

Transitioning to Adult-Centered Medical Care

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Overview



- Reasons for Transition to Adult Health Care
- Barriers to Health Care Transition
- How to Prepare for Health Care Transition
- Transition at Akron Children's Hospital



Transition vs. Transfer

- Healthcare transition: the *process* of changing from a pediatric to adult model of health care
 - “purposeful, planned movement... that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive” (Blum et al., 1993)
 - Seeks to optimize health and assist youth in reaching their full potential
- Healthcare transfer: the movement of clinical care from one provider to another
 - A point in time; typically unplanned/unexpected
 - May occur in response to a crisis



Reasons for Transition to Adult Health Care

- Adult conditions are better managed by adult providers
- Specialty care pediatric outpatient providers may be unable to follow adult patients (>18 or 25?) should inpatient care be needed
- Ensures services are available for younger patients



Pediatric vs. Adult Care

Brown et al. 2018

- Pediatric services
 - Family focused
 - Provide developmentally appropriate care
 - Significant parental involvement in decision making
- Adult services
 - Patient focused
 - Require or encourage autonomy and independence in decision making
 - Require consent or guardianship for ongoing parent/caregiver involvement



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VS.



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Transition Barriers

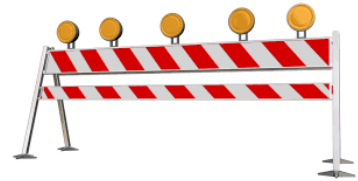


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Transition Barriers

McManus & White 2017

- Barriers cited by pediatric providers
 - Difficulty breaking bonds with patients and their parents
 - Where can I send my patients?
 - Will adult clinicians be sufficiently trained to manage childhood-onset conditions?
 - Lack of time!
- Barriers cited by adult providers
 - Practices are full
 - Inadequate exchange of information with pediatric providers
 - Lack of experience
 - Lack of resources
- Barriers cited by families
 - Difficulty letting go of longstanding relationships with pediatric providers
 - Reluctance of parents to relinquish care and decision-making responsibilities
 - Limited engagement of youth and young adults in transition planning
 - Lack of information about transition and availability of adult providers
 - More rigid eligibility criteria for adult services and disability insurance



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How to Prepare for Health Care Transition

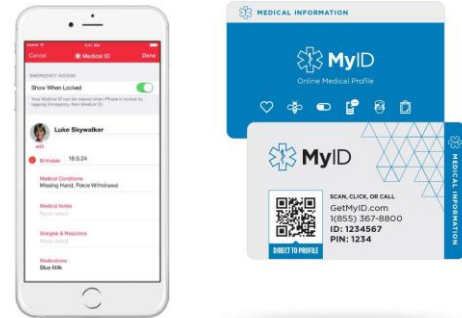


- Start planning early!
- Not a “one-size-fits-all” process
- Get organized
 - Obtain copies of all medical records
 - Work with current providers to create a concise, up-to-date medical summary
 - Verify insurance coverage
 - Consider what decision making supports may be needed for your teen/young adult



How to Prepare for Health Care Transition: Medical Summary

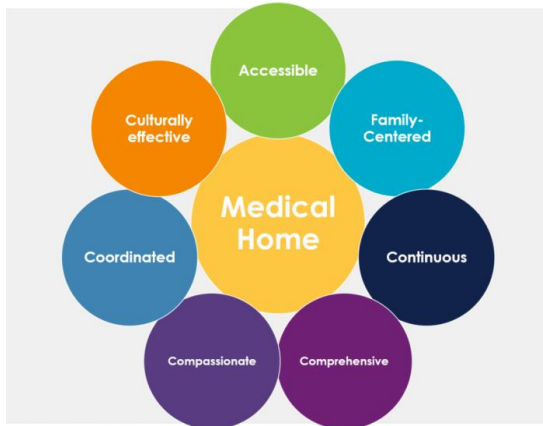
- A condensed but comprehensive health summary
 - Current diagnoses and medications
 - Allergies/procedures to be avoided
 - Vaccination/immunization information
 - Prior surgeries, procedures, hospitalizations
 - Recent labs and scan results
 - Example: <https://gottransition.org/6ce/?leaving-medical-summary-emergency-plan>
- Emergency Care Plan
 - Helpful to have something portable
 - Free Medical ID app (available on Apple and Android devices)
 - MyID Medical Wallet Card or wearable bracelet



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How to Prepare for Health Care Transition: Establishing a Medical Home

- Collaboration with medical team is key
- What type of provider will be the best “coordinator” of care?



