Improving Care for Children with Chronic and Complex Needs: A Look at the National Care Coordination Standards for CYSHCN

National Academy for State Health Policy (NASHP)

Webinar: National Care Coordination Standards for CYSHCN

October 21, 2020, 2:00 – 3:00 p.m. ET

For audio, please dial 1-888-788-0099, code 944-6594-4870

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Agenda

Welcome, Introductions and Overview

Karen VanLandeghem, Senior Program Director, NASHP

Why are the National Care Coordination Standards Needed?
Provider and Family Perspectives

David Bergman, Emeritus Faculty, General Pediatrics, Stanford University School of Medicine

Cara Coleman, Program Manager, Family Voices

What are the Core Elements of the Standards?
An Overview of National Care Coordination Standards for CYSHCN

Kate Honsberger, Project Director, NASHP

How Can States Use the Standards to Strengthen Care Coordination for CYSHCN?

Jeffrey Brosco, State Title V CYSHCN Director, Florida Department of Health, Professor of Clinical Pediatrics, University of Miami

Wendy Tiegreen, Director, Office of Medicaid Coordination & Health System Innovation, Georgia Department of Behavioral Health and Developmental Disabilities

Q&A, Wrap-up and Resources for Further Information

Kate Honsberger, Project Director, NASHP

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Why NASHP Developed the National Care Coordination Standards for CYSHCN

- Care coordination is a core component of state efforts to improve health outcomes, reduce caregiver and patient burden, decrease health care costs and strengthen systems of care for children and adults with chronic and complex conditions
  - Systems have been and are investing in care coordination
- Highly valued among families, providers and systems that serve CYSHCN and makes a difference when done well, but need for improvements
- State health leaders (e.g., Medicaid, public health, mental health) and others (e.g., families, health plans, providers) expressed a need for care coordination standards that would build upon the National Standards for CYSHCN

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National Work Group

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Kayzy Bigler, Kansas Department of Health and Environment

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Mary Daymont, Children's National Health System

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Holly Henry, Lucile Packard Foundation for Children's Health

Dennis Kuo, University of Buffalo, Jacobs School of Medicine and Biomedical Sciences

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Marie Mann, Health Resources and Services Administration, Maternal and Child Health Bureau

Jeanne McAllister, Indiana University School of Medicine

Margaret McManus, The National Alliance to Advance Adolescent Health

John Morehous, University of Cincinnati College of Medicine

Kathleen Noonan, Camden Coalition of Healthcare Providers

Jennifer Oppenheim, Substance Abuse and Mental Health Services Administration

Rylin Rodgers, Association of University Centers on Disabilities

Heather Smith, Kansas Department of Health and Environment

Colleen Sonosky, Department of Health Care Finance, Washington, DC

Kate Taft, Association of Maternal and Child Health Programs

Wendy Tiegreen, Georgia Department of Behavioral Health and Developmental Disabilities

Renee Turchi, Drexel University College of Medicine and School of Public Health

Debra Waldron, American Academy of Pediatrics

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Why are the National Care Coordination Standards Needed?

Provider and Family Perspectives

Why are the National Care Coordination Standards Needed?

Provider Perspective

Children with Complex Conditions

- See on average six different providers
- Interact with up to 30 different agencies
- Spend 11 – 20 hours a week doing care coordination

Providers

- Care coordination is critically important
- We need help
- Care coordination standards help to inform the development of appropriate care coordination services
- Standards need to be evidence based or evidence informed

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Why are the National Care Coordination Standards Needed?

Provider Perspective

What is the Evidence?

- Most studies are done at a program level…and if you have seen one program, you have seen one program.

- It is difficult to show which individual components of a program are effective.

- Studies have shown impact on:
  - ✓Cost and utilization
  - ✓Family well-being
  - ✓Unmet family needs
  - ✓Improvement in clinical outcome (e.g., diabetes)

- Successful programs had these components in common:
  - ✓Identified care coordinator
  - ✓Shared Plan of Care
  - ✓Family assessment
  - ✓Family support and advocacy
- These components map to the care coordination domains

