

# STATE OF THE STATES REPORT

## 5<sup>th</sup> Edition



**NORD**<sup>®</sup>  
National Organization  
for Rare Disorders

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# NORD: The Independent Voice of the Rare Disease Patient Community

Representing the more than 25 million Americans with rare diseases, the National Organization for Rare Disorders (NORD®) is an independent, nonpartisan, nonprofit advocacy organization and the voice of the rare disease patient community. NORD addresses complex medical, research and public policy issues through programs and services shaped by a single guiding vision: to improve the lives of all Americans affected by rare diseases.

NORD is a mission-based, non-governmental organization that operates under the guiding principle that “Alone we are rare. Together we are strong.” NORD strives to bring the rare disease community together to raise awareness, educate, empower patients and the organizations that serve them, create a supportive community, and foster collaboration among the various stakeholders who each have a part in driving progress in the fight against rare diseases in both the policy and research realms. Learn more about our work over the past 37 years at: [rarediseases.org/history](http://rarediseases.org/history).

Since 1983, NORD has worked to ensure that the voice of the rare disease patient has been front and center when important policy and regulatory decisions have been made at both the federal and state levels. NORD began when a group of parents of children with rare diseases came together to advocate for the passage of the Orphan Drug Act of 1983 (ODA). Although the ODA has been a resounding success, helping to spur the development and approval of more than 800 rare disease therapies, there is more work to be done. It is estimated that there are over 7,000 rare diseases, which are defined in the United States as diseases affecting 200,000 or fewer people.<sup>1</sup> Today, over 90% of rare diseases still do not have a treatment specifically intended to treat the disease.

But the needs of the rare disease community go beyond the imperative for therapies approved by the US Food and Drug Administration (FDA). The challenges of living with a rare disease are many, including the initial diagnostic odyssey, accessing needed therapies, navigating insurance, paying for unending medical expenses and dealing with systems and individuals that fundamentally do not understand the realities of the rare disease community. Even when a treatment exists, patients with rare diseases often face challenges obtaining insurance coverage. They also face challenges affording the coverage itself, both in the form of premiums and cost sharing. These barriers and significant obstacles require the continued partnership of patients, providers, researchers, state and federal legislators, state and federal regulators and the pharmaceutical industry.

In 2015, NORD launched its State Report Card project. The goal is to evaluate how effectively states are serving people with rare diseases. This year marks the fifth edition of the State of the States Report and was compiled using data current as of December 2019. Using these data, this report evaluates the status of policy issues that are of significant importance to the rare disease community. It is important to note, however, that these issues are not exhaustive. The issues contained herein touch on several critical and relevant policy areas at the state level, but, with each issue included, there are still many others that are capable of impacting the lives of rare disease patients. NORD hopes this report can serve as a tool for patients, advocates and policy makers as they strive to ensure that state policies best serve the needs of the rare disease community.

## NORD Mission Statement

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 280 patient organization members, is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient services.

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<sup>1</sup> 21 C.F.R. 316

# A NOTE TO THE READER ABOUT THE FORMAT OF NORD'S FIFTH EDITION STATE REPORT CARD

For those who have relied on NORD's report cards over the years, you will note a change in format in the individual state report cards. The new format is intended to bring a higher degree of transparency to NORD's grading methodology.

ALABAMA		Fifth Edition	STATE REPORT CARD
For additional information on the grading methodology, please visit the State of the States Report: <a href="http://rareaction.org/stateofthestates/">rareaction.org/stateofthestates/</a> .			
<b>Medicaid Eligibility</b>			<b>Overall Grade: C</b>
	Eligibility for childless adults		F
	Eligibility for parent of a dependent child		D
	Eligibility for pregnant women		D
	Medicaid and/or Children's Health Insurance Program (CHIP) eligibility for children		A
<b>Medicaid Section 1115 Waivers</b>			<b>Overall Grade: Fail</b>
	Alabama has sought a section 1115 waiver to implement a work requirement in its Medicaid program, but the waiver has yet to be approved by the federal government.		
<b>Out-of-Pocket Costs</b>			<b>Overall Grade: F</b>
	Prescription drug cost sharing protections		F
<b>Step Therapy</b>			<b>Overall Grade: F</b>
	Based on clinical practice		F
	Timeline		F
	Exception process		F
	Categories of exceptions		F
	Subsequent guidance from state		F
<b>Medical Nutrition</b>			<b>Overall Grade: D</b>
	Coverage requirements for commercial health plans		F
	Covered disorders requirements for commercial health plans		F
	Coverage requirements for state-run programs		C
	Covered disorders requirements for state-run programs		C
<b>Newborn Screening</b>			<b>Overall Grade: C</b>
	Screening for RUSP core conditions		C
	Adding RUSP core conditions to the state panel		B
	Funding for program		B
	Use of dried blood spots (DBS)		F
	Follow-up		B
	Quality of program		D
	Advisory complete		C
<b>Rare Disease Advisory Councils</b>			
	Alabama enacted legislation to create a rare disease advisory council (RDAC) in 2017, and the Council met for the first time in 2018. Alabama's RDAC is not currently meeting statutory requirements as the resolution states that appointments must be made within 60 days, and some positions have still not been filled by the Governor. The council continues to meet on a quarterly basis.		
<b>Individual Insurance Market Protections</b>			
	<b>Pre-existing conditions protections:</b> Only current federal protections apply in Alabama.		
	<b>Short-term, limited-duration and association health plans:</b> Alabama does not place any stricter limitations than current federal standards on short-term, limited-duration health plans. Self-funded association health plans must satisfy the same licensure and financial standards as commercial insurers.		
	<b>Reinsurance:</b> Alabama has not yet sought a section 1332 waiver to establish a reinsurance program.		

1 By clearly reflecting the “grades” on each factor that was evaluated, this year’s report card will enable more specific analysis and dialogue on the areas in states needing improvement and on the areas in which states are excelling.

2 The Medicaid Section 1115 Waiver section did not lend itself to a grade of “A” through “F.” Here, a “Pass” or “Fail” grade was assigned to provide a more general sense of performance on these issues.

3 In these areas, no grades were assigned and, instead, a description of the status of each issue was included. Within the RDAC and Individual Insurance Protections sections, you will find a detailed description of the important factors that were analyzed.

Each state was evaluated separately in the following seven categories:

1. Medicaid Eligibility
2. Medicaid Section 1115 Waivers
3. Out-of-Pocket Costs
4. Step Therapy
5. Medical Nutrition
6. Newborn Screening
7. Rare Disease Advisory Councils
8. Individual Insurance Market Protections

The overall grade in each of these categories is comprised of graded subcategories that were averaged to establish the overall grade. Grades were established as follows:

- A:** 90-100 points (A for purposes of grading was assigned 95 points)
- B:** 80-90 points (B for purposes of grading was assigned 85 points)
- C:** 70-80 points (C for purposes of grading was assigned 75 points)
- D:** 60-70 points (D was assigned 65 points)
- F:** under 60 points (F was assigned 55 points)

The average was taken to establish the overall grade for each section.

# MEDICAID ELIGIBILITY, WAIVERS, AND HOME- AND COMMUNITY-BASED SERVICES

*NORD supports the ability of eligible rare disease patients to access comprehensive Medicaid services in their states without unnecessary and harmful hurdles to such access.*

Medicaid is an entitlement program administered through a partnership between the federal government and the states, wherein individuals who meet certain criteria are guaranteed some form of health care coverage. Medicaid currently covers over 62 million Americans, making it the largest provider of health insurance in the United States and a critical safety net for its enrollees.<sup>2</sup> Medicaid also plays a significant role in supporting the rare disease community. Many individuals with rare diseases depend on Medicaid for primary or supplemental insurance.