Patient-Centered Primary Care COLLABORATIVE

Defining the Medical Home

The medical home is an *approach* to primary care that is:

- Person-Centered**
Supports patients and families in managing decisions and care plans
- Comprehensive**
Whole-person care provided by a team
- Coordinated**
Care is organized across the 'medical neighborhood'
- Committed to Quality and Safety**
Maximizes use of health IT, decision support and other tools
- Accessible**
Care is delivered with short waiting times, 24/7 access and extended in-person hours

4 Source: www.ahrq.gov PCPCC 2014. All rights reserved.



How to Prepare for Health Care Transition: Teen/Young Adult Involvement

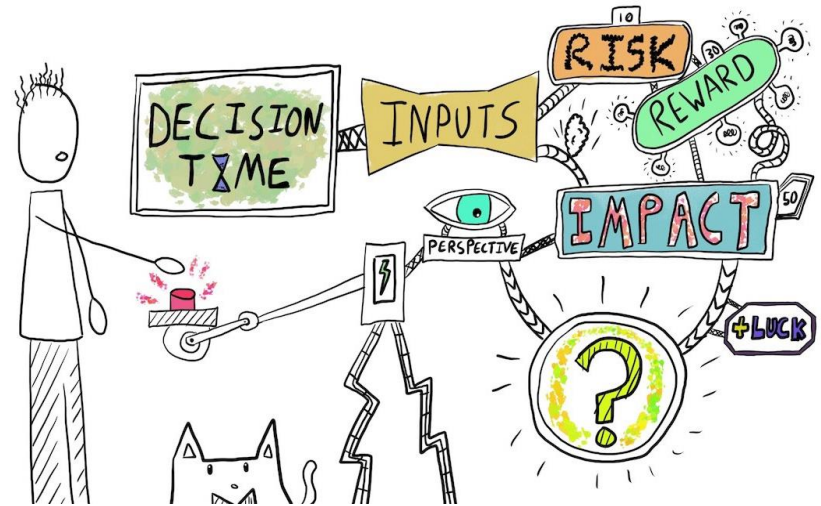


- Talk to your teen/young adult
 - Do they know current diagnoses and medications?
 - What do they know/understand about health insurance?
- Encourage your teen/young adult to:
 - Meet with current providers solo (if possible)
 - Provide medical information, such as current symptoms, and ask questions
 - Make their own appointments, carry their insurance card
 - Call for medication refills
 - Read medical consents/documents
 - Practice making healthy lifestyle choices



How to Prepare for Health Care Transition: Decision Making

- Model decision making for your teen/young adult
- What level of support is needed?
 - Informal advice from family/friends
 - Formal arrangements
 - Release of information (ROI)
 - Durable medical power of attorney or healthcare proxy
 - Guardianship
 - <https://www.disabilityrightsohio.org/guardianship>



Insurance Coverage and Transition: Private Insurance Plans

- Most youth are eligible to stay on their caregiver's plan until age 26
- Useful when:
 - Caregiver can afford to continue paying for health plan
 - Caregiver's plan covers all the young adult's healthcare needs
 - Young adult is ineligible for Medicaid or other public insurance programs
 - Young adult needs a source of insurance while waiting for alternate coverage, like Medicaid
- Less helpful when:
 - Caregiver cannot afford or maintain young adult's coverage
 - Young adult is approaching 26
 - Young adult needs long-term supports not covered by current plan
 - Young adult has access to better or more cost-effective benefits through an employer, health care exchange, or Medicare/Medicaid



Insurance Coverage and Transition:

