Regional Listening Sessions

Marylanders with developmental disabilities are losing needed services.

UNPAID ESSENTIAL SERVICES

$30.7M

in uncompensated care

Approximate total reported by only **69 surveyed providers.** There are over 200 DDA licensed providers in MD.

Services continued while people waited for Medicaid waiver coverage to be restored.

These figures reflect responses from just 69 community providers, only a small share of the statewide total. The full human and financial impact across Maryland is far greater.

COVERAGE LOSSES

2+

PEOPLE EVERY DAY

For two years, at least two Marylanders relying on disability services have lost waiver coverage daily.

DELAYED REINSTATEMENT

12+

MONTHS

Reinstatement can take months to more than a year. People still need care throughout the wait.

Essential services are at risk now

Coverage losses leave people, families and community providers in limbo

Medicaid waiver coverage pays for supports that help people live, work, and participate in their communities. When coverage is lost, families face uncertainty about whether those supports will continue. Providers keep delivering care while seeking reinstatement, often without payment for months to more than a year. Staff and operating costs continue. This is not sustainable.

Dedicated hours are essential for many people

Dedicated hours fund individualized staffing, including one-to-one or two-to-one support. Reductions and denials can leave people without the help they need to manage medical or behavioral needs and daily routines safely. Shared staffing cannot meet every person's assessed needs. Families cannot be expected to replace trained, reliable support.

Maryland must act now

Restore coverage promptly. Prevent gaps and establish clear and timely processes for reinstatement.

Protect dedicated hours. Approve necessary dedicated hours based on each person's assessed needs.

Pay for services already provided. Resolve unpaid services so providers can sustain essential support.

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The impact on people, their families and community providers

Denial of dedicated support hours

“I am writing on behalf of Jane A, to advocate for her needs and express frustration in the lack of empathy and disregard of her health and medical needs shown in the continued denial of Jane’s request for additional dedicated hours for community living group home 1:1 staffing.

Due to Jane’s significant decline in health over the last eight months, she is now on hospice care and requires 24/7 care by dedicated staff to address all medical needs, personal care, ADLs, and to provide comfort at the end of her life. This has not only been incredibly difficult physically and mentally for Jane, as she experiences her organs failing and ongoing decline, but is also distressing to the dedicated DSPs who are going above and beyond to care for her and her two housemates.

We have provided the level of staffing necessary to support Jane, for which we have received no additional funding, beyond the 40 hours per week to cover the time that she would have spent participating in meaningful day services if she were able to. We will continue to provide the level of staffing that she needs in order to maintain her dignity and respect, and to provide her the highest level of comfort possible as her condition worsens. Jane’s condition is terminal and her needs will only continue to increase until she ultimately passes.

There is no feasible way that Jane’s home can be adequately staffed by one person, as Jane requires direct, continuous attention. With only one DSP present and constantly providing support to Jane, her two housemates are then left without the level of support they need. Additionally, this poses a great safety risk to them should an emergency occur and the DSP is primarily providing care to Jane.

I implore you to consider her wellbeing in her greatest time of need and an incredibly difficult time for her housemates and staff, by approving her request for additional dedicated hours so that she may receive the care she needs until her passing.”

Note: Jane’s request for dedicated hours continued to be denied for 8 months and was finally approved one day before she died. The provider supporting Jane never received payment for the months of dedicated hours they provided.

Medicaid disenrollment and uncompensated care

“Our organization supports nearly 300 men and women with intellectual and developmental disabilities, helping them live full and meaningful lives in their communities. The services funded through the Developmental Disabilities Administration (DDA) are essential to ensuring people have access to employment, community engagement, residential supports, and the stability they need to continue to live their best lives.

Since January 2024, people have been losing their Medicaid and even when they reapply, some are being told they need to wait for a slot to open up before their DDA services can resume. The impact on people’s lives can’t be ignored. Interruptions in services mean disruptions to jobs, housing stability, daily routines, and the critical supports people rely on each day.

This has directly impacted 34 people who receive services at our organization. Rather than deny people the services that have been helping them live their best lives, we have continued to provide services without reimbursement from the state. To date this has resulted in a financial impact of just over $85,000 to our organization.

Marylanders with disabilities deserve the same real connections, real opportunities, and real experiences that all of us need to live our best lives. Continued access to DDA services makes this possible.”