December 6, 2019

Allison Taylor
Director of Medicaid
State of Indiana, Family and Social Services Administration
402 West Washington Street, Room W461, MS 25
Indianapolis, IN 46204

Re: NORD Comments on Renewal Request for the Healthy Indiana Plan (HIP) Section 1115 Waiver (Project Number 11-W-00296/5)

Dear Director Taylor:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on Indiana's Renewal Request for the Healthy Indiana Plan (HIP) Section 1115 Waiver (Project Number 11-W-00296/5).

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.

NORD strongly supports Medicaid expansion in Indiana. Over 400,000 low-income adults currently receive healthcare coverage through the state's Medicaid expansion.[i] This means that thousands of enrollees are receiving preventive, early detection and diagnostic services as well as disease management and treatment for their conditions.[ii] Medicaid expansion is clearly beneficial for patients with serious and chronic health conditions.

Indiana's application to continue the HIP 2.0 program also 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 therefore offers the following comments on Indiana's proposal.

10 Year Waiver
Indiana is requesting their waiver be approved for 10 years as opposed to five years, as is standard. NORD believes that it is irresponsible to extend the HIP renewal waiver for 10 years. While Indiana has a lengthy interim evaluation report, there are a number of policies the state is asking to continue with limited or no data available. For example, in reference to the work reporting requirement, the proposal states, "*this means that our Gateway to Work program, which started phase-in January 2019, will have almost no real operation experience before we started drafting a renewal*." This means there is no data on how this policy impacts patients and their access to care.

Many policies, including the tiered POWER Accounts and the tobacco surcharge, were only approved in February 2018, have been implemented for less than two years, and have not proven they furnish medical care to HIP 2.0 enrollees. NORD believes some of the policies in the waiver should not be approved, and in the true nature of a demonstration project, it should be approved for no more than five years.

Work Reporting Requirements
Under the application, individuals between the ages of 19 and 59 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.[iii]

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 for at least eight out of the previous 12 months, their coverage will be suspended for the next calendar year, starting January 1. Coverage will be suspended until members can demonstrate past compliance, enroll in school or training, gain full- or part-time work or qualify for an exemption. This gap in coverage could have devastating effects for the rare disease community.

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 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.[iv] 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 Indiana. 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.[v] 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 Indiana's Medicaid program.

Ultimately, these requirements do not further the goals of the Medicaid program or help low-income individuals find work. Most people on Medicaid who can work already do so.[vi] A study published in *JAMA Internal Medicine*, looked at the employment status and characteristics of Michigan's Medicaid enrollees.[vii] 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. Additionally, a study in *The New England Journal of Medicine* found that Arkansas's work requirement was associated with a significant loss of Medicaid coverage, but no corresponding increase in employment, which negates the state's argument that Medicaid enrollment is down because individuals are finding jobs and gaining other coverage.[viii] 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.

Continuous Medicaid coverage can actually help people find and sustain employment. 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).[ix] 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.

Enforceable Premiums

Indiana's Medicaid program currently charges premiums equal to two percent of modified adjusted gross income to all adults, and 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. Individuals below 100 percent of the federal poverty level move into a lesser benefit plan for failing to pay the premium. The state proposes to keep this policy. The interim evaluation finds that only a little over half of enrollees are enrolled in HIP Plus (the plan needing a premium). Lockouts for failure to pay a premium can have negative consequences for patients. 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.[x] For individuals with rare diseases, maintaining access to comprehensive coverage is vital to their overall health. NORD believes that these premiums create significant financial barriers for patients that jeopardize their access to needed care.

Tobacco Surcharge

Indiana's premiums also include an additional surcharge for tobacco users. Research is clear that these surcharges have not been proven effective in helping smokers quit and reducing tobacco use. Recent studies from Health Affairs[xi] and the Center for Health and Economics Policy at the Institute for Public Health at Washington University[xii] have suggested that tobacco surcharges do not increase tobacco cessation but do lead individuals to forgo health insurance rather than paying the surcharge. Tobacco users often have expensive comorbidities. Charging a tobacco surcharge could cause those enrollees to go without coverage and access to preventive care (including tobacco cessation), allowing comorbid health conditions to worsen and ultimately resulting in more expensive healthcare. NORD opposes this surcharge.

POWER Accounts

One of the key features of the HIP program is that it is modeled after a high deductible private health insurance plan. High deductible health plans can be financially challenging for individuals living with chronic illness or that receive a cancer diagnosis, leading to delays in care.[xiii]

The Indiana POWER account is funded by the individual's premiums and then the state, totaling $2,500 per HIP Plus enrollee. Enrollees use the funds in their accounts to cover the first $2,500 of care they need. Any additional care is not subject to additional member contributions. If a HIP Plus patient does not use all of the funds in their POWER account, the funds roll over to the next year. This is an unnecessary complicated scheme to provide coverage to low-income patients. NORD believes the POWER account structure creates confusion and barriers for patients to access care.

Removing Retroactive Coverage

Indiana has also requested to extend its current waiver limiting retroactive coverage for most populations to 30 days. Retroactive eligibility in Medicaid prevents gaps in coverage, by covering individuals for up to 90 days (or quarter of the year) prior to the month of application, assuming the individual is eligible for Medicaid coverage during that time frame. It is common that individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. Retroactive eligibility allows patients who have been diagnosed with a serious illness, such as cancer or heart disease, to begin treatment without being burdened by medical debt prior to their official eligibility determination.

