



September 12, 2019

Ms. Seema Verma, Administrator Centers for Medicare & Medicaid Services
7500 Security Blvd.
Baltimore, MD 21244

**Re: Medicaid Program; Methods for Assuring Access to Covered Medicaid Services –
Rescission, RIN:0938-AT41**

Dear Administrator Verma:

The Wisconsin Board for People with Developmental Disabilities (BPDD) is concerned the proposed rule regarding assuring access to covered services in the Medicaid program will not remedy and may exacerbate the current provider shortage crisis affecting access to critical Medicaid services for people with intellectual and developmental disabilities.

Wisconsin is facing a provider capacity shortage now that is connected to low Medicaid reimbursement rates. The need for home and community-based (HCBS) service providers to help people with disabilities and older adults stay in their homes and out of expensive Medicaid-funded institutional care is already great and projected to increase. Adequate access to Medicaid services is essential. Failure to ensure that reimbursement rates are sufficient to guarantee access to needed services risks increased institutionalization, which increases Medicaid costs to the federal and state government and positions the state to be in violation of the Supreme Court's Olmstead decision.

Wisconsin has a robust package of Medicaid services that wisely recognize the return on investment that results from good access to health care; Medicaid is especially critical for people with disabilities. Many important community-based services, therapies, treatments, drugs, and other health care services are only available through Medicaid and are not covered by private insurance. Medicaid has long subsidized care for people who need community-based supports and other services that the private sector has inadequately covered.

Wisconsin advocates have consistently raised concerns about a shortage of quality providers for many Medicaid plan and HCBS waiver services across the state, with provider shortages significantly more pronounced in some geographic areas. Provider shortages result in limits and delays in accessing many services and few or no options for specific services depending on the area of the state.

Wisconsin has worked hard to eliminate waiting lists for services to ensure that all participants have access to the same service package no matter where they live. Currently, Wisconsin is one of the only states where any eligible individual can receive long term care services without waiting. BPDD fears that provider shortages threaten to undo these accomplishments in two significant ways:

- Provider shortages can effectively create a “hidden wait list” where eligible participants are not technically on a wait list but are unable to access the complete service package due to provider shortages.

- Needs, goals, and outcomes identified in care plans may be unattainable due to few or no provider choices.

BPDD hears from individuals and families that there is often a difference between the needs identified in care plans and the amount of services rendered. We are concerned that authorized hours that are unused in care plans are assumed to be unnecessary when in fact it is a reflection of a lack of capacity and does not capture what is happening to fill in gaps in paid care (family members stepping in, or gaps are not able to be filled and care needs are going unmet).

We also consistently hear from individuals that services—especially personal cares—are delivered late or with staff that has not worked with the individual before. Late services can result in missed medical appointments, declines in health conditions, missed employment and other opportunities that facilitate independent living in the least restrictive environment possible. The number of times providers are filling shifts in “crisis” mode and are unable to have enough staff to deliver services as scheduled is another indicator of a lack of capacity.

Significant lack of access to mental health, integrated employment, integrated day, transportation, and numerous therapies, habilitative, rehabilitative, and other Medicaid services have all been documented. Low and unchanging reimbursement rates are consistently identified as a determining factor affecting whether providers take on new clients/patients and staff retention.

To illustrate, BPDD points to Wisconsin’s caregiver crisis and dental care access that have risen to our state legislature and Governor’s attention.

Wisconsin has a documented shortage of direct care workers, who are critical to meeting the daily needs of long-term care waiver participants and are essential to ensuring they can live and remain independent in the community. The shortage of paid caregivers is a crisis now, and the need for these workers is projected to increase by an additional 20,000 workers by 2026¹. Currently, 70% of personal care agencies are unable to staff all hours of care that Wisconsinites need on a daily basis, and 93% of agencies find it difficult to fill job openings. The annual turnover rate is more than 50% and can be as high as 67%³.

