The American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians: Supporting Health Care Transition in the Medical Home Clinical Report 2018

19th Annual Chronic Illness and Disability Conference

Transition of Care for YSHCN

October 25, 2018

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on behalf of the Transitions CR Revision Authoring Group

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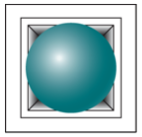

THE NATIONAL ALLIANCE TO ADVANCE ADOLESCENT HEALTH

got transition

Disclosures

We have no financial disclosures or conflicts of interest.

Got Transition™, a program of The National Alliance to Advance Adolescent Health, is funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, DHHS (U1TMC31756).

Session Objectives

- Review the 2018 Clinical Report's (CR) review process
- Discuss the new areas of emphasis in the CR
- Discuss practice based quality improvement opportunities in the CR
- Review the CR's recommendations in infrastructure, education and training, payment and research

Transitions CR Revision Authoring Group

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CR Development and Approval Process

- Intent for Updating 2011 Clinical Report approved in 10/2015
- Literature Review completed 2011 through 2017
- Authoring Group Conference calls- review the 2011 CR and the literature (2011-2017), brainstorm and prioritize revisions, approve the final copy
- Review by AAP:
  - 15 Committees
  - 7 Councils
  - 26 Sections
- Review by ACP-4 committees
- Review by AAFP
- All concerns reviewed and responded to
- Approved by the AAP, AAFP and ACP BODs in 8/2018
- Published in *Pediatrics* with joint AAP/AAFP/ACP News Release Oct. 2018

*AAP, AAFP, ACP BOD approval

State of US Health Care Transition

Transition-Aged Population

- Sixty-one million people or 19% of US population between ages 12 and 26
- 25-30% of transition age group have chronic conditions
- Insurance picture*

	Ages 10-14	15-18	19-25
• Privately insured	57%	61%	67%
• Publicly insured	38%	31%	19%
• Uninsured	5%	8%	20%

- Health care picture

• Has usual source of care*	95%	90%	75%
• Had MD visit in past yr.*	81%	77%	56%

- New Kaiser Nat'l Poll:
  - Only 55% 18-29 year olds have a PCP (compared to 72 % of 30-49 year olds)**

*Spencer et al. Health care coverage and access among children, adolescents, and young adults, 2010-2016: Implications for future health reforms. *JAH* 2018.

**Kaiser Family Foundation poll 2018 (*Wash Post* Oct 9, 2018)

Receipt Of Transition Planning Guidance From Health Care Providers (HCPS)

NSCH 2016-2017 Combined data*:

- 17% of youth with special needs (YSHCN) received transition planning guidance from HCPs
- 14% of youth without special needs received transition planning guidance HCPs
- National Performance Measure based on 1) HCP had time alone with HCP during last preventive visit (44%, 37%), 2) HCP actively worked with youth to gain self care skills or understand changes in health care at age 18 (69%, 55%), and 3) HCP discussed eventual shift to an HCP who cares for adults (41%, 52%)

*Lebrun-Harris et al, Transition planning among US youth with and without special health care needs. *Pediatrics*, 2018 and 2017 NSCH data at http://Childhealthdata.org

HCT CR Principles

Transition from pediatric to adult health care is part of a larger theoretical framework for transition affecting all youth, young adults, and families, as outlined by Meleis*, Geary and Schumacher**, and Schwartz et al.***

Transition theory informs the following overarching principles for this health care transition clinical report:

- Importance of youth/young adult-centered, strength-based focus
- Emphasis on self-determination, self-management, and family/caregiver engagement
- Acknowledgement of individual differences and complexities
- Recognition of vulnerabilities and need for a distinct population health approach for youth and young adults

*Meleis AI, editor. Transitions Theory: Middle range and situation specific theories in nursing research and practice. NY: Springer; 2010.
**Geary CR, Schumacher KL. Care transitions: Integrating transition theory and complexity science concepts. *Adv Nurs Sci*. 2012;35(3):236-248.
***Schwartz LA, et al. Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatr*. 2013;167(10):939-946

HCT CR Principles (Cont.)

