



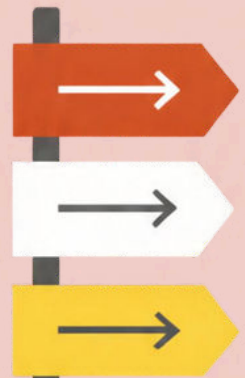
MEDICAID WORK REQUIREMENTS IN NEW YORK

Navigating Exemption
Criteria for Individuals Living
with Sickle Cell Disease (SCD)



Diagnosis alone does not
qualify for an exemption from
the work requirements rule.

Eligibility depends on the
functional and clinical impact
of SCD for each individual.



RULE EFFECTIVE

JANUARY 1, 2027

1. POLICY OVERVIEW & KEY MANDATES

SEPTEMBER 2026

JANUARY 1, 2027



NOTIFICATION TIMELINE

NY State of Health begins issuing official notices and compliance documentation to impacted individuals



EFFECTIVE DATE

Rule in effect starting January 1, 2027



WHO IS AFFECTED

Adult Medicaid expansion enrollees ages 19-64 in New York



INCREASED RENEWAL FREQUENCY

Eligibility renewals every 6 months instead of annually



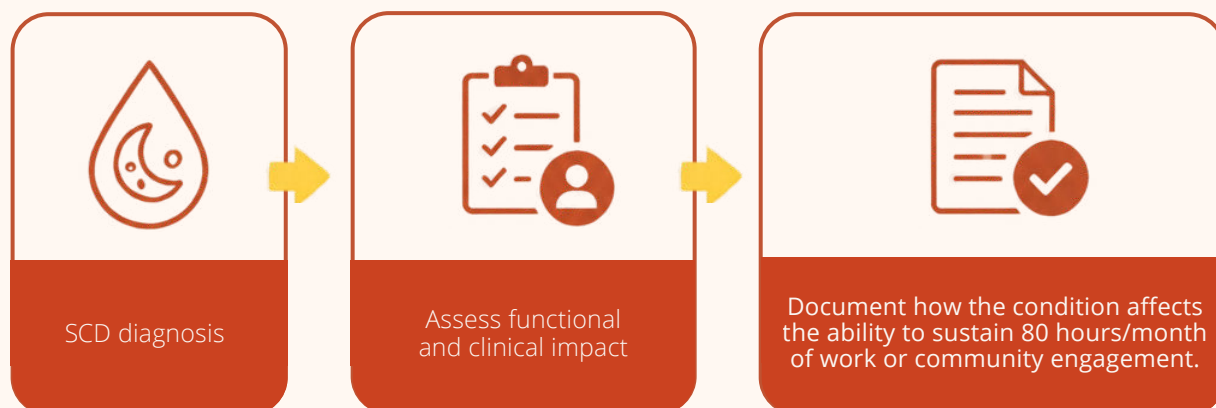
WHAT'S REQUIRED/QUALIFYING ACTIVITIES

80 hours per month of:

- Employment,
- Job training programs,
- Higher education or trade school (at least half-time), or
- Verified community service/volunteering

2. MEDICAL FRAILITY: DIAGNOSIS VS. FUNCTIONAL IMPACT

Under federal CMS guidance (CMS-2454-IFC), eligibility for an exemption depends on **how a condition affects a person's ability to meet work or community engagement requirements**—not on the diagnosis alone.



JUNE 2026

How the Medical Frailty Exemption Works (CMS-2454-IFC)



EXAMPLES OF MEDICAL FRAILITY



A condition is considered **'serious or complex'** if it meets at least one of the 11 following criteria:

1. Life threatening
2. Seriously disabling even if not life threatening
3. Causes significant pain or discomfort interrupting daily life
4. Requires major time or effort from caregivers for a substantial period
5. Requires frequent monitoring
6. Associated with severe consequences or negative consequences for someone else
7. Affect multiple organ systems
8. Requires management to tight medical parameters
9. Requires coordination of multiple specialties
10. Treatment carrying risk of serious complications
11. Requires adjustments in non-medical environments

Does the person's physical, mental, or behavioral health condition significantly impair the person's ability to meet the 80-hour community engagement requirement?

NO

Does this person fall into at least one of the categories outlined above that would identify them as medically frail? (i.e. blind or disabled, disabling mental disorder, substance use disorder, physical, intellectual, or developmental disability, and/or serious or complex medical condition)

NO

You **MAY NOT BE ELIGIBLE** for the medical frailty exemption and may be subject to work requirements.

YES

YES

You may have **POSSIBLE ELIGIBILITY** for the medical frailty exemption.



State list requirement: Each state must maintain a written list of qualifying conditions. The list must be auditable and updated regularly.

If a person's condition is not on the list, the state must have a process for that person to request consideration.