Due to the fact that each state plays a significant role in shaping its own Medicaid program, there is considerable variability among programs. Medicaid is often described as a single, cohesive program, but vast differences among state programs make it difficult to describe in general terms and to grade. There are a host of characteristics that can either result in a high-functioning state Medicaid program or, on the other hand, reduce its effectiveness. This report focuses on two of these characteristics that are of great import to the rare disease community. Specifically, this report grades state Medicaid programs on: (1) eligibility levels and (2) policies carried out through the authority granted in section 1115 of the Social Security Act.<sup>3</sup> This report also touches on another aspect of Medicaid programs, Home- and Community-based Services (HCBS), but, given the complexity in these programs, stops short of assigning a corresponding grade. Additional information on how states perform in each of these policy areas is contained within the appendices.

## Medicaid Eligibility

Prior to the enactment of the Affordable Care Act (ACA) in 2010,<sup>4</sup> United States citizens could be eligible for Medicaid in the state in which they resided if they fit into a particular category (e.g., children, parents of dependent children, pregnant women, etc.) and if their income and combined assets fell in a range determined by the state. The ACA amended this eligibility standard by removing the specific categories and establishing a nationwide minimum income eligibility level at 138% of the federal poverty level (FPL) (e.g., FPL in 2019 for a family of two was \$12,490, so 138% FPL for a family of two in 2019 was approximately \$17,236).<sup>5</sup> This policy is often referred to as Medicaid “expansion.”

In 2012, however, the Supreme Court, in *National Federation of Independent Business v. Sebelius*, found the ACA’s establishment of a national standard to be unconstitutional, leaving the decision of whether to expand Medicaid to the states.<sup>6</sup> Since that decision, many states have chosen to expand Medicaid, establishing a minimum eligibility level of 138% FPL and providing Medicaid coverage for childless adults, who had previously been ineligible. Such expansion has resulted in an increase of access to needed health services and allowed many Americans with rare diseases to gain health insurance coverage. There are still several states, however, that have opted not to expand Medicaid, depriving uninsured or underinsured Americans of the ability to access coverage through Medicaid.

The federal government also has sought to expand access to Medicaid through the creation of the State Children’s Health Insurance Program (CHIP).<sup>7</sup> Like Medicaid, CHIP is a joint venture between the federal government and the states. Unlike Medicaid, however, CHIP is not an entitlement program. Rather, CHIP is a grant program under which the federal government provides states with a limited sum of

<sup>2</sup> “Medicaid: A Primer – Key Information on the Nation’s Health Coverage Program for Low-Income People.” The Henry J. Kaiser Family Foundation, March 29, 2016. <https://www.kff.org/medicaid/issue-brief/medicaid-a-primer/>.

<sup>3</sup> 42 U.S.C. 1315

<sup>4</sup> Patient Protection and Affordable Care Act (P.L. 111-148) was signed into law on March 23, 2010.

<sup>5</sup> “2019 Poverty Guidelines.” ASPE, May 22, 2019. <https://aspe.hhs.gov/2019-poverty-guidelines>.

<sup>6</sup> 567 U.S. 519

<sup>7</sup> 42 U.S.C. 1397aa-1397mm



**Table 1: Medicaid Financial Eligibility Grading Rubric**

GRADE	DESCRIPTION			
	Eligibility for Parents of Dependent Children	Eligibility for Childless Adults	Eligibility for Pregnant Women	Eligibility for Children
<b>A</b>	138% of FPL or greater	138% of FPL or greater	Medicaid/CHIP eligibility of 220% of FPL or greater	Medicaid or CHIP eligibility of 300% of FPL or greater for all age groups
<b>B</b>	100%-137% of FPL	100%-137% of FPL	Medicaid/CHIP eligibility of 190% to 219% of FPL	Medicaid or CHIP eligibility of 195% to 299% of FPL for all age groups
<b>C</b>	90% to 99% of FPL	90% to 99% of FPL	Medicaid/CHIP eligibility of 150% to 189% of FPL	Medicaid or CHIP eligibility of 150% to 194% of FPL for all age groups
<b>D</b>	89% of FPL or less	89% of FPL or less	Medicaid/CHIP eligibility of 149% of FPL or less	Medicaid or CHIP eligibility of up to 150% for all age groups
<b>F</b>	No coverage	No coverage	No coverage	No coverage

## Section 1115 Waivers

Section 1115 of the Social Security Act grants the Secretary of Health and Human Services (HHS) the authority to waive certain requirements in the Act, including Medicaid requirements, for the purposes of allowing a state to carry out a policy proposal. Section 1115 waivers enable states to administer demonstration projects that have been approved by HHS' Centers for Medicare and Medicaid Services (CMS). By waiving certain Medicaid requirements, these projects allow a state to direct federal Medicaid funds in ways that would not otherwise be permitted under federal law. The intent of these waivers is to help states seek innovative ways to control health care costs and improve services for Medicaid beneficiaries. To be approved, these waivers are required to align with the objectives of the Medicaid program.

Several of the more recent demonstration projects proposed by states, however, aim to restructure Medicaid benefits and eligibility in ways that undermine the purpose of the program and disproportionately affect people with rare diseases. For instance, one of the more concerning uses of section 1115 waivers is to establish work requirements in state Medicaid programs. States seeking to add a work requirement often claim that it would improve the lives of beneficiaries. However, there is no evidence to support this claim. Instead, the evidence suggests that those Medicaid beneficiaries who are able to work largely already do, and those same beneficiaries, in addition to those unable to work, would be at risk of losing coverage under a work requirement due to both the complexities of implementing the requirement for the state and complying with the requirement for beneficiaries.<sup>9</sup> Some state proposals include exemptions to the work requirement; however, such exemptions are not likely to capture every deserving Medicaid beneficiary. Given the scarcity of physicians familiar with rare diseases and the prevalence of undiagnosed conditions, it is often difficult, sometimes impossible, for rare disease patients to convey the extent of their symptoms in a way that satisfies state exemption requirements. Forcing patients to justify their inability to maintain a consistent

work schedule before they can receive or maintain care could result in a devastating loss of coverage throughout the rare disease community.

Another example of a concerning trend in section 1115 waivers is when states seek to increase cost sharing and eliminate retroactive eligibility, which could leave some individuals, who may be below the federal poverty level, with extensive medical debt. Retroactive eligibility allows the start date of coverage for Medicaid beneficiaries to begin three months prior to the actual enrollment date. Many individuals who apply for Medicaid are doing so in the midst of a health emergency. Allowing coverage to apply retroactively ensures that those applying in such a situation will not be saddled with the bills they incurred prior to applying. Proposals to remove retroactive eligibility could be detrimental to all Medicaid beneficiaries, including individuals with rare diseases.

