Health Care Transition for CYSHCN: An Overview of American Academy of Pediatrics (AAP) Initiatives

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- I have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider of commercial services discussed in this activity.
- I do not intend to discuss an unapproved/investigative use of a commercial product/device in our presentation..

Thank you to AAP CYSHCN Team Members!

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Learning Objectives

By the end of this presentation, participants will be able to:

- Describe AAP's health care transition initiatives for children and youth with special health care needs (CYSHCN) and how they align with the Blueprint for Change.
- Identify at least 2 lessons learned from AAP Health Care Transition activities that you can apply.
- Identify at least 2 health care transition resources that can be utilized within your own practice or organization.

AAP Mission & Overview

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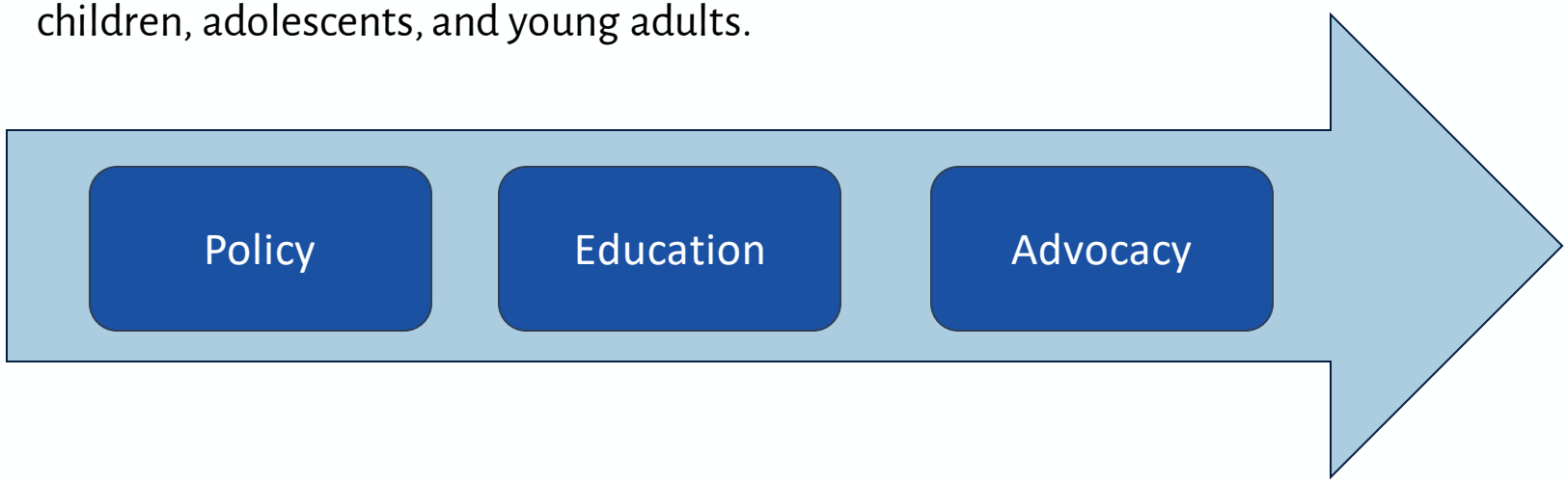
AAP Mission & Key Activities

- Nonprofit professional membership association representing more than 67,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists
- Mission is to attain optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.



Local/State Connection: AAP Chapters

- National AAP partners with its network of chapters to disseminate educational resources and implement programs and policy at the local and state level
- Chapters in all 50 states, the District of Columbia, and Puerto Rico; 7 chapters in Canada
- Find your local chapter: https://www.aap.org/en/community/chapter-websites/
  - Many Chapters have dedicated subcommittees or workgroups focused on CYSHCN

AAP Committee/Section/Councils

- Several AAP groups that work on topics related to health care transition and adolescent health, including development of AAP policy
- A few examples:
  - Council on Adolescents and Young Adults
  - Council on Children with Disabilities
  - Council on School Health
  - Committee on Practice and Ambulatory Medicine
  - Section on Med-Peds
  - And more! A full list can be found here: https://www.aap.org/en/community/

