



# 2024 STATE REPORT CARD SOUTH CAROLINA

April 12, 2024

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

Alone we are rare. Together we are strong.<sup>®</sup>

# National Organization for Rare Disorders Mission Statement

We improve the health and well-being of people with rare disease by driving advances in care, research and policy.



# Driving Life-Saving Policy

NORD is the only independent and nonpartisan U.S. organization working at the intersection of care, research, policy, and community for all rare diseases.

*We work with national and state decision-makers to advance the following priorities:*

- New and Better Therapies
- Access and Affordability of Prescription Drugs
- Comprehensive Health Insurance
- Expanding Telehealth Services
- Strengthening Policies to Support Timely Diagnosis



as of November 2023

## NORD's State Report Card<sup>®</sup>

- Since 2015, on an annual basis, NORD has evaluated how effectively states are serving people with rare diseases across 9 issue areas:

Medicaid Financial Eligibility	C
Medical Nutrition	F
Newborn Screening	B
Prescription Drug Out-of-Pocket Costs	C
Protecting Patients in State Medicaid Programs	F
Protecting Patients in State Regulated Insurance	D
Rare Disease Advisory Council	YES!
Step Therapy (Fail First)	F
Telehealth	FAIL

## REPORT CARD “F” CATEGORIES

Medical Nutrition  
Protecting Patients in Medicaid (1115)  
Step Therapy  
Telehealth



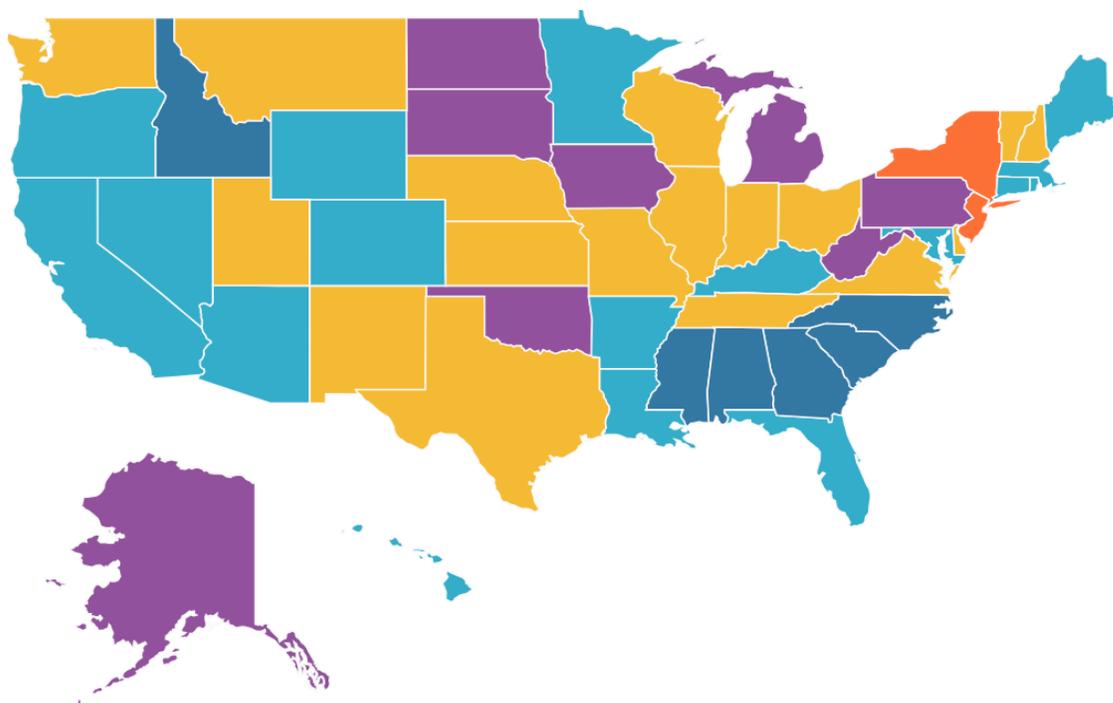
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# Medical Nutrition Grading Methodology

*“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.”*

Overall Grade ■ A ■ B ■ C ■ D ■ F



Grade state on four separate categories:

SC as of: November 2023

Coverage Requirements in Commercial Health Plans	<b>F</b>
Covered Disorders Requirements in Commercial Health Plans	<b>F</b>
Coverage Requirements in State Plans	<b>F</b>
Covered Disorders in State Plans	<b>F</b>

and an **OVERALL** state grade is determined by taking the average of the four separate grades.

