

# Innovations in Health Care Transition from Pediatric to Adult Care

CDC's Sickle Cell Disease Data Collection Program  
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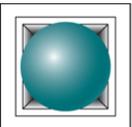
# Disclosures

- The National Alliance to Advance Adolescent Health operates Got Transition, which is funded by the federal Maternal and Child Health Bureau (U1TMC31756).
- No disclosures



# Got Transition

- National Resource Center funded by HRSA's Maternal and Child Health Bureau, 2018-2023
- Goals:
  - Increase adoption of evidence-informed health care transition (HCT) interventions
  - Engage youth/young adults/parents in importance of planned transitions
  - Provide education and training on HCT
  - Strengthen HCT evidence and policy analysis
  - Operate a national clearinghouse on HCT ([www.gottransition.org](http://www.gottransition.org))
  - Establish new network with AAP's Medical Home Center and Boston University's Catalyst Center



# Transition-Aged Population

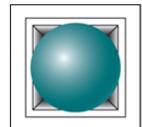
- Sixty-one million, or 19% of US population, between ages 12 and 26
- 25-30% of this transition-age population have one or more chronic conditions
- 2016 results from National Health Interview Survey:

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

Health Care Use Profile	Ages 10-14	Ages 15-18	Ages 19-25
• Has usual source of care	95%	90%	75%
• Had MD visit in past year	81%	77%	56%

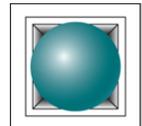
**Source:** Spencer et al. Health care coverage and access among children, adolescents, and young adults, 2010-2016: Implications for future health reforms. *JAH*.2018; 62(6):667-673.



# Receipt of Transition Planning Guidance from Health Care Providers (HCPs)

- 17% of youth with special needs (YSHCN) received transition planning guidance from HCPs, according to 2016 National Survey of Children's Health
- 14% of youth without special needs received transition planning guidance from HCPs
- National Transition Performance Measure:
  - Youth had time alone with HCP during last preventive visit
  - HCP actively worked with youth to gain self care skills or understand changes in health care at age 18
  - HCP discussed eventual shift to an HCP who cares for adults

**Source:** Lebrun-Harris et al., Transition planning among US youth with and without special health care needs. *Pediatrics*. 2018;142(4):e20180194.



# 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

## **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.

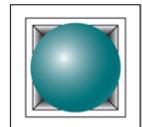
Burns et al., Access to a youth-specific service for young adults with Type 1 diabetes mellitus is associated with decreased hospital length of stay for diabetic ketoacidosis. *Int Med J*. 2018;48(4):396-402.

# Pediatric-to-Adult Clinical Foundations

- 2018 AAP/AAFP/ACP Clinical Report (CR) on Health Care Transition (HCT), newly updated in Pediatrics
- CR calls for all youth and young adults, starting early in adolescence and continuing into adulthood, to receive transition services from HCPs as part of routine care
- CR provides updated HCT processes for transition planning, transfer, and integration into adult care based on the Six Core Elements of HCT

**Source:**

White et al., Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5).

