LeadingAge New York

TBI Hearing Testimony

Provided by

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Introduction

My name is Ami Schnauber, I am the vice president of advocacy and public policy at LeadingAge New York and also the sibling of a traumatic brain injury (TBI) survivor who has struggled to obtain appropriate services under the TBI waiver program. I appreciate the opportunity to testify on the current challenges facing the TBI and nursing home transition and diversion (NHTD) waiver programs as well as the State's plan to enroll these special populations into Medicaid managed care plans.

LeadingAge NY represents over 400 not-for-profit and public providers of long term and post-acute care (LTPAC), aging services and senior housing, as well as provider-sponsored managed long term care (MLTC) plans. Many of our home and community based providers are also providers of home and community based (HCBS) waiver services including the TBI and NHTD waivers, and the long term home health care program –which is slowly being dismantled as people are moved to Medicaid managed care plans. Our providers have also served HCBS waiver recipients in congregate housing settings.

Providers and managed care plans alike are struggling to meet the challenges of a health care delivery system that is undergoing major transformation. With new payment arrangements and models of care continuously developing, the State must ensure that consumers have access to the high quality services and dedication to local communities that not-for-profit, mission-driven providers have delivered for years. If the concerns of these providers are left unaddressed, efforts to redesign the Medicaid program will be derailed, jeopardizing the well-being of elderly New Yorkers and people with disabilities.

In the face of outdated and insufficient Medicaid rates, staffing shortages in some areas of the State and rising wage costs, elderly and disabled New Yorkers are experiencing issues with access to services and concerns about quality, individual choice and satisfaction. It is imperative that Legislators work with the Executive to invest additional dollars in Medicaid to ensure our health care delivery system is meeting the needs of our most vulnerable New Yorkers. And, the Legislature should closely monitor the transition of the nursing home population into Medicaid managed care and determine if it makes sense to transition TBI and NHTD into managed care or rather allow them to remain as independent waiver programs.

A Personal Story

My younger brother was in the TBI waiver program, until just recently, and we struggled to secure him care in the community for more than fifteen years, working with five different agencies over those years. The challenge was that there were simply not enough care providers in the North Country for us to get the coverage he needed - 24 hour supervision. A minimum wage increase to $15 per hour may help providers to entice more caregivers into the field, but the reality is that they will not be able to pay those wages if their major payer, Medicaid, doesn't increase reimbursement rates to providers.

After my mother simply could not keep up the 60-plus hours per week of direct care that the agency was demanding of her – we needed to find an alternative. I tried to find congregate care alternatives that could have met his needs, but ultimately was unsuccessful. DOH has informed us that CMS required as a condition of the TBI waiver recipients to live in the community, not a congregate setting. This is simply not feasible for some consumers, and some regions of the state.

So, after not finding a better alternative, my brother, in his mid-thirties, is now residing in the Alzheimer's unit of a nursing home. They provide him with excellent care and take him to their Office for

Persons with Developmental Disabilities (OPWDD) day program twice a week, in spite of the fact that they get no reimbursement for the additional services. He is a perfect fit for their OPWDD services but because his accident happened after age 22, he does not qualify to live with his peers, even though Medicaid is the payer of both sets of services.

We have to do better by these TBI survivors. The system is not working. Sometimes, living in a home of one's own is simply not practical. It can be isolating, care and oversight can be sporadic, and it can lead to chaos and crisis. Every individual is different and families and providers need the flexibility to obtain the best care in the best setting, whether it is an apartment, congregate housing, assisted living or a nursing home. Such flexibility is critical to put together true person-centered plans of service.