# Medical Nutrition in South Carolina

State government can act to ensure insurance plans are providing coverage for medical nutrition. In South Carolina, this area of law is a **blank slate** and there is NO legislation pending in the current session year.

## *What Would Legislation Elevating South Carolina to an “A” Look Like?*

- Mandate state regulated insurance companies and Medicaid provide coverage for the cost of enteral formulas for home use, whether administered orally or via tube feeding, for which a physician or other licensed health care provider authorized to prescribe has issued a written order.
  - NO limit on route of administration, age or monetary restrictions.
  - NO limit on conditions which may be eligible.

# Protecting Patients in State Medicaid Programs

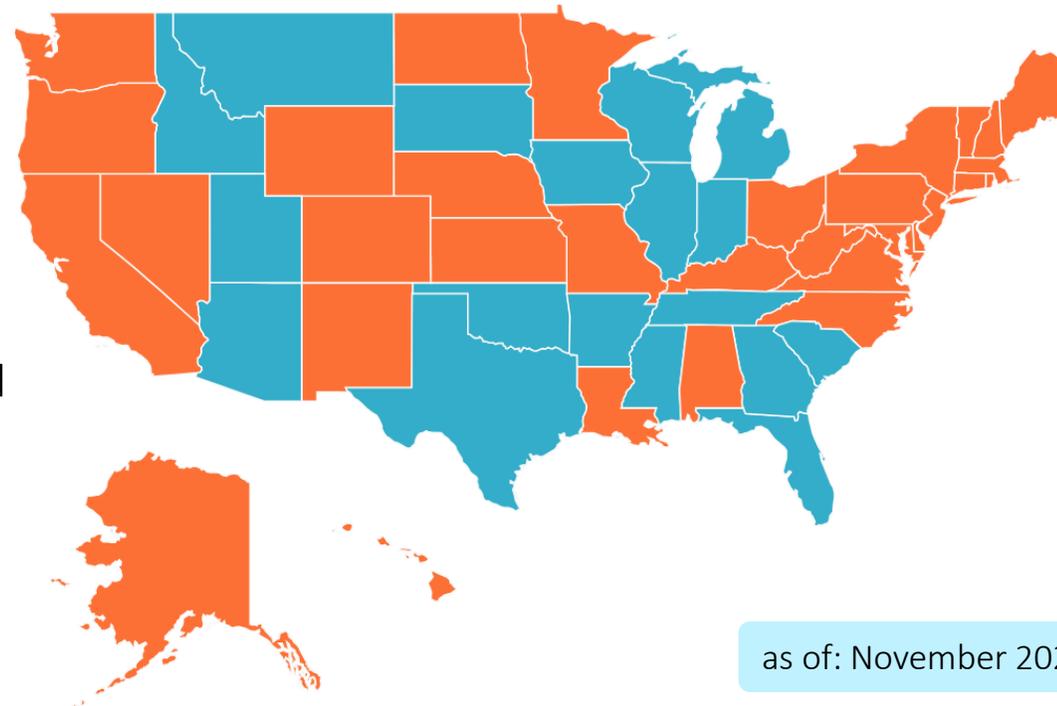
## Medicaid Section 1115 Waivers

Section 1115 of the Social Security Act allows states to request authority to tailor their Medicaid programs. Many State Medicaid programs use these “1115 waivers” to allow the state to deviate from some federal Medicaid rules regarding eligibility and benefits.

Pass Fail

This area is graded on a “Pass” or “Fail” basis considering:

- Complexities and differences amongst state Medicaid programs;
- Status of each waiver; and
- Harm posed by proposed policies.



**FAIL**  
If a state is working to implement or is currently seeking a waiver that contains policies that are less helpful to the rare disease community.

**PASS**  
The state is not making efforts to implement or seek to receive a waiver for policies that are less helpful to the rare disease community.

as of: November 2023

# Medicaid Section 1115 Waivers in South Carolina

On December 12, 2019, CMS approved two separate 1115 waivers for South Carolina which would extend Medicaid coverage from 67% to 100% FPL for its parent/caretaker relative groups and a new targeted adult group with initial and continued enrollment conditioned on compliance with work requirements at the regular match rate.

- This coverage did not qualify as a full Medicaid expansion under the ACA.