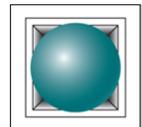
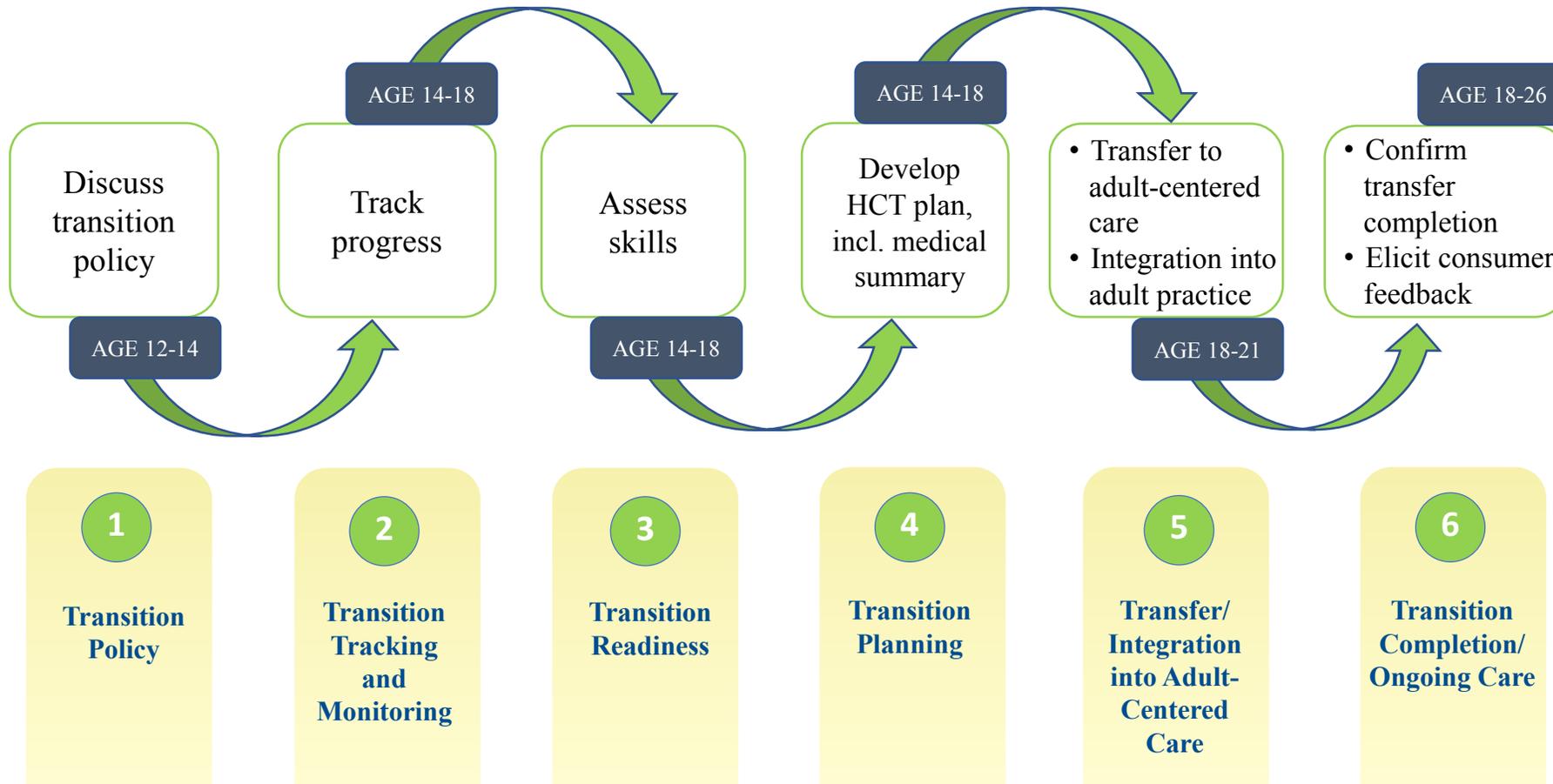


# Health Care Transition

- Goals:
  - To improve the ability of youth and young adults to manage their own health and effectively use health services
  - To ensure an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care
- TRANSITION  $\neq$  TRANSFER
- Transition is an explicit **process** and includes:
  - Planning
  - Transfer
  - Integration into adult health care



# Six Core Elements Approach to Health Care Transition



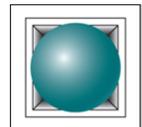
# Got Transition Six Core Elements Approach and Tools

- 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 6-9<sup>th</sup> grade reading level and Spanish translations available
- FREE (download [www.gottransition.org](http://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 funding 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)

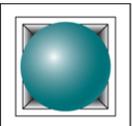
**Integrating Young Adults  
into Adult Health Care**  
(Internal Medicine, Family Medicine, and  
Med-Peds Providers)



