NORD®
National Organization for Rare Disorders

Rare Disease and HR1 Work Requirements: Model Policy Language

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
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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 for insertion Medicaid State Plan Amendments (SPAs), waivers, administrative rules, or regulatory guidance.

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.
- Provisions are organized by NORD's six implementation recommendations as outlined in our organization's position statement. Each provision can be used independently.
- 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.*

###

MODEL POLICY LANGUAGE SECTION 2

Minimize Administrative Burden

Use this language to establish the minimum federally required redetermination frequency and use available state information.

1. Eligibility Redetermination

State Discretion

H.R.1 sets the floor. More frequent verification will cost more to administer, create more opportunities for error, and generate more appeals and corrections to respond to. The evidence is consistent: when administrative requirements exceed what the law demands, the resulting coverage losses fall on people who are eligible and exempt.

SUMMARY

Exercise the state option to conduct eligibility determinations at the minimum federally mandated frequency: once every six months.

MODEL POLICY LANGUAGE

1. *Effective January 1, 2027, [the state Medicaid agency] shall conduct eligibility redeterminations once every six months for new beneficiaries enrolled under Section 1396a(a)(10)(A)(i)(VIII) of Title 42 of the United States Code. Each existing beneficiary who began receiving benefits prior to January 1, 2027, and has a scheduled renewal after the effective date, will receive benefits for the remainder of the individual's eligibility duration and then be transitioned to a redetermination schedule of once every six months.*
2. *For beneficiaries that are specified excluded individuals on the basis of medical frailty, [the state Medicaid agency] shall reverify medically frail status once every twelve months.*
3. *An applicable individual enrolled in [state Medicaid program] and receiving services must demonstrate 80 hours of community engagement, as defined in Section 435.552 of Title 42 of the United States Code, for any one month during the period between the individual's most recent determination or redetermination, as applicable, and their next regularly scheduled redetermination of eligibility, in order to be considered meeting community engagement requirements.*
    a. *[State Medicaid Agency] shall not apply the requirements of this paragraph to a specified excluded individual.*

Continued next...

1. Eligibility Redetermination *(continued)*

4. *For purposes of acquiring information necessary to conduct the eligibility redeterminations described in this section, [the state Medicaid agency] shall gather information available to the state that is relevant to the beneficiary's Medicaid eligibility prior to contacting the beneficiary. Sources for these efforts shall include information contained in the beneficiary's file or other information, including more recent information available to the state, including, but not limited to, Medicaid case files of the beneficiary or of any of their immediate family members, which are open, or were closed within the last 12 months, information accessed through any databases accessed under Sections 435.948, 435.949, and 435.956 of Title 42 of the United States Code, and, wherever feasible, other sources of relevant information reasonably available to the state.*
5. *Prior to disenrolling any applicable individual, [the state Medicaid agency] shall first do both of the following:*
    a. *Determine whether there is any other basis for eligibility for the Medicaid program or for another insurance affordability program for the individual.*
    b. *Provide written notice and grant the individual an opportunity for a fair hearing.*
        i. *Notice forms must include clear information on how to make a satisfactory showing of compliance with the community engagement requirement, including information about the short-term hardship exception under Section 435.555 of Title 42 of the United States Code.*
    c. *Provide a period of 30 calendar days beginning on the date on which such notice of noncompliance is received by the individual to make a satisfactory showing to the agency-*
        i. *Of demonstration showing that the individual met community engagement requirements; or*
        ii. *That such requirement does not apply to the individual on the basis that the individual does not meet the definition of applicable individual under Section 435.551 of Title 42 of the United States Code, including by meeting the criteria for one or more of the categories of a specified excluded individual as defined at Section 435.554 of Title 42 of the United States Code.*
    d. *Continue to furnish coverage until the notice period has ended, and the beneficiary has been informed of fair hearing rights.*

Continued next....

