

The National Center for a System of Services for CYSHCN

*Title V Virtual Café
Ask the Experts: Transition NPM*

Friday May 17th, 2024, 12-1pm CT/1-2pm ET

The National Center for a System of Services for CYSHCN is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$1,500,000 with no funding from nongovernmental sources. The information or content are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.



National Center for a
System of Services for
Children and Youth
with special health care needs

Connecting systems so CYSHCN & their families thrive

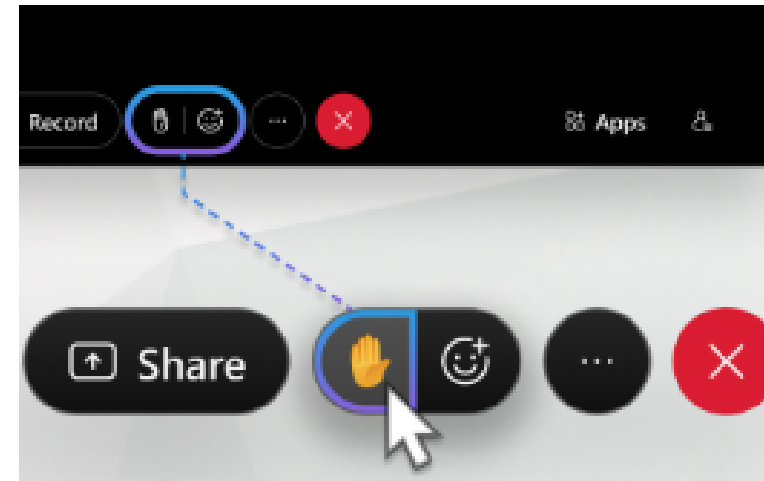
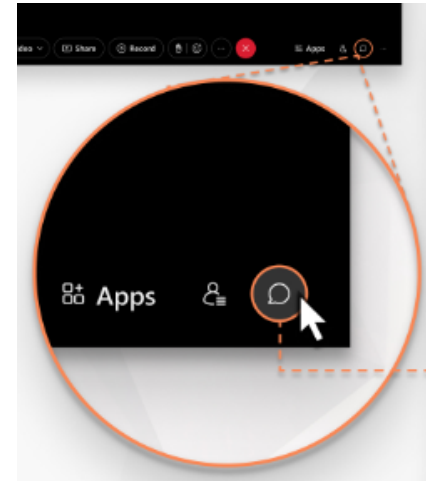
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HOUSEKEEPING

- The didactic presentation will be recorded; peer discussion will not be recorded
- All participants have been muted
- Utilize chat box to share comments, questions, or relevant resources
- Utilize hand raising feature during discussion portion
- Rename yourself to include your name and state/jurisdiction
- Direct chat AAP staff with technical issues



AGENDA

1. Introduction to the Blueprint National Center and Virtual Café
2. Overview of NPM 12 – Health Care Transition (HCT)
3. Blueprint Critical Areas and Sample HCT Strategies
4. Got Transition resources for state/jurisdiction Title V
5. Spotlights: Georgia, Rhode Island, and Minnesota
6. Discussion and Q&A
7. Evaluation Survey



BLUEPRINT FOR CHANGE

- A National Framework for a System of Services for CYSHCN
 - Federal vision to advance the system of services for CYSHCN over the next 15 years.
 - Four critical areas: health equity, quality of life/well-being, financing, access
 - **Blueprint goal in plain language:** Every child gets the services they need, so that they can play, go to school, and grow up to become a healthy adult. (And so grown-ups and siblings can thrive too.)
 - Focuses on **measuring what matters to families**



THE BLUEPRINT NATIONAL CENTER



Goal: To advance and strengthen the system of services for CYSHCN and their families/caregivers at the community, state, and national levels by leading the field to promote health care and other supports that are integrated, family-centered, evidence-informed, and culturally responsive.

