



July 23, 2020

The Honorable Brian Kemp  
206 Washington Street  
Suite 203, State Capitol  
Atlanta, GA 30334

*Submitted via online portal:* <https://medicaid.georgia.gov/patients-first-act-public-comment>

**Re: NORD Comments on Georgia's 1332 Waiver Application – GA Access Model**

Dear Governor Kemp,

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on Georgia's Section 1332 Waiver Application to implement the Georgia Access Model.

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.

While NORD supports reinsurance as a tool to stabilize premiums in the individual marketplace, we remain deeply concerned that the Georgia Access Model, as currently envisioned, will jeopardize access to quality, affordable health care coverage for patients with rare diseases. Under the Georgia Access Model, the state would deny Georgians the freedom to enroll in coverage through Healthcare.gov and instead require that they use insurers, brokers, and private websites (options available to them already). This plan increases the risk that people will enroll in coverage with inadequate benefits through private entities that may not help patients choose the best plan for their health needs. NORD urges Georgia to withdraw its application for the Georgia Access Model.

Georgia Access Model

Georgia's application proposes to no longer use Healthcare.gov for enrollment and instead require people to enroll directly through insurers or brokers. This policy will make it harder for patients to enroll in comprehensive, affordable health care coverage and NORD opposes this change.

The state asserts that enrollment will increase by 25,000 due to the change to direct and broker-mediated enrollment. There is no clear methodology for producing this estimate, except the state's unproven claim that plans will market more directly and effectively when Georgia moves away from Healthcare.gov. However, removing Healthcare.gov as a pathway to enrollment will



likely decrease, rather than increase enrollment. Many patients may be lost in the transition and therefore lose coverage. Nevada recently transitioned to a new enrollment platform for 2020, and while the transition went smoothly, enrollment declined in its first year.<sup>i</sup> NORD fears that some of the 450,000 Georgians who currently purchase coverage through Healthcare.gov would inevitably lose coverage during the transition. For rare disease patients who require daily, weekly or monthly medications and/or health care provider engagement, this sudden loss in coverage could result in their being unable to meet with their provider or get prescriptions filled, leading to hospitalization or death.

Today, patients with rare diseases who shop on Healthcare.gov can trust that they are purchasing a comprehensive health insurance plan that will allow them to manage their health conditions. This is extremely important for rare disease patients, as their health care can be complex and quality care is crucial to maintaining their overall health. However, under the Georgia Access Model, issuers and brokers could sell qualified health plans (QHPs) alongside other types of plans, often known as “skimpy plans” or “short term plans” that discriminate against people with pre-existing conditions and will not cover enrollees’ medical expenses if they get sick.

There is already evidence of misleading marketing related to short-term and other skimpy plans leading individuals to unwillingly enroll in coverage that lacks key patient protections.<sup>ii</sup> This could create confusion for all patients, including those with rare diseases and lead them to purchase coverage that does not meet their needs. Additionally, rare disease patients are diagnosed at all ages and typically have long diagnostic odysseys, averaging between 5-7 years. If a person unknowingly selects less comprehensive coverage and then is diagnosed with a rare disease, they could discover their health plan lacks comprehensive coverage and could be faced with extremely high out-of-pocket costs to maintain their health.

Healthcare.gov shows consumers all QHPs available in their area and does not favor certain plans over others. However, brokers who would be helping individuals through the enrollment process under the Georgia Access Model would not have to show individuals all of their plan options and may receive larger commissions for certain plans over others that influence their recommendations to patients. Increasing the reliance on insurers and brokers will limit the ability of patients with rare diseases to compare plan price and benefit design in an unbiased manner to choose the right plan for them and could ultimately result in harm to patients who become enrolled in sub-standard or inadequate insurance coverage that does not meet their needs. This failure to appropriately shield patients from risk is unacceptable.

The state predicts that moving to enhanced direct enrollment with web brokers will bring down premiums. Unfortunately, the opposite could happen. With this waiver, some healthy people may drop comprehensive coverage and opt for a non-compliant plan or forgo coverage altogether. Those remaining in the individual market of compliant plans would likely have more complex health conditions, which could drive premiums in the market up, instead of down. Again, NORD opposes the changes in the Georgia Access Model because they would harm the rare disease patients we represent who rely on affordable, comprehensive health plans to maintain their health.



