NORD®
National Organization for Rare Disorders

Rare Disease and HR1 Work Requirements: Model Policy Language for Lawmakers

Template policies for states to plan for people with rare diseases.



NORD® MODEL LANGUAGE

2026

About the National Organization for Rare Disorders (NORD®)

The National Organization for Rare Disorders (NORD®) is a federation of non-profit rare disease patient organizations and healthcare institutions, including Centers of Excellence (CoEs), dedicated to improving the health and well-being of people living with rare diseases.

NORD was founded more than 40 years ago, after the passage of the Orphan Drug Act (ODA), to formalize the coalition of patient advocacy groups instrumental in passing that landmark law. Our mission has always been, and continues to be, to improve the health and well-being of people with rare diseases by driving advances in care, research, and policy.

Rare disease affects fewer than 200,000 people per condition, yet collectively impacts approximately 30 million Americans — one in ten, half of whom are children. NORD supports this community through a nationwide infrastructure built over more than a decade:

34
Rare Disease Advisory Councils (RDACs)

78%
of Americans covered through RDACs

21K+
Rare Action Network (RAN) advocates

10 Years
of State Report Card® data benchmarking rare disease policy over all 50 states

175
Rare Disease Centers of Excellence across 28 states and D.C.

This model language is one part of that infrastructure. It is offered as a resource for state legislators and agency staff working to implement Medicaid work requirements in ways that protect eligible patients from coverage loss due to administrative barriers that fail to reflect the realities of complex medical conditions.

Alone we are rare. Together we are strong.®

For questions or to connect with NORD's policy team, contact policy@rarediseases.org.

Model Policy Language
At-a-Glance

Quick guide to the model language and where to find it.

01 Use the Full Implementation Timeline

Use this language to:
Take the full implementation period and provide for repeal and restoration of coverage if the federal mandate is no longer in effect.

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02 Engage Patients and Caregivers in Design

Use this language to:
Create opportunities for patients, caregivers, and RDACs to provide input into condition lists, systems, notices, and governance.

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The following model language is issued by the National Organization for Rare Disorders (NORD®) as a companion to our position statement Access is Non-Negotiable: NORD's Recommendations for Medicaid Work Requirement Implementation (May 2026). Each provision is designed as a legislative proposal for lawmaker use.

How To Use This Document

- This is model language, not final legislative or regulatory text. It is intended to be adapted to fit each state's existing statutory structure, drafting conventions, and legal requirements. NORD recommends review by state legislative counsel or agency legal staff before introduction or adoption.
- This document reflects the interim final rule (CMS-2454-IFC) as of June 1, 2026. CMS may issue a revised final rule following the public comment period and additional guidance.
- Each model provision contains a summary and ready-to-copy policy language.
- Language in brackets, shown in red, indicates a state-specific fill-in that must be customized before use (e.g., [the state medicaid agency]).
- For questions or to connect with NORD's policy team, contact policy@rarediseases.org.

MODEL POLICY LANGUAGE SECTION 1

Use the Full Implementation Timeline

Use this language to take the full implementation period and provide for repeal and restoration of coverage if the federal mandate is no longer in effect.

1. Utilization of Full Implementation Period & Immediate Repeal Upon Federal Action

State Discretion

Work and community engagement requirements demand significant operational preparation: system redesign, staff training, data integration, and beneficiary outreach. Taking the full implementation time allotted, effective January 1, 2027, for preparation creates space for thoughtful planning, systems testing, and stakeholder engagement before consequences are in effect. H.R.1 provides a good faith exemption pathway for states to seek temporary relief from compliance through December 31, 2028. This is a planning tool that can be used responsibly.

SUMMARY

Use the full implementation period and provide for immediate repeal and the restoration of coverage if federal mandate is no longer in effect.

MODEL POLICY LANGUAGE

1. *Effective no sooner than January 1, 2027, [the state Medicaid agency] shall implement work or community engagement requirements set forth in Section 1396a(xx) of Title 42 of the United States Code (Section 71119 of federal House Resolution 1 (Public Law 119-21)) to ensure that all eligible applicants and beneficiaries obtain and maintain coverage in ways that are least administratively burdensome to applicants and beneficiaries.*
2. *All community engagement requirements established within this State pursuant to H.R.1 §71119(A)(xx), shall cease to be operative and are hereby repealed upon the effective date of any federal law, regulation, or federal court order of national applicability that:*
    a. *renders compliance with community engagement requirements optional for states; or*
    b. *otherwise eliminates the federal mandate requiring states to implement community engagement requirements as a condition of Medicaid eligibility.*
3. *Upon such federal action, [the state Medicaid agency] shall immediately cease enforcement of community engagement requirements and shall restore coverage to any individual whose eligibility was affected solely by noncompliance with such requirements, without requiring a new application.*
    a. *The state shall provide such individuals notice of the restoration of their coverage. Such notice shall include the effective date of their coverage period and the date of their next renewal.*

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MODEL POLICY LANGUAGE SECTION 2

Engage Patients and Caregivers in Design

Use this language to create opportunities for patient, caregiver, and Rare Disease Advisory Councils to provide input on qualifying conditions, eligibility systems, notices, and program governance.

