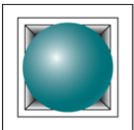


Got Transition's Latest Resources and Initiatives

*25th Annual Chronic Illness and Disability Conference:
Transition from Pediatric to Adult-Based Care*

October 2024

Patience White, Samhita Ilango, Annie Schmidt, Peggy McManus

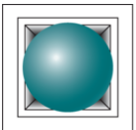


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Presentation Objectives

- Become familiar with Got Transition's new initiatives and resources
- Share information about new projects underway
- Q & A



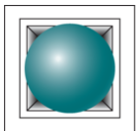
Agenda

1. Updated reports/activities

- a) Medicaid MCO study
- b) Title V Block grant analysis
- c) Aging out national and 5 state report

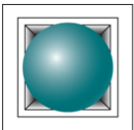
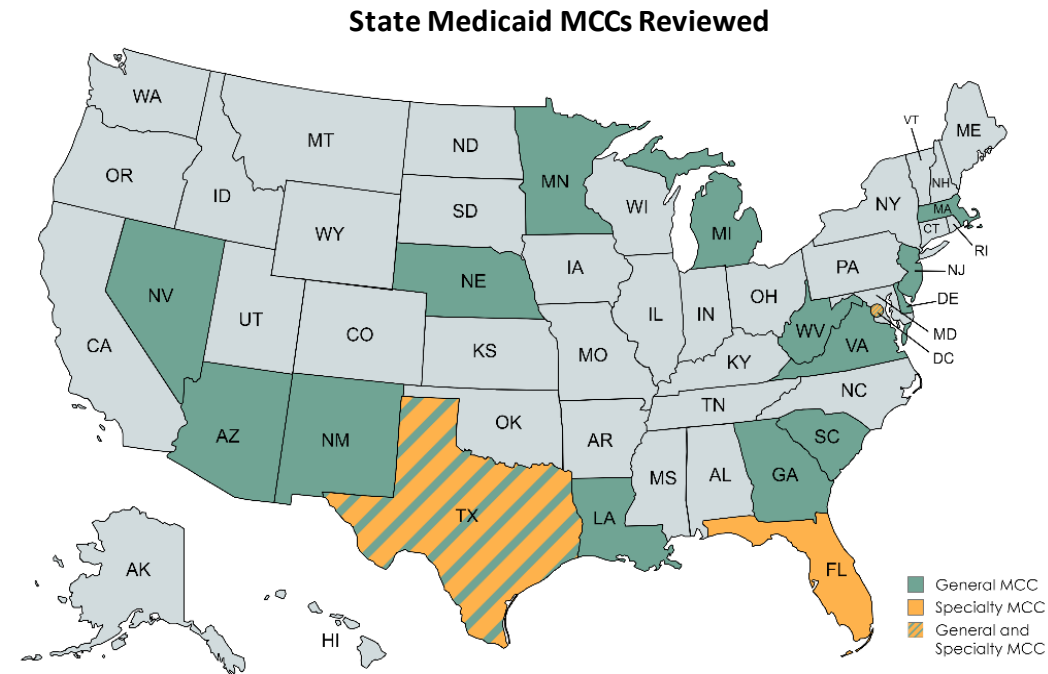
2. Current Collaborations

- a) National Center for Systems of Services for CYSHCN (AAP)
- b) Center for Transition to Adult Health Care for Youth with I/DD (Family Voices)
- c) National Center for Adolescent and Young Adult Health and Well-Being (AAP)
- d) Health System wide HCT Learning Community (Got Transition)
- e) MN HCT ECHO and Learning Community (Gillette Children's)
- f) 8-State Learning Community on Special Ed and HCT (WI Title V)
- g) NEW National Transition Coordinating Center on Autism and Epilepsy (AMCHP)
- h) Visual of customizable 6 Core elements downloaded worldwide since 2014



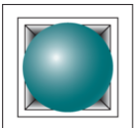
A Review of Medicaid Managed Care Contracts to Inform the CYSHCN Blueprint Roadmap

- Medicaid managed care contracts (MCCs) represent an important source of information for the National Center for Systems of Services for CYSHCN for state Title V agencies to advance health equity, quality of life and well-being, financing, and access for CYSHCN and their families
- We examined Medicaid managed care contracts in 17 states, which were selected based on their use of the National Systems of Care Standards for CYSHCN, to answer four research questions:
 1. Are systemic causes of health inequities addressed in Medicaid MCCs?
 2. Is family engagement in the design, provision, and oversight of care to CYSHCN specified in MCCs?
 3. Do MCCs include cross-system partnerships that align health and community supports for CYSHCN and their families?
 4. Is accountability for a system of services for CYSHCN and their families part of MCCs?