- Need for early and ongoing preparation, including the integration into an adult model of care
- Importance of shared accountability, effective communication, and care coordination between pediatric and adult clinicians and systems of care
- Recognition of the influences of cultural beliefs and attitudes as well as socioeconomic status
- Emphasis on achieving health equity and elimination of disparities
- Need for parents and caregivers to support youth and young adults in building knowledge regarding their own health and skills in making health decisions and using health care

Barriers: Youth/YA/Family

- **Fear of the New Health Care Delivery System:** Families and young adults find it hard to let go of long-standing relationships, negative beliefs about adult care, anxiety about the adult systems and health care system, losing control
- **Inadequate Planning:** e.g. Y/YA report feeling lost and unclear about self-care and self-advocacy, what privacy and consent changes at 18, distinctions between pediatric and adult care, and unfamiliar with navigating adult systems, youth less interested in health then other aspects of their life during transition years
- **System Difficulties:** e.g. poor communication and coordination between the two providers/systems, limited availability of adult clinicians, loss of insurance

Barriers: Adult and Pediatric Clinicians

- **Communication/Consultation Gaps:** e.g. lack of communication, coordination, guidelines, protocols between peds and adult systems, Lack of medical records from pediatric clinicians, concerns about not enough adult subspecialty and mental health clinicians
- **Training Limitations:** e.g. Lack of knowledge in ped onset conditions and adol development, caring for young adult patients reliant on parents/ caregivers, both peds and adult clinicians find caring for youth with medical complexity a challenge
- **Care Delivery/Care Coordination/Staff Support Gaps:** e.g. lack of care coord. and follow up, unfamiliarity with local resources, lack of adequate infrastructure, time, reimbursement, lack of health insurance for young adults
- **Lack of Patient Knowledge and Engagement:** eg lack of young adults knowledge about their health, meds, readiness for adult care and adult system and dependence on parents, poor adherence to care
- **Lack of Comfort with Adult Care:** e.g. lack of Pediatric clinician confidence in adult care, stylistic differences between ped and adult practice, parents' reluctance to lose control and unaware of privacy changes, loss of strong relationships

Evidence of Adverse Effects Associated with Lack of a HCT Process*

*Especially for those with chronic conditions

- Medical complications
- Lower self-reported health and wellbeing
- Problems with treatment and medication adherence
- Discontinuity of care
- Youth/young adult/ family dissatisfaction
- Inc. hospitalizations and ER use
- Higher costs of care

Evidence for Structured Transition Process

Systematic review of HCT evaluation studies between 1995-2016. With a structured transition process, statistically significant positive outcomes for YSHCN:

- **Population health:** adherence to care, self-care skills, quality of life, self-reported health
- **Experience of care:** increased satisfaction, reduction in barriers to care
- **Utilization:** decrease in time between last pediatric and 1st adult visit, increase in adult visits, decrease in ER and hospital admissions and LOS
- **Cost (2 new studies):** hospital savings for patients with Type 1 diabetes and medically complex population
- **Note:** many structured HCT interventions included several elements of the 6 Core Elements process

Sources:

Gabriel et al., Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *Journal of Pediatrics.* 2017;188:263-269.

Maeng et al., Impact of a complex care management model on cost and utilization among adolescents and young adults with special care and health needs. *Pop Health Mgmt.* 2017;20(6):435-441.

Burns et al., Access to a youth-specific service for young adults with Type 1 diabetes mellitus is associated with decreased hospital length of stay for diabetic ketoacidosis. *Int Med J.* 2018;48(4):396-402.

Reaffirmed 2011 AAP/AAFP/ACP Clinical Report on Health Care Transition*

- Targets all youth, beginning at age 12
- Algorithmic structure with emphasis on planning:
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
- Extends through transfer of care to adult medical home and adult specialists
- Proposed pediatric practice discuss HCT policy, initiation and update a HCT plan, communicate with adult provider, exchange a medical summary and adult practice clarify medical decision making support continued self care development, how to access after hours care

Age 12	Youth and family aware of transition policy
Age 14	Health care transition planning initiated
Age 16	Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care
Age 18	Transition to adult approach to care
Age 18-22	Transfer of care to adult medical home and specialists with transfer package

*Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home (*Pediatrics*, July 2011)

Updated HCT Process and Implementation

- **Definition:** HCT is the process of moving from a child to an adult model of health care with or without a transfer to a new clinician
- **Transition Goals for Youth/Young Adults and Clinicians:**
  - To improve the ability of youth and young adults to manage their own health and effectively use health services
  - To have an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care