Medicaid Coverage

- In most states (including Ohio), adults who qualify for SSI disability benefits also qualify for Medicaid
 - Must prove that young adult is unable to engage in “substantial gainful activity”
 - In some instances, an individual can begin working but maintain Medicaid if they earn less than a certain amount per year
- Many states (including Ohio) also have a “Buy-In” program
 - Individuals who are 16-64 years old identified with a disability that are employed in paid work
 - Have a monthly income less than or equal to \$2,603 and less than \$12,175 in resources
 - Pay a monthly premium, based on income level



ACH's Transition Policy

- A work in progress
- Current age limits:
 - Outpatient medical services <26
 - May vary depending on specialty area
 - Important to check with specific providers
 - Exceptions
 - Adult burn patients cared for at ACH Regional Burn Center
 - Adult patients with certain conditions, such as cystic fibrosis, congenital heart disease, and mitochondrial disease
 - Any pregnant woman carrying a fetus where clinical care may be required for impending newborn
 - Children's Home Care Group <22
 - Psychology inpatient and outpatient services <18



Pediatric to Adult Transitions of Healthcare (PATH) Committee

- Purpose: ensure that high-quality transitions occur for patients aging out of Akron Children's Hospital
- Team members from Quality Services, Informatics, Population Health, Medical Staff, Department of Nursing, Social Work, Parent Advisory Council, and Partner Institutions (e.g., Summa)
- Responsibilities:
 - Promote quality improvement in transitioning pediatric patients to adult care
 - Develop and disseminate policies and guidelines surrounding transition of older patients



PATH Progress

- Created an organizational definition of a high quality transition
- Surveyed providers and parents about the current state of transition at ACH
- Building an infrastructure in our electronic medical record to allow for easy and consistent documentation about transition progress
- Developing a more supported, direct “path” for our complex patients at Summa Health



Create Your Own Path



- Transition is a dynamic and fluid process
- Health care transition will look different for every family
- Do not hesitate to ask for help/advice when needed



Healthcare Transition Resources

- Got Transition?
 - <https://www.gottransition.org/>
 - Includes checklists for tracking medical history and assessments to determine how much your teen/young adult knows about their health
- National Collaborative on Workforce and Disability for Youth Healthcare Transition Guide
 - <http://www.ncwd-youth.info/publications/a-young-persons-guide-to-health-care-transition/>
- Cincinnati Children's Transition Resource Page
 - <https://www.cincinnatichildrens.org/patients/child/special-needs/transition/transitions>
 - Includes a summary of transition planning and a list of web-based resources for families
- Online Training Modules for Transition in Autism
 - <https://thompsoncenter.missouri.edu/welcome-to-transition-to-adulthood/>



Healthcare Transition Resources

- Webinar: Understanding Guardianship and Alternatives for Decision-making Support
 - <https://www.youtube.com/watch?v=0xXELClMHHE&feature=youtu.be>
- Tips for talking with health professionals for teens
 - <https://cshcn.org/adolescent-transition/talking-with-health-professionals-for-teens/>
 - <http://kidshealth.org/en/teens/talk-doctor.html>
- Transition Quick Guide: Take Charge of Planning and Managing Your Own Health and Career Goals
 - <https://www.dol.gov/odep/pdf/HealthcareCareerTransitionQuickGuide.pdf>
- Transition to Adulthood: A Health Care Guide for Youth and Families (includes worksheets to teach skills related to medical care management)
 - <http://www.nationaldisabilitynavigator.org/wp-content/uploads/resources-links/ASAN-healthcare-toolkit.pdf>



Insurance Resources

- Medicaid
 - Eligibility: <https://www.medicaid.gov/medicaid/eligibility/index.html>
 - FAQ's: <https://www.medicaid.gov/faq/index.html>
- Ohio Medicaid
 - <https://medicaid.ohio.gov/FOR-OHIOANS/Programs#62374-older-adults--individuals-with-disabilities>
- The Health Insurance Marketplace: Know Your Rights
 - <https://marketplace.cms.gov/outreach-and-education/know-your-rights.pdf>
- Healthcare.gov
 - <https://www.healthcare.gov/>
 - You can enroll in health plans due to the COVID-19 emergency through May 15, or anytime if you have certain life changes or qualify for Medicaid or CHIP.