1. Eligibility Redetermination *(continued)*

6. *[The state Medicaid agency] must inform beneficiaries of the eligibility determination, which includes a clear statement of eligibility and specifies whether the individual:*
   a. *Meets the criteria as a specified excluded individual; or*
   b. *Is determined to be an applicable individual, and whether the individual demonstrates community engagement or is deemed to have demonstrated community engagement for one month.*

###

2. Documentation Requirements

SUMMARY

Exercise the state option to adopt the minimum federally mandated renewal lookback period of one month, limit documentation requests and use available data sources to verify compliance.

MODEL POLICY LANGUAGE

1. *Any applicable individual who applies for [the state Medicaid program] shall demonstrate work or community engagement for one month immediately preceding the month during which the individual applies for [the state Medicaid program] to be considered meeting work or community engagement requirements.*
2. *[The state Medicaid agency] shall ensure and confirm that systems are programmed to maintain coverage with minimal information requests to an applicant or beneficiary by doing all of the following:*
    a. *Verifying compliance through interfaces with data sources that include, but are not limited to:*
        i. *Information accessed through databases under sections 435.948, 435.949, and 435.956 of Title 42 of the United States Code;*
        ii. *Information from other State or local agencies;*
        iii. *Information in the State's eligibility system;*
        iv. *Information in the individual's case record;*
        v. *Payroll data;*
        vi. *Claim(s) relevant to the individual that have been adjudicated in the preceding 12 months, including those that have been paid, pended or denied; and*
        vii. *Encounter data, as relevant to the individual, for the preceding 12 months.*
        viii. *Any other sources of reliable information that are reasonably available to the State.*
    b. *Allowing individuals the option to add, through consent-based verification platforms and any other means, information to their application or renewal for purposes of verifying compliance.*
3. *Prior to requesting more information to an applicant or beneficiary, [state Medicaid agency] will review existing data and information sources to verify [state Medicaid program] eligibility.*

Continued next...

2. Documentation Requirements *(continued)*

4. *Except with respect to verifying an individual's status as medically frail, for beneficiaries or new applicants who cannot be deemed compliant or whose status as a specified excluded individual cannot be verified following ex parte review, as required by Section 1396a(xx)(5) of Title 42 of the United States Code, [the state Medicaid agency] shall request information from the individual in accordance with the following rules:*
    a. *Before January 1, 2028, [the state Medicaid agency] shall accept documentation or other information as provided in Section 435.952(c) of Title 42 of the United States Code when there is no reliable information available to the State or the reliable information is not reasonably compatible with the information provided by or on behalf of the individual.*
    b. *Beginning on January 1, 2028, when there is no reliable information available to the State or the reliable information is not reasonably compatible with the information provided by or on behalf of the individual, [the state Medicaid agency] shall require documentation whenever documentation is reasonably available.*
5. *If [the state Medicaid agency] is unable to verify an individual's specified excluded status on the basis that the individual is medically frail using all reliable information available, the [State Medicaid Agency] shall request information from the individual in accordance with the following rules:*
    a. *Before January 1, 2028, [the State Medicaid agency] shall accept documentation or a statement or other information under penalty of perjury that demonstrates that the individual is medically frail, each time [the State Medicaid agency] verifies that the individual is medically frail.*
    b. *Beginning on January 1, 2028 [the State Medicaid agency] shall accept a statement or other information provided under penalty of perjury that demonstrates that the individual is medically frail only once during the beneficiary's period of enrollment as defined in Section 435.557(a) of Title 42 of the United States Code. After the individual's first regularly scheduled determination after such status was determined using the individual's statement provided under penalty of perjury or other information, [the state Medicaid Agency] must verify that the individual is medically frail or otherwise has special medical needs using reliable information available to the State, or if reliable information is not sufficient for verification, using documentation submitted by or on behalf of the individual.*

Continued next...