High Level Overview: Health Care Transition (HCT) Initiatives and Activities

- 6 policy statements and/or clinical reports that provide the groundwork for AAP HCT activities
  - *HCT clinical report, alternative decision-making, condition specific policy, care coordination and systems focused policy*
- Grant-funded projects/initiatives
  - National Center for a System of Services for CYSHCN (Blueprint National Center)
  - National Coordinating Center for Epilepsy
  - Early Diagnosis, Management, and Treatment of Chronic Disabling Conditions (spina bifida, muscular dystrophy)
  - Awareness of Congenital Heart Defects Among Healthcare Clinicians
- Coding and Payment Resources

Policy Statement & Clinical Reports

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Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

Audience Question: How many of you utilize AAP policies and clinical reports to support your HCT efforts?

- AAP foundational HCT clinical report published in 2018, reaffirmed in 2023
- Co-authored with the American Academy of Family Physicians and the American College of Physicians
- Provides practical guidance and tools related to key elements of health care transition
- Section on key populations, such as CYSHCN and children with medical complexity (CMC)
- Provides recommendations related to infrastructure, education/training, payment, and research
- Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

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White PH, Cooley W.C TRANSITIONS CLINICAL REPORT AUTHORING GROUP, AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS, AMERICAN COLLEGE OF PHYSICIANS. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. Pediatrics. 2018;142(5):e20182587

Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities

- New policy statement published in 2024
- Provides an overview of alternative decision-making concepts and guidance on alternative decision-making processes, including supported decision-making, power of attorney, and guardianship.
- Emphasizes the need for the least restrictive alternative to support human rights and human dignity for youth with intellectual and developmental disabilities (IDD).
- Provides practical case vignettes to help apply the concepts and links to helpful resources for practitioners
- Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities
- Additional Resources
  - PediatricsOnCall podcast: Transitioning Care for Children with Disabilities
  - YouTube video for families/caregivers: Helping Youth with IDD Make Decisions as Adults

Turchi RM, Kuo DZ, Rusher JW, et al; American Academy of Pediatrics, Council on Children With Disabilities, Committee on Medical Liability and Risk Management. Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities: Policy Statement. Pediatrics. 2024; 153(6):e2024066841

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Condition Specific Clinical Reports

- AAP has several condition specific clinical reports available that include sections with guidance on transition and transfer of care, including for youth with cerebral palsy and autism.
- Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy
- Identification, Evaluation, and Management of Children With Autism Spectrum Disorder

Noritz G, Davidson L, Steingass K, et al; AAP Council on Children With Disabilities, THE AMERICAN ACADEMY FOR CEREBRAL PALSY AND DEVELOPMENTAL MEDICINE. Providing a Primary Care Medical Home for Children and Youth With Cerebral Palsy. Pediatrics. 2022;150(6):e2022060055

Hyman SL, Levy SE, Myers SM, AAP COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. 2020;145(1):e20193447

Systems Focused Policy

- Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems
  - Outlines a multi-disciplinary care coordination framework, defines care coordination and its components, and offers tips for implementation
- Recognition and Management of Medical Complexity (CMC)
  - Describes CMC population and outlines strategies for improving health outcomes for CMC

COUNCIL ON CHILDREN WITH DISABILITIES and MEDICAL HOME IMPLEMENTATION PROJECT ADVISORY COMMITTEE, Renee M. Turchi, Richard C. Antonelli, Kenneth W. Norwood, et al, Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. Pediatrics May 2014; 133 (5): e1451–e1460. 10.1542/peds.2014-0318

Kuo DZ, Houtrow AJ, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Recognition and Management of Medical Complexity. Pediatrics. 2016;138(6):e20163021

CYSHCN & Health Care Transition Initiatives

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

Connecting systems so CYSHCN & their families thrive

National Center for a System of Services for CYSHCN or "Blueprint National Center"

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.

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Blueprint for Change: What is it?

Audience Question: How many of you have heard of the Blueprint for Change?