State Discretion

The people most affected by these implementation decisions are best positioned to identify where systems will fail before they do. Structures already exist within state governments to support meaningful engagement and states can use them.

1. Rare Disease Advisory Council (RDAC) Status Map

Rare Disease Advisory Councils (RDACs) are formal governmental bodies embedded in state government that provide expert guidance on rare disease policy. In states with RDACs, these councils are uniquely positioned to inform Medicaid work requirement implementation — bringing rare disease expertise directly into the regulatory decision-making process.

States with operational or established RDACs are listed below. NORD can facilitate direct introductions to RDAC leadership upon request. Contact policy@rarediseases.org to connect.

As of July 2026, expected impacted and expansion states that do NOT have a RDAC include Alaska, Arkansas, Hawaii, Idaho, Iowa, Nebraska, New Mexico, North Dakota, Oklahoma, Oregon, South Dakota, Washington, and Wisconsin.

If you would like to pursue the creation of a RDAC in your state, please reach out to policy@rarediseases.org. NORD would be happy to provide you with the model legislation for council establishment and technical assistance.

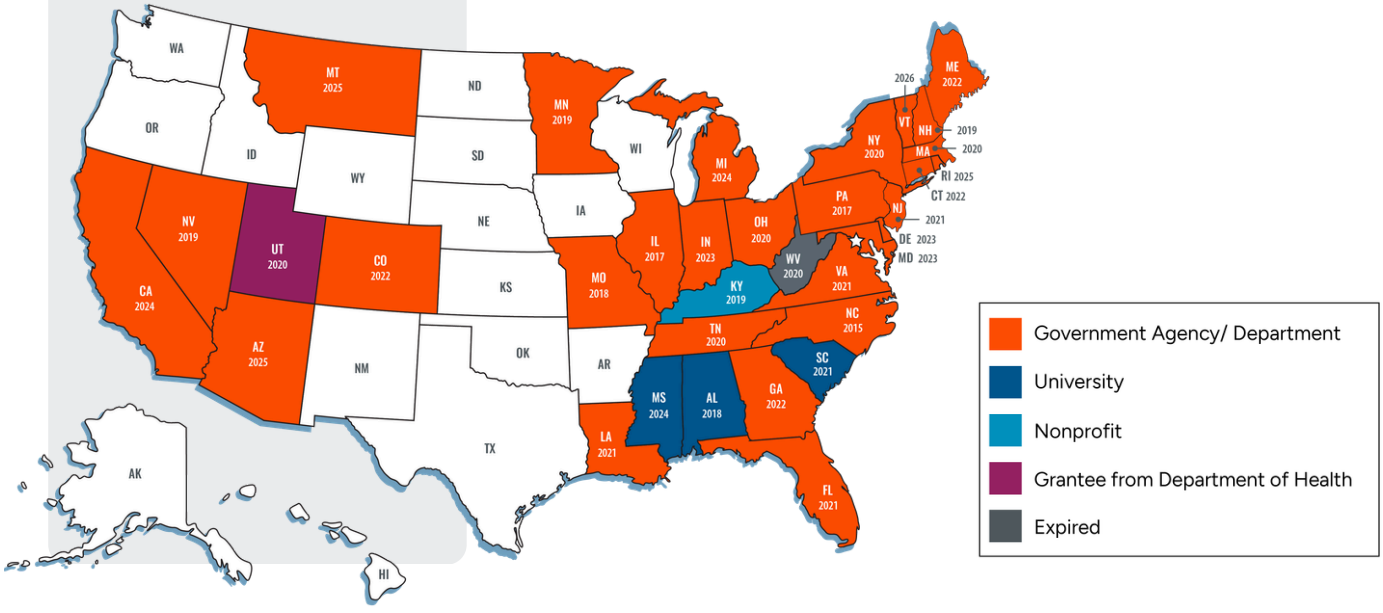
RDACS MAKE A DIFFERENCE

States with Rare Disease Advisory Councils (RDACs) earn higher rare disease policy grades on NORD's State Report Card.