What We Do



One-on-one
technical assistance



Tools



Training



Strategies



Connections to
peers and experts

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Ask the Experts: **Transition NPM**

Presented by Got Transition

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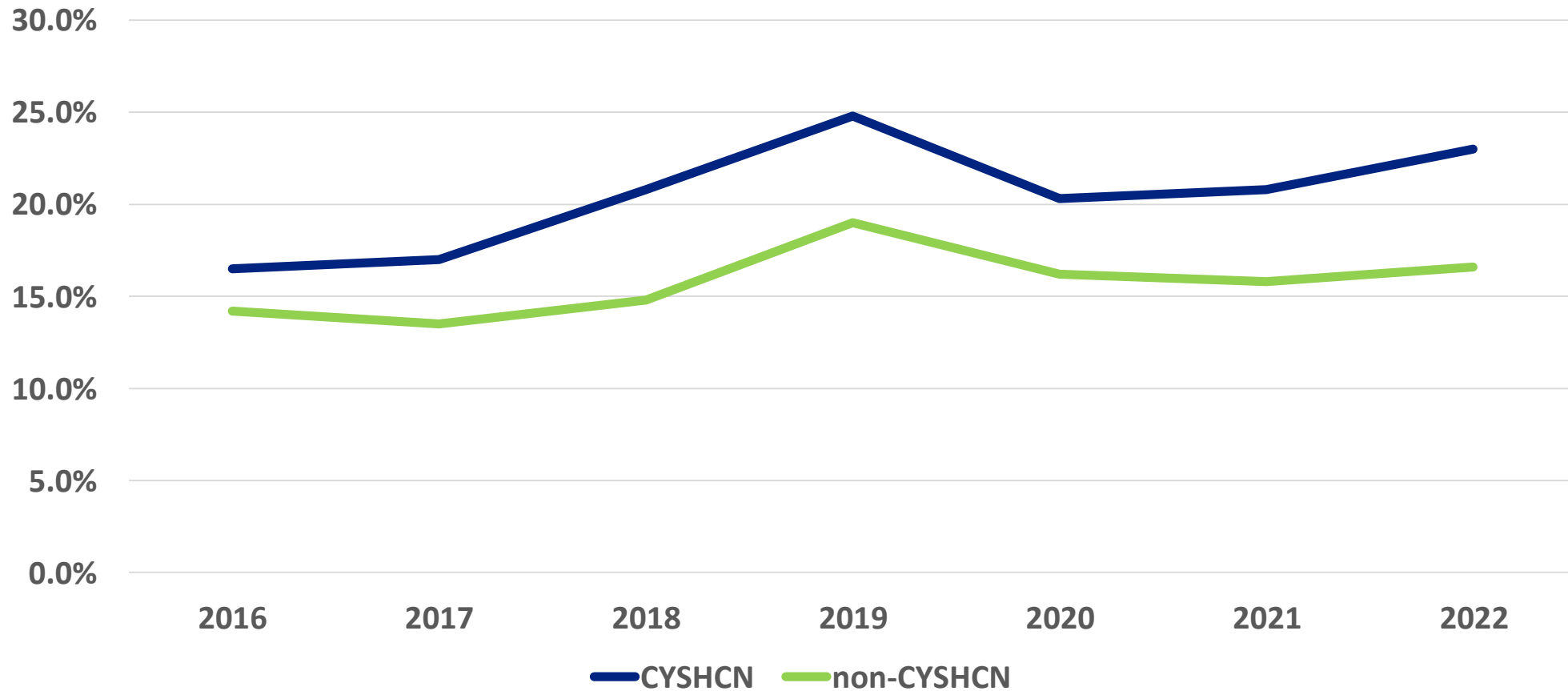


NPM 12 OVERVIEW

- The National Survey of Children's Health (NSCH) is an annual, parent-reported survey
- The NSCH uses **3 questions** to measure the percent of adolescents (with and without SHCN), ages 12-17, who received services to prepare for the transition to adult health care:
 1. At your child's last medical care visit, did they have a chance to speak with a doctor or other health care provider privately, without you or another caregiver in the room?
 2. Has your child's doctor talked with you about when they will need to see doctors or other health care providers who treat adults?
 3. Has this child's doctor or other health care provider actively worked with this child to:
 - a) Gain skills to manage their health and health care
 - b) Understand the changes in health care that happen at age 18