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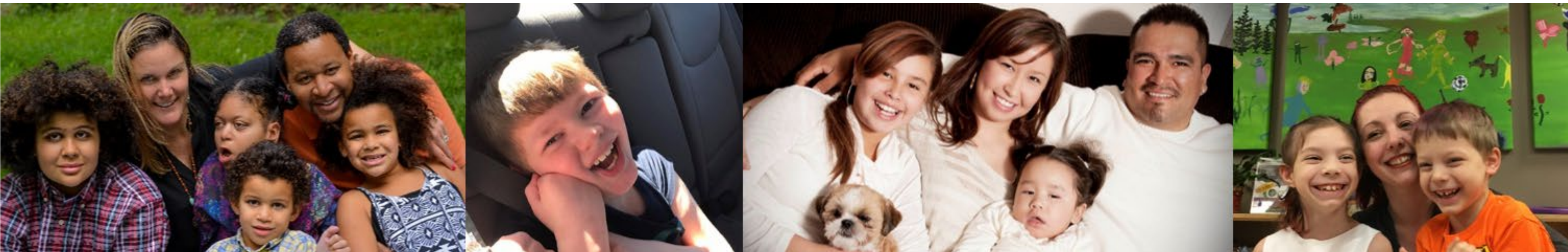
FAMILY VOICES®

Why Families (desperately) Need National Care Coordination Standards

- Eliminate variability and inequities of services, care and system
- Eliminate waste in system
    - E.g., 10 care coordinators???
    - Quality care coordination vs. quantity
- Meaningful, authentic, family-professional partnership
    - "love and marriage"- care coordination, family-centered care, shared decision making and shared plans of care
- Right care coordinated for each child's unique needs

One of the keys to the new standards = Integration of families
"Nothing about us, without us"



What are the Core Elements of the Standards?

An Overview of National Care Coordination Standards for CYSHCN

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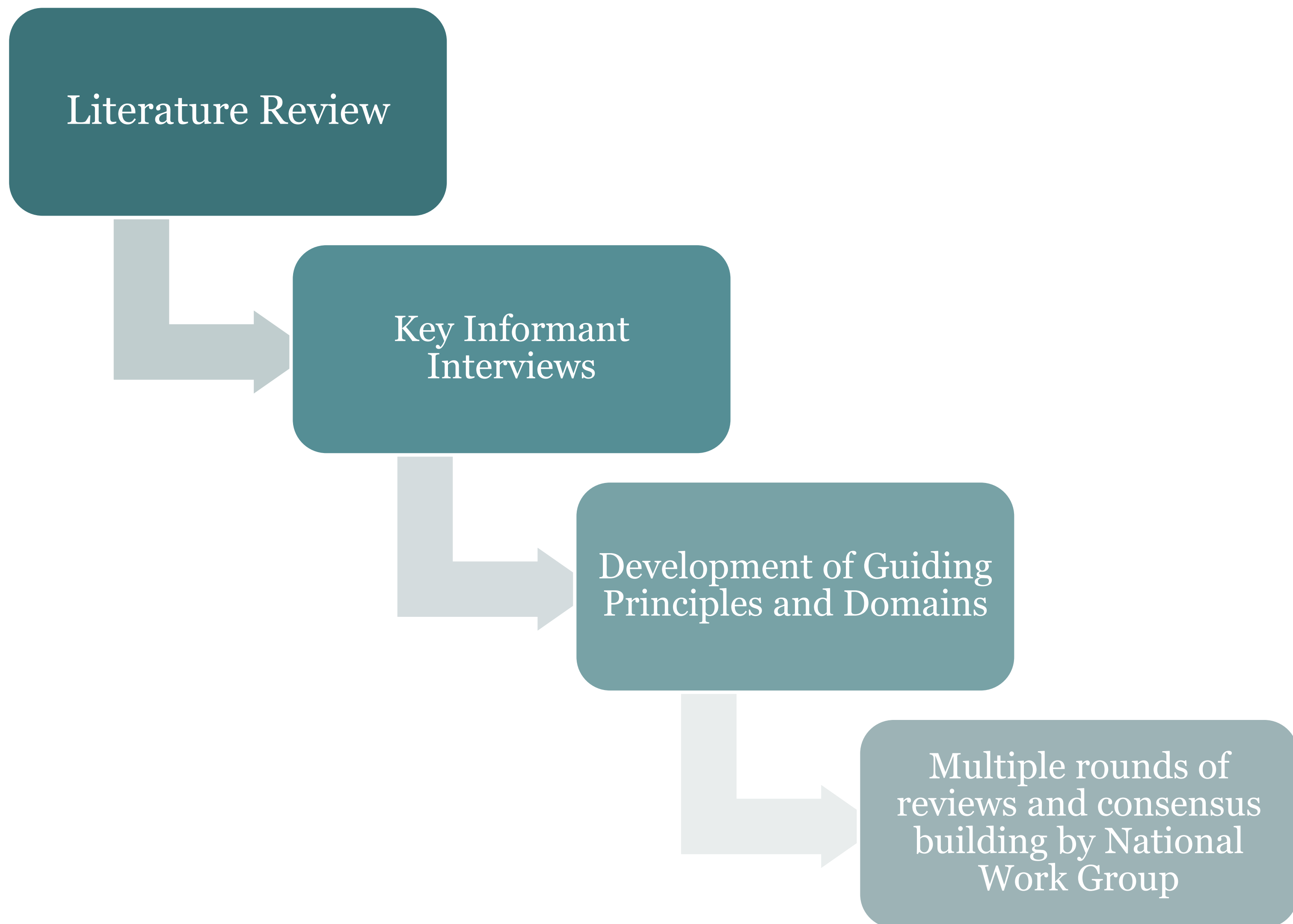
National Care Coordination Standards Development Process



