Medical Transition 101: An Introduction

Erica Krapf, PhD
NeuroDevelopmental Science Center
Special Thanks!

- **Panelists**
  - Dr. Irene Dietz from Metrohealth Medical Center
  - Dr. Eileen Herbert from the Cleveland Clinic
  - Dr. William Smucker from Summa Health Medical Group
  - Dr. Nathan Stehouwer from University Hospital’s Cleveland Medical Center

- **Collaborators**
  - Cuyahoga County Board of DD
  - Educational Service Center of Medina County
  - Educational Service Center of Northeast Ohio
  - Live Special
  - Medina County Board of DD
  - Ohio Family to Family
  - Summit DD
  - The Up Side of Downs
Questions You Hope Will Be Answered

• Almost 50 questions submitted at registration
• Key topic areas
  – Transition logistics
  – Finding the right provider
  – Focus on individual healthcare system
  – Insurance coverage
  – Employment opportunities and housing
Introduction

• Reasons for Transition to Adult Health Care
• Barriers to Health Care Transition
• How to Prepare for Health Care Transition
Transition vs. Transfer

• Healthcare transition is 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)
  – Transition seeks to optimize health and assist youth in reaching their full potential.

• Healthcare transfer is the movement of clinical care from one provider to another.
  – This is a point in time and typically unplanned/unexpected.
  – In contrast to a planned transition, “transfer” may occur in response to a crisis, such as an individual aging out of the pediatric system.
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 of the young adult in the decision making process
  – Require consent or guardianship for ongoing parent/caregiver involvement
Transition Barriers
McManus & White 2017

• 25% of youth between ages of 12 and 17 have a special healthcare need
• According to a 2009-2010 survey, 60% of those failed to receive needed transition support
  – Low utilization of medical and behavioral care during late adolescence and young adulthood
  – May lead to poor health outcomes

• 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
Transition Barriers
McManus & White 2017

• Barriers cited by pediatric providers
  – Difficulty breaking bonds with patients and their parents
  – Difficulty identifying available adult clinicians
  – Concern that adult clinicians may not be sufficiently trained in the care of young adults with childhood-onset, complex medical conditions
  – Lack of time and staff support to fully address transition concerns

• Barriers cited by adult providers
  – Practices are full
  – Inadequate exchange of information with pediatric providers
  – Lack of experience with complex conditions and developmental stages of young adults
  – Lack of resources, such as adult medical specialists, care coordination support, and community resources
How to Prepare for Health Care Transition

• Start planning early!
• Get organized
  – Obtain copies of all medical records
  – Work with current providers to create a concise, up-to-date medical summary
  – Verify insurance coverage
  – Obtain guardianship (if applicable) or have teen/young adult sign a Release of Information form
• Establish a medical home
  – Collaboration with medical team is key
  – Work with current doctors to determine what type of provider will be the best “coordinator” of care
How to Prepare for Health Care Transition

• Talk to your teen/young adult
  – Assess their knowledge of their medical condition
  – 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 (or take a more active role in their appointments, if possible)
  – Provide medical information, such as current symptoms, and ask questions
  – Make their own appointments and carry their insurance card
  – Call for medication refills
  – Read medical consents/documents
  – Practice making healthy lifestyle choices
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
Panelists

• Irene C. Dietz, M.D.
  – Director of Comprehensive Care at MetroHealth Medical Center
  – Associate Professor at Case Western Reserve University School of Medicine
  – Clinical expertise: developmental-behavioral pediatrics, hospice and palliative medicine, neurodevelopmental disabilities
  – Education
    • MD: University of Cincinnati College of Medicine
    • Residency in Pediatrics: Cincinnati Children’s Hospital Medical Center
Panelists

- **Eileen Herbert, M.D.**
  - Physician in the Department of Internal Medicine at the Cleveland Clinic’s Richard E. Jacobs Health Center
  - Clinical expertise: preventative healthcare, treatment of adults with special needs including developmental and intellectual disabilities, women’s health issues, depression and other psychological issues
  - Education
    - MD: Wright State University School of Medicine
    - Residency in Internal Medicine: MetroHealth Medical Center
Panelists

• Erica M. Krapf, Ph.D.
  – Pediatric Neuropsychologist in the Neurodevelopmental Science Center at Akron Children’s Hospital
  – Clinical expertise: cognitive and behavioral impact of neurologic and neurodevelopmental conditions, transition to adulthood
  – Education
    • PhD in Clinical Psychology: University of New Mexico
    • Residency in Pediatric Neuropsychology: Akron Children’s Hospital
Panelists

• William D. Smucker, M.D.
  – Physician in Summa Health Medical Group’s Family Medicine Center
  – Professor of Family and Community Medicine at Northeast Ohio Medical University
  – Clinical expertise: geriatrics, chronic pain, and patients with complex medical needs
  – Education
    • MD: Case Western Reserve University School of Medicine
    • Residency in Family Medicine: Akron City Hospital
Panelists

• Nathan Stehouwer, M.D.
  – Assistant Professor and Director of the Med/Ped Consult Service at University Hospital’s Cleveland Medical Center
  – Clinical expertise: children with complex health care needs, sickle cell disease, and transition from adolescence to adulthood
  – Education
    • MD: Case Western Reserve University School of Medicine
    • Residency in Internal Medicine/Pediatrics: UH Case Medical Center
Insurance Coverage and Transition

- **Private insurance plan**
  - 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
Insurance Resources

• Medicaid
  – 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; 2020 Open Enrollment Nov 1- Dec 15, 2019
  – https://www.healthcare.gov/
Healthcare Transition Resources

• Got Transition?
  – 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
  – 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/autism-training/online-training-modules/](https://thompsoncenter.missouri.edu/autism-training/online-training-modules/)
Healthcare Transition Resources

- Webinar: Understanding Guardianship and Alternatives for Decision-making Support
  - 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/

- 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)