Receipt of services to prepare for the transition to adult health care over time, 2016-2022

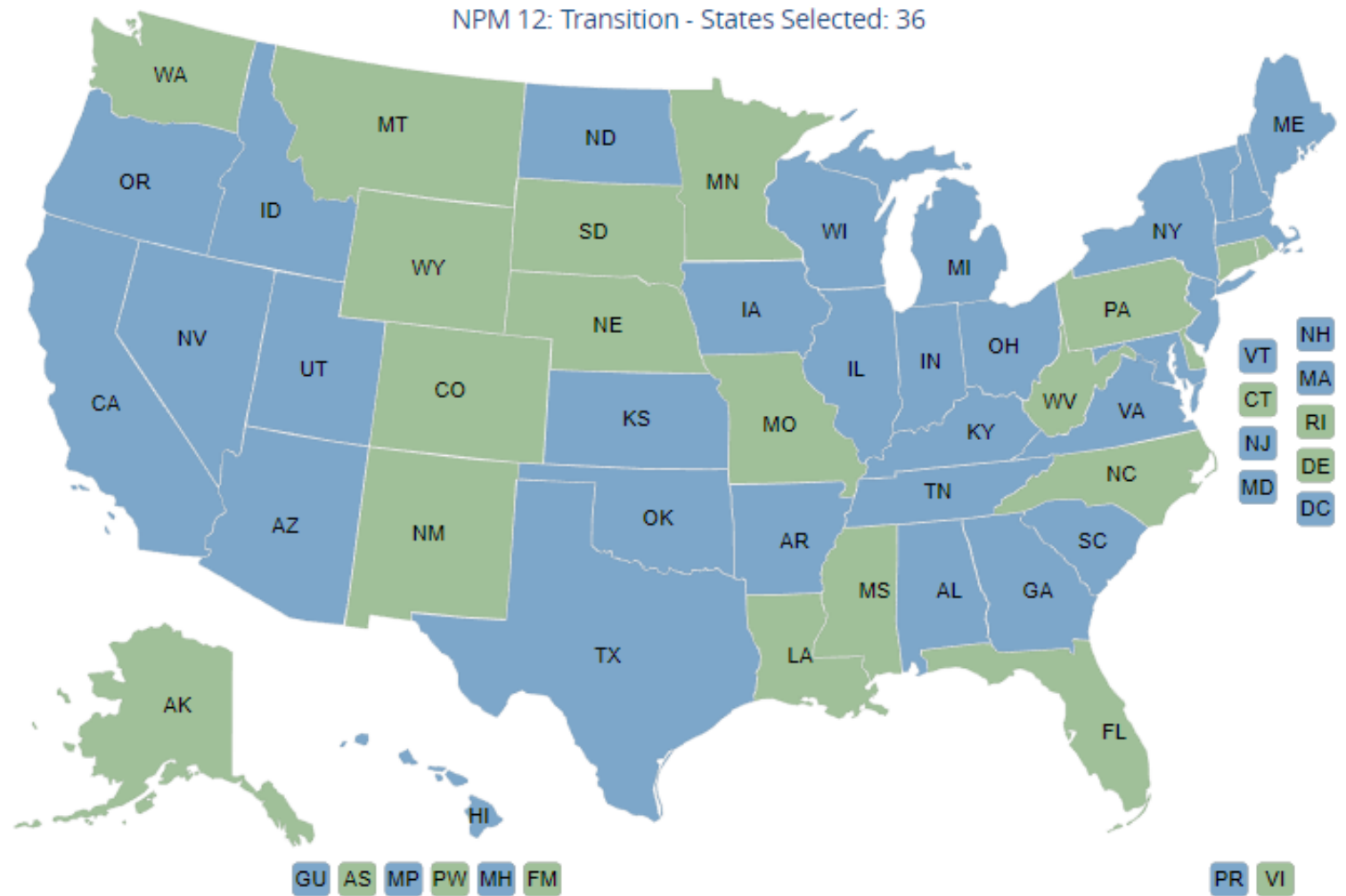


HCT PERFORMANCE FROM 2021-2022 NSCH

- 22.1% received HCT preparation from health care providers (HCPs)
 - 51.9% had time alone
 - 66.1% actively worked with HCPs to gain skills to manage health and health care
 - 33.9% worked with HCPs to understand health care change at age 18
 - 24.0% discussed shift to HCPs treating adults