## NOTABLE WAIVER INFORMATION

**August 23, 2018** | SC Submits Application for Transition to Preconception Care (*still pending*)

**August 10, 2021** | CMS Rescinds Approval of SC Healthy Connections Works

**September 14, 2021** | CMS Rescinds Approval of SC Palmetto Pathways to Independence

# Step Therapy Grading Methodology

Step therapy is a process by which insurers (public or private) require patients to try one or more alternative medications or treatments, and fail on those, before they can access the medicine or form of care initially ordered by their provider.

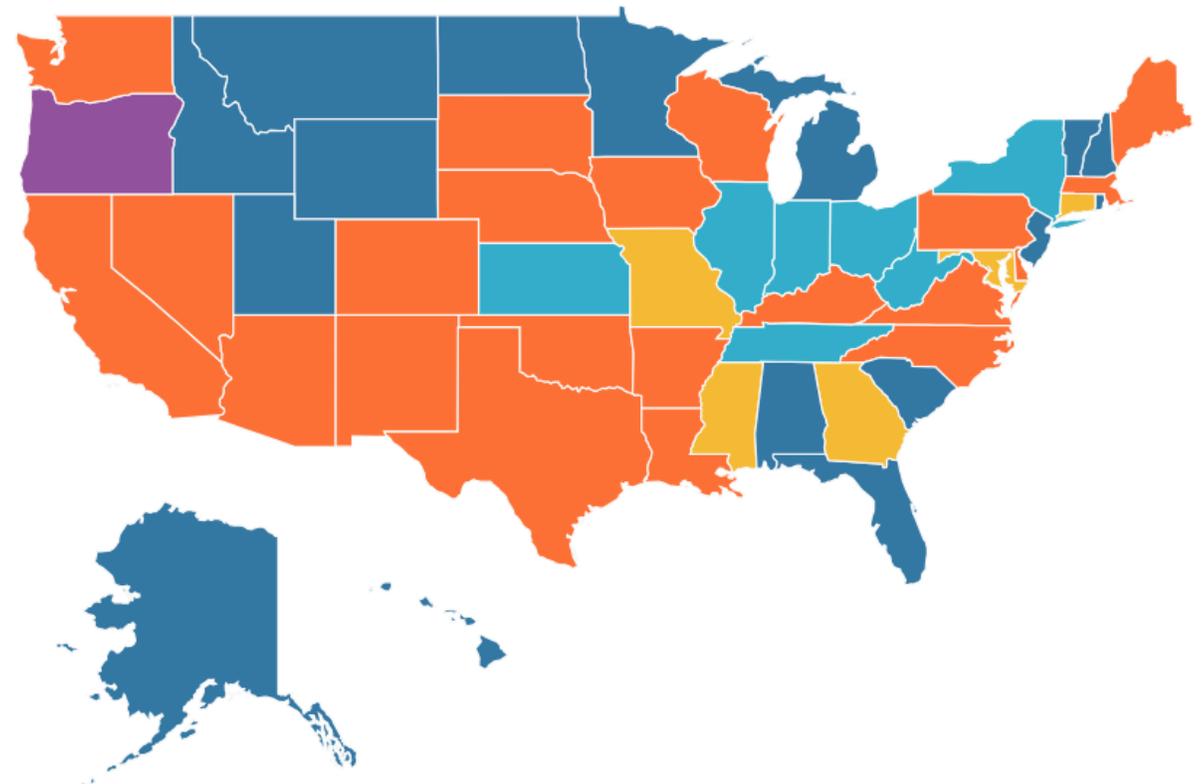
NORD considers how states have instituted protections around the use of step therapy:

SC as of: November 2023

Protocols Based on Clinical Practice	<b>F</b>
Timelines for Plan Response	<b>F</b>
Clarity of the Exceptions Process	<b>F</b>
Categories of Exceptions	<b>F</b>

an **OVERALL** state grade is determined by taking the average of the four separate grades.