Pediatric to Adult Transition

February 25, 2021

Carrie Cuomo, DNP, CPNP

Julie Corder, MSN, CPNP



Cleveland Clinic



Agenda

- Introductions
- Review Transition
- Review Work to Date
- Discussion



What Is Transition?

Healthcare transition is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care.

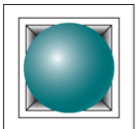


Vision Statement

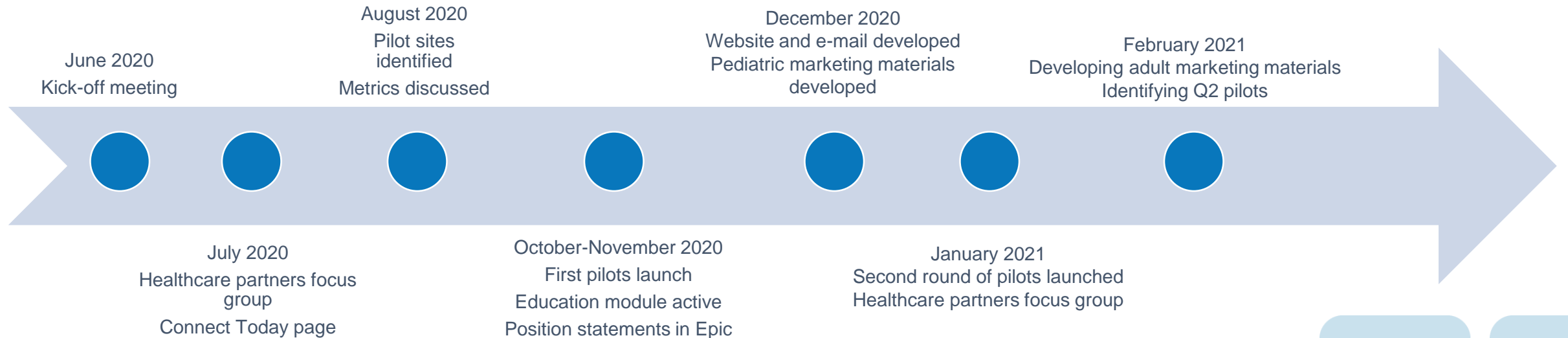
Cleveland Clinic caregivers will partner with patients and their families to successfully transition adolescent and young adult patients from pediatric to adult care, using a thoughtful, consistent and coordinated process.



SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE



Cleveland Clinic Healthcare Transition



Projects completed

- Online education module for all caregivers who interact with patients
- Position statements from 3 different perspectives:
 - Pediatric to Adult Care
 - Pediatric to Adult model of care within Family Medicine
 - Adult care model following transfer
- Marketing tools
- Website with links to Got Transition resources
- Epic tools
 - Position statement included in the After Visit Summary for all youth ≥ 12 yrs of age
 - Readiness assessments annually for all youth at well visits with discussion of goals for coming year/next steps
 - Readiness assessments tailored to youth with ID/DD to plan for needs prior to 18th birthday



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Pediatric to Adult Healthcare Transition

Course Overview

The purpose of this course is to increase your knowledge about transitioning from a pediatric to an adult module of care. This course is for all caregivers who interact with children, young adults, or their parents/guardians. All caregivers at Cleveland Clinic can partner with young adults and their families to improve their transition journey with our guidance and empathy. Transition from pediatric to adult care is similar to other life events: moving from elementary to middle school, gaining independence in making choices and decisions, graduating from school and planning for a fulfilling future! Any transition can be exciting and scary.

Click the radio button below to access the appropriate course for your role:

Course Completion Instructions

This course uses Decision Points to determine which instructional content you need. To receive a **completion status** for this course, you are required to complete the activities based on your responses to the Decision Points.