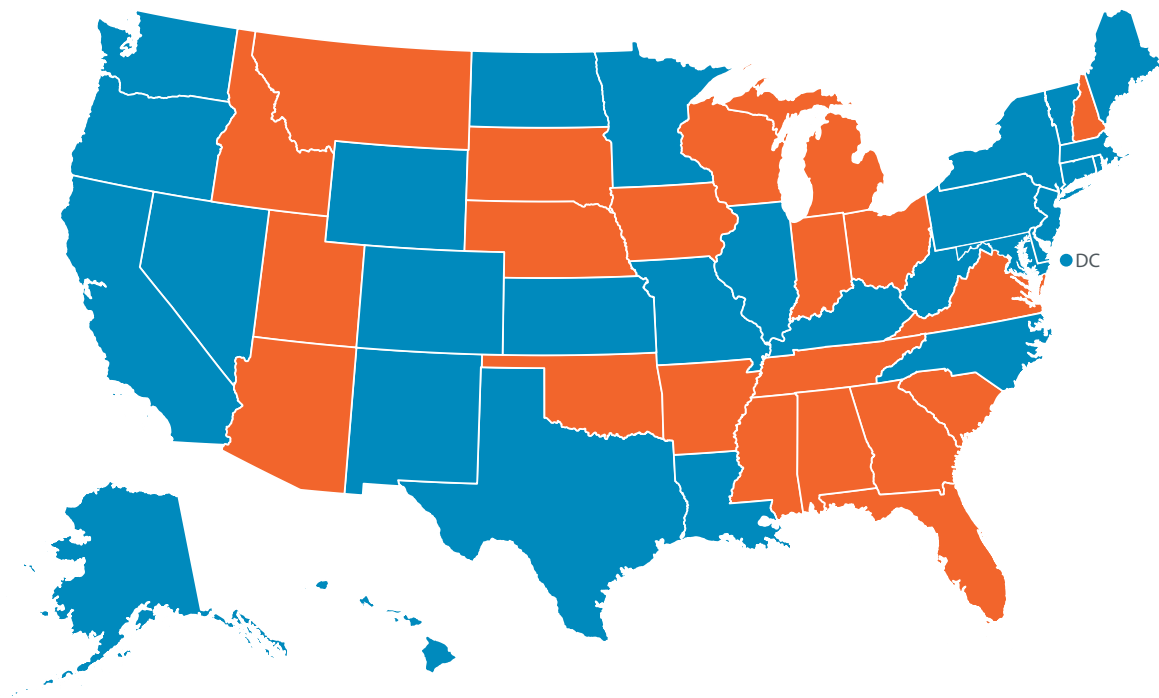
These concerns are not exhaustive, but they are representative of the ways in which the rare disease community may be harmed by some of the uses of section 1115 waivers. States are also attempting to create enrollment caps, restrict or remove benefits, and alter funding in ways that could severely limit the number of individuals capable of accessing Medicaid coverage. As noted above, Medicaid exists to be a safety net for those who cannot access other forms of health care coverage. Substantially altering the program in ways that reduce benefits for people in need is not only contrary to the goals of the Medicaid program, it could also worsen healthcare outcomes and increase costs for rare disease patients and their caregivers.

Given the complexities and differences amongst state Medicaid programs, active changes in the legislatures, the different status of each waiver, and the significant harm posed by many of the proposed policies, this report grades each state's waiver activity on a "Pass" or "Fail" basis. If a state sought and is working to implement or is currently seeking a waiver that contains policies capable of harming the rare disease community, it received a failing grade. All other states received a passing grade.

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<sup>9</sup> Benjamin D. Sommers, MD, PhD "Medicaid Work Requirements—Results from the First Year in Arkansas." *New England Journal of Medicine*. June 19, 2019. Accessed at: <https://www.nejm.org/doi/full/10.1056/NEJMSr1901772>





**MEDICAID SECTION 1115 WAIVERS OVERALL GRADE SCALE**

■ Pass ■ Fail

It is important to note, however, that the political backdrop against which section 1115 waivers are playing out is constantly changing. Recent elections have resulted in changes in the control of state executive and legislative branches. As of December 2019, some states, including Michigan, Virginia, Indiana and Arizona, have shown indications that their harmful section 1115 waivers may be revoked. But, on the basis of data available to NORD as of December 2019, this report still assigns these states a “Fail” grade. NORD is hopeful that throughout 2020, these states may take actions to improve the concerning policies currently reflected in their waiver applications. NORD will continue to monitor these states and will update the Rare Action Network website with relevant changes. More information regarding the details of section 1115 waivers within each state can be found in the appendices.

## Home- and Community-based Services (HCBS)

All Medicaid programs are required to include long-term services and supports (LTSS) as a benefit. Long-term services and supports include, but are not limited to, skilled nursing care, transportation, assistance with activities of daily living and medication management. Many within the rare disease community require and greatly benefit from LTSS.

For the most part, the LTSS that states are mandated to provide are those taking place in an institution. States can also choose to provide these LTSS outside of an institution through the implementation of Home- and Community-based Services (HCBS). At the start of the 21st century, the majority of LTSS were provided in an institutional setting. Over time, however, states increasingly sought out and implemented HCBS, and, now, the majority of LTSS take place in the home.<sup>10</sup> This shift was due, in part, to the 1999 Supreme Court decision in *Olmstead v. L.C.*, which held that unjustified institutionalization of individuals with disabilities violates the Americans with Disabilities Act.<sup>11</sup> Today, every state provides some form of HCBS through its Medicaid program. While these programs can never fully supplant the role and responsibility of families and caregivers, the coverage they provide is essential.

Similar to the rest of Medicaid, despite the fact that all states offer HCBS, there is significant variability among these programs. States can choose to implement HCBS through a number of different avenues, including through state plan amendments, section 1115 waivers, and section 1915(c) waivers. Within these options, states can then choose to enact several different waivers or one all-encompassing waiver. Through state plan amendments, states can take advantage of section 1915(k) of the Social Security Act, which establishes a Community First Choice program, a state option that provides enhanced federal funding for LTSS and helps remove waiting lists. States can also seek to exercise the authority granted by the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), which enables states to ignore the income of the parents when considering the Medicaid eligibility status of their child. This program is often referred to as a “Katie Beckett waiver.” Once implemented, HCBS programs can then differ on their approaches to parental income, wait lists, benefits, eligibility and more. In light of this variability, this report does not grade states on their HCBS programs. Additional information on each state’s HCBS, however, can be found in the appendices.



*“The Texas STAR Medicaid program is important to my family because it is crucial for the ongoing care of our 8 year old daughter with Late Infantile Metachromatic Leukodystrophy - a severely disabling genetic condition that on set at age 2. Medicaid allows for the continuous, 24-hour care with skilled nurses who administer frequent medications, respiratory treatments, tube feedings, catheterizations, and monitoring.”*

**Melissa Skolaski, Daughter-in-law of TX RAN Volunteer State Ambassador**

<sup>10</sup> “Home- and Community-Based Services.” MACPAC. Accessed December 5, 2019. <https://www.macpac.gov/subtopic/home-and-community-based-services/>.

<sup>11</sup> 527 U.S. 581. See, also, Reaves, Erica L., and MaryBeth Musumeci. “Medicaid and Long-Term Services and Supports: A Primer.” The Henry J. Kaiser Family Foundation, June 28, 2017. <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>.

# PRESCRIPTION DRUG OUT-OF-POCKET COST SHARING PROTECTIONS

*NORD supports policies that maximize access to the therapies rare disease patients need by lowering out-of-pocket expenses.*

Innovative new treatments are enabling rare disease patients to live longer, healthier lives. Unfortunately, the cost of these medicines can often be prohibitive. NORD recognizes that the high cost of drugs has a direct impact on patient access.

