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
Transition Barriers
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
  – Reticence 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
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](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
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?
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

Akron Children’s Hospital
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

From ASAN Healthcare Transition Guide
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

• 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=0xXELCIMHHE&feature=youtu.be](https://www.youtube.com/watch?v=0xXELCIMHHE&feature=youtu.be)

- Tips for talking with health professionals for teens
  - [https://cshcn.org/adolescent-transition/talking-with-health-professionals-for-teens/](https://cshcn.org/adolescent-transition/talking-with-health-professionals-for-teens/)

- Transition Quick Guide: Take Charge of Planning and Managing Your Own Health and Career Goals

- Transition to Adulthood: A Health Care Guide for Youth and Families (includes worksheets to teach skills related to medical care management)
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

- 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
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

1. POLICY/GUIDE
   Develop, discuss, and share transition and care policy/guide
   AGE 12-14

2. TRACKING & MONITORING
   Track progress using a flow sheet registry
   AGE 14-18

3. READINESS
   Assess self-care skills and offer education on identified needs
   AGE 14-18

4. PLANNING
   Develop HCT plan with medical summary
   AGE 14-18

5. TRANSFER OF CARE
   Transfer to adult-centered care and to an adult practice
   AGE 18-21

6. TRANSITION COMPLETION
   Confirm transfer completion and elicit consumer feedback
   AGE 18-23
Cleveland Clinic Healthcare Transition

- **June 2020**: Kick-off meeting
- **August 2020**: Pilot sites identified, Metrics discussed
- **October-November 2020**: First pilots launch, Education module active, Position statements in Epic
- **December 2020**: Website and e-mail developed, Pediatric marketing materials developed
- **February 2021**: Developing adult marketing materials, Identifying Q2 pilots

- **July 2020**: Healthcare partners focus group, Connect Today page
- **January 2021**: Second round of pilots launched, Healthcare partners focus group
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
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:
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.
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
Cleveland Clinic

Every life deserves world class care.