Transition to Adult Care

Overview

Cleveland Clinic Children's and Cleveland Clinic are here to assist you and your child for their transition to adult medical care.

Why is it so important to transition my child to adult care?

Healthcare transition has become an important area of focus. This may be because evidence shows that adolescents and young adults use of healthcare services declines during this time and that can lead to worse health outcomes.

There are currently 31.2 million young adults in the United States who are transitioning into adulthood. Every adolescent will eventually need to switch to adult-centered medical care and they need a thoughtful, consistent and coordinated process to do so.

Signs my child is ready for adult care

Got Transition®, a federally funded national resource on healthcare transition, says there are key questions to ask yourself.

1. Does your child see a doctor that sees adult patients, or a doctor who only sees children?
2. Does your child know the phone number of their doctor's office?
3. Does your child know what to do if they feel really sick but the office is closed?
4. Is your child prepared for a health emergency? Do they have their "Medical ID" information (their medical conditions, medications, allergies, emergency contact, and insurance information) stored in their phone?
5. Does your child have health insurance? If not, do you know how to help them get health insurance?
6. Does your child know how their health care privacy changes at age 18?

Take Got Transition's "Is your child ready to transition to adult health care" quiz



Is Your Child Ready to Transition to Adult Care?

Every adolescent will eventually need to switch to adult-centered medical care and they need a thoughtful, consistent and coordinated process to do so. Cleveland Clinic Children's and Cleveland Clinic are here to help.

Help prepare your child. Learn more at clevelandclinicchildrens.org/peds2adult.

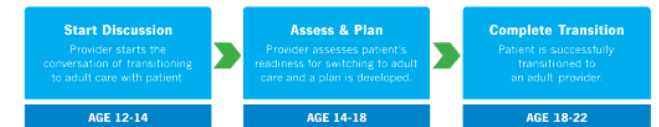


Is Your Child Ready to Transition to Adult Care?

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PEDIATRIC TO ADULT HEALTHCARE TRANSITION



As children grow into young adults, their healthcare needs change. Cleveland Clinic has developed a program to ease the transition to adult healthcare providers for young adults and their families.

Guidelines to Prepare Your Child*

AGE 12-13

- > Help your child learn about their own health condition(s), medications and allergies.
- > Encourage your child to ask their doctor questions about their own health.

AGE 14-15

- > Learn what your child knows about their family medical history.
- > Encourage your child to see the doctor alone for part of their doctor's visit.

AGE 16-17

- > Ask the doctor to talk with your child about their privacy rights when they turn 18.
- > Discuss with your child if they will need help making health care decisions.
- > Talk with your child about the age they want to transfer to a new doctor for adult care.

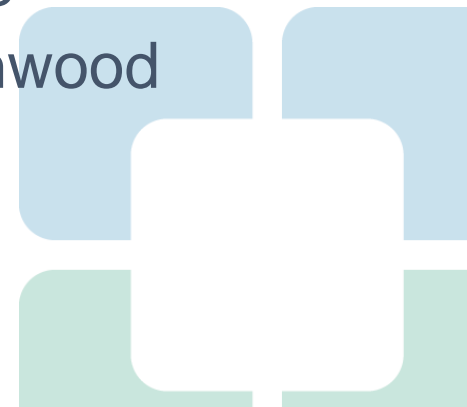
AGE 18-21

- > Ask your young adult to talk to their current doctor about finding them a new adult doctor.
- > Encourage your young adult to call their new doctor and schedule their first appointment.

* Copyright Got Transition® (www.gottransition.org). This version of the Guidelines to Prepare Your Child has been modified and is used with permission.

Projects in progress

- Enhancements to EMR for patients and providers
 - Dashboard for tracking process
 - Readiness assessment – both parent, youth, and parent of ID/DD
 - Medical summary letter
 - Complex medical summary letter
 - Development of micro-learning module for young adults
- Quarterly pilots
 - 2020 – Gen Peds/Int Med Main Campus; Asthma; CP/Rehab
 - 2021 – Q1: Spina Bifida; Nephrology/Transplantation; Beachwood





Every life deserves world class care.