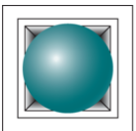
A Review of Medicaid Managed Care Contracts to Inform the CYSHCN Blueprint Roadmap

Most Common Medicaid Managed Care Contract Provisions Relevant to the Blueprint for Change	
Health Equity	
<ul style="list-style-type: none">• Development of health equity/cultural competency plans• Quality assessment and improvement related to reduction in health disparities and social determinants of health• Equity-focused screening, data collection, and reporting	
Family Engagement	
<ul style="list-style-type: none">• General definition of family-centered care• Representation on advisory councils/quality improvement (QI) committees• Care management and treatment planning	
Cross-System Partnerships	
<ul style="list-style-type: none">• Referrals to community organizations• Collaborative initiatives to address social determinants of health• Coordination with community organizations around services for children	
System of Services Accountability	
<ul style="list-style-type: none">• Performance measurement and QI for CYSHCN and/or special-needs populations• Reference to specific standards, policies, and procedures	



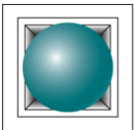
A Review of State Title V Block Grant Applications to Inform the CYSHCN Blueprint Roadmap

- Each state Title V program submits an annual Block Grant application/annual report that outlines planned strategies to improve the system of system for mothers and children, including CYSHCN and their families.
- In this analysis, each application was reviewed for distinctive strategies that align with the Blueprint for Change domains of health equity, family and child well-being and quality of life, access to services, and financing of services
- The questions that guided this analysis were:
 1. To what extent did states select national performance measures (NPMs) related to CYSHCN and include reference to the National System of Care and National Care Coordination Standards)?
 2. To what extent did state Title V Block Grant applications address MCHB's Blueprint for Change?
 3. What are examples of state performance measures (SPMs) and distinctive initiatives states are planning related to the Blueprint domains of health equity, family and child well-being and quality of life, access to services, and financing of services)?



A Review of State Title V Block Grant Applications to Inform the CYSHCN Blueprint Roadmap

- Of the four NPMs reviewed, the most commonly selected priority NPMs were developmental screening (NPM 6), medical home (NPM 11), and health care transition (NPM 12) (33, 32, and 32 states, respectively). Six states selected adequate insurance (NPM 15) as a priority.
- Almost half (45%) of states explicitly mentioned the Blueprint for Change.
- The most common distinctive strategies found were as follows:
 - **Health equity:** Data collection to address service gaps and inequities (13 strategies in 10 states)
 - **Family and child well-being and quality of life:** Mental, behavioral, and emotional health (12 strategies in 8 states)
 - **Access to services:** Health care transition (39 strategies in 26 states)
 - **Financing of services:** Connection to health coverage and services (15 strategies in 13 states)



Number of States Title V Agencies with Distinctive Strategies that Align with Blueprint Domains

Financing of Services Strategies

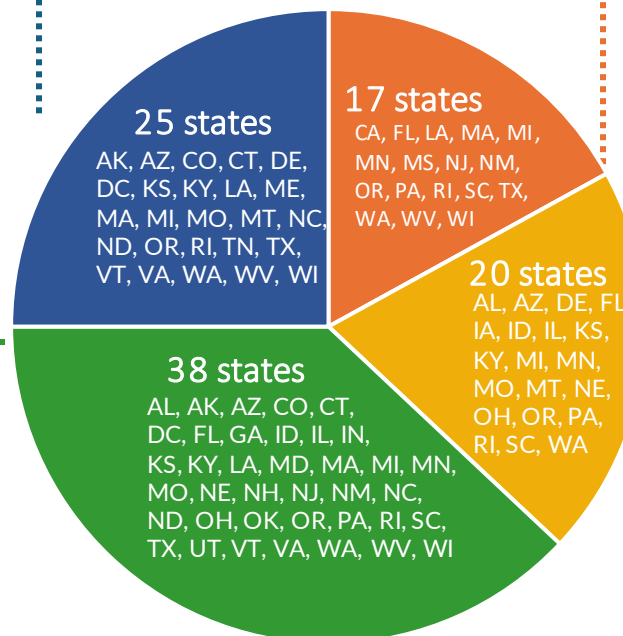
- **Connection to health coverage and services**
13 states: AK, CO, DE, DC, KY, MA, MO, MT, ND, OR, VT, VA, WI
- **Develop/implement alternative payment model**
9 states: AZ, CT, MA, NC, OR, RI, TX, VT, WA
- **Collaboration with Medicaid/MCOs**
6 states: AK, DE, LA, MI, OR, WV
- **Research/advocate for reimbursement of services**
6 states: KS, MI, ME, RI, TN, WA
- **Specific populations**
4 states: OR, NC, WA, WV

