August 20, 2019

Marie Matthews
Medicaid State Director
Montana Department of Public Health and Human Services
PO Box 4210
Helena, MT 59604

Re: Montana Health and Economic Livelihood (HELP) Demonstration Program

Dear Director Matthews:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on Montana's proposal to extend and amend its existing Health and Economic Livelihood (HELP) Demonstration Program.

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

The purpose of the Medicaid program is to provide healthcare coverage for low-income individuals and families. NORD is committed to ensuring that Montana's Medicaid program provides adequate, affordable and accessible healthcare coverage.

In Montana, over 92,000 low-income adults currently receive healthcare coverage through the state's Medicaid expansion. This means that thousands of enrollees are receiving prevention, early detection and diagnostic services as well as disease management and treatment for their conditions.[i] 1-in-10 individuals in Montana have one of the approximately 7,000 known rare diseases.[ii] Medicaid expansion is beneficial for patients with rare, serious, and chronic health conditions.

Montana's application to continue the HELP Demonstration Program includes policies that threaten access to healthcare by creating new financial and administrative barriers that could lead patients with rare diseases to lose their healthcare coverage. NORD is concerned about these policies and offers the following comments on Montana's proposal.

Premiums
Montana's Medicaid program currently charges premiums equal to two percent of modified adjusted gross income to adults with incomes above 50 percent of the federal poverty level ($889 for a family of three). Individuals with incomes above 100 percent of the federal poverty level ($1,778 per month for a family of three) can lose their coverage for failing to pay these

premiums. The state proposes to increase premiums by 0.5 percent each year, up to a maximum of four percent, after individuals have been covered by the program for two years. This policy would likely both increase the number of enrollees who lose Medicaid coverage and discourage eligible people from enrolling in the program, as research has shown that even relatively low levels of cost-sharing for low-income populations limit the use of necessary healthcare services.[iii] For example, when Oregon implemented a premium in its Medicaid program, with a maximum premium of $20 per month, almost half of enrollees lost coverage.[iv] For individuals with rare diseases, maintaining access to comprehensive coverage is vital to ensure they have access to needed treatment and therapies. Based on an evaluation of the state's current premium requirement, the state's application estimates that 2.9 percent of individuals will lose coverage as a result of this coverage, likely an underestimate given the increase in premiums under the proposed policy. NORD believes that these premiums create significant financial barriers for patients that jeopardize their access to needed care.

Work Reporting Requirements

Under the application, individuals in the expansion population between the ages of 19 and 55 would be required to prove that they work at least 80 hours per month or meet exemptions. One major consequence of this proposal will be to increase the administrative burden on individuals in the Medicaid program. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. For example, Arkansas implemented a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. During the first six months of implementation, the state terminated coverage for over 18,000 individuals and locked them out of coverage until January 2019.[v] Montana's own application includes an estimate that between 4,000 and 12,000 individuals could lose coverage as a result of the work reporting requirements alone but acknowledges that coverage losses could be even higher.[vi]

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases. If the state finds that individuals have failed to comply with the new requirements after 180 days, their coverage would be suspended for 180 days unless they are able to demonstrate compliance or qualification for an exemption.

NORD is also concerned that the current exemption criteria may not capture all individuals with, or at risk of, serious and chronic health conditions that prevent them from working. Regardless, even exempt enrollees may have to self-report their exemption, creating opportunities for administrative error that could jeopardize their coverage. In Arkansas, many individuals were unaware of the new requirements and therefore unaware that they needed to apply for such an exemption.[vii] No exemption criteria can circumvent this problem and the serious risk to the health of the people we represent.

Administering these requirements will also be expensive for the state of Montana. States such as Kentucky, Tennessee and Virginia have estimated that setting up the administrative systems to track and verify exemptions and work activities will cost tens of millions of dollars.[viii] This

would divert federal resources from Medicaid's core goal – providing health coverage to those without access to care – and compromise the fiscal health of Montana's Medicaid program.

Ultimately, these requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care. Most people on Medicaid who can work already do so.[ix] A study published in *JAMA Internal Medicine*, looked at the employment status and characteristics of Michigan's Medicaid enrollees.[x] The study found only about a quarter were unemployed (27.6 percent). Of this 27.6 percent of enrollees, two thirds reported having a chronic physical condition and a quarter reported having a mental or physical condition that interfered with their ability to work. In another report looking at the impact of Medicaid expansion in Ohio, the majority of enrollees reported that that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively).[xi] That report also found that many enrollees were able to get treatment for previously untreated health conditions, which made finding work easier. Suspending individuals' Medicaid coverage for non-compliance with these requirements will hurt rather than help people search for and obtain employment.

