SUBJECT: Adult Sickle Cell Services

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A. POLICY STATEMENT

Individuals with medically diagnosed sickle cell disease who meet stated eligibility criteria will receive financial assistance for the cost of medically necessary covered services related to their sickle cell disease diagnosis. Children and Youth with Special Health Care Needs (CYSHCN) financial assistance coverage may include insurance premium assistance, copay assistance and ancillary services, or may include allotment of funds. The financial assistance is limited to the level that can be supported with available funds. This coverage is not intended to meet all medical needs of individuals with a qualifying diagnosis. Limits based on per person, per item or per event expenditures may be established by Department of Public Health (DPH) at any time to ensure that expenditures do not exceed available or anticipated funding.

B. STANDARDS

1. Eligibility Criteria:
    a. Citizenship: Must be a US citizen or lawful permanent resident.
    b. Residency: Must be a South Carolina resident.
    c. Age: Must be 18 years old or over.
        i. Children diagnosed with sickle cell disease are covered under the CRS policy up to the last day of the month of their 18th birthday.
    d. Income:
        i. Must have a household income at or below 250% of the federal poverty level with or without private insurance (Appendix 15) in accordance with the Financial Assistance Services Overview policy.
        ii. Must not be currently eligible for Medicaid or a Medicaid HMO. Exception: May have Family Planning Medicaid only.
    e. Clinical: Medical (physician, physician assistant, or advanced practice registered nurse) documentation of diagnosed sickle cell disease and corresponding ICD code.

2. For adults approved for financial assistance and the sickle cell allotment program, see Appendix 15 for eligibility and allotment guidelines.

3. For adults approved for health insurance sourcing, coverage will include premium assistance, copay assistance (deductible, copayment, and/or coinsurance), and ancillary services.

    a. Health insurance coverage will be for up to 3 years if the individual remains eligible through the CYSHCN program. At the end of 3 years, the individual will cycle off the premium/copay assistance program and may be offered payment services through an allotment program. This will allow other eligible individuals the opportunity to receive premium assistance.

    b. Eligibility for premium/copay assistance will be re-assessed annually or with availability of funds.

4. Record Updates:

    a. Document via 'CYSHCN Note' (DPH 1619A) care coordination contacts (and attempted contacts) with client according to the client's acuity level and as needed.

    b. CYSHCN annual eligibility updates will be completed **every September** regardless of the client's approval date. This ensures all Adult Sickle Cell clients are on the same cycle should there be an opening for premium/copay assistance. Notify the CYSHCN Central Office (CO) Nurse Coordinator when the annual update is completed.

    c. Acuity levels (Appendix 16) will be reviewed at least annually and amended as needed.

    d. Transition services may be provided when indicated in accordance with the Transition Planning policy.

    e. To ensure client's continued eligibility, Medicaid eligibility will be checked every three (3) months from the application date.

    f. Close the record and remove from caseload in accordance with the Documentation and Quality Assurance policy. Notify CYSHCN CO Nurse Coordinator of closures.

5. Document in the Electronic Health Record (EHR).

    a. All health record documentation is entered into the EHR.

    b. If the EHR system experiences a system interruption, then follow the EHR Downtime policy.

        i. References in this policy to DPH paper forms are provided for guidance during EHR downtime.

C. PROCEDURES

1. Referring Provider Responsibilities:
    a. For persons not currently enrolled in CYSHCN Adult Sickle Cell Services, referring provider will send the CYSHCN Services Request Form (DPH 4290) with supporting documentation (Standard 1.e clinical eligibility criteria) to the CYSHCN Regional Office.
    b. Upon enrollment to the allotment program, the provider submits written requests for services (including description of services requested, corresponding procedure code(s), and estimated cost) to the CYSHCN Regional Office.
        i. Contact the CYSHCN Regional Office at least two (2) weeks prior to medical/lab appointments and 72 hours before pharmacy refills to ensure timely approval.
        ii. Requests must be received and authorized prior to the date of service. Non-authorized services are not covered.
        iii. The 'Adult Sickle Cell Services Authorization Request Form' (DPH 4507) may be used as a services request template, or the services request may be documented via the provider's own template.
2. CYSHCN Regional Office Responsibilities:
    a. Create an electronic health record if indicated.
    b. Verify that applicant meets Adult Sickle Cell Services enrollment requirements, per Standard 1.
    c. Obtain agency and program required consents, including 'General Consent for Health Services' (DPH 0788), 'Authorization to Release Health Information' (DPH 1623), and 'CYSHCN Client/Family Responsibilities' (DPH 3150).
        i. The 'Client Responsibilities Agreement for Insurance Premium Assistance' (DPH 4514) is required only if and when the applicant is approved for insurance premium assistance services.
    d. Complete intake application, including the following EHR Ad Hoc Forms: 'CYSHCN Intake & Assessment' (DPH 4384), 'CYSHCN Eligibility Determination' (DPH 4501), and 'CYSHCN Sickle Cell Disease Health Assessment' (DPH 4012). 'CYSHCN Note' (DPH 1619A) will include summary of applicant's clinical history and reasons for applying to the program (ex. lost Medicaid).
    e. Send completed application to CYSHCN Central Office (CO) Nurse Coordinator for review and determination (approval or denial).
        i. Eligible individuals will be enrolled in the allotment program for financial assistance or referred to an external vendor for insurance premium assistance and copay assistance.
    f. Upon application determination (approval or denial) by the CYSHCN CO Nurse Coordinator (or designee):
        i. CYSHCN Regional Nurse Unit Manager (or designee) will review the CO determination and review the intake application and then complete a 'CYSHCN Referral Disposition' Ad Hoc Form (DPH 4503).

