Alliance for the Betterment of
Citizens with Disabilities

**Empowering People: Providers Shaping Policies**

Requests for Inclusion in the 2028 1115 CMS Demonstration Waiver
June 24, 2026
A Running List

Under the Social Security Act, the 1115 CMS Demonstration Waiver permits federal authorizations which allow states to test innovative, experimental or pilot projects in the Medicaid programs. Federal requirements may be “waived” to expand eligibility, cover new services or reform delivery systems. Changes may be broad or targeted applicable to a specific population.

NJ’s 5-year Waiver expires on June 30, 2028

**Advancing healthcare quality for targeted IDD populations. The high need IDD**

Founded in 1995, the main purpose for which the Alliance for the Betterment of Citizens with Disabilities was founded was “To advocate on behalf of people with multiple developmental and physical disabilities, and their family members.”

Individuals with high need IDD often face significant disadvantages within the HCBS waiver system. Despite the purpose of providing community alternatives to institutional care, systemic issues frequently leave those with the most complex, high-cost needs underserved. Because of gaps, individuals with high need IDD often face unmet needs and preventable health conditions. The ADA’s “integration mandate” may apply to this subset of citizens if they are not getting the services they need to stay in the community.

An Oversimplistic Solution which neglected to consider a significantly “transportation-disadvantaged population.”[1]

Transportation is crucial for independent living and community inclusion. So much so that inadequate transportation is often framed as a civil rights issue. Though transportation is probably one of the largest service needs for people with I/DD, it is frequently reported as a problem.

[1] Ground Transportation for People with Mobility Disabilities 2025: Challenges and Progress. National Council on Disability. July 23, 2025. P18

The current Waiver requires a mileage catchment within which the DH provider is required to transport without receiving additional funds. Outside of the catchment a flat per mile amount is paid which does not account for the additional costs of transporting individuals in wheelchairs.

Transportation to and from DH may be included in the rate, but as a percentage of revenue, many DH spend more on this utility than businesses for which this utility is the service. And, disturbingly, for a small percentage of DH which transport mobility impaired I/DD the cost of this utility exceeds that of direct services.

Motorized wheelchair and scooter users, and some manual wheelchair users require wheelchair accessible vehicles (WAV). WAVs are expensive as they require ramps, lifts, lowered floors, w/c security, and hand controls. They are also more expensive to operate, often requiring additional staff and time to help individuals enter and exit the van in addition to seating fewer mobility impaired individuals. Buying and operating a WAV can cost between 2 to 3 times that of a regular van.

The effort of the original rate setters to simplify the formula failed to distill and instead distorted the results. Time spent on transport and wheelchair use are not factored in the rates. As a result, there is a financial disincentive to transport individuals who have mobility disabilities particularly in rural and urban areas. Lack of access will contribute to increased isolation, negative emotional and mental issues and barriers to a life in the community for IDD with mobility disabilities.

We request consideration of a DH wheelchair rate based on miles and/or time.

A Woefully Narrow Care Spectrum which structurally discriminates against individuals with IDD and co-occurring mental health conditions

Individuals with intellectual/developmental disabilities (IDD) are five times more likely to have mental illnesses (MI) than the general population. However, services focusing on both types of health conditions are rare, and very few healthcare providers are trained to recognize and effectively treat them.

DHS/DDD is to be commended for its commitment to ramping up the mental health service system for individuals with IDD. The last few years saw an increase in emergency capacity beds, the development of mobile crisis response teams, 3000 front line workers certified in NADD Competency-Based IDD/MI Dual Diagnosis DSP Certification Program, and increased rates for behavioral supports. Additional resources have been allocated for crisis response and treatment including the creation of IDD/Behavioral Health Stabilization Homes in the community and, for those individuals who may also need on-site medical care and oversite, at New Lisbon. Preventive services have secured additional attention too, as evidenced by the benefit alignment of behavioral health and SUD coverage for DDD members in MMCO plans, the growth of the Psychiatric Residency Expansion Program which trains psychiatrists to provide services to individuals served by DHS, including individuals dually diagnosed with mental health conditions and IDD, and the bolstering of behavioral supports in our service system.