In the face of rising costs, many insurers are resorting to methods that shift costs to patients, such as requiring higher deductibles and transitioning from copays to coinsurance, where the patient is responsible for a percentage of the cost as opposed to a flat rate. In many instances, out-of-pocket costs are outpacing wages, and patients are struggling. For example, in 2019, 93% of plans in the individual market offered plans with four or more tiers for prescription drugs.<sup>12</sup> Cost sharing increases with each tier, thus, each additional tier represents greater spending by patients. For many people with a rare disorder, these costs can be untenable. As a consequence, patients can be forced to go without their medication or use alternative treatments that are not as safe and effective. This type of cost sharing structure in health plans is occurring with increased frequency. For instance, in 2019, close to 80% of individual-market silver plans (the most common type of health insurance plan on the individual market) did not offer coverage of specialty drugs until beneficiaries had met the deductible. After meeting the deductible, plans then charged beneficiaries a copayment or median coinsurance rate of 40%.<sup>13</sup>

To assist patients in these difficult situations, several states have passed legislation mandating a limit on out-of-pocket costs for specialty medications. These limits range from \$100 to \$500 per-month, per-medication, depending on the type of plan. Third-party analysis has demonstrated that these types of limits on copays can be instituted with little to no impact on overall plan premiums for all beneficiaries.<sup>14</sup>

States have also sought to assist patients by requiring insurers to provide “copay-only” plan options. These policies can vary, but, generally, they mandate each insurance carrier to ensure that at least 25% of their plans at all levels include a copay-only option wherein, in lieu of a deductible, the beneficiary pays a flat copay each month that cannot exceed 1/12 of the plan’s out-of-pocket maximum for the year. By creating a set copay and establishing a financing structure for cost sharing, copay-only models offer patients greater control and predictability.

For example, in 2015, Colorado and Montana released guidance for innovative copay-only models in their state. In Colorado, the Division of Insurance released a bulletin requiring plans to comply with a copay-only model.<sup>15</sup> In Montana, the Commissioner of Securities and Insurance released a memorandum advising plans to offer at least one plan that applies a flat copay to all prescription drugs prior to the deductible.<sup>16</sup>

As yet another example of the kind of policies sought to assist patients, in 2018, Connecticut’s Insurance Department released a bulletin requiring plans that use coinsurance to not impose cost sharing that exceeds 50% for both in- and out-of-network benefits.<sup>17</sup>

<sup>12</sup>“Marketplace Pulse: Cost-Sharing for Drugs Rises Sharply at Higher Tiers.” RWJF, July 26, 2019.

<https://www.rwjf.org/en/library/research/2019/03/cost-sharing-for-drugs-rises-sharply-at-higher-tiers.html>.

<sup>13</sup>Meyer, Harris. “Silver Health Plans Set Stiffer Cost-Sharing on Drugs than Employer Plans.” Modern Healthcare, March 1, 2019. <https://www.modernhealthcare.com/insurance/silver-health-plans-set-stiffer-cost-sharing-drugs-employer-plans>.

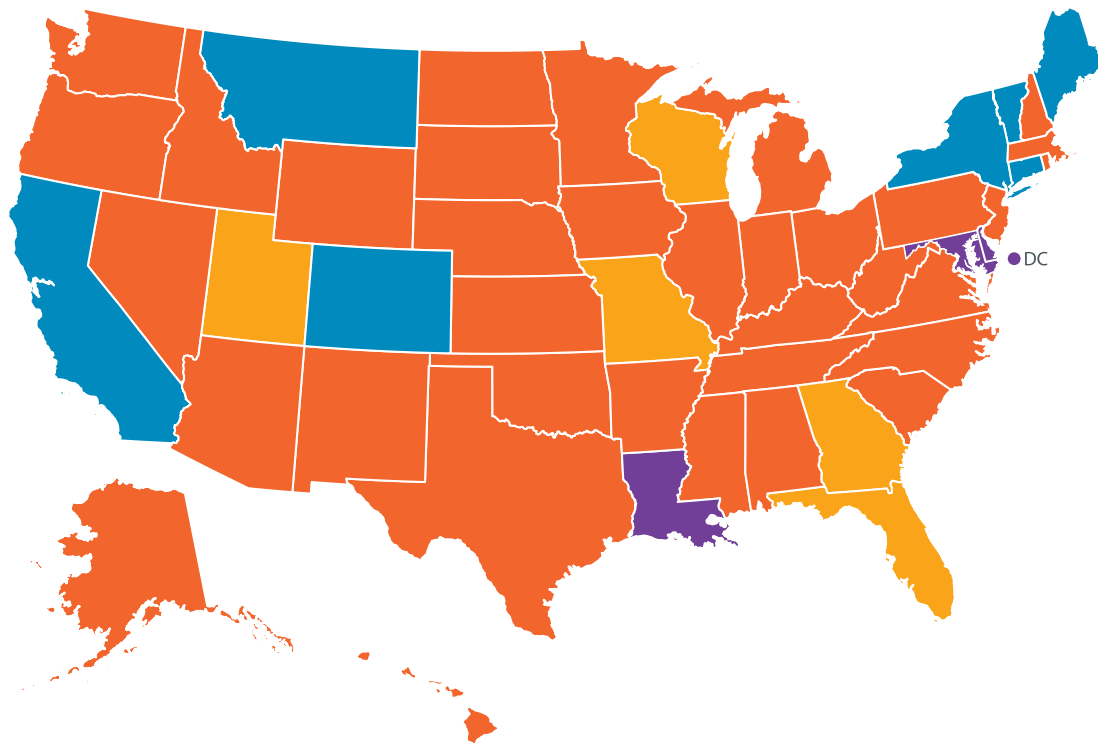
<sup>14</sup>“Impact of a \$150 Prescription Drug Cost Sharing Cap on Silver Tier Individual Exchange Plans.” Milliman, Inc. January 2017.

<sup>15</sup>B-4.82 Consumer Cost Share for Prescription Drug Benefits.” January 28, 2015. [https://drive.google.com/file/d/0B7EeY5Lrg3\\_qaWFEVzJFUWRYenc/view](https://drive.google.com/file/d/0B7EeY5Lrg3_qaWFEVzJFUWRYenc/view).

<sup>16</sup>“Health Insurers Intending to Issue or Renew Major Medical Health Insurance in 2016.” March 18, 2015.

<http://csimt.gov/wp-content/uploads/2016formfilinginstructionsfinal.pdf>

<sup>17</sup>“Bulletin HC-124 Maximum Copayment Amounts Eliminated.” October 24, 2018 <https://portal.ct.gov/-/media/CID/BulletinHC-124-maxcopay.pdf?la=en>



**RX OUT-OF-POCKET COST PROTECTIONS OVERALL GRADE SCALE**



**GRADING METHODOLOGY**

States received higher grades if they instituted caps for all drugs, whether per-drug or total, or, as is the case in Colorado, Montana and Connecticut, employed another policy to limit costs, such as a copay-only model. The grading rubric for this section can be found to the right.

**Table 2: Out-of-Pocket Grading Rubric**

DESCRIPTION	
GRADE	Prescription Drug Cost Sharing Protections
A	State has a total cap or per-drug cap on Rx cost sharing that applies to all Rx drugs
B	State has a total cap or per-drug cap on cost sharing for specialty-tier drugs only
C	The state has cost sharing limits for a small number of treatments
D	State only limits cost sharing for chemotherapy
F	State does not have a cap on cost sharing



*“On my health insurance policy many of my medications are on a higher cost sharing tier. When all is said and done, my annual out-of-pocket costs just to maintain my health without co-pay assistance would be at least \$3,900 or more. Patients like me are burdened with a significantly higher cost to simply afford medications needed to stay alive.”*

**Maria Bellefeuille, IL RAN Volunteer State Ambassador**

# STEP THERAPY PATIENT PROTECTIONS

*NORD supports policies to reform step therapy and protect patients by requiring that protocols are based on clinical criteria, clear exceptions processes exist, and certain automatic exceptions are outlined and respected.*

Step therapy is a procedure by which insurers (public or private) require patients to take one or more alternative medications before permitting patients to access the medicine prescribed by their provider. While this is done by insurers as an attempt to control health care costs, step therapy has been increasingly applied to patients with little regard to their medical situation or treatment history. As a result, step therapy requirements can delay appropriate treatment and ultimately increase healthcare costs, not lower them.

