Primary Care Provider Toolkit for Supporting Transition of Youth from Pediatric to Adult Health Care

INTRODUCTION

For the purpose of this Toolkit, health care transition (HCT) is defined as the purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented health care systems. HCT is a **process** where the responsibility for managing health care shifts from the parent/caregiver to the young adult. In an ideal setting, the patient should receive uninterrupted and developmentally appropriate medical care.

In 2018, The American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) updated their original 2011 clinical report on health care transition. This updated clinical report, "Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home," provides practice-based quality improvement guidance on key elements of transition: planning, transfer, and integration into adult care.

Despite the recommendations, the 2017/2018 National Survey of Children's Health revealed that the majority of youth (age 12-17 years old) with and without special health care needs (SHCN) are not receiving necessary support for transition from their health care providers. According to the data, less than 20% of youth receive appropriate transition support which suggests improvement efforts are necessary to promote positive health outcomes and lifelong surveillance.

This toolkit was developed for primary care providers (PCPs) to utilize during HCT and includes resources for PCPs, patients and parents/caregivers. These tools can be used to facilitate successful pediatric to adult transition planning.

White P.H. & Cooley W.C., Transitions Clinical Authoring Group, et al. (2018) Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics.* 2018;142(5):e20182587.

Got Transition. State, Region, and National Health Care Transition Performance for Youth With and Without Special Health Care Needs: The National Survey of Children's Health 2017-2018. Washington, DC: Got Transition, 2018.

BACKGROUND

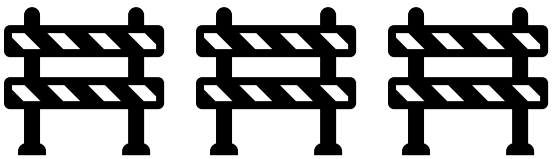
Adolescents and young adults are recognized as a vulnerable population in terms of higher rates of behavioral health risks and traditionally under-utilization of health care.

A smooth transition from pediatric/adolescent to adult healthcare is important for continuity of care, which has been associated with improved health outcomes, including lower frequency of hospital admissions and emergency room visits and increased use of preventive services.

The role of the pediatrician is to ensure an organized process to facilitate transition preparation, transfer of care, and integration into adult-centered health care. In an ideal transition scenario, the PCP will empower adolescents and young adults with and without SHCN to manage their own health care and effectively navigate health services.