Overall Grade: ■ A ■ B ■ C ■ D ■ F



# Step Therapy in South Carolina

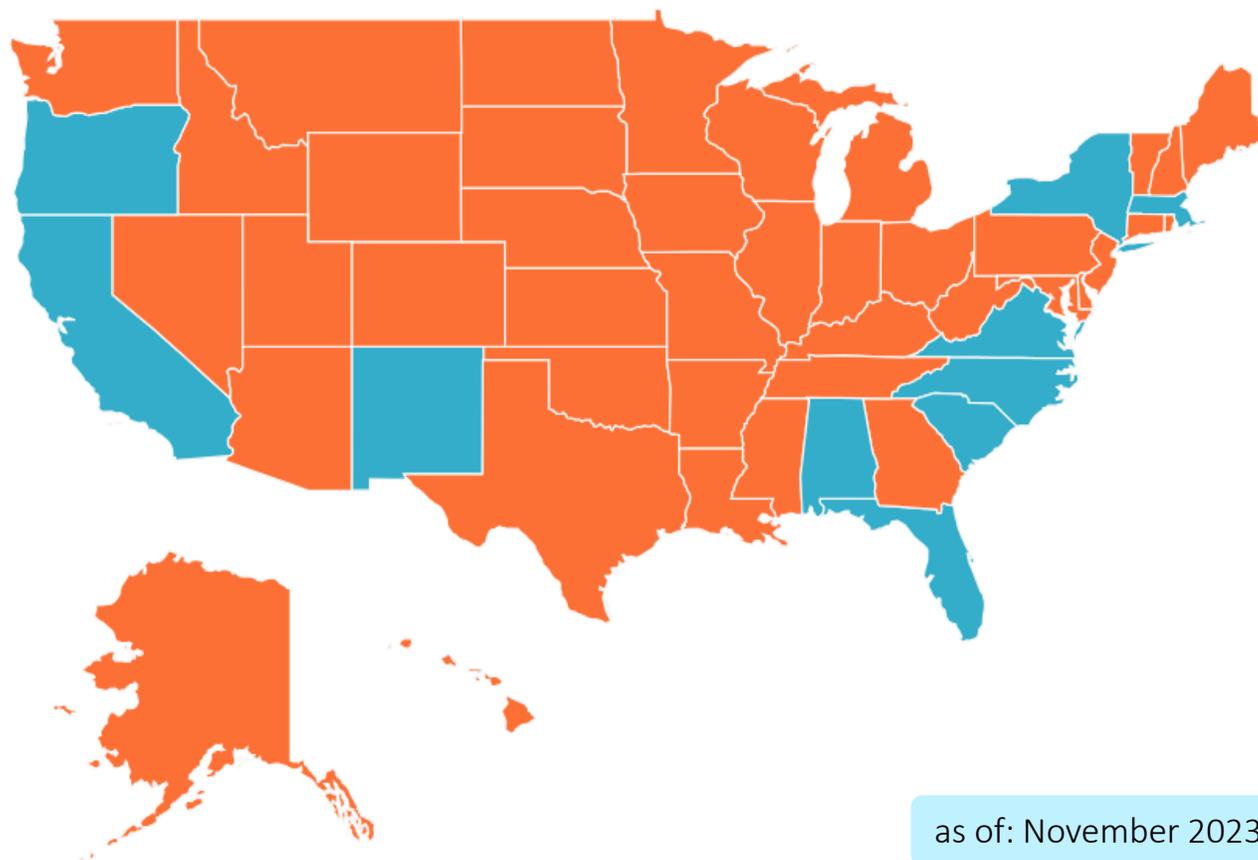
Over half the states in the country have enacted protections for patients and regulation around the practice of step therapy. In South Carolina, this area of law is another **blank slate** and there is NO legislation pending in the current session year.

*What Would Legislation Elevating South Carolina to an “A” Look Like?*

Regulate Protocols	Establish Categories for Exemptions from Protocols	Set Timelines for Responses to Requests from an Exemption
Require protocols be based upon medical criteria and <b>clinical guidelines</b> developed by <b>independent experts</b> and consider the needs of <b>atypical populations</b> .	Allow the <b>provider or patient</b> to request an exemption if any one of the following apply: <ol style="list-style-type: none"><li>1) Rx is <b>contraindicated</b></li><li>2) Rx is expected to be <b>ineffective</b></li><li>3) The patient has already <b>tried and failed</b> – even if on different insurance</li><li>4) Rx is not in the <b>best interest</b> of the patient.</li><li>5) The patient is <b>stable</b> on the medicine the provider ordered initially.</li></ol>	Establish a clear timelines for a response from the health plan  URGENT → 72-Hours NON-URGENT → 24-Hours

# Telehealth Grading Methodology

Pass Fail



**NORD supports robust access to telehealth services to benefit rare disease patients.**

For the purposes of the State Report Card, States are evaluated based upon whether they participate in the **Interstate Medical Licensure Compact (IMLC)** (MDs and DOs).