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

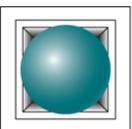
\* Providers that care for youth/young adults throughout the life span would complete both sets of core elements without the transfer process

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
<b>Pediatric*</b>	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
<b>Adult*</b>	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



# TRANSITION POLICY

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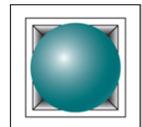


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# Pediatric Core Element #1: POLICY

- **Purpose:** Formalize practice's approach, reduce clinician variability, offer a transparent explicit approach to youth/young adults and families  
\*\*\*Voted most important element by youth and families\*\*\*
- **Content:**
  - Define practice approach and recommended ages for transition preparation for adult-focused care, transfer, and integration into adult care
  - **Key point:** Clarify and practice an adult approach to care at age 18 (including legal changes)
  - Include youth/young adult and family input
  - Reading level should be appropriate
- **Post:** Communicate it to all involved early in the process





# TRACKING & MONITORING

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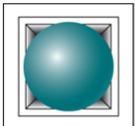


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# Core Element #2: Tracking and Monitoring

- Purpose: Facilitate systematic identification of transitioning youth/young adults (YA) and to track completion of the Six Core Elements
- Content:
  - Demographic and diagnostic/complexity data
    - Stratify those that have poorer outcomes and need more HCT support such as poor compliance in pediatric setting, low SES, cognitive challenges
  - Date of receipt of each core element (eg, policy shared, readiness assessment administered, etc.)
- Format: paper check list, excel spread sheet, EHR





# TRANSITION READINESS

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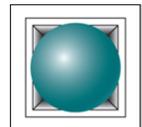


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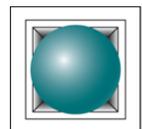
# Pediatric Core Element #3: Transition Readiness

- **Purpose:** Assess the youth's/young adult's skills to manage their health/health care
- **Content:**
  - Ranks importance of changing to adult provider before age 22
  - Ranks confidence about ability of changing to adult provider
  - Assesses self-care skills related to own health and using health care services
- **Use:**
  - Completed (parents and youth) several times during the transition process
  - **Does not predict transition success**
  - Used as a discussion tool to plan disease and skill-building education
  - Customized to meet the needs of the practice's patient population

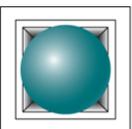


# ACP Council on Subspecialties Transition Initiative

- Partnership with Got Transition in 2016
- Customized Six Core Elements' transition readiness assessment, self-care assessment, and medical summary for selected conditions (teams included representatives from pediatric and adult professional and patient groups):
  - General Medicine (SGIM, SAHM, HCTN, ACP, AAP, AAFP, AOA, Med-Ped Program Directors)
    - ID/DD
    - Physical disabilities
  - Hematology (Hemophilia, Sickle Cell Disease), Cardiology (CHD), Endocrine Society (Diabetes), Gastroenterology (IBD), Neurology (Epilepsy), Nephrology (ESRD), Rheumatology (JIA, SLE)
- Available at [www.GotTransition.org](http://www.GotTransition.org) in News and Announcements or ACP website: [www.acponline.org/acp-newsroom/guidelines-and-tools-developed-for-pediatric-to-adult-health-care-transitions-initiative](http://www.acponline.org/acp-newsroom/guidelines-and-tools-developed-for-pediatric-to-adult-health-care-transitions-initiative)



# TRANSITION PLANNING

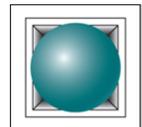


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# Pediatric Core Element #4: Transition Planning

- **Purpose:** Establish agreement between youth and provider about set of actions to address priorities and access current medical information
- **Content:**
  - Identify what matters most to youth in becoming adult beyond health goals
  - Define how learning about health and health care supports youth's over all goals (add readiness assessment skill needs to the plan)
  - Outline and offer education such as disease and self management knowledge and medication and visit adherence (inc. role of disease groups and Family 2 Family info centers)
- **Also complete (update) portable medical summary and emergency care plan with “special information” for adult provider**
  - Include non medical information that the youth and family want to share and will assist the adult provider to engage the youth easily in the first visit