As the use of step therapy has increased (at least 60% of commercial health plans have implemented it), so has the need for states to ensure that these requirements do not interfere with appropriate care for patients.<sup>18</sup> For example, patients switching insurance plans may be required to go off a successful treatment and take a less effective medicine simply because it is also less expensive. This is commonly experienced by patients when they change their employer-sponsored health care insurance.

Approximately half the country has instituted protections around the use of step therapy to ensure patients obtain the care and treatment they need at the right time. In general, these protections:

1. Ensure step therapy protocol is based on medical criteria and clinical guidelines developed by independent experts;
2. Create a simple and accessible exceptions process for providers and patients to challenge the use of step therapy; and

3. Establish a basic framework for when it is most appropriate to exempt patients from step therapy.

These laws protect patients while still enabling health plans to achieve the cost-saving benefits of step therapy when appropriate.

## GRADING METHODOLOGY

The grading rubric for this section can be found on page 15. States were graded separately on the following five separate categories, and an overall state grade for step therapy was determined by taking the average of these five separate grades:

- 1. Step therapy protocol based on clinical practice:** Step therapy protocols should be based on clinical practice to guarantee the best interest of the patient. States received a higher grade if they mandate that protocols be based on clinical practice.
- 2. Timeline:** A clear and expedited timeline, for both emergency and non-emergency situations, is important. This ensures patients have access to the prescription drugs they need without experiencing any delays in treatment. States received a higher grade if they specify timelines for both in their statutes.
- 3. Clarity of exceptions process:** A clear exceptions process is crucial for both the provider and the patient. States received a higher grade if they had a clear process for both the provider and patient.
- 4. Categories of exceptions:** There are five automatic exceptions from step therapy that states could require and states received a higher grade if they included all five exceptions. The five exceptions include: (1) The required prescription drug is contraindicated or will likely cause an adverse reaction or physical or mental harm to the patient; (2) The required prescription drug is expected to be ineffective based on the known clinical characteristics

<sup>18</sup> Avalere. PlanScape Review of Formulary Coverage of Selected Treatments, 2015-2017. March 2018



**Table 3: Step Therapy Grading Rubric**

DESCRIPTION					
GRADE	Based on clinical practice	Timeline	Exceptions process	Categories of exceptions	Subsequent guidance from state
<b>A</b>	The state mandates a step therapy protocol process based off of clinical practice	The state mandates a clear and expedited timeline, including for emergency circumstances	The state mandates a clear exception process for patient and provider	The state step therapy protocols mandate five exceptions including: (1) The required Rx drug is contraindicated or will likely cause an adverse reaction or physical or mental harm to the patient; (2) The required Rx drug is expected to be ineffective based on the known clinical characteristics of the patient and the known characteristics of the Rx drug regimen; (3) The patient has tried the required Rx drug while under their current or a previous health insurance or health benefit plan, or another Rx drug in the same pharmacologic class or with the same mechanism of action and such Rx drug was discontinued due to lack of efficacy or effectiveness, diminished effect, or an adverse event; (4) The required Rx drug is not in the best interest of the patient, based on medical necessity; (5) The patient is stable on a Rx drug selected by their health care provider for the medical condition under consideration while on a current or previous health insurance or health benefit plan	The state has published subsequent guidance to implement step therapy protections
<b>B</b>	-	-	The state mandates a clear exception process for provider	The state step therapy protocols mandate at least four of the five exceptions above	-
<b>C</b>	The state mandates a step therapy protocol process, not based off of clinical practice	The state mandates a clear timeline	The state mandates an exception process	The state step therapy protocols mandate at least three of the five exceptions above	The state has not yet published subsequent guidance to implement step therapy protections
<b>D</b>	-	The state mandates an expeditious timeline	-	The state step therapy protocols mandate at least one of the five exceptions above	-
<b>F</b>	The state does not mandate a step therapy protocol process	The state does not have a specified mandated timeline	The state does not mandate an exception process	The state step therapy protocols mandate none of the five exceptions listed above	State has no step therapy protections



*“I was required to ‘trial’ a less-expensive medication, in ‘hopes’ that it would help my symptoms. But both my physician and I knew this drug my insurance company wanted me to take was not the right medication for my condition.... Forcing me to undergo step therapy ultimately led to the worsening of my condition and the need for an expensive hospital stay.”*

**Jennifer Melanson, Former MA RAN Volunteer State Ambassador**

# MEDICAL NUTRITION

## *NORD supports robust medical nutrition coverage for any condition for which medical nutrition is a medically necessary component of effective treatment.*

Medical nutrition is defined in the Federal Food, Drug, and Cosmetic Act as “a food which is formulated to be consumed or administered enterally under the supervision of a physician and which is intended for the specific dietary management of a disease or condition for which distinctive nutritional requirements, based on recognized scientific principles, are established by medical evaluation.”<sup>19</sup> Many rare disorders require medical nutrition to prevent serious disability and allow for normal growth in children and adults. A few examples of diseases that require medical nutrition include, maple syrup urine disease, food protein-induced enterocolitis syndrome (FPIES) and homocystinuria. Medical nutrition for these and other conditions is often the only viable treatment option available.

Unfortunately, medical nutrition is expensive and often not covered by insurance. For example, the average annual cost of formula for the rare disease phenylketonuria (PKU) can be up to \$12,000, depending on factors such as age.<sup>20</sup> Insurers often decline to cover medical nutrition because FDA does not regulate it as a drug. Additionally, insurers often view medical nutrition as elective in nature, instead of the lifesaving treatment that it is.

Insurance coverage of medical nutrition for special dietary use is inconsistent and varies widely depending on a patient’s diagnosis, plan type and state. Some states require that eligible private plans sold within their state provide coverage of medical nutrition, but only for inherited metabolic diseases, such as PKU. More recently, states have begun to expand coverage to other conditions that require specialized nutrition. Disorders such as eosinophilic esophagitis or FPIES require highly specialized nutritional products in order to be properly treated. These treatments can be lifesaving for many patients, but patients still encounter difficulties.

Some states also mandate coverage through their Medicaid programs. For states that do not mandate coverage through

Medicaid, a few have chosen to provide access to medical nutrition through other publicly-funded health programs or provide coverage on a case-by-case basis (which can lead to high variability in access). States that mandate coverage of medical nutrition in Medicaid often can have arbitrary limits based on cost, age or gender.

In states without mandates or with limited mandates, patients are often forced to pay for medical nutrition out-of-pocket. For high cost forms of medical nutrition, this situation can leave patients with a devastating decision of whether to pay the mortgage or buy the critical nutrition needed for survival.

These examples illustrate the work that needs to be done at state level to increase access to medical nutrition. But NORD also advocates for improvements in coverage at the federal level since states lack the authority to change coverage under federally regulated plans. NORD also supports passage of the Medical Nutrition Equity Act (MNEA)<sup>21</sup> at the federal level to ensure patients have access to their treatment in Medicaid, the Children’s Health Insurance Program (CHIP), Medicare, the Federal Employee Health Benefit program and private insurance. If passed, this law would dramatically improve medical nutrition coverage for all patients.