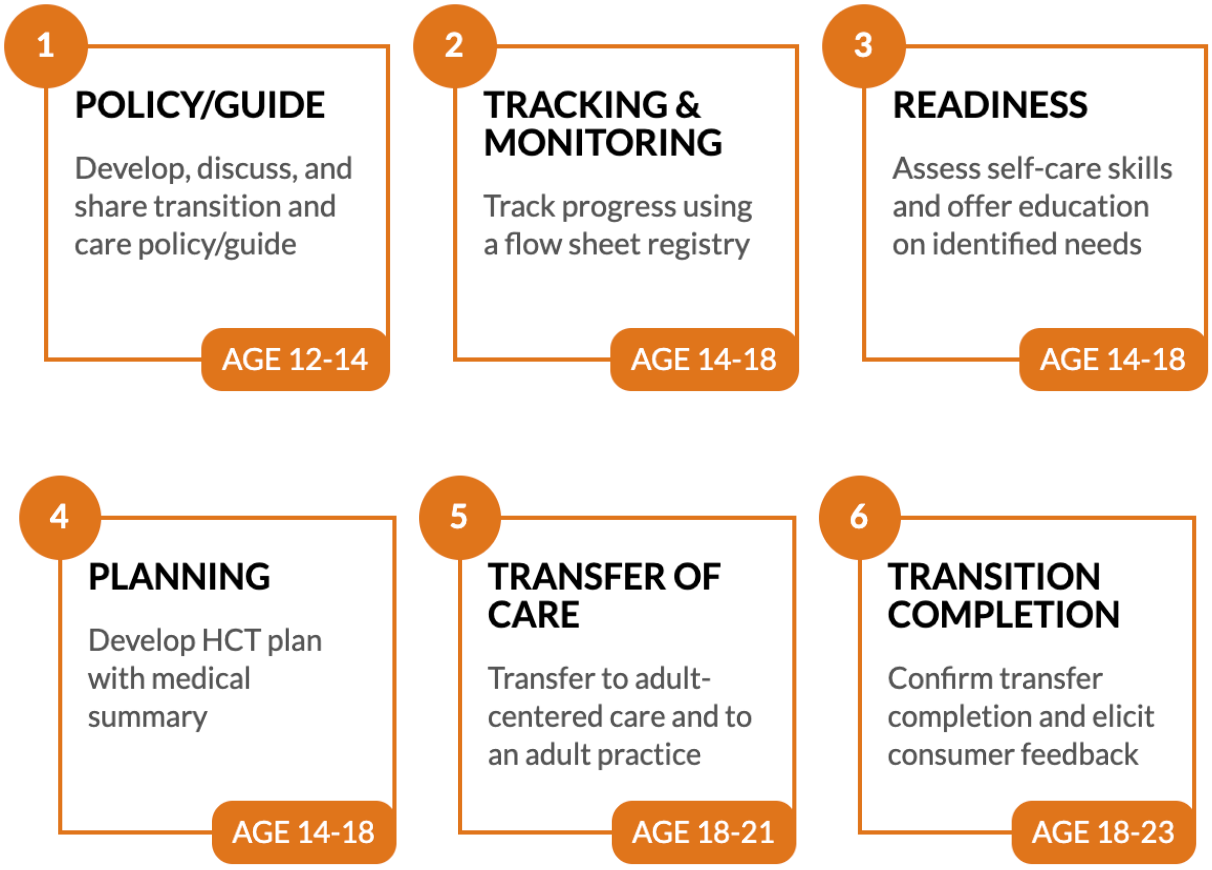
BARRIERS TO SUCESSFUL TRANSITION

- Patients may fear leaving a provider who has known them all their lives, particularly if they have complex medical problems, developmental and/or intellectual disabilities, mental and/or behavioral health conditions.
- Parents who remain over involved (continue to schedule and accompany their children to their appointments) even after they turn 18
- Loss to follow up once patient enters college (misconceptions about health conditions or distance from provider)
- Time constraints during office visits



GOT TRANSITION® SIX CORE ELEMENTS

Got Transition® is a program of the National Alliance to Advance Adolescent Health. The Six Core Elements define the basic components of a structured HCT process, which include establishing a transition and care policy/guide, tracking and monitoring progress, administering transition readiness assessments, planning for an adult approach to care, transitioning to an adult approach to care, and continuing with ongoing care. This HCT approach, recommended in the 2018 AAP/AAFP/ACP Clinical Report, can be customized for practices serving young adults.



Overview: Transitioning Youth to an Adult Health Care Clinician
https://www.gottransition.org/6ce/?leaving-overview

1. TRANSITION POLICY

Below is a transition policy which was created by the MGH Transitions Committee and Transitions Program. It is recommended that this policy be distributed to adolescents and their parents beginning at age 12 to 14 and regularly during wellness exams in accordance with AAP/AAFP/ACP recommendations.

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Transition of Care Policy for Youth and Young Adults

Massachusetts General Hospital is committed to a transition from pediatric care to adult care. We feel that a smooth transition from adolescence to young adulthood requires preparation and planning. We look forward to working with you and your family on this journey.

MGH TRANSITION POLICY

"As recommended by the American Academy of Pediatrics, we at Massachusetts General Hospital want to support your smooth transition from our practice to adult-oriented care. Our office endorses and follows the policies below to help you (and your parents) prepare you for adult care and adulthood.

- Transition planning, preparation, and training will start by age 12.
- At age 18, most youth in our practice will transition to an adult model of care with modifications as needed for youth with intellectual disabilities.
- We respect the preferences of the youth and family regarding the eventual transfer of care to an adult primary care medical home, but this tends to occur between age 18 and 22.
- A health summary which includes past medical history, current medications and pertinent care plan with specific recommendations will be provided prior to transfer."

Click here for a PDF copy for your practice.

2. TRACKING & MONITORING (AGES 14-22)

A transition registry can be used to identify track and monitor youth throughout the pediatric-to-adult health care transition process. Goal is to stratify those that need more HCT support (non-compliance in pediatric setting, low SES, cognitive challenges)

A registry can be on paper, an Excel spreadsheet, or if possible integrated into the EMR.

Sample Transition Registry from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *https://gottransition.org/6ce/?leaving-registry*

Sample transition flow sheet from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" https://gottransition.org/6ce/?leaving-flow-sheet

3. TRANSITION READINESS ASSESSMENT (BEGIN AT AGE 14–16)

Providers should begin to allocate time alone with patient (Adult Model of Care). Regular transition readiness assessment should be conducted to identify and discuss with youth and parent/caregiver their needs for self-care and how to engage in health care services. Continue assessments throughout the HCT period until the youth has transferred.

Adolescents and young adults should be able to identify their medical problems, medications and allergies without support from their parents, or at least know how to access that information. Education and resources should be offered based on needs identified from assessment.

Transition Readiness Assessment Questionnaire (TRAQ)
Validated tool comprised of 20 questions divided into 5 subcategories

- Managing medications
- Appointment keeping,
- Tracking health issues,
- Talking with providers
- Managing daily activities.

Patient Name: _____ Date of Birth: ___/___/___ Today's Date ___/___/___ (MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes ***your*** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***your*** skill level. **Check here** if you are a parent/caregiver completing this form. ☐

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

https://carma.massgeneral.org/clinical_topics/transitions/TRAQ5.pdf

Developing workflow processes in which the assessment tool is completed prior to the start of the visit (such as when patient in exam room waiting) can allow the patient to gain a sense of privacy as well as not feel rushed. The TRAQ can be used as a discussion tool to plan disease and skill-building education.