Health Equity Strategies

- **Data collection to address service gaps and inequities**
10 states: CA, FL, LA, MN, NJ, OR, PA, RI, SC, WA
- **Education/training**
6 states: LA, MS, MN, OR, RI, WV
- **Marginalized population outreach**
5 states: OR, NM, MN, MA, WI
- **Reduce racial or ethnic disparities**
4 states: MA, MI, MN, TX

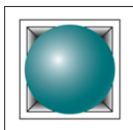
Access to Services Strategies

- **Health care transition**
26 states: AL, AZ, AK, CT, DC, FL, GA, ID, IL, KS, KY, MA, MI, MN, NH, ND, NC, OH, OR, PA, RI, TX, UT, VA, VT, WV
- **Specific populations**
13 states: AK, FL, IN, LA, MI, MN, NM, OK, OR, PA, UT, VA, WV
- **Connection and coordination of services**
12 states: AK, GA, KS, KY, MO, NE, ND, PA, RI, VA, VT, WI
- **Collaboration**
7 states: FL, IN, MN, MO, NH, UT, WV
- **Data collection**
7 states: IN, KS, NJ, NC, VA, WA
- **Training/education**
5 states: MD, NE, OH, PA, SC
- **School/college health**
4 states: CO, MO, MN, PA



Family and Child Well-Being and Quality of Life Strategies

- **Family engagement**
10 states: AZ, AL, IA, MI, MN, MO, MT, NE, OH, SC
- **Mental, behavioral, and emotional health**
8 states: AZ, ID, IL, MI, MN, PA, RI, WA
- **Outreach/education**
5 states: AL, KS, KY, MT, OR
- **Collaboration with Family Voices**
2 states: AL, DE



Youth and Young Adults with Disabilities Aging Out of Public Program Services: Barriers, Inequities, and Recommendations

- New reports and three policy briefs on the significant challenges and inequities that youth and young adults with disabilities face when aging out of Medicaid, CHIP, SSI, and Title V Programs
- Peggy McManus will be presenting on the full methods, findings, and recommendations on Friday at 2:15pm

National Report



Policy Brief On Medicaid & CHIP



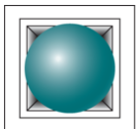
Policy Brief on SSI



Policy Brief on Title V

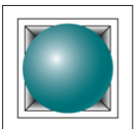


Five State Case Study



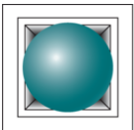
National Center for Systems of Services for CYSHCN/Blueprint National Center (MCHB)

- Partnership with AAP (PI), Catalyst Center, Family Voices, UNC Workforce Center, Altarum, & several advisory groups
- Aim is to develop a roadmap to create a well-functioning system of services
- Four Blueprint focus areas: equity, financing, access, child and family well-being and quality of life
- *Pediatrics Supplement* in June 2022 contains series of great articles
- HCT can be included in all domains
- Our role: Medicaid managed care analysis, Title V block grant analysis, expansion of special ed learning community, HCT TA, and more



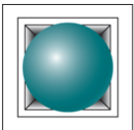
Center for Transition to Adult Health Care for Youth with I/DD (ACL)

- Partnership with FV (PI), GT, SPAN, UMKC, & Waisman Center
- GT created a website with a youth steering committee (movingtoadulthealthcare.org)
 - New set of HCT Kits coming, produced by UMKC's Charting the LifeCourse Group
- Produce annual profile on HCT performance
- Identify new data opportunities for including HCT



National Center for Adolescent & Young Adult Health and Well-Being (MCHB)

- Partnership with AAP (PI), GT, YMCA-USA, ASTHO, Youth Move-National, National Assn of School Nurses, National Council for Mental Well-Being
- Aim is to create a cross-sector alliance to create a toolkit for advancing systems integration for AYA
- GT analyzing several national surveys to identify measures of AYA well-being
- Conducting review of 51 state block grant applications for cross-sector innovations



Got Transition's HCT Learning Community: Current Members

- Representatives from the health systems below are working together to improve HCT outcomes and are excited that the larger NIH clinical Center will be rejoining the community.
- Over the past 10 years the learning community has had monthly calls to share challenges and opportunities and to collaborate on finding best practices, presentations and publishing papers.