To date, 39 states, Guam and the District of Columbia have chosen to join the (IMLC).

# Telehealth in South Carolina and Legislation

Both the federal government and state governments have the power to regulate aspects of telehealth including health provider licensure requirements, reimbursement rates and eligible services. There are several areas of South Carolina law that dictate the practice of telehealth or telemedicine – most notably *Title 40, Chapter 42 of the Code of South Carolina*.

“Telehealth or “telemedicine” is the use of any electronic communication, information technology or other means of delivering care between a provider in one location and a patient in another.

“Telemedicine” means the practice of medicine.

“Telehealth” includes clinical health care, patient and professional health-related education, public health, or health administration.

# Telehealth Considerations for Discussion

In 2020, at the peak of the COVID-19 Pandemic, the telehealth landscape saw numerous changes nationwide and state-by-state. Recognizing the importance of telehealth to the rare disease community, NORD drafted [principles](#) to guide our engagement on the issue.

Access Should be Equal &  
Effective for All

Patient Choice Must be  
Prioritized



Ensure Transparency  
Regarding Privacy Protection  
& Cost Sharing

Decision Making Must Be  
Data-Driven

# REPORT CARD “C” AND “D” CATEGORIES

Medicaid Financial Eligibility  
Rx Out of Pocket Costs  
Protections in State Marketplace (STLDI)



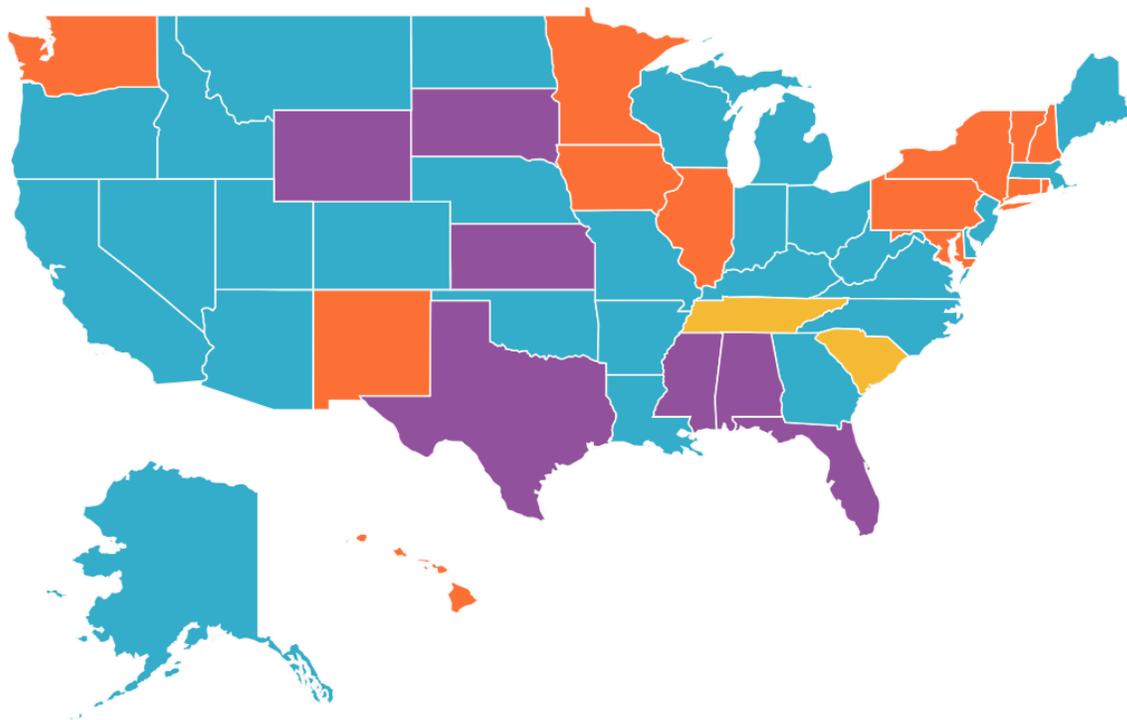
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# Medicaid Financial Eligibility

Medicaid is a joint federal and state program that helps cover medical costs for some people with limited income. South Carolina's Medicaid Program is called *Healthy Connections*.