ii. CYSHCN Regional Office will notify applicant and referring provider of enrollment approval or denial.

1. If approved, mail the 'CYSHCN Sickle Cell Allotment Approval' or the 'CYSHCN Premium Assistance Approval' letter (as indicated), which is generated and uploaded in the client's record by the CYSHCN CO Nurse Coordinator.

    a. If approved for premium assistance, obtain and file the program required consent: 'Client Responsibilities Agreement for Insurance Premium Assistance' (DPH 4514).

2. If denied, mail the 'CYSHCN Sickle Cell Program Denial' letter, which is generated and uploaded in the client's record by the CYSHCN CO Nurse Coordinator. Include with the denial letter a copy of the Community Based Organizations (CBO) Service Area resource listing.

    a. All Adult Sickle Cell program denials due to funding limitations will be held by the CYSHCN CO Nurse Coordinator and if/when additional funding is made available, applications will be reviewed based on the order of original receipt.

g. Upon enrollment for all Adult Sickle Cell services clients, the assigned CYSHCN Care Coordinator (or designee) will:

i. Document via 'CYSHCN Note' (DPH 1619A) care coordination contacts (and attempted contacts) with client according to the client's acuity level and as needed.

ii. Check Medicaid eligibility in CARES every three (3) months from application date. If Medicaid eligible, document a 'CYSHCN Note' (DPH 1619A) in the client's record and notify the CO Nurse Coordinator.

iii. Complete annual updates **every September** for all Adult Sickle Cell clients regardless of the client's approval date to ensure all clients are on the same cycle should there be an opening for premium/copay assistance. Notify CYSHCN CO Nurse Coordinator when annual update is completed.

1. Use of DPH EHR Ad Hoc Forms: 'CYSHCN Intake & Assessment' (DPH 4384), 'CYSHCN Eligibility Determination' (DPH 4501), and 'CYSHCN Sickle Cell Disease Health Assessment' (DPH 4012) are the minimal forms needed to ensure annual update is complete.

2. At time of annual update, request an updated medical note dated within the preceding year from the client's sickle cell provider and upload to the client's record if/when received.

3. Minimum contact attempts for annual update will follow those for routine matters as per the Overview and Definitions policy to include at least three (3) documented attempts to communicate with the client, one (1) of which must be a letter to the last known mailing address (unless mailing is noted as prohibited in the

client's record). The 'CYSHCN Annual Eligibility' letter (with corresponding 'Annual Eligibility Update Worksheet' and 'Update Questionnaire') may be used to communicate the need for annual update.

a. If no response after two (2) documented phone calls and 'CYSHCN Annual Eligibility' letter, mail 'CYSHCN Final Notice' letter. Allow a minimum of two (2) weeks for client response to letter(s).

4. For clients not responsive to above-stated contact attempts for annual updates and before possible client closure to the program, CYSHCN CO Nurse Coordinator will notify CYSHCN Regional Offices of wait list status for program enrollment.

a. If there is a wait list, close client to the program if no response to 'CYSHCN Final Notice' letter after two (2) weeks. Prior to closing client, consult with CYSHCN CO Nurse Coordinator.

b. If there is not a wait list, the final deadline for completion of annual updates is **November 15th**.

i. Clients will remain open to the program during this time.

ii. No authorizations (allotment clients) will be created and issued until the annual update is completed.

iii. Further contact attempts may cease during this period.

iv. If the annual update is not completed by November 15th: Close client to the program and remove from caseload in accordance with the Documentation and Quality Assurance policy. Notify the CYSHCN CO Nurse Coordinator when client is closed to Adult Sickle Cell Services.

1. For clients closed to premium/copay assistance, their insurance will expire after December 31st. Notify the CYSHCN CO Nurse Coordinator of client closure.

c. If the annual update is completed by November 15th, program enrollment will continue uninterrupted.

iv. Review acuity levels (Appendix 16) at least annually and amend as needed.

v. Provide transition services when indicated in accordance with the Transition Planning policy.

vi. Close the record and remove from caseload in accordance with the Documentation and Quality Assurance policy. At closure, document DPH EHR Ad Hoc Forms 'CYSHCN Closure' (DPH 4500) and 'CYSHCN Eligibility Determination' (DPH 4501) and document a CYSHCN Note (DPH 1619A), which includes reason for closure. Mail closure letter to

client and provider. Notify CYSHCN CO Nurse Coordinator when client is closed to Adult Sickle Cell Services.

h. For Adult Sickle Cell allotment clients only, the assigned CYSHCN Care Coordinator (or designee) will:

i. Receive written requests for services (including description of services requested, corresponding procedure code(s), and estimated cost) from the client's sickle cell provider.