STATES/JURISDICTIONS SELECTING NPM 12 AS A PRIORITY (BLUE)



States that selected the specified measure are highlighted in blue.

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NPM 12 DATA IN THE LITERATURE

- Only 1 in 5 CYSHCN receive care in a well-functioning system, “with the most opportunity for improvement for the medical home and adolescent transition to adult care.”
 - [Source: Ghandour et al 2022](#)
- HCT preparation is positively associated with receipt of the combined components of a system of care (i.e., medical home, continuous screening, medical home, adequate health insurance, family partnership, and access to community-based services)
 - [Source: Ilango et al 2021](#)



ADDITIONAL ITEMS TO MEASURE HCT IN NSCH

- **Not** part of HCT composite measure, but available for use:
- 73.1% YSHCN received a summary of their medical history
- 40.3% YSHCN has a plan of care to meet their health goals and needs
- 29.4% YSHCN plan of care addresses transition to adult HCP
- 49.3% HCP discussed children's health insurance coverage moving into adulthood



NSCH LONGITUDINAL COHORT & HCT QUESTIONS

- Data expected 4/2025
- Follow-up survey with parent/caregiver (previously surveyed) of young adults up to age 24.
- HCT questions:
 - Since turning 18, has X made the transfer to a PCP who treats adults?
 - If yes, how satisfied were you with the HCP's help to transfer X to adult care?
 - How confident were you that X was prepared to move to a PCP who treats adults?



NSCH LONGITUDINAL SURVEY - MORE

- Did you or this person receive a summary of their medical history?
- Has a HCP talked with you or X about the process of transferring to adult care?
- Have any of X's HCPs helped with finding a new PCP who treats adults?



BLUEPRINT CRITICAL AREAS AND SAMPLE HCT ACTIVITY IDEAS



BLUEPRINT CRITICAL AREAS AND SAMPLE HCT ACTIVITY IDEAS:

EQUITY

- Collect and share data on disparities in receipt of HCT support. Convene conversations with communities that experience disparities to better understand their perspectives (for example: those who are male, without a medical home, without insurance, Asian/Pacific Islanders, households with high school education only)



BLUEPRINT CRITICAL AREAS AND SAMPLE HCT ACTIVITY IDEAS: WELL-BEING AND QUALITY OF LIFE

- Partner with Family Voices, community-based organizations, care coordination programs, and state interagency groups to inform and prepare youth and young adults with SHCN and families about ending of childhood eligibility and options for insurance coverage, SSI, and disability programs as an adult.



BLUEPRINT CRITICAL AREAS AND SAMPLE HCT ACTIVITY IDEAS:

FINANCING

- Coordinate with Medicaid and Family Voices to identify and provide outreach and referrals to youth and young adults with SHCN who have lost Medicaid coverage following the ending of the public health emergency



BLUEPRINT CRITICAL AREAS AND SAMPLE HCT ACTIVITY IDEAS:

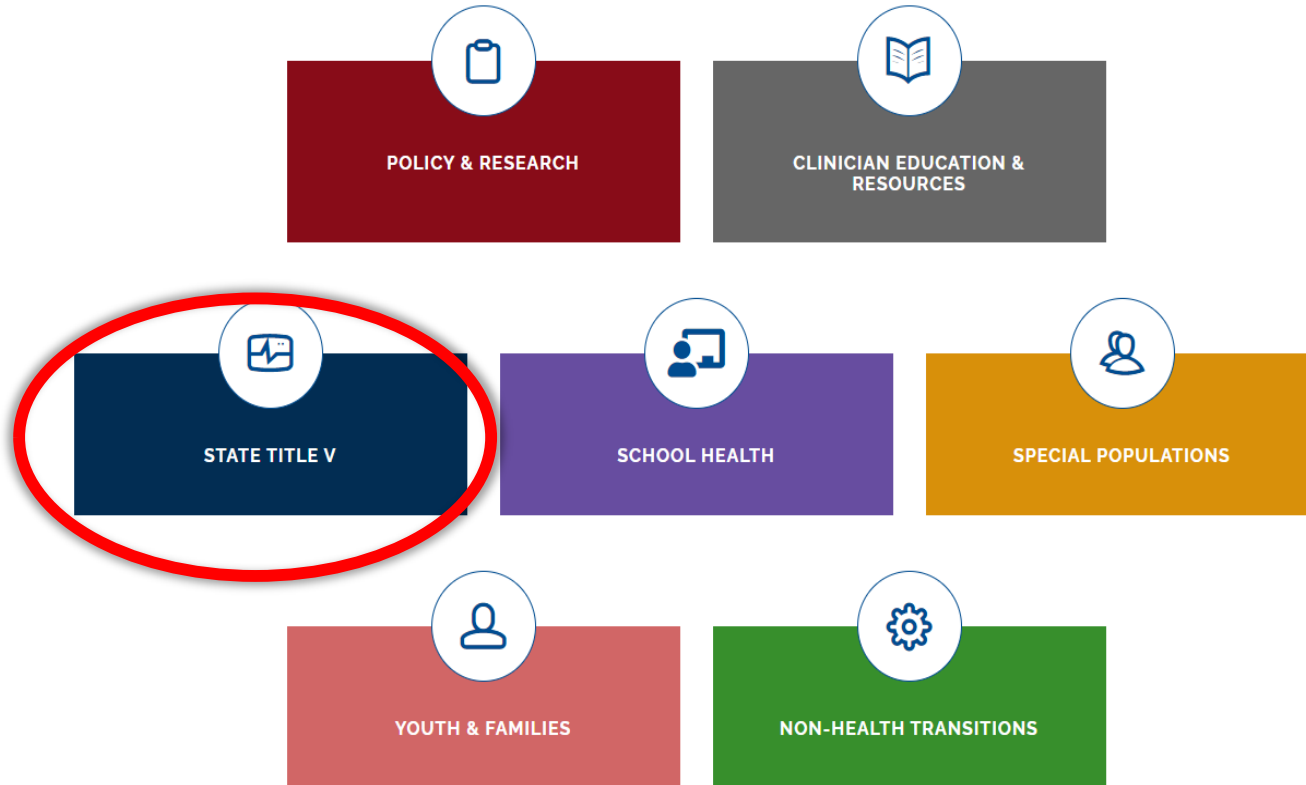
ACCESS

- Offer training and quality improvement support on recommended HCT approaches in alignment with medical home.
- Encourage collaborative arrangements between pediatric and adult systems of care.



GOT TRANSITION RESOURCES FOR TITLE V

Click on each section for resources related to the topic.



SPOTLIGHTS

Georgia

Sharifa Peart, Title V Director
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Rhode Island

Susanne Campbell, Title V contractor
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Minnesota

Wendy Berghorst, Coordinated Systems Specialist
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DISCUSSION QUESTIONS

1. How are you aligning your transition strategies with new Blueprint directions?
2. What additional examples of Blueprint and HCT strategies would you like to share?
3. Are there particular TA needs that you have around transition and Blueprint directions?



ANY OTHER QUESTIONS?

For TA needs on HCT related to the Blueprint, please email us:

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CONTACT US!

- Blueprint4CYSHCN@aap.org
- [National Center for a System of Services for CYSHCN Web site](#)
- Subscribe to the [National Center for a system of services for CYSHCN listserv](#) to get access to valuable resources, event notifications, and so much more!



VIRTUAL CAFÉ EVALUATION SURVEY