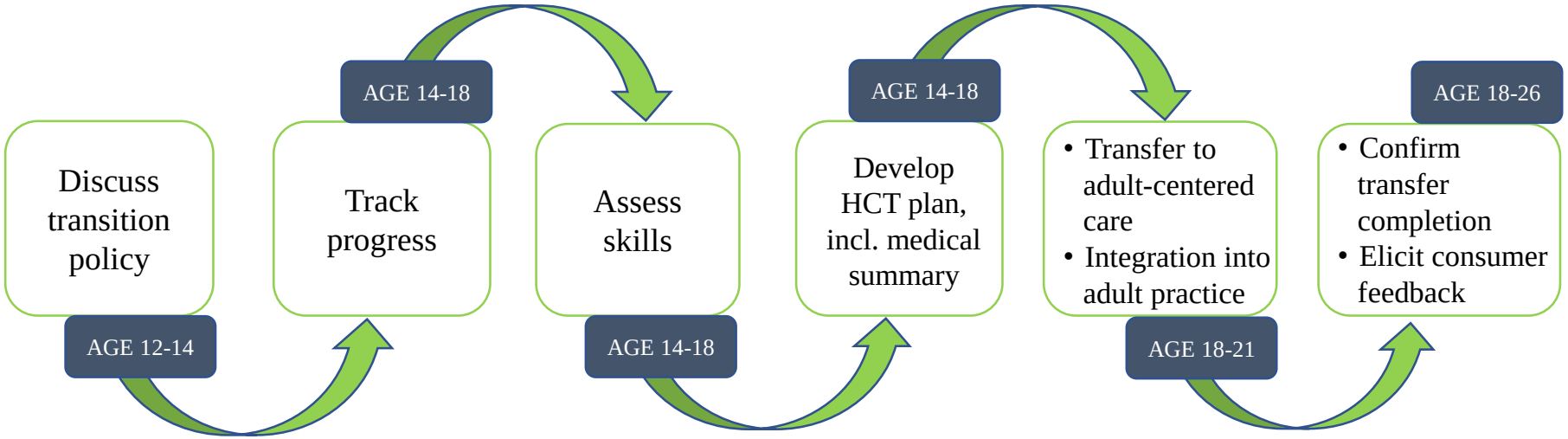
Updated HCT Process and Implementation

- Reaffirms that TRANSITION ≠ TRANSFER or PLANNING alone
- TRANSITION = planning, transfer and integration into adult care
- Provides more clarity, specificity and practical guidance on three components of transition process.
  - **Planning:** Emphasis on practicing an adult model of care at age 18, on time alone with clinician, guidance on how to independently use health care and assistance with identifying a vetted adult PCP, actively engage youth in HCT and conveying positive messages about the adult clinicians and the differences in the systems of care
  - **Transfer:** Emphasis on improved communication strategies, check lists including medical summaries shared with youth/young adults and responsibility of pediatric practice until 1st adult visit
  - **Integration:** Emphasis on adult clinician's role: development of processes for adult providers to welcome young adults into their practice, responsibility with pediatric clinicians on improving adherence to care

Updated HCT Process and Implementation

- Learning that
  - transition is a three stage process all of which are equally important
  - a structured process is a key component for HCT process improvement
- Got Transition translated the 2011 AAP/AAFP/ACP CR for clinical practice and then with extensive involvement of experts and teams developed and tested the 6 Core Elements Process in many settings
  - Tested in QI learning collaboratives in DC*, MA, NH, WI, MN, CO using IHI breakthrough QI research approach
  - Took learnings from LCs and gained further input from transition experts including clinicians, clinic staff, youth, young adults and families
  - In 2014, released the Updated 6 Core Elements process for different clinical settings (peds, med-peds, family and internal medicine) along with tools for customization and measurement options

Six Core Elements of Health Care Transition™ Approach



Got Transition's Six Core Elements Approach and Tools

- Based on the 2011 AAP/AAFP/ACP Clinical report
- Six Core Elements available in three packages with sample tools for each core element
  - includes measurement options
  - can be used by all members of the health care team
- Tools between 6-9th grade reading level and Spanish translations available
- FREE (download www.gottransition.org)
- CUSTOMIZABLE tools and process
  - use what works for your clinical setting
  - use your own logos on the tools with credit to federal finding source
  - tip Sheet on Starting a HCT Improvement Process

Transitioning Youth to Adult Health Care Providers
(Pediatric, Family Medicine, and Med-Peds Providers)

Transitioning to an Adult Approach to Health Care Without Changing Providers
(Family Medicine and Med-Peds Providers)

Integrating Young Adults into Adult Health Care
(Internal Medicine, Family Medicine, and Med-Peds Providers)

Summary of Six Core Elements of Transition Approach Roles for Pediatric and Adult Practices*

* Providers that care for youth/young adults throughout the life span would complete both sets of core elements without the transfer process