Medicaid paperwork can be burdensome and often times confusing. A Medicaid enrollee may not have understood or received a notice of Medicaid renewal and only discovered the coverage lapse when picking up a prescription or going to see their doctor. With a shorter period of retroactive eligibility, Medicaid enrollees could face substantial costs at their doctor's office or pharmacy. When Ohio was considering a similar provision in 2016, a consulting firm advised the state that hospitals could accrue as much as $2.5 billion more in uncompensated care as a result of the waiver.[xiv] Patients should not be left to choose between massive medical bills and treating their illness. NORD encourages Indiana to reverse this policy in the waiver renewal application.

Co-Payments for Non-Emergent Use of the ED

Indiana's renewal application includes the continuation of the policy to charge all enrollees an eight-dollar copayment for non-emergent use of the emergency department (ED). This policy can deter people from seeking necessary care during an emergency. Delays in care could have harmful impacts on the short- and long-term health of individuals with serious, acute and chronic diseases.

People should not be financially penalized for seeking lifesaving care for emergencies or any other critical health problem that requires immediate care. When people do experience severe symptoms, they should not try to self-diagnose their condition or worry that they can't afford to seek care. Instead, they must have access to quick diagnosis and treatment in the ED.

Evidence suggests cost-sharing may not result in the intended cost savings.[xv] Research demonstrates that low-income individuals served by Medicaid are more price sensitive compared to others, more likely to go without needed care, and more likely to experience long-term adverse outcomes. A study of enrollees in Oregon's Medicaid program demonstrated that implementation of a copay on emergency services resulted in decreased utilization of such services but did not result in cost savings due to subsequent use of more intensive and expensive services.[xvi] This provides further evidence that copays may lead to inappropriate delays in needed care. NORD urges Indiana to remove this punitive cost-sharing provision for non-emergent use of the emergency department from the waiver renewal.

Eliminating Non-Emergency Medical Transportation
Indiana has also requested to extend its waiver to eliminate Non-Emergency Medical Transportation (NEMT) benefits. Low-income patients may not own a car and may lack access to reliable public transportation, especially in rural areas. Removing this benefit will therefore harm patients who need to attend regular visits with their providers to manage their medications and treatments. For example, one study found patients with asthma, hypertension or heart disease who needed multiple visits to a medical professional more likely to keep their appointments if they had NEMT.[xvii] Indiana should reinstate the NEMT benefit so that patients in HIP 2.0 are able to keep appointments to manage their conditions and stay healthy.

NORD supports the continuation of Medicaid expansion in Indiana; however, there are many policies that limit the potential benefits of this coverage and do not further the furnishing of medical services to enrollees. NORD urges Indiana to modify the waiver renewal prior to its submission to the Centers for Medicare and Medicaid Services. Thank you for the opportunity to submit comments.

Sincerely,

/s/

Rachel Sher,
Vice President of Policy and Regulatory Affairs

[i] https://www.kff.org/health-reform/state-indicator/medicaid-expansion-enrollment/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

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

[iii] 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

[iv] 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/.

[v] 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.

[vi] 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/.

[vii] 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

[viii] 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, https://cdf.nejm.org/register/reg_multistep.aspx?promo=ONFGMM02&cpc=FMAAALLV0818B

[ix] 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.

[x] Id.

[xi] Friedman, A.S., Schpero, W. L., Busch, S.H. Evidence Suggests That The ACA's Tobacco Surcharges Reduced Insurance Take-Up and Did Not Increase Smoking Cessation. Health Aff 2016; 35:1176-1183. doi: 10.1377/hlthaff.2015.1540 accessed at: http://content.healthaffairs.org/content/35/7/1176.abstract

[xii]Monti, D., Kusemchak, M., Politi, M., Policy Brief: The Effects of Smoking on Health Insurance Decisions Under the Affordable Care Act. Center for Health and Economics Policy Institute for Public Health at Washington University. July 2016. Accessed at: https://publichealth.wustl.edu/wp-content/uploads/2016/07/The-Effects-of-Smoking-on-Health-Insurance-Decisions-under-the-ACA.pdf

[xiii] "The Challenges Of High-Deductible Plans For Chronically Ill People, " Health Affairs Blog, April 22, 2019. DOI: 10.1377/hblog20190416.47741

[xiv] Virgil Dickson, "Ohio Medicaid waiver could cost hospitals $2.5 billion", Modern Healthcare, April 22, 2016. (http://www.modernhealthcare.com/article/20160422/NEWS/160429965)

[xv] See for example: Chernew M, Gibson TB, Yu-Isenberg K, Sokol MC, Rosen AB, Fendrick AM. Effects of increased patient cost sharing on socioeconomic disparities in health care. J Gen Intern Med. 2008. Aug; 23(8):1131-6. Ku, L and Wachino, V. "The Effect of Increased Cost-Sharing in Medicaid: A Summary of Research Findings." Center on Budget and Policy Priorities (July 2005), available at http://www.cbpp.org/5-31-05health2.htm.

[xvi] Wallace NT, McConnell KJ, et al. How Effective Are Copayments in Reducing Expenditures for Low-Income Adult Medicaid Beneficiaries? Experience from the Oregon Health Plan. Health Serv Res. 2008 April; 43(2): 515–530.

[xvii] Michael Adelberg and Marsha Simon, "Non-Emergency Medical Transportation: Will Reshaping Medicaid Sacrifice An Important Benefit?" Health Affairs, September 20, 2017. Accessed at: https://www.healthaffairs.org/do/10.1377/hblog20170920.062063/full/