Tragically, for those whose behavior is a manifestation of a pathological process, New Jersey's additional services provided under Behavioral Acuity may help with a symptom but not with proper treatment. One need only consider a member of the IDD population with a serious mental illness (SMI) who repeatedly damaged property, attempted to elope and begged to be readmitted to an institution, despite provider's orthodox continuation of an approved behavioral plan because state staff insisted that it was behavioral. For too many in this subgroup interventions are either insufficient, incorrect, or beyond the capabilities of agency staff.

As a result, we continue to press for accessible proactive and preventative mental health support and interventions to enrich the day and residential environments.

We request consideration for the inclusion of social workers, psychologists, psychiatrists, and psychiatric nurse practitioners (PMHMP) in the Waiver's approved list of delivery service professionals.

<u>People with complex intellectual and developmental disabilities require complex treatment. Sometimes a nurse is the only profession that can do the job.</u>

Like any subgroup of the general population, there are members of the IDD population who have complex medical needs. Many ABCD member agencies specialize in providing services for this subgroup of individuals. For this subgroup to thrive in the community, certain reasonable accommodation must be made. By way of example, an individual with g-tube must have access to a nurse at certain points in the day for feeding and medication. Regrettably, the current Waiver does not include payment for nursing services leaving agencies to have to fund raise for these services or limit/deny entry to their program(s).

At a time when resources are at risk, it is imperative that we find ways to optimize HCBS health care spending for IDD. The ability for agencies to hire nurses will serve to reduce the need for emergent care, identify early signs of health decline and behavior changes, promote chronic condition management and improve care coordination to high need IDD.

We request consideration for the inclusion of nursing in the Waiver's approved delivery list of service professionals.

<u>To be truly effective, individuals with intellectual and developmental disabilities must have access to clinical services for which there is cross-training or generalization across settings.</u>

In the school setting for individuals with intellectual and developmental disabilities, services are typically provided utilizing two methods of service delivery: the "Pull-out" method of services delivery, during which individuals are removed from their classroom space to receive services or the "Push-in" model of service delivery, during which services are conducted within the classroom setting. While some research indicates that no model is superior to the other, the consensus is that collaboration with other professionals in the classroom setting results in

increased gains in speech-language skills as compared to services that were provided independently of each other.[2]

When individuals graduate from and/or leave the school system, access to these critical services decreases significantly. Pre-graduation services are provided during the day, presenting opportunities for communication with peers, participation in the occupation of living, and ambulation between different environments. Post-graduation services are provided in settings that do not allow for tangible practice with actual activities and settings, nor do they allow for increased collaboration between staff and caregivers. As participants increase in age, skill regression becomes apparent. As such, "adults with complex communication needs may have a history of failure or learned helplessness that may require longer interventions to learn new skills."[3] Research has shown that, "interventions can be effective when implemented by everyday communication partners in naturally occurring environments over relatively short periods. [4]

Today, Behavioral Supports (both Assessment and Monitoring) are included in the *Appendix K-Quick Reference Guide to Overlapping Claim for Supports Program Services under DH* with the expectation that there will be ongoing implementation of the plan and ongoing training and supervision of caregivers and behavioral aides. The ability of BCBAs and Behaviors to provide ongoing implementation and training to all staff members relies on these services being innately overlapping.

This scenario should also be the case for Clinical Services but regrettably, Clinical Service Provision are limited to a non-overlapping service. This means that this service is only being practiced or utilized in the service setting and with the licensed practitioner. However, these interventions should be trained on and utilized across caregivers and across settings to ensure continuity and generalization of skills.

We request consideration in including Clinical Services for physical, occupational and speech language therapist be included as an overlapping claim for support program services under day habilitation.

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[2] Thorneburg, Rebecca A., et al. "A Comparison of Service Delivery Models: Effects on Curricular Vocabulary Skills in the School Setting." *American Journal of Speech-Language Pathology, vol. 9, no. 1*, 1 Feb. 2000, pp. 10-20, https://doi.org/10.1044/1058-0360.0901.10. https://doi.org/10.1044/1058-0360.0901.10

[3] O'Neill, T, et al. (2018). "Effects of interventions that include aided augmentative and alternative communication input on the communication of individuals with complex communication needs: A meta-analysis." *Journal of Speech, Language, and Hearing Research*, *61*(7), 1743–1765. https://doi.org/10.1044/2018_jslhr-l-17-0132

[4] https://www.asha.org/profind/