Overall Grade: ■ A ■ B ■ C ■ D ■ F



Grades states on four separate categories:

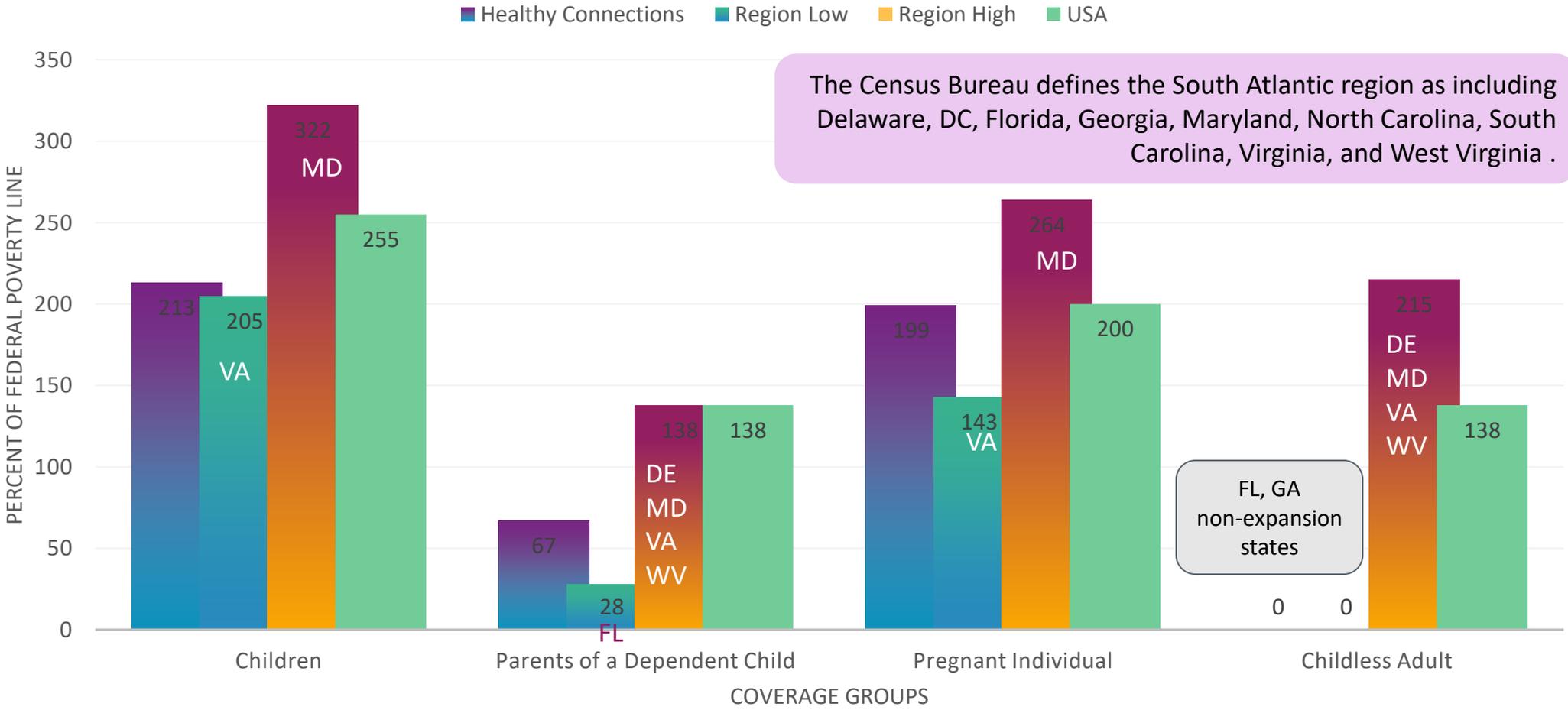
SC as of: November 2023

Eligibility for Parents of Dependent Children	<b>D</b>
Eligibility for Childless Adults	<b>F</b>
Eligibility for Pregnant Women	<b>B</b>
Eligibility for Children (incl. CHIP-Funded)	<b>B</b>

and an **OVERALL** state grade is determined by taking the average of the four separate grades.