2. Documentation Requirements *(continued)*

6. *When there is a conflict in reliable data sources that adversely impacts an applicant's or beneficiary's eligibility, the [state Medicaid agency] shall request the applicant or beneficiary to confirm information before taking any adverse action on the application or renewal.*
7. *If an individual provided information on an application, renewal or other State form, or when reporting a change in circumstances indicating they qualify for an exception and there is no reliable information available to the State, [the State Medicaid agency] shall elect the option under section 1396a(xx) of Title 42 of the United States Code not to seek further information from the applicable individual.*
8. *All renewal or application forms, notices, determinations, and any other informational material shall be written in plain-language, translated into languages spoken within [state], and accessible to persons who are limited-English proficient and persons with disabilities consistent with all federal and state requirements.*
    a. *[State Medicaid agency] shall accept applications, renewal forms, and any other related information provided by the beneficiary, in person or via written mail, by telephone, online via e-mail, or through commonly available electronic means.*

###

MODEL POLICY LANGUAGE SECTION 3

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.

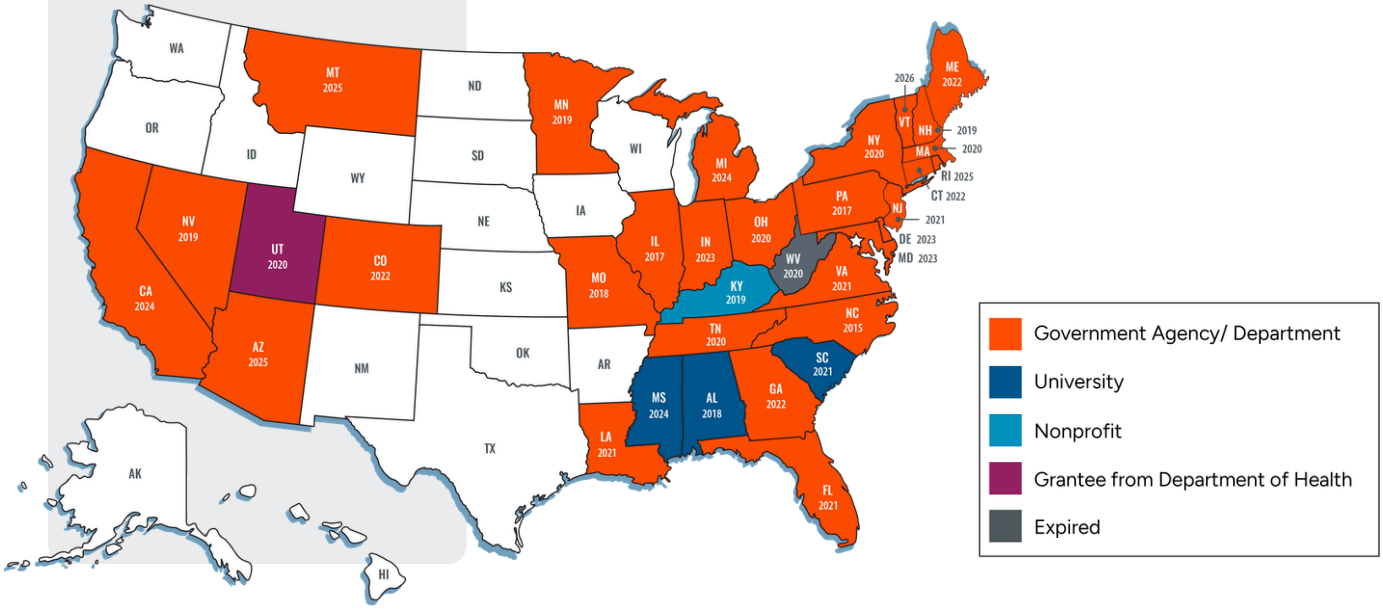
RDACS MAKE A DIFFERENCE

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. Developing a List of Conditions That Meet Medical Frailty Criteria – RDAC Consultation

SUMMARY

Ensures in-state rare disease experts help determine which conditions qualify for medical frailty exemptions, with a 30-day review before any condition is removed.