- Federal vision to advance the system of services for CYSHCN over the next 15 years
- Aspirational document
- Builds on numerous existing efforts; published in 2022 with input from diverse partners, including families/caregivers and others with lived expertise
- Four focus areas: health equity, quality of life/well-being, financing, and 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 parents/caregivers and siblings can thrive too.)
- Focuses on **measuring what matters to families**

Blueprint for Change: 4 Interconnected Critical Areas

- **Health equity:** Seeking to address the upstream and downstream factors that inhibit CYSHCN from a fair and just opportunity to be healthy
- **Quality of Life/Well-being:** Need for systems to acknowledge and measure outcomes that are meaningful to children and their families
- **Financing of services:** Need for a service system to support and finance improvements to ensure access, equity, and system integration, and ease the financial burden on families
- **Access to services:** Need an adaptive, responsive system built around the needs of children and families, not just a diagnosis or treatment protocol

How does this all relate to health care transition?

- Quality of life/well-being examples:
  - Service sectors promote and support flourishing, enhanced self-management, and peer-to-peer social connections
  - Health systems evaluate and link payment models to quality of life for all children and youth
- Access to services examples:
  - CYSHCN receive services that anticipate their needs and provide service options/guidance, including a roadmap to care
  - Essential providers are available in communities where families live or via other service delivery technologies
  - Innovative and alternative training programs explore opportunities to ensure a diverse and inclusive workforce
- Financing of services examples:
  - Care coordination and care integration across sectors are considered medically necessary and adequately funded to manage varying service needs as defined by the family
  - Care integration across service sectors is adequately financed

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

Connecting systems so CYSHCN & their families thrive

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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Blueprint National Center Partners

- To implement this work, the AAP is partnering with:
  - Center for Innovation in Social Work and Health at Boston University/Catalyst Center
  - Family Voices
  - The National Alliance to Advance Adolescent Health/Got Transition
  - UNC Chapel Hill
  - Association of University Centers on Disabilities
  - The Altarum Institute
- Our work is guided by multi-disciplinary National Advisory Board, Steering Committee, and Family and Youth Advisory Board

Phase 1: Technical Assistance

- Technical assistance topics (this list is not exhaustive):
  - Helping Title V understand how to support successful transition from pediatric to adult health care
  - Aligning health care transition with special education
  - Helping Title V partner with Medicaid to finance health care transition services for CYSHCN
  - Integrating the Blueprint for Change into Title V needs assessments
  - Building equitable partnerships, especially with young adults and individuals with lived expertise
  - Implementing evidence-based or informed population health strategies across each of the 4 Blueprint critical areas
  - Leveraging current financing models to support care coordination, case management, and addressing social determinants of health

Phase 1: Learning Collaboratives

Years 1-2

- Learning Collaborative with 5 state teams to pilot Blueprint strategies
  - Co-led by Title V and family/caregiver
  - Participants: MI, NC, RI, TX, WA
- A few examples of state activities
  - Implementing a targeted case management benefit for children with medical complexity
  - Designing transition payments and seeking consensus among payers, state agencies, and state legislature
  - Aligning cross-sector systems to support multi/interdisciplinary care coordination that includes use of shared plans of care with a peer support component

Phase 1: Blueprint Implementation Roadmap

Years 1-2

- Publish Blueprint Implementation Roadmap
  - Will support implementation of the Blueprint for Change strategies
  - A way for us to move from **WHAT** to **HOW**
  - The project's environmental scan should yield potential innovative approaches to help us understand
    - **How** are the Blueprint strategies being implemented?
    - **Who** is already doing this work?
    - **How** are they implementing these innovative approaches?

Phase 1: Environmental Scan

- Key informant interviews
- Focus groups
  - Including a young adult focus group
- Literature search
- Review of Title V block grant applications
- Review of National Survey of Children's Health
- Review of Medicaid Managed Care contracts

Phase 2 Activities

Years 3-5

- Blueprint Roadmap implementation via:
  - Hosting Blueprint Cafes
  - Collecting and disseminating promising practices
  - Developing resources
  - LEND training curriculum
  - Learning collaboratives and learning communities
    - Got Transition leading learning community with states on special education and HCT
  - Innovation awards

Resources and Contact Information

- 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!

