



February 22, 2018

The Honorable Seema Verma, Administrator  
Centers for Medicare & Medicaid Services  
200 Independence Avenue, SW  
Washington, DC 20201

**Re: BadgerCare Section 1115 Demonstration Waiver Extension Application**

Dear Administrator Verma:

On behalf of the 30 million Americans with one of the estimated 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) submits the following comments on the Wisconsin BadgerCare 1115 Waiver Extension Application.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD appreciates Wisconsin's stated goal of enhancing the lives of Medicaid beneficiaries in Wisconsin. However, after reviewing the proposed alterations to its Medicaid program and consulting with our member organizations, we are concerned that a number of provisions within the Demonstration will threaten access to care for many within Wisconsin's rare disease community.

**Wisconsin's Proposal to Implement Work Requirements:**

We oppose the implementation of work requirements within the Wisconsin Medicaid program because we believe the exemptions to these requirements will not be nuanced or precise enough to avoid harming the health and wellbeing of Wisconsin rare disease patients and their families. While the list of exemptions appears comprehensive, we can still easily envision many scenarios in which individuals with rare diseases or their caregivers will be unduly subjected to onerous and inappropriate work requirements.

For example, the determination of disability included within the demonstration is, in large part, tied to the Social Security Administration's standard of disability, with one exemption described as a beneficiary who, "receives Social Security Disability Insurance (SSDI)."<sup>1</sup> Unfortunately, it is not uncommon in the rare disease community for individuals to have a great deal of trouble securing disability status from the Social Security Administration. With a scarcity of physicians familiar with rare

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<sup>1</sup> Wisconsin 1115 Waiver Demonstration Extension Application Appendix C Pg.11

diseases and the prevalence of undiagnosed conditions, it is often difficult, even impossible, for rare disease patients to convey the extent of their symptoms.

Additional unwarranted applications of work requirements could arise from situations that are unaccounted for within this proposal. For example, it remains unclear from the given information within the demonstration what would happen to caregivers of those with a rare disease. The Demonstration notes that a beneficiary who is a, “primary caregiver for a person who cannot care for himself or herself,” would be exempt.<sup>2</sup> The Demonstration does not say, however, how that would be adjudicated. It is not clear in this context what it means to not be able to care for oneself. Consequently, It is not difficult to imagine a scenario in which this exemptions process would leave out a deserving caregiver.

Similarly, the Demonstration proposes to exempt those who are, “physically or mentally unable to work.”<sup>3</sup> Yet, once again, the Demonstration does not articulate how such a determination would be made or, perhaps more importantly, who would be making it.

These are just a handful of ways in which rare disease patients and their loved ones could slip through the cracks and lose access to their healthcare. In order to avoid the kind of delay or termination of care that could gravely impact the lives of Wisconsin’s rare disease patients and their families, the State would need to generate an absolutely airtight exemption process. Unfortunately, this proposal is anything but. Therefore, we would urge the Centers for Medicare and Medicaid Services (CMS) to refrain from approving this provision.

### **Wisconsin’s Proposal to Create Time Limits:**

We wish to express our grave concerns with the proposal to limit eligibility to 48-month intervals, with a 6-month gap in between. Continuity of care is absolutely critical for individuals with rare diseases. Time limits on care disproportionately harm individuals with rare diseases due to the genetic, life-long nature of their disease, as well as the incredibly expensive therapies and orphan drugs used to treat them. Cutting off rare disease patients from healthcare for 6 months every 48 months would do irreparable harm to their health and well-being.

Further, in the section of the Demonstration describing this proposal, there is no indication of who would be exempt from this limit other than for those who are over the age of 49 years old, those who meet eligibility standards for anything other than being a childless adult, or those whom are subject to the work requirement and are compliant with said requirement. Rather, it is in the subsequent section of the Demonstration describing work requirements that the full list of exemptions is located. Prior to listing the exemptions, the Demonstration explains that the list describes those who would be exempt from, “the work requirement and the associated eligibility time limit.”<sup>4</sup> The fact that this language is not

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<sup>2</sup> Wisconsin 1115 Waiver Demonstration Extension Application Appendix C Pg.11

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

also included within the section of the Demonstration pertaining to time limits presents a highly concerning contradiction. As it stands, the exemptions process for the time limit is far too ambiguous.

Yet, even if the exemptions truly did apply to the time limit, we would still strongly object to this proposal for those reasons articulated above. Consequently, we strongly urge CMS to reject this proposal.

**Wisconsin’s Proposal to Implement Copays for Emergency Department Utilization:**

We oppose Wisconsin’s proposal to implement an \$8 copay for use of the emergency department by beneficiaries. We understand that in instituting this policy, Wisconsin hopes to create a disincentive for non-emergency uses of the emergency department. Our fear, however, is that it will also create a disincentive for emergency uses of the emergency department and create an entirely inappropriate barrier to vital healthcare.

Considering that this proposal does not exempt emergency uses and that it will apply to all beneficiaries regardless of income, it is almost certain that this proposal will prevent rare disease patients from acquiring the care they need in times when they need it most. Therefore, we strongly encourage CMS to reject this provision.

**Wisconsin’s Proposal to Implement Premiums:**

We have acute reservations regarding Wisconsin’s proposal to implement monthly premiums for childless adults between 51 and 100 percent of the Federal Poverty Line (FPL), as we believe it could result in an insurmountable hurdle to care for some rare disease patients.

According to the Demonstration, inability to pay premiums will result in ineligibility for services, “until all outstanding premiums are paid.”<sup>5</sup> As previously stated, it is crucial that rare disease patients have uninterrupted access to healthcare. Medicaid exists to be a safety net for those who cannot access other forms of health care coverage. Completely removing access to care for an inability to continually pay \$8 a month is in direct opposition to the intent of the program and will greatly afflict the rare disease community. We urge CMS to deny this provision.

Thank you for the opportunity to provide comments on Wisconsin’s application for a Section 1115 waiver extension. Once again, NORD urges you to reject the provisions of the proposed Demonstration detailed in this submission. For further questions, please contact me at [pmelmeyer@rarediseases.org](mailto:pmelmeyer@rarediseases.org).

Sincerely,



Paul Melmeyer  
Director of Federal Policy

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<sup>5</sup> Wisconsin 1115 Waiver Demonstration Extension Application Appendix C Pg.7