In Wisconsin, 85% of individuals with disabilities who require direct care for some or all of their support cannot find paid help⁴. People with disabilities rely on family⁵ caregivers to make up for gaps in paid support; many rely on family caregivers to provide some or a large proportion of the caregiving needed⁶. Low wages are consistently identified as a major factor affecting the recruitment and retention of

¹ National Alliance for Caregiving 2015 Report on Caregiving in the U.S.

² Family & Individual Needs for Disability Supports Community Report 2017. https://www.thearc.org/file/documents/finds/FINDS_report-2017-FINAL-VERSION.pdf

³ National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

⁴ In 2016, Survival Coalition conducted a statewide survey of more than 500 people who rely on direct care services and their families found 95% had trouble finding workers, 85% did not have enough workers to cover all their shifts, 43% couldn’t find a worker 7 or more times per month, and 60% said they get sick more often when they do not have enough staff. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

⁵ The term "Family Caregiver" includes immediate and extended family members, domestic partners, friends, neighbors, volunteers or others who provide help and supports so that individuals can remain living in the community.

⁶ Family members and friends reported spending an average of 57 hours each week in a support role for those with disabilities assisting with everything from feeding to dressing, providing behavior supports and managing finances. Family caregivers are reporting greater unmet needs, and with a paid workforce crisis they simply cannot find help.

quality workers⁷. The direct care worker shortage--especially when coupled with aging family caregivers and smaller family sizes--is reducing access to HCBS services, putting HCBS waiver participants at greater risk of institutionalization and putting the state in danger of Olmsted violations.

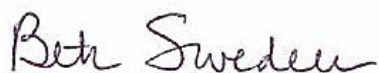
Likewise, the lack of dental care for people with I/DD is almost universal and of crisis proportions. In Wisconsin more than 50% of adults with disabilities have had at least one permanent tooth removed due to tooth decay or gum disease in the past year; 35% have not been to a dentist in the past year⁸. Many can only visit a dentist when something is wrong or causing pain/other health impacts, and often they may have to wait weeks or months for an appointment even in these situations. For people with I/DD, especially those who have difficulty communicating or explaining/identifying their pain, chronic tooth pain is often correlated with challenging behaviors. Frequently, by the time a person with I/DD finally is seen, tooth extraction is the only option. Low reimbursement rates are frequently cited as the reason dentist will not accept Medicaid recipients; inadequate rates are directly correlated to lack of access to care.

Wisconsin's home and community-based waiver (HCBS) programs—including Family Care, IRIS, and Children's Long-Term Support programs—have been used to demonstrate the state's work towards compliance with the Olmsted decision. Rates that have remained the same are already resulting in limited or no access to state plan services. Historical underfunding may mean that even increased rates may not result in increased provider capacity. Without independent ongoing assessment of provider capacity and gaps in capacity that result in a lack of access to services, many people with disabilities stand to lose the health care and services that enable them to work and live independently. Provider capacity shortages are becoming a direct threat to the civil rights of people to live in the community.

CMS has a strong role in monitoring access to health and long-term care services authorized under state plans. The current rule is an important tool to ensure that Wisconsin's twenty-five-year progress away from high-cost institutions is not undone. BPDD urges CMS to keep the current rule in effect and expand it to include services provided through waivers, including managed care and HCBS so that it covers all Medicaid beneficiaries and most Medicaid services.

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities.

Thank you for your consideration,



Beth Swedeen, Executive Director, Wisconsin Board for People with Developmental Disabilities

⁷ Paid caregiver wages are dependent on Medicaid rates; these critical jobs are also low-income positions. In Wisconsin, the average paid caregiver's wage is \$10.47 per hour. Many skilled caregivers are leaving the profession for other low wage jobs without benefits that have a slightly higher hourly rate. Others want to contribute more caregiving hours, but must restrict their incomes in order to preserve their access to BadgerCare health care.

⁸ Healthiest Wisconsin 2020 Baseline and Health Disparities Report, Wisconsin Department of Health Services, January 2014. <https://www.dhs.wisconsin.gov/hw2020/baseline.htm>