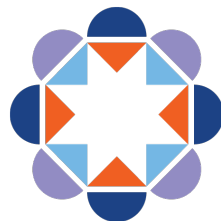


Advisory Council

On Financing & Access to Sickle Cell
Disease Treatment & Other
High-Cost Drugs & Treatment

September 24, 2024



HFS

Illinois Department of
Healthcare and Family Services



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Illinois Department of
Healthcare and Family Services

OUR VISION FOR THE FUTURE

We improve lives.

- ▶ We address social and structural determinants of health.
- ▶ We empower customers to maximize their health and well being.
- ▶ We provide consistent, responsive service to our colleagues and customers.
- ▶ We make equity the foundation of everything we do.

This is possible because:

- ▶ **We value our staff as our greatest asset.**

We do this by:

Fully staffing a diverse workforce whose skills and experiences strengthen HFS.

Ensuring all staff and systems work together.

Maintaining a positive workplace where strong teams contribute, grow and stay.

Providing exceptional training programs that develop and support all employees.

- ▶ **We are always improving.**

We do this by:

Having specific and measurable goals and using analytics to improve outcomes.

Using technology and interagency collaboration to maximize efficiency and impact.

Learning from successes and failures.

- ▶ **We inspire public confidence.**

We do this by:

Using research and analytics to drive policy and shape legislative initiatives.

Clearly communicating the impacts of our work.

Being responsible stewards of public resources.

Staying focused on our goals.



Agenda

Presenter: Director Whitehorn



Summary of Agenda

Presenter:
Lizzy Whitehorn, Director

- I. Call to Order
- II. Housekeeping
- III. Roll Call of Advisory Council Members
- IV. Introduction of HFS Staff
- V. Review and Approval of Meeting Minutes
- VI. Live Poll: Recommendations for Improving Access to Cell and Gene Therapies and Other High-Cost Drugs
- VII. Improving Access to CGTs Wrap-Up Discussion
- VIII. Next Steps
- IX. Public Comments
- X. New Business
- XI. Announcements
- XII. Adjournment



II.

Housekeeping

Presenter: Melishia Bansa



Comments or questions
during the meeting

Housekeeping

- Please note, this meeting is being recorded.
- To ensure accurate records, please type your name and organization into the chat.
- If possible, members are asked to attend meetings with their cameras turned on, however, if you call in & need materials, please email Melishia.Bansa@Illinois.gov as soon as safely possible.
- Please be sure to mute your audio except when speaking.
- Please note that HFS staff may mute participants to minimize any type of disruptive noise or feedback.

Meeting Basics

Housekeeping

- If you are an Advisory Council member and wish to make a comment or ask a question during the meeting, please use the WebEx feature to raise your hand, contact the host/co-host, or unmute yourself during QA sections facilitated by chair.
- Please state your full name when asking a question or passing a motion.
- If you are a member of the general public and wish to make a comment, please register to make a public comment prior to the meeting. Instructions to make public comments have been provided for you in the public meeting posting located on the HFS Boards and Commissions website.
- If you have a question during the meeting, please utilize the Webex chat feature to send your question directly to the host or co-host.

Meeting Basics

Housekeeping

- HFS is committed to hosting meetings that are accessible and ADA compliant. Closed captioning will be provided. Please email Melishia.Bansa@Illinois.gov in advance to report any requests or accommodations you may require or use the chat to alert me of challenges you may have encountered during the meeting.
- Patience, please – many meeting attendees may be new to these advisory council proceedings.
- After today's meeting, meeting minutes will be circulated to Committee members in advance of the next meeting. Once approved, they will be posted to the website along with today's presentation deck.



III.

Roll Call of Advisory Council Members

Presenter: Melishia Bansa



Advisory Council Representation

Lizzy Whitehorn

Illinois Department of Healthcare and Family Services (state Medicaid agency)

Joan Ehrhardt

Illinois Department of Public Health

Adam Flores

Illinois Department of Insurance

Theodore (Ted) Tapas

Governor's Office of Management and Budget

Beverly Chukwudozie

Persons with lived experience as a person with sickle cell disease

Alexandra Carpenter

Persons with lived experience as a person with a condition requiring access to new, innovative drugs or treatment

Dr. James LaBelle

Providers treating sickle cell disease patients

TaLana Hughes

Sickle cell disease advocacy organization

Nathan Schaefer

Advocacy organization for a condition(s) requiring access to new, innovative drugs and treatment

Steve Sproat,

Brian Smolich

Health insurance industry

George Kitchens,

Susan Stuard

Experts in prescription drug rebate negotiations and outcomes-based agreements

Melissa Creary,

Rachel Sachs

Experts with published research in financing new, innovative drugs and treatments within public health insurance programs

Dr. Anirban Basu,

Rena Conti

Experts with health economist or actuarial backgrounds

Dr. Radhika Peddinti,

Mark Trusheim

Members who may or may not meet the qualification requirements for the other appointees.