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Note. Adapted from Under New CMS Guidance on Medicaid Work Requirements: A Diagnosis Alone Does Not Automatically Qualify [Infographic], by National Organization for Rare Disorders (NORD), 2026 (https://rarediseases.org/wp-content/uploads/2026/06/NORD_RA)

3. 11 CRITERIA FOR SERIOUS OR COMPLEX MEDICAL CONDITIONS



DOCUMENTATION NOTE

Your medical documentation should clearly connect the individual's Sickle Cell Disease to at least **one** of 11 criteria. Examples of how SCD may apply to each is below:

1



LIFE THREATENING

High risk of acute chest syndrome, stroke, splenic sequestration, organ failure

2



SERIOUSLY DISABLING

Avascular necrosis, severe anemia, chronic pain preventing regular attendance

3



SEVERE PAIN INTERRUPTING DAILY LIFE

Recurrent & unpredictable vaso-occlusive crisis (VOCs) causing severe pain halting work and daily life

4



MAJOR CAREGIVER BURDEN

Substantial assistance from caregivers while recovering from VOCs, transfusions, or hospitalizations

5



FREQUENT MEDICAL MONITORING

Laboratory markers (CBC, reticulocyte count), organ function tests, transcranial doppler (TCD) scans

6



SEVERE CONSEQUENCES FOR OTHERS

Unpredictable crisis onset creates a high risk when responsible for caregiving or safety-dependent responsibilities

7



MULTI-ORGAN SYSTEM INVOLVEMENT

Lungs, heart, kidneys, spleen, eyes, bones

8



TIGHT MEDICAL PARAMETER MANAGEMENT

Hemoglobin, hydration, prophylactic antibiotics, tailored pain management

9



MULTI-SPECIALTY CARE COORDINATION

Hematology, Pulmonology, Nephrology, Cardiology, Orthopedics, Pain Management

10



HIGH-RISK TREATMENT COMPLICATIONS

Hydroxyurea monitoring, chronic transfusion, iron overload, post-transplant immunosuppression

11



NON-MEDICAL ENVIRONMENT ADJUSTMENTS

Avoiding extreme temperatures, continuous hydration, eliminating physical exertion



4. ACTION PLAN FOR INDIVIDUALS & CAREGIVERS

- 1** **Update contact details immediately**
Update mailing address, phone number, and email with NY State of Health or local Department of Social Services (LDSS)
- 2** **Request clinical documentation**
Schedule appointments with your hematologist or primary care clinician. Explain how SCD limits the ability to work 80 hours/month, linked to the 11 CMS criteria
- 3** **Submit exemption requests early**
File exemption forms after receiving notification or during the 6-month renewal window
- 4** **Retain copies and track submissions**
Record all delivery confirmations, keep all copies of clinical statements, dates, and call confirmation numbers

5. GENERAL EXEMPTIONS BEYOND MEDICAL FRAILITY



SSI/SSDI DETERMINATION

Exempt for individuals determined eligible for Supplementary Security Income (SSI) or Social Security Disability Insurance (SSD)



PRIMARY CAREGIVER STATUS

Exempt for individuals who are the primary caregiver of a dependent child or dependent adult



PREGNANCY & POSTPARTUM

Exempt for individuals who are pregnant or up to 12 months post-pregnancy



ACTIVE PARTICIPATION IN A CERTIFIED SUD TREATMENT PROGRAM

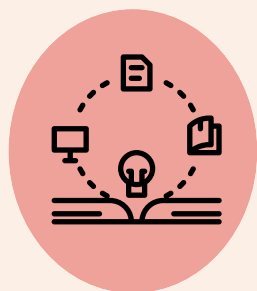
Exempt for individuals actively participating in a certified Substance Use Disorder (SUD) treatment program.



MEDICARE PART A OR PART B ENROLLMENT

Exempt for individuals enrolled in Medicare Part A or Part B

IF AN INDIVIDUAL DOES NOT QUALIFY UNDER MEDICAL FRAILITY, THEY MAY STILL QUALIFY FOR AN EXEMPTION UNDER STANDARD MEDICAID CRITERIA



6. OFFICIAL ASSISTANCE & RESOURCES



NY State of Health Customer Service
1-855-355-5777



TTY
1-800-662-1220



Online Portal
www.nystateofhealth.ny.gov



Local Department of Social Services
Contact the local county LDSS office.



National Organization for Rare Disorders
<https://rarediseases.org/medicaid-work-requirements/>



WHAT SICK CELLS OFFERS

Toolkits

Toolkits can be applicable for all levels of advocacy. Our aim is to provide readers with ideas for creating their own SCD advocacy initiatives.



State Advocacy Map

Interactive map to find advocacy resources to help your state and local advocacy efforts



Coverage for SCD Summit

The annual Coverage for SCD Summit provides a collaborative forum to discuss the changing landscape of healthcare coverage for sickle cell disease (SCD) and how to tackle the complexities of coverage and access to SCD treatments and care.

SCD Policy Forum

The National SCD Policy Forum brought together sickle cell advocates nationwide for a two-day federal advocacy event. Featured educational sessions on federal advocacy trends and provided an opportunity to discuss concrete solutions to existing gaps in sickle cell disease (SCD) policy.

AMBASSADOR PRIORITY TOPIC MEETING

1-HOUR MONTHLY SKILL-BUILDING ADVOCACY WORKSHOPS. EACH MONTH HAS A DIFFERENT THEME, FROM WELLNESS TO FEDERAL LEGISLATION.

Medicaid Landscape Analysis

Sick Cells is pleased to support the sickle cell disease research in SCD community engagement and will participate as a gatekeeper to the SCD patient population for research.

TEA CHAT

30-minute monthly meetings to discuss upcoming events