### Reinsurance

Reinsurance is an important tool to help stabilize health insurance markets. Reinsurance programs help insurance companies cover the claims of very high cost enrollees, which in turn keeps premiums affordable for other individuals buying insurance on the individual market. Reinsurance programs have been used to stabilize premiums in a number of health care programs, such as Medicare Part D. A temporary reinsurance fund for the individual market was also established under the Affordable Care Act and reduced premiums by an estimated 10 to 14 percent in its first year.<sup>iii</sup> A recent analysis by Avalere of seven states that have already created their own reinsurance programs through Section 1332 waivers found that these states reduced individual market premiums by an average of 19.9 percent in their first year.<sup>iv</sup>

Georgia's proposal will create a reinsurance program starting for the 2022 plan year and continuing for five years. Based on the initial analysis commissioned by the state, this program is projected to reduce premiums by 10 percent in 2021 and increase the number of individuals obtaining health insurance through the individual market. NORD applauds the state for their work to create a reinsurance program that would help patients with pre-existing conditions obtain affordable, comprehensive coverage. However, we remain deeply concerned about the reinsurance program being coupled with a provision in the application that would divert Georgia citizens away from QHPs that deliver on affordable, comprehensive health care through [healthcare.gov](http://healthcare.gov).

### Comment Period

A fifteen-day comment period is not sufficient to solicit meaningful comments on a proposal that would have such a substantial impact on access to care for rare disease patients in Georgia. A change of this significance should be subject to a full comment period of at least 30 days to ensure that stakeholders, including the healthcare industry, patients and consumers and other interested parties in the state are able to adequately respond to the request for comment.

Since the state released the first, now outdated, version of its waiver application last year, COVID-19 has overwhelmed our health care system and highlighted that the need for adequate and affordable health insurance coverage more than ever. If someone without health insurance contracts the COVID-19 virus, they may be forced to make the difficult decision to not be tested and treated due to fears about the cost of care. That puts all Georgians – particularly the rare disease community – at risk. The state's proposals are not directly related to COVID-19 and not slated to take effect until 2022. NORD asks that the state reconsider its decision to cut short the public comment period on the new application and instead allow additional time to facilitate public review of and input on these important proposals.

NORD thanks the state of Georgia for the opportunity to comment on this 1332 waiver application and looks forward to working with the state to ensure that rare disease patients have access to quality, affordable health care. For questions regarding NORD or these comments, please contact me via email at [hross@rare diseases.org](mailto:hross@rare diseases.org)



Sincerely,

Heidi Ross  
Director of Policy

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<sup>i</sup> Nevada health insurance marketplace: history and news of the state's exchange. Louise Norris, HealthInsurance.org. June 11, 2020. Available at: <https://www.healthinsurance.org/nevada-state-health-insurance-exchange/>

<sup>ii</sup> Seeing Fraud and Misleading Marketing, States warn Consumers About Alternative Health Insurance Products. The Commonwealth Fund, Dania Palanker, JoAnn Volk, and Maanasa Kona. October 30, 2019. Available at; <https://www.commonwealthfund.org/blog/2019/seeing-fraud-and-misleading-marketing-states-warn-consumers-about-alternative-health>, and The Marketing of Short-Term Health Plans, The Robert Wood Johnson Foundation, January 31, 2019. Available at: <https://www.rwjf.org/en/library/research/2019/01/the-marketing-of-short-term-health-plans.html>

<sup>iii</sup> American Academy of Actuaries, Individual and Small Group Markets Committee. *An Evaluation of the Individual Health Insurance Market and Implications of Potential Changes*. January 2017. Retrieved from [https://www.actuary.org/files/publications/Acad\\_eval\\_indiv\\_mkt\\_011817.pdf](https://www.actuary.org/files/publications/Acad_eval_indiv_mkt_011817.pdf).

<sup>iv</sup> Avalere. *State-Run Reinsurance Programs Reduce ACA Premiums by 19.9% on Average*. March 2019. Retrieved from <https://avalere.com/press-releases/state-run-reinsurance-programs-reduce-aca-premiums-by-19-9-on-average>.