moving him into another uncertain and unstable one.

I recognize that DDA serves many families, some with extreme needs, and that so many are still awaiting services. I am thankful that Ralph is on the path to obtaining services. But attorneys, elected officials, appeals, and a physical relocation into an unstable situation should not be prerequisites for receiving services. The current system creates a perverse incentive to let something awful happen to a loved one in order to secure services for him.

## **MDH's concerns about this bill are unconvincing.**

I am aware of certain concerns that MDH has raised about this bill, but none of them are warranted. Their concerns about people “skipping the line” are unfounded for three reasons. First, the decision to move a loved one away from the life they have always known is not one that any caregiver - including myself - takes lightly. I repeatedly cried when making this decision. The notion that a family with a loved one who is already receiving services elsewhere would orchestrate a complex scheme to move a caregiver to MD for two years, leaving the applicant behind in another state, in anticipation of some other caregiver’s death or incapacitation is beyond far-fetched. Merely writing those words shows how absurd MDH’s argument is.

Second, this bill furthers Maryland’s already-existing public policy prioritizing continuity of services. [For example](#), youth transitioning from school “are prioritized regardless of the severity of their situation and their relative need for immediate services.” As the [MD Developmental Disabilities Council has explained](#), this priority ensures that those “with significant disabilities do not regress after completing their special education schooling” because they “typically stayed at home with nothing to do, losing skills invested through the educational system.” So, too, here. Ralph has been without day programming for over two months and his behavior is declining. He stays up through the night and becomes overstimulated and agitated, awakening my children. Someone, like Ralph, who has been receiving services in another state for decades and has to relocate due to a caregiver loss should not be forced to languish for years in a Maryland basement, deteriorating and losing valuable skills.

Finally, MDH built “skipping the line” into the regulatory framework. The crisis resolution category already exists, which by definition allows certain applicants to be prioritized over others who have been waiting longer. In fact, one of the existing bases for the crisis resolution priority category is when the applicant is “Living with a caregiver who is unable to provide adequate care due to the caregiver’s impaired health, which may place the applicant at risk of serious physical harm.” This bill is not a shocking departure from current practice. It simply codifies another narrow basis for crisis resolution status, building on existing priority categories. There’s nothing inherently unfair about that.

As to MDH’s purported legal risk of running afoul of the Medicaid rules, the process for receiving DDA services involves multiple steps and this bill would not interrupt the Medicaid eligibility process. The first step is eligibility for DDA services. This has nothing to do with Medicaid. It is based on the individual’s disability and need for care. Then there’s the priority category placement. Again, that has nothing to do with Medicaid. Finally, once a waiver becomes available, only then does an applicant develop a

person-centered plan, which, along with Maryland residency, are two of the technical eligibility requirements for the waiver. As long as an applicant has moved to Maryland and is not receiving waived services elsewhere at that point, there should be no issue in processing that application.

Nothing in this bill requires MD to accept someone's eligibility for waived services in another state as dispositive proof of waiver eligibility in Maryland. Instead, that bill requirement is used to *narrow* the universe of people who may fit into its new crisis resolution criteria. After placement in crisis resolution, all rules for Medicaid eligibility would apply and if the applicant cannot meet those, he would not receive the waiver.

Long-term Maryland residents like myself have lost faith in the support systems that should be there for us when needed. MDH and DDA are broken. Instead of providing a system of approving benefits, they look for reasons to delay and deny services. This is evident in many ways, not the least of which is the hundreds of individuals [pursuing a class action lawsuit](#) over arbitrary removal from their waived services.

In a perfect world, people with disabilities would have the same ability to move between states that other individuals do. Unfortunately, the patchwork Medicaid system does not uniformly allow that. Bigger changes are necessary. But this bill leaves comprehensive reform for another day. Instead, it offers a narrow path to service continuity for a very limited segment of the population who are left without a caregiver in their prior state and therefore relocate to Maryland to be with a suitable, long-term Maryland resident caregiver. That is manifestly in keeping with the existing regulatory framework, Medicaid rules, and already-acknowledged public policy priorities.

Thank you for your time,  
Stefanie Hennes

I'm really sad because I  
have no new program but  
tell me when I new program  
starts soon as ~~the~~ possible Ralph  
see PCP RENOXX caregivers  
yeah ok we will are on next  
mouth out because I'm waiting  
+ thank YOU