# TRANSFER OF CARE



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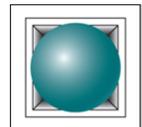


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# Pediatric Core Element #5: Transfer of Care

- **Purpose:** Ensure completion and sharing of transfer package with adult provider and support engagement of young adult with a new clinician
- **Content:** (transfer check list)
  - Transfer letter, clarifying coverage of youth's care until initial adult visit, with transfer package with the last readiness assessment, updated plan of care, medical summary and emergency care plan, condition fact sheet, decision support doc. (if needed),
  - Communicate directly with the adult clinician(s), Use of telemedicine (Face time, ECHO), offer consultation support, agreement to care for young adult until first adult clinician visit completed
- Transfer when disease is stable, stagger transitions with multiple providers, begin with adult PCP



# Core Element #6: Transfer Completion / Ongoing Care

- Transition feedback surveys
  - Learn how the transition process went (share anonymously with pediatric practice) and how integration into the adult practice is going
- Asking for feedback can build a bond between the young adult and the new practice making to less likely the young adult is lost to follow up.

 **Sample Health Care Transition Feedback Survey for Youth**  
Six Core Elements of Health Care Transition 2.0

This is a survey about your experience changing from pediatric to adult health care. You may choose to answer this survey or not. Your responses to this survey are confidential.

1. How often did your previous health care provider explain things in a way that was easy to understand?  
 Always  
 Usually  
 Sometimes  
 Never
2. How often did your previous health care provider listen carefully to you?  
 Always  
 Usually  
 Sometimes  
 Never
3. Did your previous health care provider respect how your customs or beliefs affect your care?  
 A lot  
 Some  
 A little  
 Not at all
4. Did your previous health care provider discuss with you or have an office policy that informed you at what age you may need to change to a new provider who treats mostly adults?  
 Yes  
 No
5. Did you talk with your previous health care provider without your parent or guardian in the room?  
 Yes  
 No
6. Did your previous health care provider actively work with you to gain skills to manage your own health and health care (e.g., know your medications and their side effects, know what to do in an emergency)?\*  
 A lot  
 Some  
 A little  
 Not at all
7. Did your previous health care provider actively work with you to think about and plan for the future (e.g., take time to discuss future plans about education, work relationships, and development of independent living skills)?\*  
 A lot  
 Some  
 A little  
 Not at all
8. How often did you schedule your own appointments with your previous health care provider?  
 Never  
 Sometimes  
 Usually  
 Always
9. Did your previous health care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?  
 Yes  
 No
10. Did your previous health care provider actively work with you to create a written plan to meet your health goals and needs?\*  
 Yes  
 No
11. Did your previous health care provider create and share with you your medical summary?  
 Yes  
 No
12. Did your previous health care provider have information about community resources?  
 Yes  
 No
13. Do you know how you will be insured as you become an adult?†  
 Yes  
 No

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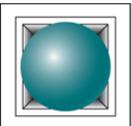
# Current Assessment for HCT: Pediatric Example



## Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers

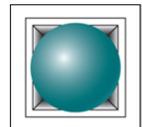
Six Core Elements of Health Care Transition 2.0

Element	Level 1	Level 2	Level 3	Level 4	Score
<b>1. Transition Policy</b>	Clinicians vary in their approach to health care transition, including the appropriate age for transfer to adult providers.	Clinicians follow a uniform but not a written policy about the age for transfer. The approach for transition planning differs among clinicians.	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information and addresses the practice's transition approach and age of transfer. The policy is not consistently shared with youth and families.	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice's approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12 to 14. The policy is publicly posted and familiar to all staff.	
<b>2. Transition Tracking and Monitoring</b>	Clinicians vary in the identification of transitioning youth, but most wait until close to the age of transfer to identify and prepare youth.	Clinicians use patient records to document certain relevant transition information (e.g., future provider information, date of transfer).	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete some but not all transition processes.	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete all "Six Core Elements of Health Care Transition 2.0," using EHR if possible.	