1. The sickle cell provider may use the 'Adult Sickle Cell Services Authorization Request Form' (DPH 4507) as a services request template, or the provider may use their own template.

2. Exception: Adult Sickle Cell clients may call the Regional CYSHCN Office to verbally request authorization for prescription copayment. The client should provide the name of the medication(s), the name and location of the pharmacy, and (if known) the estimated cost. The Care Coordinator (or designee) will call the pharmacy to confirm the prescription is received and the cost.

3. Requests for services should be submitted to the CYSHCN Regional Office by the provider or client at least two (2) weeks prior to medical/lab appointments and 72 hours before pharmacy refills to ensure timely approval.

4. Requests must be received and authorized prior to the date of service. Non-authorized services are not covered.

ii. Complete the 'CYSHCN Adult Sickle Cell Services Request' Ad Hoc form (DPH 3960) and submit to the CYSHCN CO Nurse Coordinator for approval.

iii. Upon approval by the CYSHCN CO Nurse Coordinator, issue authorization(s) for covered services per policy and per Appendix 15.

3. CYSHCN Central Office (CO) Nurse Coordinator responsibilities:

a. Review applications for Adult Sickle Cell services.

b. Seek approval from the CYSHCN CO Section Director (or designee) to determine:

i. If applicant appropriately meets program enrollment criteria, and

ii. If space/funds are available to cover the addition of the applicant to the program.

1. If there is not available space/funding, inform CYSHCN Regional Office to notify the applicant and provider of wait list status. Add applicant to the program's wait list as indicated. When space/funding becomes available, review wait list in order of original receipt and notify CYSHCN Regional Office to proceed with intake as indicated.

c. Once the type of assistance is determined (allotment or premium/copay assistance), document application approval or denial in the applicant's electronic health record via a 'CYSHCN Adult Sickle Cell Program Enrollment Disposition' Ad Hoc Form (DPH 4499), corresponding 'CYSHCN Note' (DPH 1619A), and the

appropriate letter ('CYSHCN Sickle Cell Allotment Approval,' 'CYSHCN Premium Assistance Approval,' or 'CYSHCN Sickle Cell Program Denial' letter). Notify the Regional Care Coordinator and Nurse Unit Manager.

i. Include with the denial letter a copy of the Community Based Organizations (CBO) Service Area resource listing.

ii. If approved for premium assistance, CYSHCN Regional Office will obtain and file the program required consent: 'Client Responsibilities Agreement for Insurance Premium Assistance' (DPH 4514).

d. For applicants approved for premium/copay assistance, complete the referral and send to the vendor. The vendor will directly contact the client regarding insurance coverage. Clients referred for premium/copay assistance will follow the instructions of the outsourcing vendor.

e. For enrolled clients receiving premium/copay assistance, document via 'CYSHCN Note' (DPH 1619A) care coordination contacts (and attempted contacts) with the client following the vendor's request or need for follow-up.

f. Notify the vendor of any closures to Adult Sickle Cell premium assistance.

g. For enrolled clients receiving allotment assistance, review regional requests for payment assistance via the 'CYSHCN Adult Sickle Cell Services Request' Ad Hoc Form (DPH 3960). Document approval or denial via the 'CYSHCN Adult Sickle Cell Services Disposition' Ad Hoc Form (DPH 4498) and corresponding 'CYSHCN Note' (DPH 1619A). Notify the Regional Care Coordinator.

h. Track, log, and reconcile Adult Sickle Cell program's wait list, requests, allotment expenditures, and premium assistance caseload for the CYSHCN Section.

D. DATE OF APPROVAL/REVISION

Approved: 4/1/2011
Revision Dates: 9/10/2018, 2/6/2023
Revisions 1/2/2026:

- Title: Added "Adult."
- Added disclaimer of contract of employment.
- Transferred from Department of Health and Environmental Control (DHEC) to DPH.
- Revised throughout to reflect current EHR processes.
- Policy Statement: Changed "physician diagnosed" to "medically diagnosed."
- Standard 1.c.: Revised for clarity (no content change).
- Standard 1.d: Added reference to Appendix 15 Sickle Cell Eligible Adult Services.
- Standard 1.e.: Expanded to include diagnosis by PA or APRN. Added "and corresponding ICD code."
- Standard 2 and 4 added.
- Standard 3 expanded for clarity.
- Previous Section C: Covered Services deleted due to content incorporated in Standards 1 and 3.
- Procedures: Broken out by responsible party (referring provider, CYSHCN Regional Office, and CYSHCN CO Nurse Coordinator). Expanded to capture current processes.