Practice/ Provider	#1 Transition policy	#2 Tracking and Monitoring	#3 Transition readiness/ Orientation to adult practice	#4 Transition planning/ Integration	#5 Transfer of care/Initial visit	#6 Transition Completion/ Ongoing care
Pediatric*	Create and discuss with youth/family	Track progress of youth/family readiness for transition	Transition readiness assessment (RA)	Develop transition plan including needed RA skills	Transfer of care with information and communication	Obtain feedback on the transition process
Adult*	Create and discuss with young adult (YA)/ guardian, if needed	Track progress to increase YA's knowledge of health and adult health care system	Share/discuss Welcome and FAQs letter with YA/guardian, if needed	Update transition plan with additional skills required	Self care assessment	On going care with self care skill building

Six Core Elements™ Process

- Six Core Elements is not a model of care but a process (road map) that should be customized for use in busy practices with different models of care. Intensity of the intervention should be guided by: medical complexity of the youth/young adults, social determinants of health, ACEs and the availability of practice resources.
- Applied in many different systems/models of care: primary* and subspecialty clinics*, Medicaid managed care*, prof org.*, state title V agencies, care coordination services*, children's hospitals*, FQHCs, SBHCs, behavioral health settings. All have incorporated the 6 Core Element Process and improved their HCT processes.
- Since the release of the updated 6 CE in 2014 to 8/2018, 1,836 customizable word 6CE packages have been downloaded and 41, 290 views of the HCP web page have occurred.

*published articles

Updated CR Discusses

- Special Populations Issues
  - Young adults
  - Developmental/intellectual disabilities
  - Medical complexity
  - Mental or behavioral health conditions
  - Social complexity with or without chronic conditions
- Education and Training in the Care of Youth/Young Adults with Pediatric onset conditions: e.g., resident training examples, MOC opportunities, available Med-Peds and other curriculum, new books on HCT
- Current payment opportunities (e.g., billing for a variety of readiness assessments)

Infrastructure Recommendations

To address infrastructure gaps, the following recommendations are called for:

1. Integrate HCTs into routine preventive* primary, specialty and subspecialty, and mental/behavioral health care.
2. Support QI processes within health care systems and pediatric and adult practices to:
   - Implement a structured HCT process (e.g. the Six Core Elements approach) with active youth, young adult, and family engagement and feedback.
   - Work directly with their electronic health record (EHR) support team/vendor representative to integrate the Six Core Elements (transition policy, registry, readiness and self-care assessments, transition plan of care, medical summary, transition/transfer checklists, and feedback surveys) in a way that supports their own workflow and practice needs.
3. Incorporate HCT support as a recommended element in all medical home** and health home recognition and certification programs, including standards developed by the National Committee for Quality Assurance, The Joint Commission, and the Utilization Review Accreditation Commission.

*New Got Transition and Univ. of CA Tip Sheet, "Incorporating Health Care Transition Services into Preventive Care For Adolescents and Young Adults: A Tool Kit for Clinicians"
**Incorporating Pediatric-to-Adult Transition into NCQA Patient-Centered Medical Home Recognition

Infrastructure Recommendations Cont.

4. Articulate specific HCT roles and responsibilities among pediatric and adult health care clinicians/ systems to facilitate the provision and coordination of recommended transition support.
5. Increase the availability and quality of care coordination support, particularly for adult practices/ systems serving young adults with chronic medical and behavioral conditions and social complexity.
6. Integrate health care transition support into other life course systems such as in education, independent living, employment, decision making support, and power of attorney as needed.
7. Expand the availability of pediatric consultation for adult clinicians caring for youth with pediatric-onset conditions.
8. Incorporate HCTs into the transition policies and plans of other public program systems (e.g., special education, foster care).
9. Create up-to-date listings of community resources (e.g., adult disability programs) and adult clinicians interested in caring for young adults with pediatric-onset conditions and other special populations.

Education and Training Recommendations

In partnership with families and youth, increase education and training opportunities for pediatric and adult health care clinicians in HCT, youth and young adult development, pediatric-onset diseases, inter-professional practice, and team-based care by adding:

1. CME opportunities (e.g., learning modules such as focusing on young adult health and pediatric onset conditions, clinical experiences, curriculum, and intraprofessional training opportunities)
2. Enhanced training opportunities during residency and subspecialty training, including joint pediatric and adult training
3. HCT processes and support into education systems such as school-based health centers, college and university clinics.

Payment Recommendations

To align HCT delivery system innovations with payment incentives, public and private payors and their contracted plans should:

1. Compensate clinicians and systems of care for the provision of recommended HCT support related to planning, transfer, and integration into a new adult practice
2. Recognize and pay for CPT and Healthcare Common Procedure Coding System (HCPCS) codes important to transition to adult care
3. Develop a CPT Category II code that can be used as a quality measure for tracking the use of transition services by pediatric and adult clinicians

Payment Recommendations Cont.