Managed Care Transition

The State continues to pursue very aggressive timeframes for the transition of Medicaid beneficiaries and benefits to mandatory managed care, which often leads to managed care plans having to function with an unacceptable level of uncertainty in their business operations. Planning for the future in this environment becomes extremely difficult because managed care plans are unsure of how to allocate resources when their enrollee populations are rapidly changing and their Medicaid payments are not kept current. The State itself has often had to backtrack on published deadlines, often due to the lack of federal approvals. By delaying and revising timelines, major disruptions are caused for both managed care plans and service providers, and may undermine the credibility of the process.
Perhaps most concerning for plans is the incorporation of the nursing home benefit and population into managed care, which began Feb. 1, 2015 downstate and July 1, 2015 elsewhere. This is a new, large and expensive cohort of individuals for the managed care plans to incorporate, and the premiums plans are currently receiving do not cover the costs of permanent placements in nursing homes.

Given these current challenges, we question whether the TBI and NHTD populations should even be absorbed into Medicaid managed care at all. Under longstanding federal requirements, both waivers have to be cost-neutral to Medicaid, so there doesn't appear to be any cost savings that can be attributed to this transition. We strongly encourage the Legislature to closely monitor how the nursing home transition plays out before allowing the TBI and NHTD waivers to be incorporated into managed care.

If waiver participants are to be transitioned to Medicaid managed care, we would recommend that the State first transition the NHTD participants in 2017 through a pilot to measure outcomes, gaps in service delivery and access to services. It would be critical to develop and track benchmarks to assess whether the transition is successful. Before the transition of any waiver participant there would need to be a complete evaluation of the critical elements of each waiver service to ensure those elements are transitioned into the managed care benefit package. The TBI and NHTD waiver services have been critical to keeping participants safely in the community for many years.

An NHTD and TBI waiver transition workgroup was established by the Department of Health (DOH) in conjunction with extending the effective date for both the NHTD and the TBI populations to transition to mandatory Medicaid managed care to Jan. 2017. This workgroup is charged with suggesting strategies for a smooth transition into managed care. Through the workgroup we hope to address critical questions we have about this transition. We encourage the Legislature to ensure that these questions are answered before these most vulnerable individuals – who have specialized needs – are transitioned into managed care:

1. If the transition occurs, an existing participant would be grandfathered into Medicaid managed care with similar waiver services. What happens to a newly diagnosed TBI member – would they qualify or be able to obtain similar services? How will the determination be made that the individual's needs are at the nursing home level of care (which is currently used to qualify individuals into these waiver programs)?
2. Current providers of waiver services have had extensive training in TBI or other cognitive impairments. Would this be required for all providers in the managed care plan network? How can the expertise of current waiver providers be assimilated into managed care?
3. Service Coordinators have been vital to helping waiver participants safely remain in the community. They have numerous ongoing face-to-face meetings with the participant, their family, the courts, their landlords and other stakeholders. Their caseload size is limited. Currently, case managers with a managed care plan might have a caseload of 85 to 200 enrollees and the service is usually telephonic. What mechanism will be put in place to ensure that these populations with high needs have someone who can perform this "high touch" approach? Without this type of "high touch" approach the first crisis might land the participant in jail, an emergency room, or in an institution unnecessarily.
4. How will the State ensure the Medicaid managed care plan premiums are sufficient to ensure uninterrupted and quality care for TBI and NHTD populations?
5. What can the State do to challenge the federal government's assertion that everyone must live in the community? How can we assure that TBI and possibly other waiver participants have access to fully array of settings available in their region—to choose the one that best meets their needs?

Conclusion

As this testimony illustrates, there are a number of concerns and unanswered questions relative to the TBI and NHTD programs. In that regard, LeadingAge NY applauds the Assembly for holding this important hearing. LeadingAge NY stands ready to assist the State and the Legislature – as do I personally – as you work to ensure the best possible care for individuals in the TBI and NHTD waivers. For questions or concerns, please feel free to contact me at 518-867-8383.

Founded in 1961, LeadingAge New York is the only statewide organization representing the entire continuum of not-for-profit, mission-driven and public continuing care including home and community-based services, adult day health care, nursing homes, senior housing, continuing care retirement communities, adult care facilities, assisted living programs and Managed Long Term Care plans. LeadingAge NY's 400-plus members serve an estimated 500,000 New Yorkers of all ages annually.