B- vs. C+
AVERAGE GRADE
B- with an RDAC vs. C+ without

70%
TOP PERFORMING STATES
~70% have an RDAC

STATISTICAL CONFIDENCE
Significant at p = 0.002



RDAC Directory — Public Contact Information

State	RDAC Name	Status	Public Contact
Alabama	Alabama Rare Disease Advisory Council	Active	bkorf@uab.edu
Arizona	Arizona Rare Disease Advisory Council	Active	ARDAC@azdhs.gov
California	Jacqueline Marie Zbur Rare Disease Advisory Council	Appropriations Required	Contact NORD for Information
Colorado	Colorado Rare Disease Advisory Council	Active	Co.rarediseaseadvisorycouncil@gmail.com
Connecticut	Connecticut Rare Disease Advisory Council	Active	melia.allan@ct.gov
Florida	Rare Disease Advisory Council	Active	Boardsandcouncils@FLHealth.gov
Delaware	Rare Disease Advisory Council	Active	LGinfo@delaware.gov
Georgia	Georgia Rare Disease Advisory Council	Active	info@gararedisease.org
Illinois	Illinois Rare Diseases Commission	Active	217-782-0843
Indiana	Rare Disease Advisory Council	Active	317-233-1325
Kentucky	Rare Disease Advisory Council	Dormant	Contact NORD for Information
Louisiana	Louisiana Rare Disease Advisory Council	Active	gina.easterly@la.gov
Maine	Rare Disease Advisory Council	Implementing	(207) 287-3707
Maryland	Rare Disease Advisory Council	Active	lauren.whiteman@maryland.gov.
Massachusetts	Rare Disease Advisory Council	Active	zakaria.ahmed-gas2@mass.gov
Michigan	Michigan Rare Disease Advisory Council	Active	MDHHS-RareDiseases@michigan.gov
Minnesota	Minnesota Rare Disease Advisory Council	Active	info@mnraredisease.org

RDAC Directory — Public Contact Information *(continued)*

State	RDAC Name	Status	Public Contact
Mississippi	Mississippi	Active	rdac@umc.edu
Missouri	Advisory Council on Rare Diseases and Personalized Medicine	Active	mhd.pharmacyadmin@dss.mo.gov
Montana	Rare Disease Advisory Council	Active	Jeremy Royal jeremy.royal@mt.gov
Nevada	Rare Disease Advisory Council	Active	atorrez@health.nv.gov
New Hampshire	Rare Disease Advisory Council	Active	603-271-4517
New Jersey	Rare Disease Advisory Council	Active	DOH-NJRDAC@doh.nj.gov
New York	New York State Rare Disease Advisory Council	Implementing	dohweb@health.ny.gov
North Carolina	Advisory Council on Rare Diseases	Active	Contact NORD for Information
Ohio	Ohio Rare Disease Advisory Council	Implementing	ORDAC@odh.ohio.gov
Pennsylvania	Pennsylvania Rare Disease Advisory Council	Active	info@pardac.org
Rhode Island	Rare Disease Advisory Council	Implementing	Contact NORD for Information
South Carolina	South Carolina Rare Disease Advisory Council	Active	https://rarediseasessc.org/
Tennessee	Tennessee Rare Disease Advisory Council	Active	info@tnrdac.org
Utah	Utah Rare Disease Advisory Council	Active	https://utahrdac.org/contact/
Vermont	Vermont Rare Disease Advisory Council	Implementing	Contact NORD for Information
Virginia	Virginia Rare Disease Council	Active	https://www.vdh.virginia.gov/rare-disease-council/contact-us/
West Virginia	West Virginia Advisory Council on Rare Diseases	Expired	https://wvrare.org/

2. System Design & Governance - RDAC Consultation & Engagement

SUMMARY

Ensures in-state rare disease experts help design eligibility systems and notices so they work for people with rare & complex conditions and are engaged in ongoing program governance.

MODEL POLICY LANGUAGE

1. *[The state Medicaid agency] shall consult the [state Rare Disease Advisory Council] on eligibility system and notice design as it affects individuals with rare and complex conditions, including plain-language and accessibility review of forms, and shall provide the RDAC a reasonable opportunity to review and comment on proposed system and notice designs before they are finalized.*
2. *[The state Medicaid agency] shall amend the bylaws of the state's Medicaid Advisory Committee (MAC) or Beneficiary Advisory Council (BAC) to include a seat for [state Rare Disease Advisory Council] or rare disease patient representation.*

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Related NORD Resources

This Language Companion works alongside a broader set of tools NORD has developed to support state implementation of Medicaid work requirements. We encourage you to consult these resources together:

Access is Non-Negotiable: NORD's Recommendations for Medicaid Work Requirement Implementation

NORD's full position statement, outlining recommendations across six areas of state design discretion — the same six areas organizing this Language Companion.

Medical Frailty Exemptions Explained *(Infographic)*

A plain-language walkthrough of how the medical frailty exemption works under CMS-2454-IFC, including the 11 criteria for a "serious or complex" condition, the decision pathway, and the state qualifying condition list requirement.

NORD® Rare Disease Database

NORD's continuously updated database of more than 10,200 rare diseases, available as a reference tool to support state verification plans and medical frailty determinations.

NORD State Report Card®

A decade of state-level rare disease policy benchmarking across all 50 states and Washington, DC, providing context for how a state's broader rare disease policy landscape intersects with Medicaid implementation choices.

Rare Disease Advisory Councils (RDACs)

Formal governmental bodies providing embedded rare disease policy expertise in state government. See the directory in this document, or contact NORD to connect with your state's council.

We're Here to Help

State implementation decisions are moving quickly, and the window to shape them is narrow. NORD's policy team is available to:

- Walk through any provision in this document in more detail
- Connect your team with RDAC leadership in your state
- Provide condition-specific information through our Information and Resource Services team
- Discuss how other states are approaching similar implementation questions

Information and Resource Services
(800) 469-0283
informationservices@rarediseases.org

Policy Team
policy@rarediseases.org

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