MODEL POLICY LANGUAGE

1. *When developing a list of diseases, diagnoses, disorders or other health conditions for the purpose of defining medically frailty pursuant to Title 42 CFR Section 435.555(c)(5)(ii) and Section 1902(xx) of the Social Security Act, [the state Medicaid agency] shall seek input from the [state Rare Disease Advisory Council] to identify rare and complex conditions that meet the criteria outlined in Title 42 CFR Section 435.555(c)(5)(i)(E).*
    a. *[The state Medicaid agency] may consult with [state Rare Disease Advisory Council] whenever it seeks to add to this list. It shall not remove a disease, diagnosis, or condition from this list unless it has provided the [state Rare Disease Advisory Council] no fewer than 30 days to review and comment on the proposed removal, and has considered any comments received.*

###

3. 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.*

###

MODEL POLICY LANGUAGE SECTION 4

Define Exemptions Broadly

Use this language to incorporate rare disease information, clinical trials, and permanent or stable conditions into medical frailty processes.

ONLY 500 OF 10,000+ RARE DISEASES HAVE A ICD-10 CODE.



NORD's Rare Disease Database

The largest continuously updated database of rare diseases; a resource to support medical frailty determinations. Over 10,000 known rare diseases recorded.

State Discretion

Exemption frameworks built around narrow diagnostic categories will systematically fail the rare disease community. States have the discretion to define medically frail and complex medical condition expansively. People across many conditions with medical complexity face similar barriers, and the broadest interpretations will serve them all.

1. The NORD Rare Disease Database as a Resource for Medical Frailty Determinations

SUMMARY

Provides states with a trusted rare disease database resource to improve medical frailty determinations as part of the State Verification Plan.

MODEL POLICY LANGUAGE

1. *[The state Medicaid agency's] verification plan required under 42 C.F.R. Section 435.557 shall include the NORD® Rare Disease Database[1] as a tool to identify medically frail patients.*

###

2. The NORD Rare Disease Database as a Resource for Medical Reviewers Downstream

SUMMARY

Provides states with a trusted rare disease database resource to improve medical frailty determinations downstream of the State Verification Plan in policy manuals and employee guidance.

MODEL POLICY LANGUAGE

1. *[The state Medicaid agency] shall integrate the NORD® Rare Disease Database in internal policy manuals and eligibility worker guidance as a tool for identifying rare and complex conditions, making medical frailty determinations, and informing which specific diagnosis and procedure codes to add to the state's medically frail conditions list.*

###

3. Clinical Trial Participation as an Indicator of a "Serious or Complex Medical Condition" and Permanent & Stable Exemptions for Permanent & Stable Conditions

SUMMARY

Recognizes clinical trial participation as evidence of serious medical complexity and creates permanent medical frailty exemptions for lifelong conditions, eliminating unnecessary re-documentation.

MODEL POLICY LANGUAGE

1. *Clinical trial participation shall be considered an indicator of a "serious or complex medical condition" under the medically frail exclusion as described under 42 CFR Section 435.555(c)(5)(i)(E) if and to the extent allowable under then-current federal law and CMS guidance.*
2. *[The state Medicaid agency] shall grant permanent medical frailty exemptions for individuals whose conditions are lifelong, degenerative, terminal, or otherwise permanent and unlikely to improve, and shall not require re-documentation of such status once established, if and to the extent allowable under then-current federal law and CMS guidance.*

###

MODEL POLICY LANGUAGE SECTION 5

Fully Utilize Flexibility

Use this language to adopt available hardship exceptions and establish related eligibility and verification processes for circumstances including clinical trial participation.

1. Short-Term Hardship Exceptions

State Discretion

Many rare disease patients and their caregivers face particularly severe time burdens that can also be unpredictable and would make work requirement compliance impossible. States can help minimize unintended coverage losses and protect patients with complex conditions who must travel far for care and those participating in clinical trials.

SUMMARY

Allows states to adopt all temporary hardship exceptions to prevent eligible people from losing coverage during short-term life events..