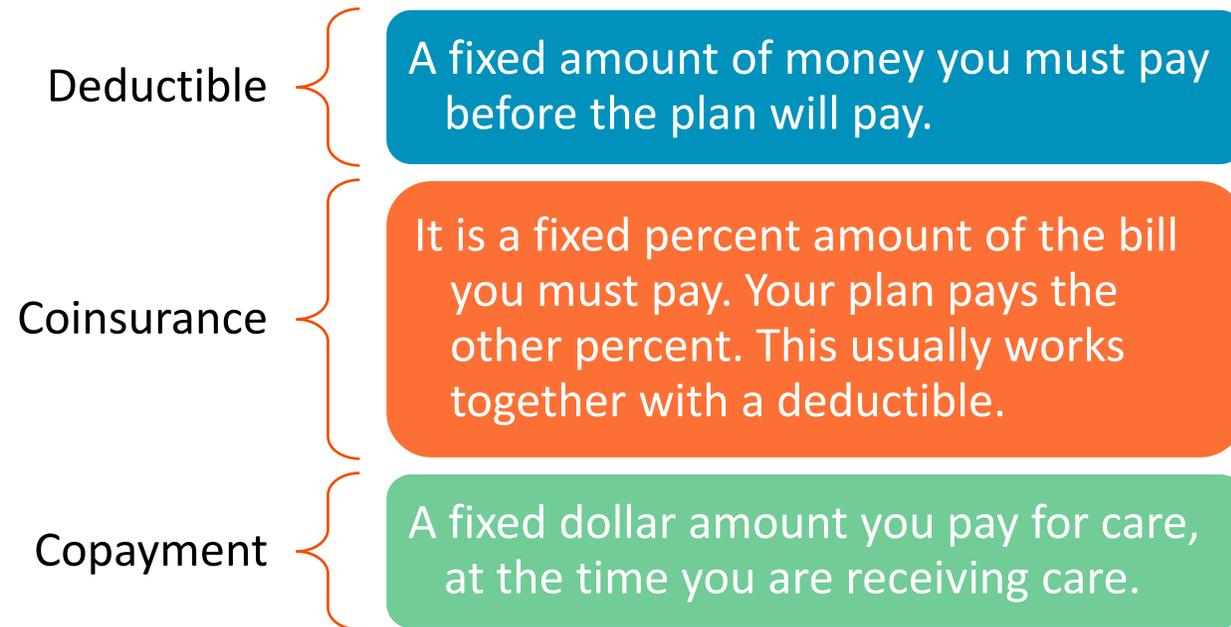
# Medicaid Financial Eligibility in South Carolina

*Healthy Connections* Eligibility for Certain Groups Compared to Region Lows/Highs and USA



# Prescription Drug Out-of-Pocket Costs

Out-of-Pocket costs are the expenses for medical care that are NOT paid for by your insurance company. Your plan may use one of any combination of these forms of “cost-sharing”



## What Can SC Do?

- Deductible Protections** – Prohibit or limit deductibles for Rx drug costs.
- Drug Cost Caps** - Cap the amount a patient pays per month per drug or create a fixed copay.
- ✓ **Standardize Benefit Plan Design** – Make it easier to compare plans by making sure plans offer standard options.
- Separate Annual Drug Costs** – Place a limit on the total amount a patient pays on Rx drugs annually.
- Ban Copay Accumulators** – Ensure all payments to count towards a patient’s deductible – no matter the source.

# Protecting Patients in State-Regulated Insurance

## *Short-Term, Limited-Duration Health Plans*

S

- What are short-term, limited-duration health plans (STLDIs)?

These plans were designed for people who experience a temporary gap in health insurance coverage. These plans provide coverage for a limited term, typically less than 365 days.

T

- How else is that different from typical health insurance?

STLDI is exempt from the definition of individual health insurance coverage under the Public Health Service Act and, therefore, is generally not subject to the applicable federal individual market consumer protections and requirements for comprehensive coverage under the ACA. For example, STLDIs are exempt from rules that prohibit medical underwriting, pre-existing condition exclusions, and lifetime and annual limits, and that require minimum coverage standards.

L

- So, how are these plans regulated?

The Federal Department of Health & Human Services has a [rule](#) in place regarding duration and renewal of these plans. However, some states also have laws on the books related to these plans. **South Carolina Department of Insurance permits a plan that provides benefits for no longer than 11 months and may be renewed.**