NATIONAL COORDINATING CENTER *for* EPILEPSY

National Coordinating Center for Epilepsy (Center)

The National Coordinating Center for Epilepsy was 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 $614,249 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.

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Goals and Objectives

- Improve access to coordinated, comprehensive, and quality care for children and youth with epilepsy (CYE), particularly in medically underserved and/or rural areas
- Objectives:
  - Provide national leadership via partnerships, best practice sharing and resource development
  - Provide infrastructure and technical assistance to 7 HRSA/MCHB-funded *Transforming Health Care for CYE* grantees

Video Highlighting Key CYE Learning Collaborative Results

https://www.aap.org/en/patient-care/epilepsy/sustainability-resource-guide/

Example CYE Grantee Activities

- Creation of an online interactive game to help young adults with epilepsy learn how to manage their medications
- Launch of a comprehensive Spanish immersion clinic for families who identify Spanish as their preferred language
- Partnering with young adults to develop several tools / resources, including a “Meet Me” intake document, a shared decision-making guide, and a decision aid to help CYE identify an adult health care provider
- Development of a telehealth-based transition clinic led by clinic social workers
- Building health care transition assessment process into organizational infrastructure / workflow with automatic email alerts
- For additional information on these activities and others, check out the epilepsy virtual symposium proceedings and promising practices page.

Resources and Tools

- Center Website
  - Teens & Epilepsy page
- Health Care Transition Toolkit for Adult Clinicians
- Strengthen & Enhance Epilepsy Knowledge Training
- Young Adults with Epilepsy Share Their Story
- HealthyChildren.org articles
  - Epilepsy in Children and Teens: Diagnosis & Treatment
  - How to Support a Child or Teen with Epilepsy
  - Seizure Medications for Children & Teens
- Promising Practices and Symposium Proceedings
- Program Sustainability Resources

Early Diagnosis, Management, and Treatment of Chronic Disabling Conditions

This project is funded through a cooperative agreement (#5NU38OT000282) between the American Academy of Pediatrics and the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities.

Goals & Objectives

- Goal is to improve the early identification and evaluation of children with global developmental delay and/or intellectual disabilities
- Objectives:
  - Based primarily on improving care for two rare diseases/conditions -- muscular dystrophy (MD) and spina bifida (SB)
  - Improving transition coordination for patients with spina bifida

Key Activities: QI Learning Collaborative

- Implemented two cohorts of a Spina Bifida Transition QI Learning Collaborative between September 2019 and July 2021
  - Included 14 practices total, made up of a pediatric and adult clinic dyads (team pair)
  - Led to improvements in HCT processes and resulted in 85 individuals successfully transitioning from pediatric to adult-centered care
- Example successes and activities:
  - Development of a transition grid
  - Development of decision-making supports for families to help with the transition process
  - Incorporating transition readiness questionnaire into EMR

Key Activities: Health Care Transition from Pediatric to Adult-focused Care for Youth with Spina Bifida ECHO

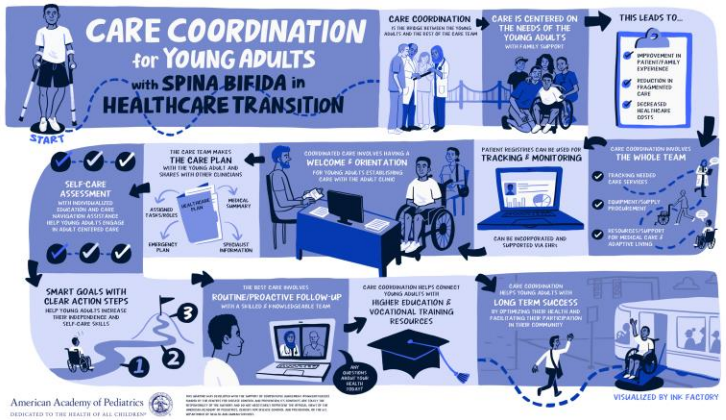
- Implemented 3 successful cohorts of Extension for Community Health Outcomes (ECHO) project
  - Telementoring program that brings together health care providers and experts in topical areas using didactic and case-based presentations
  - Third cohort included 44 multi-disciplinary participants, including social workers, nurses, and care coordinators
  - Increased knowledge and confidence of participants among 11 of 12 objectives
- ECHO session recordings