MODEL POLICY LANGUAGE

1. *[The state Medicaid agency] shall exercise its authority to adopt the optional short-term hardship exceptions pursuant to 42 U.S.C. Section 1396a(xx)(3)(B)(ii).*
2. *Applicable individuals who meet any of the short-term hardship event criteria described in this section are deemed by [the state Medicaid agency] to have demonstrated community engagement requirements for that month.*
3. *In accordance with 42 U.S.C. Section 1396a(xx)(3)(B)(ii) and criteria specified under 42 C.F.R. Section 435.555, an applicable individual experiences a short-term hardship event during a month if, for part or all of that month, any of the following is met:*
    a. *The individual receives inpatient hospital services, nursing facility services, services in an intermediate care facility for individuals with intellectual disabilities, inpatient psychiatric hospital services, or other services of similar acuity, including outpatient care that, but for the receipt of such services, would likely result in the applicable individual receiving services specified in this paragraph, and the individual requests a short-term hardship exception.*
    b. *The individual resides in a county or equivalent unit of local government in which an emergency or disaster was declared by the United States President under the federal National Emergencies Act (50 U.S.C. Sec. 1601 et seq.) or the federal Robert T. Stafford Disaster Relief and Emergency Assistance Act (42 U.S.C. Sec. 5121 et seq.) and the emergency affects the ability of applicable individuals to demonstrate community engagement in a particular county, equivalent unit of local government, multiple counties, or statewide.*

Continued next...

1. Short-Term Hardship Exceptions *(continued)*

c. *The individual resides in a county or equivalent unit of local government with an unemployment rate that is at or above the lesser of 8 percent or 1.5 times the national unemployment rate, subject to a request from [the state Medicaid agency] to the United States Secretary of Health and Human Services.*

d. *The individual or their dependent must travel outside of their community for an extended period of time to receive medical services necessary to treat a serious or complex medical condition that are not available within their community of residence, and the individual requests a short-term hardship exception.*

4. *[The state Medicaid agency] must -*

a. *Use reliable information available to the State before seeking additional information to verify whether, for part or all of a month for which an applicable individual is required to demonstrate community engagement, the applicable individual received care specified under 42 C.F.R. Section 435.555(d)(1) or the applicable individual or their dependent had to travel outside of their community residence for an extended period of time to receive medical services specified under Section 435.555(d)(4).*

b. *Apply an automatic short-term hardship exception to applicable individuals if, for part or all of a month for which such applicable individuals are required to demonstrate community engagement, the individuals reside in a county or equivalent unit of local government in which there exists an emergency disaster as specified under Section 435.555(d)(2) or for which the Secretary has approved an unemployment-based short-term hardship exception as specified under Section 435.555(d)(3), without requesting any additional information from such applicable individuals.*

5. *[The state Medicaid agency] shall seek input from [state Rare Disease Advisory Council] to further define eligibility determination processes and criteria for applicable individuals receiving other non-institutional services of similar acuity specified under 42 C.F.R. Section 435.555(d)(1)(ii)(E) or for applicable individuals or their dependents traveling outside of their community for an extended period of time to receive medical services specified under Section 435.555(d)(4).*

Continued next...

1. Short-Term Hardship Exceptions *(continued)*

6. *The [state Medicaid agency] must provide notice:*
    a. *Informing applicable individuals that the State offers the short-term hardship exceptions;*
    b. *For emergency or disaster and unemployment short-term hardship exceptions as specified under Sections 435.555(d)(2) and 435.555(d)(3), notice of:*
        i. *Whenever the exception becomes available, and*
        ii. *The anticipated end date of the exception;*
    c. *For the inpatient services and travel for care exceptions as specified under Sections 435.555(d)(1) and 435.555(d)(4), notice of:*
        i. *How to request the short-term hardship exception;*
        ii. *Timeframe for requesting the short-term hardship exception;*
        iii. *The process for determination; and*
        iv. *The state's determination, including the anticipated end date of the exception (if granted) and process for appeal.*
    d. *If ever the state chooses to no longer offer the exceptions, with a minimum of 10 days advance notice including fair hearing rights;*
    e. *Whenever there is anticipated expiration of a hardship event, with a minimum of 10 days advance notice including fair hearing rights.*
7. *For the inpatient services and travel for care exceptions as specified under Sections 435.555(d)(1) and 435.555(d)(4), [the state Medicaid agency] must also develop:*
    a. *A timely process for determining whether a request for a short-term hardship exception will be granted; and*
    b. *A process under which an applicable individual or an individual acting on behalf of the applicable individual can appeal an adverse determination.*
8. *Outreach shall:*
    a. *Provide explanations of the exceptions in plain-language, including examples and instructions on how people can qualify; and*
    b. *Be translated into languages spoken within [state], and accessible to persons who are limited-English proficient and persons with disabilities relying on asccessible communication technology consistent with all federal and state requirements including the Americans with Disabilities Act.*
9. *[The state Medicaid agency] shall also develop a process to transition individuals with ongoing medical hardship into specified excluded individual categories for longer-term exemption where appropriate.*