4. Develop innovative payment approaches to encourage collaboration between pediatric and adult care clinicians in the adoption of HCT processes, including the following:
   - Financial incentives for collaboration between pediatric and adult practices around HCT
   - A per-member per-month additional payment involved in preparing youth, young adults for transfer out of pediatric care and for outreach and follow up of young adults coming into a new adult care setting
   - Performance-based incentives to encourage pediatric practices to transfer their patients at a certain age with a current medical summary, readiness assessment, and evidence of communication with the new practice and to encourage adult practices to accept a certain volume of new young adults with SHCN with pediatric consultation support
   - Payment rates for transition as well as future related research and evaluation studies should stratify for patient risk, taking into consideration not only disease complexity but also social determinants of health, adverse childhood experiences, and availability of family and community supports

New Report on HCT Value-Based Payment Approaches

- New 2018 Payment Leadership Roundtable Report, published by Got Transition, based on interviews with 65 key informant interviews and 24 roundtable participants representing:
  - Payers
  - Professional association officials/clinicians
  - Consultants/researchers
  - Foundation/federal/advocacy leaders
- Roundtable participants prioritized:
  - Value Based payment recommendations (top three: Enhanced FFS, infrastructure investment and pay for performance)
  - Transition Quality measures in population health, experience of care and utilization and cost
- Annually updated Coding and Reimbursement Tip Sheet available
- Both available at www.gottransition.org

Research Recommendations

To promote a stronger evidence base for HCT, funders and researchers should consider:

1. Incorporate all 3 components of HCT—preparation, transfer, and integration into adult care—in their study design and evaluate HCT processes and outcomes.
2. Examine transition outcomes in terms of population health (e.g., adherence to care, self-care skill development); experience of youth, young adults, and families; and utilization (e.g., time between last pediatric and first adult visit, adherence to initial and follow-up adult clinician appointments, decreased emergency room use, and urgent care visits) and cost savings.
3. Develop pediatric to adult HCT measures as a part of the CMS Child and Adult Core Measure Set and the National Quality Forum measures.
4. Study the impact of HCTs from pediatric to adult health care in terms of long-term outcomes of young adults.
5. Encourage national health surveys to include HCT questions for young adults.

2018 State of Transition Innovation

- HCT is a structured complex health care intervention that takes time, effort and improves outcomes
- Most of pediatric and adult delivery systems are not offering structured transition process; no value based transition payment innovations yet
- Early adopter delivery systems are showing positive results*
- Literature continues to document adverse outcomes and barriers, esp. for those with chronic conditions
- Transition structured process/tested road map available (Six Core Elements),
  - aligns with 2011 and 2018 AAP/AAFP/ACP clinical recommendations
  - offers guidance for all three components of transition
  - can be adapted (customized) into many different care delivery models through a QI process
- This new CR offers recommendations endorsed by the AAP, AAFP and ACP that the transition community can utilize to move the field of transition forward
- Examples of ways to proceed and resources available for many of the recommendations

*Jones MB et al. Evaluation of a Health Care Transition Process in 7 Large Health Care Systems. Journal of Pediatric Nursing 47 (2019) 44–50

Next Steps: Got Transition

5 year federally funded national resource center, 2018-2023

Goals:

1. Increase adoption of evidence-informed HCT interventions
2. Engage youth/young adults/parents in importance of planned transitions
3. Provide education and training on HCT
4. Strengthen HCT evidence and policy analysis
5. Operate a national clearinghouse on HCT (www.gottransition.org)
6. Establish new network with AAP's Medical Home Center and Boston University's Catalyst Center

Next Steps: What You Can Do

- The Transitions Clinical Report Authoring group encourages this audience to share the new 2018 AAP/AAFP/ACP Clinical Report widely and use it and its recommendations to support your HCT efforts
  - For the first time the AAP/AAFP/ACP have a joint press release and will have a joint WebEx available on the updated Clinical Report
  - Report was released on line by *Pediatrics* on Oct 22, 2018 and can be downloaded from www.gottransition.org
- Promote a structured HCT approach to planning, transfer and integration into adult care called for in the Clinical Report and increase the demand from families and youth for improved HCT support

Next Steps: What You Can Do

Got Transition is requesting your expert help in updating the Six Core Elements of Health Care Transition™

Please provide your feedback here:

https://tinyurl.com/6CEsurvey

Thank you!

Thank You and Questions

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