Additionally, as Montana itself notes in its application, recent research shows that the work reporting requirement in Arkansas did not lead to increased employment among the Medicaid population. A study in *The New England Journal of Medicine* found that the implementation of Arkansas's work requirement was associated with a significant loss of Medicaid coverage and significant increase in the number of uninsured individuals.[xii] The study found no corresponding increase in employment, which negates the argument that Medicaid enrollment is down because individuals are finding jobs and gaining other coverage. The study also estimates that 95 percent of Arkansans subject to the requirements already worked enough hours to meet the requirements or qualified for an exemption, which further confirms that most Medicaid beneficiaries are working if they are able to do so.

Montana's Medicaid program already connects enrollees with Montana's Health and Economic Livelihood Partnership Link (HELP-Link), which provides workforce training to unemployed enrollees who face barriers to work such as limited skills and lack of access to support such as childcare and transportation. This program has reached 25,000 low-income adults since its launch, 70 percent of whom found jobs within a year after completing the program.[xiii] HELP-Link provides low-income adults a pathway to the labor market and employment opportunities that have increased Montanans earning potential without imposing administrative barriers that jeopardize patients' access to care.

Continuous Eligibility

Finally, Montana's application would continue its current policy providing 12 months of continuous eligibility to the Medicaid expansion population. This policy helps to reduce churn in the Medicaid program and minimize the administrative burden to both the state and enrollees. NORD supports Montana's request to continue this policy.

NORD believes that healthcare coverage should be affordable, accessible and adequate for patients with rare diseases. Thank you for the opportunity to provide comments.

Sincerely,

/s/

Rachel Sher,
Vice President of Policy and Regulatory Affairs

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[i] Montana Department of Public Health and Human Services, Montana Medicaid Expansion Dashboard January 28, 2019. Available at: https://dphhs.mt.gov/helpplan/medicaidexpansiondashboard

[ii] Id.

[iii] Samantha Artiga, Petry Ubri, and Julia Zur, "The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings," Kaiser Family Foundation, June 2017. Available at: https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/.

[iv] Id.

[v] Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, "A Look at November State Data for Medicaid Work Requirements in Arkansas," Kaiser Family Foundation, December 18, 2018. Available at: https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-in-arkansas/; Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Available at: http://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf

[vi] Montana Department of Public Health and Human Services, Section 1115 Demonstration Amendment and Extension Application, July 23, 2019. Available at: https://dphhs.mt.gov/Portals/85/Documents/MedicaidExpansion/UpdatedApplicationforAmendmentandExtension-draft.pdf.

[vii] Jessica Greene, "Medicaid Recipients' Early Experience With the Arkansas Medicaid Work Requirement," Health Affairs, Sept. 5, 2018. Available at: https://www.healthaffairs.org/do/10.1377/hblog20180904.979085/full/.

[viii] Misty Williams, "Medicaid Changes Require Tens of Millions in Upfront Costs," Roll Call, February 26, 2018. Available at https://www.rollcall.com/news/politics/medicaid-kentucky.

[ix] Rachel Garfield, Robin Rudowitz, and Anthony Damico, "Understanding the Intersection of Medicaid and Work," Kaiser Family Foundation, February 2017. Available at: http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/.

[x] Renuka Tipirneni, Susan D. Goold, John Z. Ayanian. Employment Status and Health Characteristics of Adults With Expanded Medicaid Coverage in Michigan. *JAMA Intern Med.* Published online December 11, 2017. doi:10.1001/jamainternmed.2017.7055

[xi] Ohio Department of Medicaid, 2018 Ohio Medicaid Group VII Assessment: Follow-Up to the 2016 Ohio Medicaid Group VIII Assessment, August 2018. Accessed at: http://medicaid.ohio.gov/Portals/0/Resources/Reports/Annual/Group-VIII-Final-Report.pdf.

[xii] Benjamin D. Sommers, MD, et al. "Medicaid Work Requirements—Results from the First Year in Arkansas," *New England Journal of Medicine*. Published online June 18, 2019. Available at: https://cdf.nejm.org/register/reg_multistep.aspx?promo=ONFGMM02&cpc=FMAAALLV0818B.

[xiii] Hannah Katch, "Proposed Restrictions Could Undermine Montana's Successful Medicaid Expansion," Center for Budget and Policy Priorities, February 13, 2019, https://www.cbpp.org/research/health/proposed-restrictions-could-undermine-montanas-successful-medicaid-expansion#_ftn1