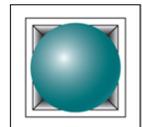
# NEW Young Adult Health Care Transition Quiz: “Are you ready to transition to adult health care?”

- Created by GT Young Adult Advisory Group and available on GT’s Youth & Families page <http://gottransition.org/youthfamilies/index.cfm>
- Questions:
  - Do you see a doctor that sees adult patients, or a doctor who sees only children?
  - Do you know the phone number of your doctor's office?
  - Do you know what to do if you feel sick but the doctor's office is closed?
  - Are you prepared for a health emergency? Do you have your "Medical ID" information (your medical conditions, medications, allergies, and insurance information) stored in your phone?
  - Do you have health insurance? If not, do you know how to get health insurance?
  - Do you know how your health care privacy changes at age 18?



# Transition Efforts in State Public Health Programs (Title V)

- HRSA's Maternal and Child Health Bureau, in 2015, established a performance measurement framework, with 15 possible national measures for states to select, including:
  - Increase the percentage of adolescents with and without special health care needs who receive services necessary to make transitions to adult care.
- 32 states (including DC) and 5 territories selected HCT as one of their measures.
- Got Transition conducts annual reports reviewing innovative state HCT approaches related to practice improvements, health professional and consumer education and training, communications, and interagency planning efforts



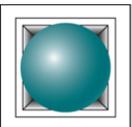
# State Title V Agencies and Care Coordination

- Since so many Title V Programs for YSHCN support care coordination, Got Transition requested 32 states to complete the “Current Assessment of HCT Activities” (customized from Six Core Elements)
- States rank level of implementation for each core element (1 to 4).
- Survey was conducted in 2017 and 2018, with plans to conduct annually; 91% response rate
- Key findings: In 2018, states received an overall average score of 15 out of total of 28, up from 13.8 in 2017 – an improvement, but not statistically significant. Transition readiness assessments – greatest improvement. Opportunities for improvement in ALL core elements, but esp. youth and family engagement, transfer of care, and transition completion



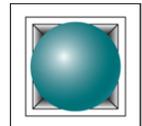
# Additional Transition Resources

- In 2018, updated AAP/AAFP/ACP Transition Clinical Report released – *Pediatrics* online and Nov. publication. [pediatrics.aappublications.org/content/early/2018/10/18/peds.2018-2587](http://pediatrics.aappublications.org/content/early/2018/10/18/peds.2018-2587)
- 2018 Transition Coding and Reimbursement Tip Sheet – Tip sheet of transition-related CPT codes, corresponding Medicare fees and RVUs and clinical vignettes. <http://gottransition.org/resourceGet.cfm?id=368>
- Recommendations for Value-Based Transition Payment for Pediatric and Adult Systems: A Leadership Roundtable Report – Report presenting new value-based payment recommendations for pediatric to adult health care transition, It is intended to guide commercial and Medicaid payers, health plans, employers, and pediatric and adult systems of care in implementing and evaluating payment options for transitional care. [[tinyurl.com/VBPreport](http://tinyurl.com/VBPreport)]
- Webinar Series: Health Care Transition & Title V Care Coordination Initiatives – This five-part Webinar Series features examples of best practices among state Title V agencies, tools and resources, and problem-solving strategies. [gottransition.org/webinars/](http://gottransition.org/webinars/)
- Incorporating Health Care Transition Services into Preventive Care for Adolescents and Young Adults: A Toolkit for Clinicians – Toolkit providing suggested questions and anticipatory guidance for clinicians to introduce health care transition during preventive visits with early adolescents (ages 11-14), middle adolescents (ages 15-17), late adolescents (ages 18-21), and young adults (ages 22-25). [[gottransition.org/resourceGet.cfm?id=468](http://gottransition.org/resourceGet.cfm?id=468)]
- Transition Planning Among US Youth With and Without Special Health Care Needs– This article, published in *Pediatrics* in October 2018, shows that nationally, only 17% of youth with special needs and 14% of youth without special needs receive guidance on planning for health care transition from teen health care providers. [[gottransition.org/resourceGet.cfm?id=481](http://gottransition.org/resourceGet.cfm?id=481)]



