



February 5, 2018

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

Re: Arizona Section 1115 Waiver Amendment Request

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 Arizona Health Care Cost Containment System (AHCCCS) Section 1115 demonstration.

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 AHCCCS' stated goal of enhancing the lives of Medicaid beneficiaries in Arizona. However, after reviewing the proposed changes to Arizona's Medicaid program and consulting with our member organizations, we are concerned that the work requirement proposal, and the accompanying five-year cap on eligibility, will threaten access to care for many within Arizona's rare disease community.

Arizona's Proposal to Implement Work Requirements:

We oppose the implementation of work requirements within the Arizona 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 Arizona 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 the caregivers will be unduly subjected to onerous and inappropriate work requirements.

For example, the determination of disability included within the demonstration is, in part, tied to the words "medically frail," which have yet to be defined. While we appreciate that Arizona has recognized the need for the definition of medically frail to go through "the standard AHCCCS policy development process which includes a 45-day public comment period," we do not believe it is appropriate to move forward with a proposal in which such important definitions are missing.¹ As it stands, there are an alarming number of ways rare disease patients could be overlooked. Unfortunately, it is not uncommon in the rare disease community for individuals to have a great deal of trouble securing recognition of their disability. With a scarcity of physicians familiar with rare diseases and the prevalence of undiagnosed conditions, it is often difficult, even impossible, for rare disease patients to convey the extent of their symptoms.

¹ AHCCCS Section 1115 Demonstration Waiver Amendment Request Section IV Pg. 9

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. Parents, caretaker relatives, foster parents, caregivers of a family member who is enrolled in the Arizona Long Term Care System, and individuals who are, “the sole caregiver of a family member who is under six years of age” are exempt, while caregivers more generally are not.² It is not difficult to imagine a scenario in which this exemptions process would leave out a deserving caregiver, such as a young wife caring for her husband or vice versa.

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 Arizona’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.

Arizona’s Proposal to Create Five-Year Eligibility Limits:

We also wish to express our grave concerns with the proposal to limit eligibility to five years within a lifetime for “able bodied adult member who are subject to the [work requirement] and do not fall under one of the exemptions.”³ Lifetime limits 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. Rare disease patients who are subjected to work requirements, whether appropriately so or not, will suddenly find themselves entirely without coverage, despite the fact that they have adhered to the work requirements as requested.

Continuity of care is absolutely critical for individuals with rare diseases. Consequently, we strongly urge CMS to reject these kinds provisions.

Thank you for the opportunity to provide comments on Arizona’s application for a Section 1115 waiver demonstration. 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.

Sincerely,



Paul Melmeyer
Director of Federal Policy

² AHCCCS Section 1115 Demonstration Waiver Amendment Request Appendix 2 Pg. 1

³ AHCCCS Section 11115 Demonstration Waiver Amendment Request Section II Pg. 3