TRANSITION PLANNING (AGE 14 – 18)

- Develop and regularly update transition care plan, including readiness assessment findings, youth's goals and prioritized actions.
- Maintain a brief medical summary with basic information such as such as allergies, surgeries and medications can be easily shared with new providers and specialists (maintained in EPIC).
- Prepare youth and parent/caregiver for an adult approach to care and the optimal timing of transfer.
- Assist youth in identifying an adult clinician and provide insurance resources, self-care management information, and community support services.

• TRANSFER OF CARE (AGE 18-21)

- Ensure completion and sharing of transfer package (use Transfer Checklist to confirm all items are in EMR) Transfer youth/young adult when their condition is as stable as possible. https://gottransition.org/6ce/?leaving-transfer-checklist
- Communicate directly with selected adult clinician about pending transfer of care. Offer consultation support and agree to care for patient until youth/young adult is seen by an adult clinician.

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Sample Transfer of Care Checklist

Preferred name *Legal name* *Date of birth*

Primary diagnosis

Social/Medical complexity information

TRANSFER OF CARE

Prepared transfer package including: _____ *Date*

- ☐ Transfer letter, including date of transfer of care
- ☐ Final transition readiness assessment
- ☐ Plan of care, including transition goals and prioritized actions
- ☐ Medical summary and emergency care plan
- ☐ Guardianship or health proxy documents, if needed
- ☐ Condition fact sheet, if needed
- ☐ Additional clinician records, if needed

Sent transfer package _____ *Date*

Communicated with adult clinician about transfer _____ *Date*

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6. TRANSITION COMPLETION

Contact youth/young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm attendance at first adult appointment.

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BENEFITS OF A STRUCTURED APPROACH

PATIENT OUTCOMES

- Enhanced self-management skills and self-esteem
- Increase in access to resources as they are needed
- Increased confidence in their physician and team of providers
- Decrease in ER visits, hospitalizations, & school absences

PARENT/CAREGIVER OUTCOMES

- Improved satisfaction with team communication
- Decreased worry and frustration
- Increased sense of partnership with professionals

PRACTICE/SYSTEM OUTCOMES

- Decreased fragmentation and duplication
- Better documentation and transmission of information
- Improved communication and coordination
- More cost-effective use of resources
- Improved communication and coordination of care

***Complete Transition Package liked below. All items are free and customizable. Use what works for your practice and add MGH logos*.**

https://www.gottransition.org/6ce/?leaving-full-package

ADDITIONAL RESOURCES FOR PROVIDERS:

Condition-Specific Tools from the American College of Physicians are available for the following subspecialties: general internal medicine (intellectual/developmental disabilities and physical disabilities), cardiology, endocrinology, gastroenterology, hematology, nephrology, and rheumatology.

Coding and Reimbursement Tip Sheet. Got Transition and the American Academy of Pediatrics developed a transition payment tip sheet to support the delivery of recommended transition services in pediatric and adult primary and specialty care settings. It provides a summary of alternative payment methodologies and comprehensive listing of transition-related CPT codes and corresponding Medicare fees (2020).

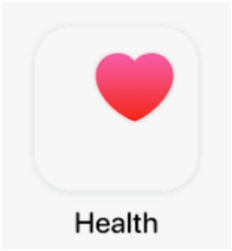
Letter Template to Payers Regarding Recognition of Codes Related to Pediatric to Adult Transition Services. A letter template to payers requesting recognition of transition-related codes. Edit and personalize PDF, or copy and paste into a Word document to edit and personalize, from Got Transition (2017)

RESOURCES FOR PATIENTS & FAMILIES

GOT TRANSITION FAMILY TOOLKIT: PEDIATRIC-TO-ADULT HEALTH CARE TRANSITION: Toolkit developed for families to use during pediatric to adult HCT and includes resources for both parents/caregivers and youth/young adults. https://www.gottransition.org/resource/?hct-family-toolkit

MyMedSchedule Plus:

A mobile app designed to give patients and caregivers access to their medication schedules anywhere they go. Patients can add multiple providers to their care team and receive updated medication schedules from each of their providers all in one place. The app can also automatically provide medication reminders. https://medactionplan.com/mymedschedule/



Patients can set up their Medical ID in the Health app their cellphones. Here are the resources to help:

- https://support.apple.com/en-us/HT207021
- https://www.gottransition.org/resource/?setting-up-medical-id-smartphones

MYHEALTH 3 The MyHealth 3 provides some tips on how patients can describe their health and current needs in about three sentences.
https://www.childrensmercy.org/siteassets/media-documents-for-depts-section/documents-for-your-visit/your-visit-three-sentence-summary-ah.pdf

SickKids

Patients can create a MyHealth Passport which is a customized, wallet-size card that gives them instant access to their medical information.
https://wapps.sickkids.ca/myhealthpassport/Default.aspx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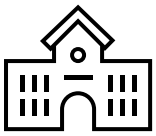
Feelings - Dealing with anxiety and depression: MGHfC handout



General College Health Information

https://youngmenshealthsite.org/guides/college-health/