## GRADING METHODOLOGY

The grading rubric for medical nutrition can be found on page 17. States were graded separately on the following four categories, and an overall state grade for Medical Nutrition was determined by taking the average of these four separate grades:

- 1. Coverage requirements for commercial health plans**
- 2. Covered disorders requirements for commercial health plans**
- 3. Coverage requirements for state-run programs**
- 4. Covered disorders requirements for state-run programs**

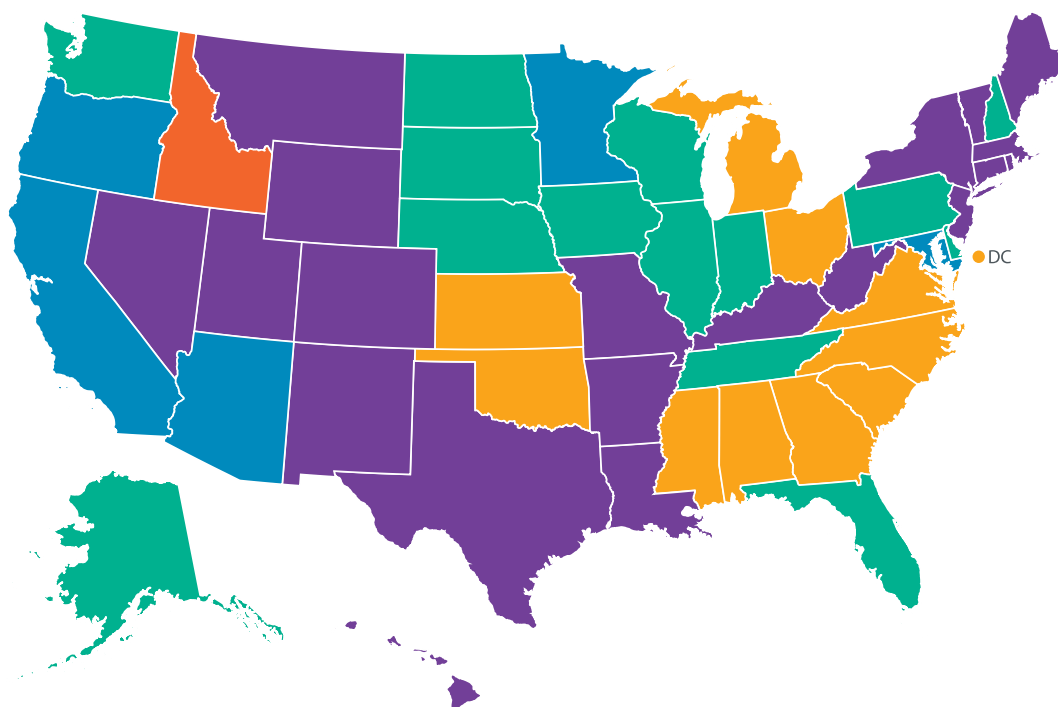
States that placed age or monetary restrictions on coverage earned lower grades than states that had no such restrictions. Similarly, states with more covered conditions (ideally any condition for which medical nutrition is medically necessary) earned higher grades than states with fewer covered conditions.

<sup>19</sup> 21 U.S.C. 360ee (b) (3)

<sup>20</sup> <https://journals.lww.com/topicsinclinicalnutrition/toc/2009/10000>

<sup>21</sup> H.R. 2501 (<https://www.congress.gov/116/bills/hr2501/BILLS-116hr2501ih.pdf>)





**MEDICAL NUTRITION COVERAGE OVERALL GRADE SCALE**



**Table 4: Medical Nutrition Grading Rubric**

DESCRIPTION				
GRADE	Coverage Requirements for Commercial health Plans	Covered Disorders Requirements for Commercial Health Plans	Coverage Requirements for State-Run Programs	Covered Disorders Requirements for State-Run Programs
<b>A</b>	Coverage is required for both formula and low-protein nutrition with no limits on eligibility or coverage	Covered disorders include all inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition	Mandated Medicaid coverage for medical nutrition with no age or eligibility restrictions (or through a supplemental program)	Covered disorders include all inborn errors of metabolism, eosinophilic disorders/FPIES and other conditions requiring medical nutrition
<b>B</b>	Coverage is required for formula and low-protein food but with age or dollar limits	Covered disorders include all inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition	Mandated Medicaid coverage for formula and low-protein nutrition with restrictions (or through a supplemental program)	Covered disorders include all inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition
<b>C</b>	Coverage is required for both formula and low-protein nutrition but with age and dollar limits	Covered disorders include three or more metabolic conditions, but exclude eosinophilic disorders/FPIES and other medically necessary uses	Coverage for formula and low-protein nutrition is on a case-by-case basis	Covered disorders include three or more inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition
<b>D</b>	Coverage is required but with limits on eligibility (such as age) or coverage (such as a dollar cap or formula only)	Covered disorders include two or fewer metabolic conditions (such as PKU-only)	Mandated Medicaid coverage for formula but no coverage of low-protein nutrition	Covered disorders include two or fewer metabolic conditions (such as PKU-only)
<b>F</b>	State does not mandate private insurance coverage of medical nutrition	State does not mandate private insurance coverage of medical nutrition	State does not mandate coverage for Medicaid. The state does not offer supplemental programs to provide coverage	State does not mandate coverage for Medicaid. The state does not offer supplemental programs to provide coverage



*“For the first 3 months of Norah’s life, our insurance company denied the formula completely, stating that if she wasn’t fed through a feeding tube they were not required to cover it.”*

**Staci Stincelli, Former NY RAN Volunteer State Ambassador**

# NEWBORN SCREENING

## *NORD supports robust, well-funded newborn screening programs in every state.*

Newborn screening (NBS) programs throughout the United States have had great success at increasing the number of newborns screened at birth and, as a result, saving lives. Each year, approximately four million babies are screened through these programs. Of that four million, screening identifies over 12,000 infants each year with a disorder that, left undiagnosed and untreated, would cause severe developmental disability or death.<sup>22</sup> In many cases, newborn screening allows physicians to detect a heritable disease early enough to begin treatment before irreversible damage can occur. Newborn screening programs are typically regulated and operated at the state level, allowing each program to be customized to fit the state's specific needs.

For example, states have flexibility in terms of the conditions screened and the use of samples following a blood spot test. The strength of a state's NBS program, however, is not limited to the number of conditions detected. Funding of the program, follow-up guidelines, quality assurance, the use of the remaining dried blood spots (DBS), the existence and structure of an advisory committee and the process by which states can add new conditions to its program are also important characteristics. If a condition is added without proper quality assurance, follow-up programs, or expert recommendation, there could be a surge in inaccurate screening results (false-positives or false-negatives), creating the potential for confusion and fear among patients and their families. This report evaluates state performance on each of these issues.

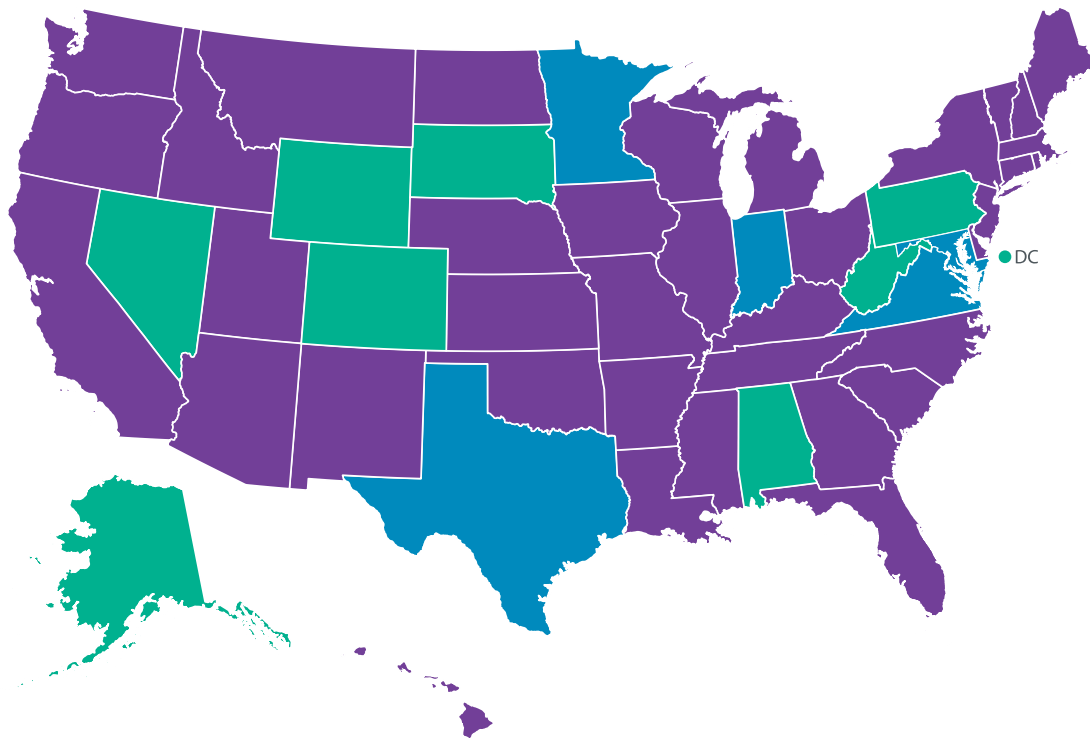
## GRADING METHODOLOGY

The grading rubric for this section can be found on page 20. States were graded separately on the following seven separate categories, and an overall state grade for NBS was determined by taking the average of these seven separate grades:

- 1. Screening for RUSP core conditions:** It is crucial that states screen for as many RUSP core conditions as possible. The more conditions on the state panel, the higher grade the state received.
- 2. Adding RUSP core conditions:** States should have a procedure to add conditions to RUSP panels in an efficient and appropriate manner without unnecessary barriers. States with processes that meet these goals received a higher grade.
- 3. Funding:** NBS programs require funding for everything from laboratory personnel to equipment. Health departments should be permitted to independently set newborn screening fees to meet the needs of their program, and such funds should be used only to improve such program. States with adequate funding that is directed to appropriate uses received a higher grade.
- 4. Using Dried Blood Spot (DBS):** The DBS that remain following screening of an infant are an invaluable source of research data on not only the diseases covered by NBS programs but also for a host of other conditions. Use of DBS generally falls into three categories: (1) DBS are used for quality assurance and quality control (QA/QC) purposes, such as to verify the results of other NBS tests; (2) states use DBS to advance knowledge and tools for screening itself, such as the development of new tests and improvement of existing testing technology; and (3) DBS are provided to outside researchers to conduct clinical studies on the diseases themselves or to better understand the genetic origins of disease. In some cases, this research can lead to new treatments. In

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<sup>22</sup>"How Many Newborns Are Screened in the United States?" Eunice Kennedy Shriver National Institute of Child Health and Human Development. US Department of Health and Human Services. Accessed December 5, 2019. <https://www.nichd.nih.gov/health/topics/newborn/conditioninfo/infants-screened>.



## NEWBORN SCREENING OVERALL GRADE SCALE

■ A ■ B ■ C ■ D ■ F

all three scenarios, the DBS are de-identified, or stripped of anything that could link them to the infant. States that retain DBS samples and use them for research, as well as QA/QC, received a higher grade.

5. **Follow-up:** Once a baby has been screened, it is critical that states have programs to guide the baby and parents. For example, if a screen comes back positive, the state needs to be prepared to relay that information to the parents, explain what it means, take care of the baby and connect the family to appropriate resources in a timely fashion. States with follow up procedures that meet these goals received a higher grade.
6. **Quality:** Quality in NBS programs is critical. Any slight adjustment or miscalculation can result in screens failing to identify potentially fatal conditions.

Therefore, it is crucial that a state have programs in place to ensure that its NBS laboratories are engaging in adequate quality assurance and quality control (QA/QC). States with well-run quality programs received the highest grades.

7. **Advisory committee:** It is important that states' NBS programs have an advisory committee comprised of experts in the field, including laboratory personnel who can make recommendations on how to improve the program, and that such advisory committees meet at least once a year. States with advisory committees that meet these goals received a higher grade.

**Table 5: Newborn Screening Grading Rubric**

DESCRIPTION							
GRADE	Screening for RUSP Core Conditions	Adding RUSP Conditions	Funding	DBS Use	Follow-Up	Quality	Advisory Committee
A	Screens for all core conditions	Conditions are added automatically	NBS program has a distinct stream of revenue AND Health Department can easily set fee	Uses for research and for QA/QC	Has a robust short-term and long-term program in place with funding	Has an excellent program in place OR has a good program in place with funding	Has an entity that includes a diverse membership AND meets more than once a year
B	Up to 3 that it does not screen	Health Department can easily add conditions on its own	NBS program has a distinct stream of revenue OR Health Department can easily set fee	Uses for QA/QC only	Has a short-term and long-term program	Has a good program in place	Has an external entity that meets more than once a year
C	4-5 that it does not screen	Health Department can add conditions on its own	Revenue comes from general funds and it is hard to change fee OR there are supplemented appropriations (e.g., Title V)	Retains for > 1 year but conducts no further research	Has a short-term program	Has a program in place	Has an external entity that only meets once a year
D	More than 5 that it does not screen	Legislature must approve the addition of conditions	The NBS fee and the resulting revenue are subject to the legislature	Retains for 6-12 months but conducts no further research	Has some education materials	Does not have a program OR only focuses on specimen collection	Does not have an external entity but has an internal entity
F	No screening	State does not add conditions	Does not have anything	Destroys in 6 months or less and conducts no further research	Does not have anything	Low quality	Does not have anything



*“Knowing [that Landon had SMA] ahead of time had a profoundly positive impact on our family, from psychologically handling another difficult diagnosis to being able to prepare for the day-to-day equipment we would need as well as planning for our daily routine with a newborn who may have special needs. And now that a treatment option is available and data indicates that pre-symptomatic treatment results in the most positive outcomes, it is even more important for affected newborns to be screened as soon as possible.”*

**Dany Sun, WI RAN State Volunteer Ambassador**

# RARE DISEASE ADVISORY COUNCILS

*NORD supports the establishment of robust, well-organized, and high functioning Rare Disease Advisory Councils in every state that can support the needs of the rare disease community.*

Rare Disease Advisory Councils (RDAC) act as an advisory body that helps give the rare disease community a stronger voice in state government. In 2015, the first RDAC was created in North Carolina by patients, caregivers, families and providers. Since then, other advocates have sought to build councils in many states to help better represent their community. With the support of NORD and other patient organizations, RDACs are enabling each of these states to address barriers that prevent individuals living with a rare disease from obtaining proper treatment and care for their condition.

With over 7,000 known rare diseases, it is difficult for state policymakers to have an in-depth understanding of the entire rare disease community. This lack of awareness contributes to common difficulties that rare disease patients face every day, such as delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs and limited access to medical specialists.

Although research into rare diseases is advancing and producing new breakthrough treatments for patients, state policies affecting patient access to these breakthroughs are often determined without consulting individual disease communities. In the absence of greater representation in state government of the rare disease community, legislators and other officials cannot adequately address the problems of the community when making health policy decisions.

RDACs help address the needs of the rare disease community within a state by giving patients, families, caregivers and other stakeholders an opportunity to make formal recommendations to state leaders about the most important issues they face. The membership of these councils includes a variety of stakeholders who represent the rare disease community, including patients, caregivers, doctors, insurers, drug manufacturers and researchers.

Based on feedback from advocates in several states, NORD has identified key features of how an RDAC should carry out its mission and be structured. First, it is critical that councils include stakeholders from across the rare disease community at the outset. These stakeholders should be committed, as a group, to ensuring the success of the RDAC after it is enacted in law. Second, it is important that the council identify a committed entity to host the council. This will allow for a smooth transition once the council is enacted. Finally, NORD recommends that every council have membership that includes the following representatives:

- Health department officials
- Elected legislative officials
- Academic researchers
- Health care providers (physicians, nurses, geneticists, pharmacists, etc.)
- Hospital administrators
- Patients and caregivers
- Health care industry representatives (drug manufacturers, insurance companies, etc.)