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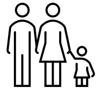
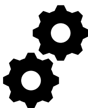
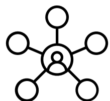
Guiding Principles for the Development of the National Care Coordination Standards

Evidence-based


Family-centered

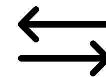
Applicable to various policy contexts and care coordination models, systems, and payers


Reflect involvement of service systems outside of health care


Acknowledge the impact of social determinants of health

Companion to the National Standards

Focused on system-level and process


Designed for CYSHCN but applicable across ages

Considered existing care coordination guidance and federal requirements

The result of consensus, not endorsement, from the National Work Group

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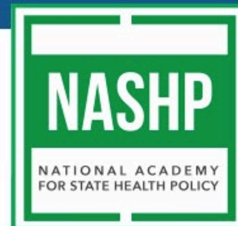
National Care Coordination Standards for Children and Youth with Special Health Care Needs

October 2020



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Foundational Standards

There are seven foundational standards that are critical for comprehensive care coordination for CYSHCN. High-quality care coordination systems should:

1. Be based on health equity
2. Address social, behavioral, environmental, and health care needs
3. Include families are core partners
4. Use evidence-based, evidence-informed, and promising practices
5. Be culturally competent, linguistically appropriate, and accessible
6. Consider insurance coverage as key to accessibility
7. Assess performance with outcome measures

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Care Coordination Standard Domains

The foundational standards are used to guide the remaining standards, which are grouped into **six domains**.

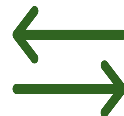
Screening, Identification, and Assessment

Child and Family Empowerment and Skills Development

Shared Plan of Care

Care Coordination Workforce

Team-Based Communication


Care Transitions

Key Components of the Standards

Screening, Identification, and Assessment

- Identifies a family's strengths, needs, beliefs, culture, and preferences
- Evaluates the complexity of the child's health condition and the impact on social determinants of health

Shared Plan of Care

- Addresses clinical, functional, social, and aspirational issues
- Identifies contacts for emergent and routine issues

Team-based Communication

- Outlines clear roles and responsibilities for team members
- Designates a single point of contact for the family

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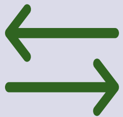
Key Components of the Standards

Child and Family Empowerment and Skills Development

- Builds a child's self-management and efficacy skills
- Appropriately reimburses people with lived experience

Care Coordination Workforce

- Is culturally, linguistically, racially, and ethnically diverse
- Accounts for case complexity when determining case load ratios



Care Transitions

- Includes policies to facilitate effective transition between entities
- Collaborates with adult providers for youth transitioning to adult health care systems

How Can States Use the Standards to Strengthen Care Coordination for CYSHCN?

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What are the common challenges the National Work Group identified as challenges to providing high-quality care coordination to children and youth with special health care needs?

- CYSHCN and their families participating in multiple treatment teams and care coordination processes
- CYSHCN and their families not feeling empowered to self-manage/coordinate care
- Lack of shared cross-provider Electronic Health Records or data sharing platforms
- Establishing mechanisms to finance care coordination
- Lack of quality measurement of care coordination
- Authority for care coordination across multiple system and provider types
- Care coordination services or programs often don't include or focus on:
  - Other confounding health conditions
  - Social Determinants of Health
  - Cultural/Linguistic family factors
  - Family strengths, preferences, desires, and resilience (i.e., often deficit-based versus strength-based)
  - Level of coordination need (too much/too little/none)

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How Can States Use the Standards to Strengthen Care Coordination for CYSHCN?

- How can the National Care Coordination Standards be used to help address these challenges and strengthen high-quality care coordination?

- What advice would you give to state officials (and others) who are interested in using the National Care Coordination Standards?

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Q&A

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National Standards for CYSHCN Resources

National Care Coordination Standards for CYSHCN (PDF, webpage)

Blog on National Care Coordination Standards

National Standards for Systems of Care for CYSHCN

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Thank You!

Please contact NASHP with any questions:

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