Dr. Ruchika Goel

Providers treating patients with another condition requiring access to new, innovative drugs or treatment



IV.

Introduction of HFS Staff

Presenter: Melishia Bansa





V.

Review and Approval of Meeting Minutes

Presenter: Melishia Bansa





VII. Recommendations Discussion:

Access and Public Health and Provider
Partnership Opportunities // Improving
Access to CGT

Presenter: Director Whitehorn



Survey Responders

Advisory Council members will participate in the following discussion and survey responses.

- Alexandra Carpenter
- Joan Ehrhardt
- Adam Flores
- Beverly Chukwudozie
- Theodore (Ted) Tapas
- Dr. James LaBelle
- TaLana Hughes
- Nathan Schaefer
- Steve Sproat
- Brian Smolich
- George Kitchens
- Susan Stuard
- Dr. Anirban Basu
- Melissa Creary
- Dr. Radhika Peddinti
- Rachel Sachs
- Dr. Rena Conti
- Mark Trusheim
- Dr. Ruchika Goel

Joining the Survey

Slido.com



Join at
Slido.com
#9884 021

OR



Enter passcode **sickle24** and full name

Only the Advisory Council Members are invited to the live survey.
Results from each vote will be shown live.

Access Pressure Points Overview

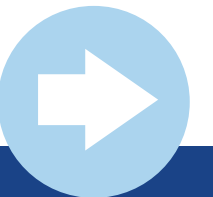
Advisory Council members have previously highlighted access pressure points including:

+ Health Insurance Coverage

- + Potential gaps in continuity of care through coverage transitions
- + Inconsistent prior authorization and utilization management criteria
- + Coverage for services and medications/coverage denials

+ Provider Capacity

- + Geographic distance to care
- + Infrastructure and resources
- + Culturally competent care
- + Hospital Finance



Access Pressure Points Overview

Advisory Council members have previously highlighted access pressure points including:

Patient Needs

- + Care coordination
- + Logistical: Lodging, Transportation, Childcare, Parking
- + Dental care for immunocompromised patients
- + Chronic pain management
- + Changing needs based on patient life stage
- + Long and complex treatments making adherence challenging
- + Inability to take off work for appointment
- + Patient education/genetic counseling
- + Fertility counseling/fertility services



Access Pressure Points Overview

Health Insurance Coverage

- † Potential gaps in continuity of care through coverage transitions
- † Inconsistent prior authorization and utilization management criteria
- † Coverage for services and medications/coverage denials

Provider Capacity

- † Geographic distance to care
- † Infrastructure and resources
- † Culturally competent care
- † Hospital Finance

Patient Needs

- † Care coordination
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Access Pressure Points

Are there any other access pressure points we have not captured?



Medicaid Coverage



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Presenter: Helena Lefkow

Illinois Medicaid Overview

HFS operates as
Illinois' single
oversight
authority of
Medicaid

⊕ Managed Care

- | Manages care of 80% state's Medicaid population.
- | Five (5) contracted MCOs
 - Four (4) operate statewide.
 - Fifth owned by a county-owned health system, operating only in that county: Cook County, which includes Chicago.

Access Levers

Illinois has several tools to enhance recipient access



Preferred Drug List

HFS operates its own PDL which governs preferred drug status.

- This applies to MCOs and fee-for-service



MCO Contract

Establishes standards for what MCOs can and cannot do to approve medical benefits, largely requiring any criteria for prior authorization for services to be clinically sound.



Single Case Agreement

Allows hospitals and MCOs to come to agreeable terms outside of standard contract terms.

Uniform Criteria

Should HFS consider uniform criteria across managed care for the approval of cell and gene therapies (CGT) and other high-cost drugs?