D

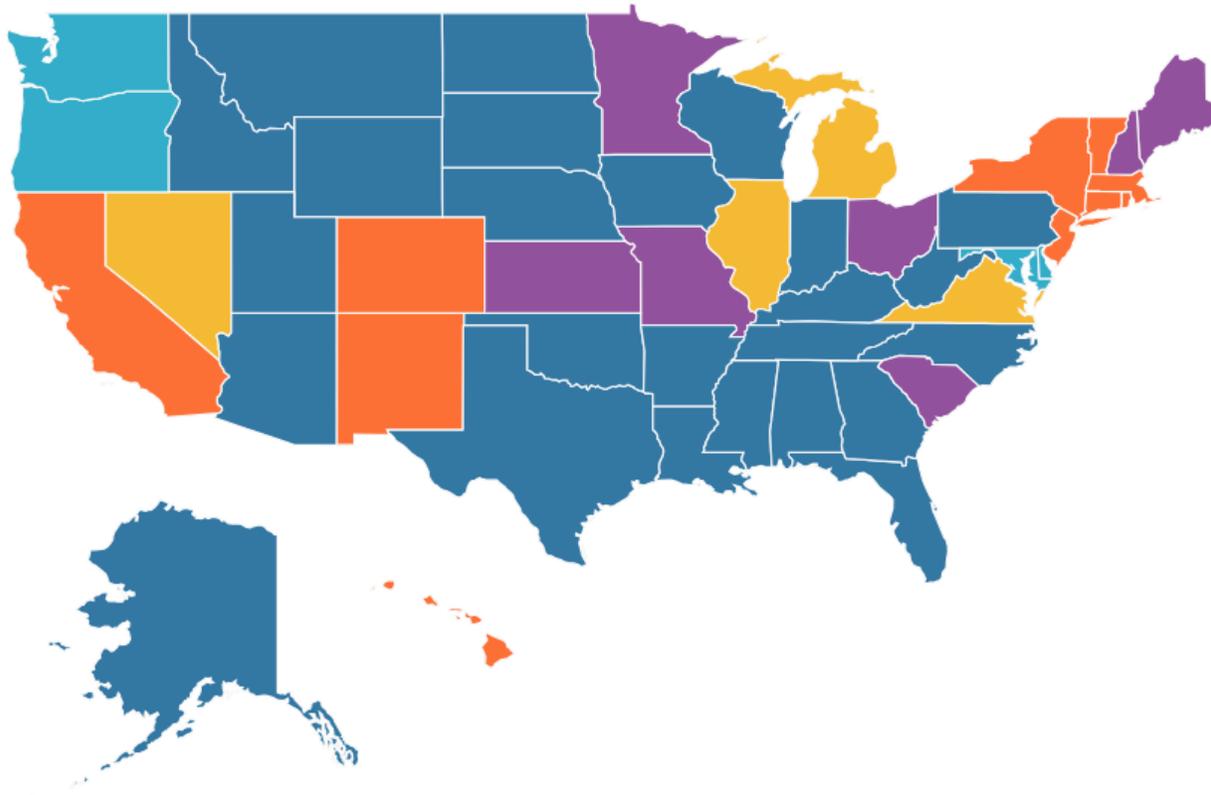
- What does the HHS rule require?

Current rules allow for a STLDI to initially be issued for 364 days, permit renewals of the same policy up to 3 times, and permit individuals to purchase additional STLDI policies.

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# STLDI Plans in South Carolina

Overall Grade: ■ A ■ B ■ C ■ D ■ F



NORD considers what actions, if any, states have taken to mitigate the expansion of short-term, limited-duration health plans.

SC as of: November 2023

Limits on Initial Plan Duration	<b>D</b>
Regulation of Renewability	<b>F</b>
Limitations on Maximum Duration	<b>D</b>

an **OVERALL** state grade is determined by taking the average of the three separate grades.

# REPORT CARD “A” AND “B” CATEGORIES

Newborn Screening  
Rare Disease Advisory Councils (RDAC)



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# RDAC News & Opportunities to Engage

## SAVE THE DATE!

**April 25, 2024** | Region C Policy and Advocacy Taskforce Meeting (Virtual)

**June 7 -8, 2024** | Living Rare, Living Stronger Patient and Family Forum in Los Angeles, CA

**June 8, 2024** | Rare Impact Awards in Los Angeles, CA

**October 20-22, 2024** | NORD Breakthrough Summit in Washington, DC

## Mississippi RDAC Bill Approved by Governor Tate Reeves!

On Monday, April 8<sup>th</sup> NORD's eastern region welcomed a new member to the RDAC family! Governor Tate Reeves approved SB2156, championed by Senator Kevin Blackwell, going into law. There will be a bill signing event in Jackson next week!

Take Action!  
Share South Carolina's Report Card



**Tell Your Elected Officials  
About How South Carolina  
Did on the State Report Card**



Share your state's grade on rare disease policies with your elected officials.

Take Action!

# Thank You!

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