Overall, the purpose of the council is to act as an advisory body on rare diseases to the governor, legislature, state agencies and other important stakeholders (such as state universities). Currently, every RDAC is required to report on its activities to the state and make specific recommendations to improve public policy.

Councils typically meet throughout the year, convene public hearings, consult experts and conduct informal research. The ultimate goal of this work is to develop policy recommendations and best practices to share widely.

Given that RDACs are a relatively new policy development in many states, NORD did not assign grades within this section. Instead, additional information on the status of each state's RDAC is contained within each state report card, as well as in the appendices.

# INDIVIDUAL INSURANCE MARKET PROTECTIONS

## *NORD supports the ACA and efforts to extend and protect the benefits it offers for rare disease patients.*

The ACA established a range of critical protections for individuals with pre-existing conditions, including prohibiting insurers from denying patients coverage because of a pre-existing condition, charging patients more because of their health status and excluding certain benefits in order to discourage individuals with health complications from enrolling in their plans. The ACA also drastically changed the health care system in an attempt to secure health insurance for all Americans and establish a minimum standard of quality for all plans. One essential piece of this change is the so-called “individual mandate,” which is the requirement in the ACA that everyone obtain health insurance or else pay a tax penalty. The individual mandate is key to ensuring the success of the nation’s insurance marketplace. In order for the health costs of those with complex health conditions to remain affordable and sustainable, there must be significantly more people without complex health conditions participating in the same system.

Despite the obvious achievements of the ACA, much more needs to be done to strengthen the United States’ health care system and build upon the policies put in place by the law. Unfortunately, in recent years, Congress and the current Administration have taken various actions to destabilize the ACA and, by extension, insurance marketplaces across the country. In 2018, prior to the open enrollment period in the ACA marketplaces, the Administration substantially reduced the resources for certified health insurance navigators and enrollment assistants.<sup>23</sup> In April 2018, the Administration announced various changes to the marketplaces within its Notice of Benefit and Payment Parameters for 2019 final rule that allow states to weaken their essential health benefit and network adequacy requirements.<sup>24</sup> In December 2017, Congress lowered the penalty for violating the ACA individual mandate to zero as part of the Tax Cuts and Jobs Act of 2017, in effect repealing the individual mandate.<sup>25</sup> In August 2018, the Administration released its Short-Term, Limited-Duration Insurance final rule, which allows for the expanded use of short-term, limited-duration health

plans and association health plans, both of which include fewer comprehensive requirements for coverage and benefits.<sup>26</sup> Finally, the Administration has declined to defend the constitutionality of the ACA in a lawsuit brought by some state attorneys general that, if successful, could mean the end of the ACA and the protections it affords all those with pre-existing conditions.<sup>27</sup>

Each of these actions has contributed to the destabilization of private insurance markets within the states and has threatened access to adequate and affordable coverage for rare disease patients. Ultimately, these actions must be addressed at the federal level. In the meantime, many states are exploring ways to counter or mitigate these damaging actions. For example, some states have chosen to enact their own individual mandates and tightly regulate the sale of short-term, limited-duration health plans and association health plans.<sup>28</sup> Others have sought to implement reinsurance policies through waivers permitted in section 1332 of the Social Security Act that help to stabilize the marketplace and keep costs low for all.<sup>29</sup>

Given the significance of these developments and the increasing burden on states to address the resulting damage, this report includes information on what actions, if any, states have taken to target individual insurance protections in this report. NORD chose not to grade this category, however, as this is a new and rapidly evolving area of policy, and there is yet to be a clear course of action that all states should take to ensure comprehensive insurance coverage for their citizens.

<sup>23</sup> Corlette, Sabrina, and Rachel Schwab. “States Lean In as the Federal Government Cuts Back on Navigator and Advertising Funding for the ACA’s Sixth Open Enrollment.” Commonwealth Fund, October 26, 2018. <https://www.commonwealthfund.org/blog/2018/states-lean-federal-government-cuts-back-navigator-and-advertising-funding>.

<sup>24</sup> 83 FR 16930

<sup>25</sup> Tax Cuts and Jobs Act (Pub.L. 115–97) (December 22, 2017).

<sup>26</sup> 83 FR 38212

This report details state action in the following three individual policy categories:

- 1. Pre-existing Conditions Protections:** If the ACA is struck down in court, many patients with pre-existing conditions will be vulnerable to discrimination on the part of insurers. States can attempt to mitigate this challenge, in part, by creating their own pre-existing conditions protections. These include:
  - a. Guaranteed issue (requiring insurers to issue coverage regardless of health status);
  - b. Community rating (requiring insurers to base their pricing on an entire group of individuals as opposed to one person's health status);
  - c. Elimination riders (prohibiting insurers from excluding coverage of certain health conditions); and
  - d. Individual mandate (requiring all individuals to have insurance or else pay a tax penalty).
- 2. Association Health Plans and Short-Term, Limited-Duration Health Plans:** Short-term, limited-duration health plans and association health plans are not required to adhere to all of the policies that compose the minimum standard of quality established by the ACA. Consequently, these plans can ultimately divide the marketplace into people in need of more comprehensive health coverage and relatively healthy people who may not need extensive coverage. In doing so, these plans can drastically raise costs for those needing the higher quality, more comprehensive plans. Some policies that states can explore to prevent such segmentation include:
  - a. Limitations placed on association health plans;
  - b. Limits on the initial contract duration of short term, limited-duration health plans;
  - c. Prohibition on renewability of short-term, limited duration health plans; and
  - d. Limitations on the duration of renewability periods for short-term, limited-duration health plans.
- 3. Reinsurance:** Some research has shown that implementing reinsurance programs can help stabilize the marketplace and lower premiums by essentially providing insurance for insurers with respect to high cost beneficiaries.<sup>30</sup> States can implement these programs by applying for a waiver and having it approved by the Centers for Medicare and Medicaid Services (CMS) via authority granted in section 1332 of the Social Security Act. The components of analysis for these programs include the following:
  - a. Whether the state sought to implement a reinsurance program through a section 1332 waiver; and
  - b. Whether the reinsurance program is attachment point or conditions-based (attachment point means the program applies to anything above a certain cost whereas conditions-based means the program applies only to specific conditions).

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<sup>27</sup> Keith, Katie. "Trump Administration Declines To Defend The ACA." Trump Administration Declines To Defend The ACA | Health Affairs, June 8, 2018.

<sup>28</sup> Tolbert, Jennifer, Maria Diaz, and Cornelia Hall. "State Actions to Improve the Affordability of Health Insurance in the Individual Market." The Henry J. Kaiser Family Foundation, November 1, 2019. <https://www.kff.org/health-reform/issue-brief/state-actions-to-improve-the-affordability-of-health-insurance-in-the-individual-market/>.

<sup>29</sup> Ibid.

<sup>30</sup> Sloan, Chris, Neil Rosacker, Elizabeth Carpenter, Chris Sloan, Neil Rosacker, Elizabeth Carpenter, Joanna Young, Mark Adelsberg and Denee McCloud. "State-Run Reinsurance Programs Reduce ACA Premiums by 19.9% on Average." Avalere Health, March 13, 2019. <https://avalere.com/press-releases/state-run-reinsurance-programs-reduce-aca-premiums-by-19-9-on-average>.

Data supporting this report can be found in the appendices. To view these appendices, please visit: [rareaction.org/stateofthestates](http://rareaction.org/stateofthestates)

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**NORD: Fighting for the rare community every day for more than 35 years.**

NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient support services. NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians.

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