- Yes, for CGT only
- Yes, for CGT; yes to high-cost drugs, although framework will depend on disease state
- Yes, broadly to both
- No
- Sometimes/other [describe in chat]

Implementing Uniform Criteria

What policies should HFS consider to implement uniform criteria:

- Standardized Single Case Agreement parameters for cell and gene therapies and other high-cost drugs
- Model MCO Contract
- HFS Policy & Procedure governing MCO activities
- Something else [explain in chat]



Patient Needs

Presenter: Helena Lefkow



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Care Management in Illinois

MCOs must offer care coordination when membership are:

- + Stratified moderate/high risk
- + Pregnant
- + Residing in nursing facility
- + Dually eligible for Medicare and Medicaid
- + Receiving home and community-based waiver services
- + Proactively requesting such services

How MCOs Stratify Clinical Risk

Illinois MCO contracts set minimum thresholds for risk-levels across enrolled population, and set expectations for care coordination service levels:

Risk
Level

Low

MCO provides prevention and wellness messaging and condition-specific education materials, at a minimum

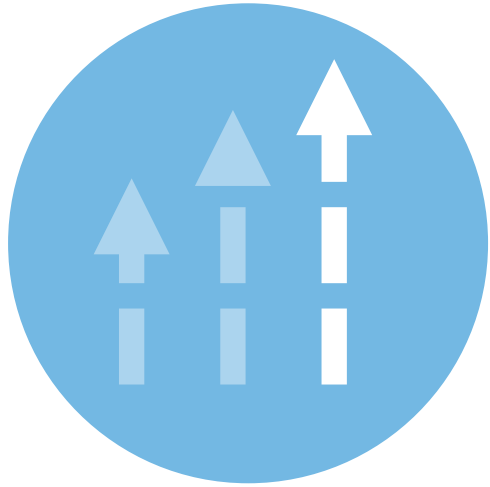
Moderate

MCO provides problem-solving interventions

High

MCO provides intensive Care Management to address acute and chronic health needs, behavioral health needs, and social support needs





How MCOs Stratify Clinical Risk

MCOs use a variety of data sources to establish each member's clinical risk profile (incl. results from Health Risk Assessment (HRA), historical claims data, and predictive modeling).

Initial strat. required 15 days of enrollment.

MCOs are required to conduct HRAs for moderate and high-risk enrollees w/in 90 days.

MCOs must update the enrollee's risk stratification when there is a change in their health status

Care Management

MCOs should stratify individuals with sickle cell disease and other rare diseases as high-risk (mark all that apply):

- Upon diagnosis
- Once treatment plan is established
- As treatment plan compliance has been confirmed
- When approved for cell and gene therapy
- For up to one year after cell and gene therapy has been performed
- Other: put in chat

Unique Care Management Services

Are there unique care management services that Medicaid MCOs should provide that would be helpful for individuals living with sickle cell and other rare diseases and/or undergoing these treatments?

Incentivizing Better Care Coordination

What else can HFS do to incentivize better care coordination for cell and gene therapy patients enrolled in Medicaid?

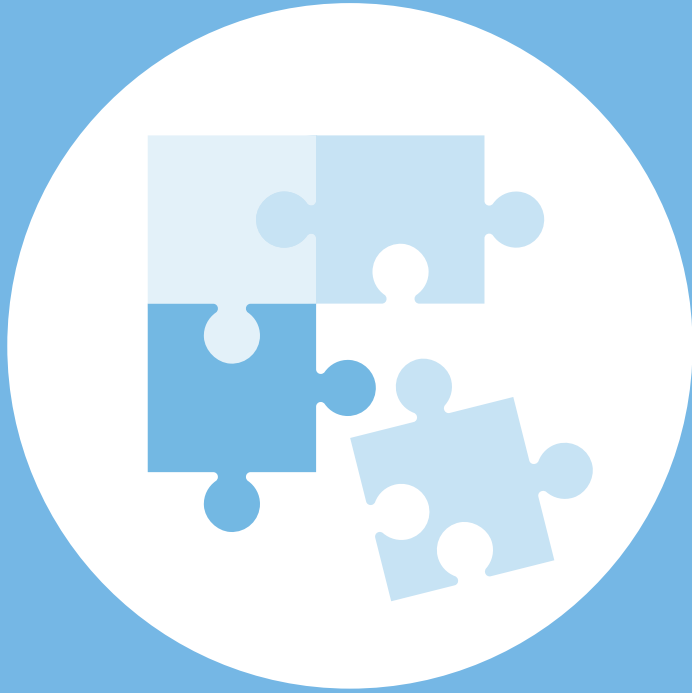
Additional Financial Resources

Have other states been successful in obtaining resources to support other patient health needs, like lodging, childcare, or other benefits outside of the traditional Medicaid benefit package?