Cleveland Clinic, Cleveland, Ohio

Colorado Kaiser Permanente Medical Group, Denver, Colorado

Children's Hospital of Colorado, Denver, Colorado

Children's Hospital of Orange County, CA

Children's Hospital of Philadelphia, Philadelphia, PA

Children's Mercy Kansas City, Kansas City, MO

Stanford Ravenswood Family Health Center, East Palo Alto, California

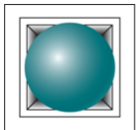
University of Rochester, Rochester, New York

Medical University of South Carolina, Charleston, South Carolina

Henry Ford Health System, Detroit, Michigan

Intermountain Health, Salt Lake City, Utah

Oregon Health & Science University, Portland, OR

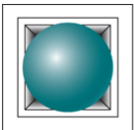


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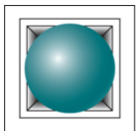
MEC Transition of Healthcare Subcommittee

- Catherine Gordon, NICHD (Chair)
- Morgan Similuk, NIAID
- Deborah Merke, NIH, PEDS
- Betty Marciano, NIAID
- Alison Han, CC/HES
- Sara Talvacchio, NICHD
- Lori Wiener, NCI
- Ariane Soldatos, NINDS
- Sahar Lotfi-Emran, NIAMS
- Alexandra Laufer, NICHD
- Deborah Snyder, NIMH
- Patricia Driscoll, NIAID
- Janice Lee, NIDCR
- Jessica Chong, NHGRI
- Ruth Parker, NIH, PEDS
- Karen Hughes, NIMH
- Simona Simmons, NIDCR
- Nakiia Buyck, NIDCR
- Tonia Shuler, NIMH
- Maryland Pao, NIMH
- Susan Roy, NIH, NURS
- Tricia Coffey, HIMD



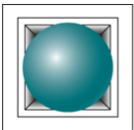
MN HCT ECHO and Learning Community (MN Title V)

- Gillette Children's Specialty Clinic (PI) and GT
- Just completed 10-ECHO sessions on trauma-informed HCT & annual MN HCT summit
- Guided 4 QI HCT projects in a learning community over 4 months
- New work: 4 ECHOs, key informant interviews with state leaders to identify potential opportunities for collaboration, piloting HCT collaborative approach between Gillette (children's) and Regions (adult hospital)



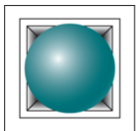
8-State Learning Community on Special Ed & HCT (MCHB)

- Aim is to elevate HCT in special ed transition planning
- Partners: GT (PI); FL, GA, MN, NC, NM, OR, TX, WI; and NTACT:C from UNC
- Analyzed state statutes, administrative rules, guidance to assess if HCT mentioned
- Analyzed state dept of special ed's website to identify HCT resources for IEP transition planning
- Create a state profile on HCT and special ed to make the case
- Building partnerships between Title V, Special Ed, and family leaders
- Sharing best practices



NEW National Transition Coordinating Center for Autism and Epilepsy (MCHB)

- Aim: To support 11 MCHB-funded transition demonstration projects for youth with autism (4) and epilepsy (7), and to develop measurement frameworks for a successful transition for those with complex health and social needs.
- AMCHP (PI), Family Voices, AAP, and Child Trends
- GT to serve on their National Advisory Committee and provide HCT TA to demonstration sites and measurement frameworks



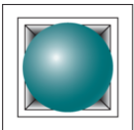
Demonstration Project for NCCT

Autism

- Cincinnati Children's Hospital
- Long Island Jewish Medical Center
- Univ of Colorado
- Univ of Wisconsin

Epilepsy

- Boston Medical Center
- Children's Hospital of Philadelphia
- Children's Mercy (Missouri)
- Epilepsy Florida
- Michigan Health And Human Services
- Univ of Minnesota
- Univ of N Carolina (Chapel Hill)



Thank you! Questions?

Access these tools and additional HCT resources on
GotTransition.org

For more information, contact:

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Samhita Ilango: silango@thenationalalliance.org

Annie Schmidt: aschmidt@thenationalalliance.org



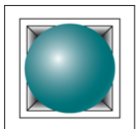
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