December 3, 2019

Submitted via online portal

Re: NORD Comments on Georgia's 1115 Medicaid Wavier Application

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on Georgia's 1115 Demonstration Waiver Application for its Georgia Pathways to Coverage initiative.

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 Georgia Pathways plan is not a sufficient solution to improve access to quality and affordable healthcare for low-income Georgians. The state estimates that approximately 50,000 individuals would gain coverage under the plan, whereas over 500,000 Georgians could access coverage if the state fully expanded its Medicaid program.

NORD opposes the Georgia Pathways program and offers the following comments on the draft waiver application.

Eligibility

Under the Georgia Pathways plan, only individuals with incomes below 100 percent of the federal poverty level ($1,778 per month for a family of three) who can prove that they work at least 80 hours per month would be eligible for Medicaid. This drastically limits the number of patients with rare diseases and other serious and chronic health conditions who will receive access to the quality and affordable healthcare coverage that they need.

While no exemption criteria can prevent the potential coverage losses associated with work reporting requirements, Georgia has not proposed any exemption criteria that would allow individuals who are unable to meet the work reporting requirements to apply for coverage. This means that patients who have serious health conditions that prevent them from working 80 hours per month would have **no pathway to coverage** that could help them to treat these conditions. This discrimination against patients with health conditions that prevent them from working is unacceptable.

Once enrolled, individuals may be able to qualify for short-term exemptions in certain situations. Still, NORD is concerned that these exemption criteria may not capture all individuals with 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. Again, no exemption criteria can circumvent these problems and the serious risk to the health of the people we represent.

For the first six months, members will have to report their hours and work activities monthly. This will put a significant administrative burden on enrollees, which will likely decrease the number of individuals with Medicaid coverage. For example, Arkansas also implemented a work reporting requirement where Medicaid enrollees had to report their hours worked or their exemption. During the first six months of implementation, the state terminated coverage for over 18,000 individuals.[i] Georgia has not provided an estimate of the coverage losses associated with this proposal in its waiver application.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with rare diseases. If the state finds that individuals have failed to comply for one month, their coverage will be suspended, and if the state finds that individuals have failed to comply for three months, they will be disenrolled.

If individuals are able to meet the reporting requirements for six consecutive months, they will be exempt from further reporting and re-evaluated for eligibility during their annual redetermination. However, if individuals do not report a change in their employment status, they will be responsible for any capitation and cost-sharing expenses. This exposes already low-income individuals to enormous financial risk.

If Georgia truly cares about incentivizing and promoting employment, full Medicaid expansion would be the best way to achieve this goal. In a report looking at the impact of Medicaid expansion in Ohio, the majority of enrollees reported that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively).[ii] That report also found that many enrollees were able to get treatment for previously untreated health conditions, which made finding work easier. Preventing individuals from enrolling in Medicaid coverage until they comply with these requirements will therefore hurt rather than help people search for and obtain employment.

Finally, Georgia would be the first state to require enrollees to comply with the work reporting requirement prior to enrolling in the Medicaid program with no opportunity to demonstrate a medical or other exemption. Changing the eligibility for Medicaid is the sole purview of Congress and cannot be waived. NORD opposes this policy.

<u>Financial Barriers</u>

For the few individuals who are able to meet this limited eligibility criteria, the proposal still creates numerous financial barriers that will jeopardize their coverage. Individuals with incomes above 50 percent of the federal poverty level will have to pay monthly premiums and will lose coverage if they fail to pay premiums for three months. This policy would likely both increase the number of enrollees who lose Medicaid coverage and also discourage eligible people from enrolling in the program. 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]

This policy will not only apply to – and jeopardize coverage for – new enrollees, but for individuals who are currently enrolled in Medicaid through the Transitional Medical Assistance (TMA) program. Additionally, it unclear how the state may try to recoup capitation and other payments for any months that individuals do not pay their premiums and if, as with the work reporting requirement policy above, patients may be put at significant financial risk. NORD believes that these premiums will create significant financial barriers for patients that jeopardize their access to needed care and therefore opposes this policy.

Georgia's premium proposal also includes 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[v] and the Center for Health and Economics Policy at the Institute for Public Health at Washington University[vi] 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, ultimately resulting in more expensive healthcare. NORD opposes this surcharge.

Georgia's proposal also includes a number of copayments for individuals with incomes above 50 percent of the federal poverty level that could be a significant financial burden for patients. The most egregious of these is a $30 copay for non-emergency use of the emergency department (ED). This policy could deter rare disease patients from seeking necessary care during an emergency.

People should not be financially penalized for seeking lifesaving care for their rare disease 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 cannot afford to seek care. Instead, they must have access to quick diagnosis and treatment in the ED.

Evidence suggests this type of cost sharing may not result in the intended cost savings.[vii] 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 because of subsequent use of more intensive and expensive services.[viii] This provides further evidence that copays may lead to inappropriate delays in needed care. NORD opposes this punitive proposal for a $30 copayment for non-emergent use of the ED.

<u>Reduced Benefits</u>

Individuals would be required to enroll in employer sponsored insurance (ESI) if it is available and determined to be cost effective for the state. However, the state would not provide any wraparound services for individuals regardless of the benefit package in their ESI. Additionally, the state would not help individuals with the costs of coinsurance or deductibles required in their ESI. NORD opposes the requirement to enroll in ESI without wraparound services and full financial protection for patients.

The state has also requested to waive non-emergency transportation (NEMT) for the entire demonstration population. NEMT helps low-income patients overcome barriers to care due to transportation and allows patients to keep appointments with doctors and other healthcare providers. For example, one study found patients with asthma, hypertension or heart disease who needed multiple visits to a medical professional to maintain their health were more likely to keep their appointments if they had NEMT.[ix] NORD opposes a waiver of NEMT.

Additional Costs

Administering all of these requirements will be expensive for the state of Georgia. States such as Kentucky, Tennessee and Virginia have estimated that setting up the administrative systems to track and work activities alone will cost tens of millions of dollars.[x] 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 Georgia's Medicaid program.

NORD opposes this waiver proposal. Instead, we urge Georgia to focus on solutions that promote adequate, affordable and accessible coverage, including a full expansion of the state's Medicaid program.

Sincerely,

/s/

Rachel Sher,
Vice President of Policy and Regulatory Affairs

[i] 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

[ii] 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.

[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] 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

[vi]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

[vii] 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.

[viii] 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.

[ix] https://www.healthaffairs.org/do/10.1377/hblog20170920.062063/full/

[x] 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.