- Federal match through an 1115 waivers for lodging, childcare, medical respite
- Federal match through a sickle cell disease State Plan Amendment
- Private foundation dollars
- Other

Supporting Provider Capacity

Are there any other changes in Medicaid policy HFS can make to improve access to providers in central and southern Illinois (more rural areas) for Medicaid customers with rare diseases?



Provider Capacity



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Provider Support

How can HFS support providers as they grow capacity to provide these new drugs and treatments while maximizing access for Medicaid customers?

- Infrastructure dollars
- Drugs carved out of DRGs
- A streamline single case agreement process across Medicaid MCOs
- Require MCOs to place these services in their standard contracts for these provider types
- Other put in chat



Other Related Issues



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Culturally Competent Care

What can HFS do to support culturally competent care for Medicaid customers, such as enhanced provider education around chronic pain for those living with sickle cell disease?

Impact of Employer and Private Health Insurance Coverage on Medicaid Costs

News articles have described self-insured plans excluding coverage for cell and gene therapies and high-cost drugs, leaving Medicaid to be the primary payer. How can the state address this challenge?

- Consider a publicly funded coverage pool
- Review state regulatory options for private and employer plans
- Other: Describe in chat

State Implementation Resources

What resources would HFS need to implement the recommendations discussed during council meetings?

- Specific staff positions or skillsets (provide details in chat)
- Specific staffing structures (provide details in chat)
- Specific consulting support (provide details in chat)
- Other

Federal Recommendations

Are there any federal policy solutions you recommend the State of Illinois advocate for?

- New national drug benefit: coverage outside of the MDRP
- Increased FMAP for a specific set of high-cost therapies
- Other (describe in chat)



VIII.

Next Steps

Presenter: Director Whitehorn



— Advisory Council: Looking Ahead —→

📍 Report Review & Submission

September

**Post Meeting
Surveys**

October 4th

**Outline for
Report to Council**

October 11th

**Feedback template
due to report writer**

November 13th

**First Draft of
Report to Council**

November 27th

**Feedback template
due to report writer**

Week of December 9th

**Final Council
Meeting to Vote on
Report.**

By December 31st

**Report Submitted Officially
to the Governor and Illinois
General Assembly**



IX.

Public Comments

Presenter: Melishia Bansa



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Public Comments

Name	Title	Org	Comment
Jessica Lynch	Director, State Policy	PhRMA	Written comment submitted for agency to review





X.

New Business

Presenter: Director Whitehorn





XI.

Announcements

Presenter: Melishia Bansa



Mandatory Ethics Trainings Reminder Email

All appointees must complete the following trainings on OneNet:

- 1 Security Awareness Training 2024
- 2 Diversity, Equity, Inclusion and Accessibility Training 2024
- 3 LGBTQIA+ Equity and Inclusion 2024
- 4 Ethics Training Program for State Employees and Appointees 2024
- 5 Harassment and Discrimination Prevention Training 2024
- 6 HIPAA & Privacy Training 2024

You can access the trainings at the following link: <http://onenet.illinois.gov/mytraining>

Please see attached memo for additional details. Please complete the trainings through OneNet no later than December 13, 2024. If anyone has any issues logging into OneNet, please email HFS.BureauofTraining@Illinois.gov



Advisory Council Operational Reminders

<https://hfs.illinois.gov/about/boardsandcommisions.html>

Advisory Council Meeting Resources:

[Boards and Commissions | HFS \(illinois.gov\)](#)

- + Executive Order
- + Members
- + Bylaws
- + Meeting Schedule
- + Meeting Presentation Deck
- + Meeting Notice: Public Meeting Postings & Agendas

[Resources Tab](#)

<https://hfs.illinois.gov/about/boardsandcommisions/advcouncilofaatoscdaohcdt/sickle-cell-resources.html>





XII.

Adjournment

Presenter: Director Whitehorn



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