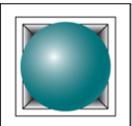
# State of Transition Innovation

- In early stages of implementing this complex intervention
- Vast majority of pediatric and adult delivery systems NOT offering structured transition process; no VBP transition payment innovations as yet
- Adverse outcomes resulting, especially for those with chronic conditions
- Increasingly pediatric ambulatory and hospital systems are establishing age limits, but without readily identifiable adult ambulatory and hospital systems and without Y/YA prepared for adult-focused care
- Structured HCT approach/tested product available (Six Core Elements), which aligns with 2018 AAP, AAFP, ACP clinical recommendations
- Pediatric and adult care systems need to customize and pilot Six Core Elements to create operational processes
- Payers need to find and support pediatric and adult systems to establish needed transition infrastructure, invest in early adopters, share results, and disseminate widely and quickly!



# Conclusion

- Patterns of care established in adolescent and young adult years have long-term impacts on future adult health. Payers, employers, health plans, and public health programs have a critical role to play in establishing the needed infrastructure within and between pediatric and adult delivery systems to ensure a safe and effective transition from pediatric to adult health care.



# Want more information? Got Transition: Federally funded resource center on HCT: [www.gottransition.org](http://www.gottransition.org)

**What is Health Care Transition?**  
Health care transition is the process of changing from a pediatric to an adult model of health care. The goal of transition is to optimize health and assist youth in reaching their full potential. To achieve this goal requires an organized transition process to support youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without disruption in care.

**What are the Six Core Elements?**  
The Six Core Elements of Health Care Transition 2.0 define the basic components of health care transition support. These components include establishing a policy, tracking progress, administering transition readiness assessments, planning for adult care, transferring, and integrating into an adult practice.

**Recommended Health Care Transition Timeline**

AGE	12	14	16	18	18-22	23-26
Make youth and family aware of transition policy						
Initiate health care transition planning						
Prepare youth and parents for adult approach to care and discuss transfer to adult health care						
Transition to adult approach to care						
Transfer care to adult medicine or specialty with home and/or specialists with transfer package						
Integrate young adults into adult care						

**How do I implement the Six Core Elements?**  
As all transition approaches need to reflect the local capacity, a quality improvement (QI) approach has been a successful and efficient way to implement the Six Core Elements. To begin your QI process, assemble a team with pediatric and adult providers, clinic support staff, and youth and family consumers to review, customize, test and disseminate each of the core elements.

**How can I assess my progress in implementing the Six Core Elements?**

**Youth & Families** [En Español]

**What is Health Care Transition?**  
Health care transition is the process of getting ready for health care as an adult. During childhood, parents usually help with medical needs—they call for doctor appointments, fill out forms, and keep track of medications. As youth get older, managing medical needs becomes their own responsibility. Achieving this independence requires an organized transition process to gain independent health care skills, prepare for an adult model of care, and transfer to new providers. There are several steps you can take to make sure the transition to adult health care goes smoothly. Be sure to also check out our Resources section for additional information.

**Health Care Transition FAQs**  
Transitioning from childhood to adulthood is exciting and challenging—both as a young person and as a parent of a young person. Preparing for health care transition often receives less attention than preparing for other transitions in school, work, relationships, and independent living. We're here to help you know everything you need to about health care transition. Below is a set of Frequently Asked Questions with answers provided by experienced youth, young adults, and parents. The questions are organized into six steps:

discovering → tracking → preparing → planning → transferring → completing

**discovering: learn about your doctor's approach to transition**

- What should I be asking my doctor about transition?
- I go to a pediatric doctor; why do I have to change?
- My doctor is a family medicine physician who I plan to stay with as an adult, so why do I have to think about transitioning?

# Thank You and Questions



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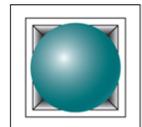


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