###

2. Clinical Trial Participation as a Qualifying Activity for Short-term Hardship Exceptions

SUMMARY

This language ensures trial participation and related travel qualify for the hardship exception regardless of whether the underlying condition is on the state's medically frail list, and provides a fallback so participation is still considered even when a patient hasn't proactively requested an exemption.

MODEL POLICY LANGUAGE

1. *Clinical trial enrollment and travel to a clinical trial site shall be considered a qualifying activity under the travel for medical care Short-Term Hardship Exception as specified under 42 C.F.R. Section 435.555(d)(4), if and to the extent allowable under then-current federal law and CMS guidance, even when the underlying condition for the clinical trial is not included on [the state Medicaid agency's] medically frail conditions list.*
    a. *Where such recognition is not available, [the state Medicaid agency] will consider clinical trial participation as an indicator of potential qualification for that exception when making determinations.*

###

MODEL POLICY LANGUAGE SECTION 6

Recognize and Protect Caregivers

Use this language to adopt all optional caretaker relative categories and recognition of multiple caregivers within a household.

1. Electing Full Recognition of Caretaker Relatives

State Discretion

States have discretion under 42 C.F.R. Section 435.554(a) to recognize additional caretaker relatives beyond the federal rule's guaranteed list — including other blood relatives, unmarried domestic partners, and unrelated adults who live with and care for the individual.

SUMMARY

Adopts all optional caretaker relative categories allowed under federal law.

MODEL POLICY LANGUAGE

1. *Pursuant to the option available to States under 42 C.F.R. Section 435.554(a) (defining "caretaker relative"), [the state Medicaid agency] shall recognize the following individuals as caretaker relatives of a dependent child or disabled individual, in addition to those relationships specified in subparagraphs (i) through (iii) of that section: (a) A relative of the dependent child or disabled individual based on blood, including relatives of half-blood, adoption, or marriage, who is not otherwise specified in subparagraphs (i) through (iii); (b) An individual in a domestic partnership with the parent or other caretaker relative of the dependent child or disabled individual, regardless of marital status; and (c) an adult with whom the dependent child or disabled individual is living and who assumes primary responsibility for the dependent child's or disabled individual's care, including a foster parent who resides with the dependent child or disabled individual.*
2. *[The state Medicaid agency] shall apply the elections described in this section consistently with any elections made by the State for purposes of eligibility for the group described at 42 C.F.R. Section 435.110.*

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2. Requiring Recognition of Multiple Caregivers Per Household

SUMMARY

Turns the federal option to recognize more than one caregiver per household into a state requirement.

MODEL POLICY LANGUAGE

1. *Consistent with 42 C.F.R. Section 435.554(c)(3)(ii), in a residence with more than one parent, guardian, caretaker relative, or family caregiver, [the state Medicaid agency] shall permit each individual who independently meets the relevant definitions at 42 C.F.R. Section 435.554(a) to separately qualify as a specified excluded individual.*
2. *[The state Medicaid agency] shall not deny, limit, or decline to process an application or redetermination for specified excluded individual status on the basis that another individual in the same residence has already qualified as a specified excluded individual under this section.*
3. *[The state Medicaid agency] shall ensure that eligibility determination and verification systems are designed to independently evaluate and record specified excluded individual status for each applicable individual in a residence, consistent with paragraph (1).*

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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
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Policy Team
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