Key Results of ECHO: Knowledge and Confidence of Participants

Objective	Before	After
Understand aging considerations for individuals with spina bifida	2.8	3.5
Understand the healthcare transition process	2.8	3.6
How to effectively partner with young adults and family members for health care transition	2.6	3.5
Understand cultural considerations for health care transition	2.4	3.5
Strategies to support decision making and guardianship for individuals living with spina bifida	2.4	3.8
How to navigate payment during health care transition	2.3	3.3
Understand how to create a consistent health care transition approach	2.3	3.5
Strategies for a safe transfer of care	2.3	3.5
Understand the models of care for health care transition	2.3	3.3

Ratings were collected using a 5-point scale (1 = no skill, 5 = expert, can teach others)

Additional Resources and Tools



- Care Coordination Infographics in English and Spanish
- AAP Voices Blog
  - Helping Those with Spina Bifida Make Developmentally Appropriate Transition to Adult Care
- Duchenne Muscular Dystrophy Diagnosis and Care Pedialink Course
- Health Care Transition Support Videos for People Impacted by Spina Bifida
- Spina Bifida: Helping Teens Transition to Adult Centered Care
- Coming Soon: Spina Bifida Health Care Transition Toolkit

Awareness of Congenital Heart Defects Among Healthcare Clinicians

This project is supported by the Centers for Disease Control and Prevention of the US Department of Health and Human Services (HHS) as part of a cooperative agreement between the American Academy of Pediatrics and the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by American Academy of Pediatrics, CDC/HHS or the US Government.

Goals & Objectives

- Goal & objectives
  - Increase awareness of congenital heart defects (CHDs) among physician groups
  - Increase awareness of the need for lifelong cardiac care
  - Improve referrals to appropriate cardiac specialty care
- Target Physician Groups:
  - Pediatricians/Family Medicine who treat children
  - Internal Medicine Care/Family Medicine who treat adults
  - Obstetrician-gynecologists (OB-GYNs)
  - Emergency Medicine (ER) physicians

Congenital Heart Defects TOOLKIT
Improving Continuity of Care Between Primary Care and Specialty Cardiac Care Physicians

Resources & Tools

- Congenital Heart Defects Toolkit
  - Video based curriculum
  - Infographics and conversation starters
  - Sample social media posts and graphics
  - Case-based mini trainings
    - Primary Care for Children with Complex Congenital Heart Defects mini-training includes information on HCT
  - Point-of-care tools
  - Healthychildren.org articles
  - Podcast segment

Coding and Payment

- Transition Care for Adolescents Tip Sheet
  - Developed in partnership with Got Transition®
- Adolescent Health Tip Sheet
- AAP Coding Hotline

Key Themes

Lessons Learned

- Blueprint for Change can be used as a framework to guide HCT and other CYSHCN efforts
- There is no need to reinvent the wheel…lots of resources and tools already available
- For HCT specifically:
  - Partner with young adults to develop HCT resources/tools for your practices and for families/caregivers/young adults, including decision-aids
    - Respecting independence and human dignity of YSHCN when helping them and their families navigate the transition process
    - Integrating an anti-ableist lens into transition focused efforts
    - Incorporating cultural humility and sensitivity into your efforts
  - Think about transition more holistically
    - Young adults need support in navigating education, employment, benefits transition (SSI, Medicaid, etc)
    - Role in medical home neighborhood to support these efforts

Lessons Learned Continued

- Workforce development challenges
  - Opportunities to engage adult providers more
- Incorporate a team-based approach with nurses, social workers, and young adults/families in HCT activities
- Having an organized care plan is a must have
- Improved coordination of care among all systems serving YSHCN is essential
- Find ways to automate processes with email alerts/email blasts and incorporation of transition readiness assessments into EMRs

Thank you!