

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



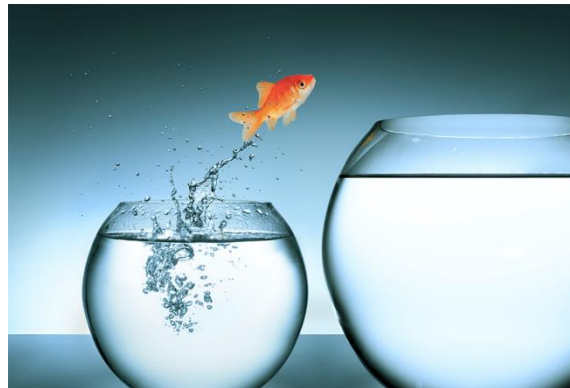
Transition vs. Transfer

- 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

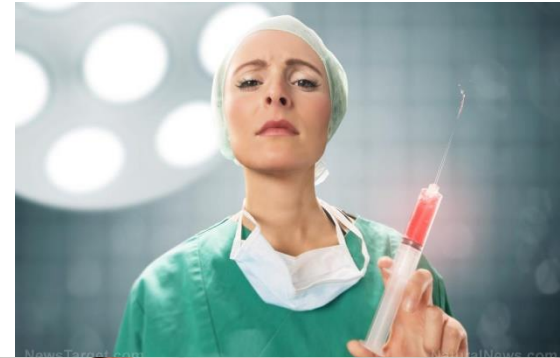
Brown et al. 2018

- 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





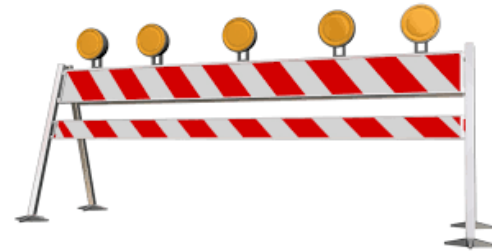
VS.



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



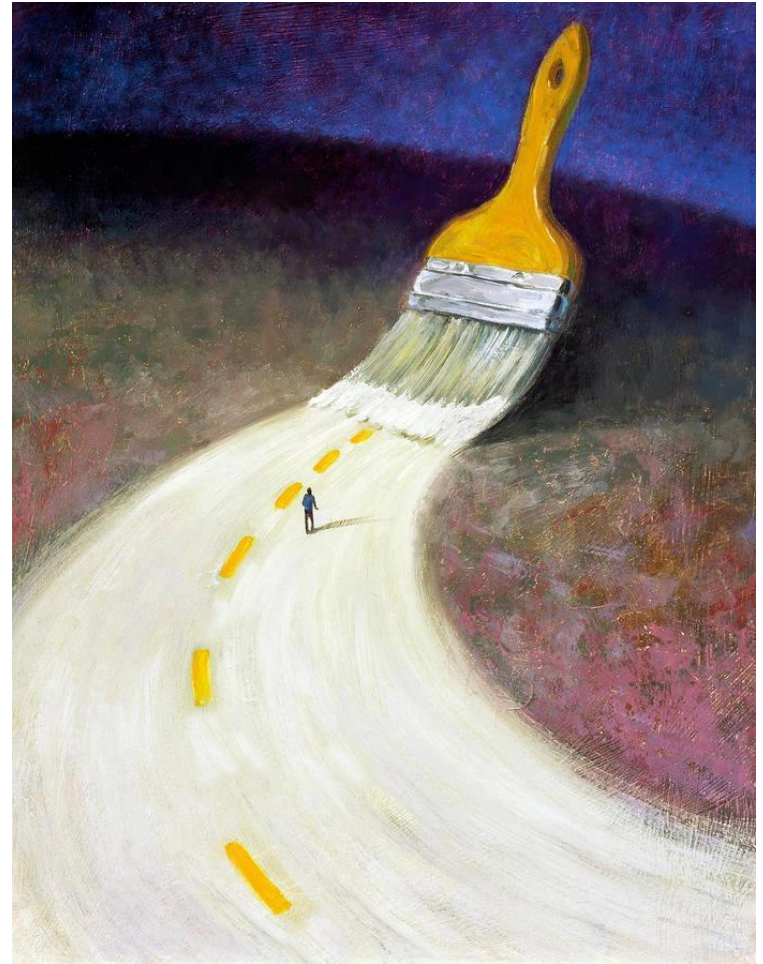
How to Prepare for Health Care Transition

- 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



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
 - 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; 2020 Open Enrollment Nov 1- Dec 15, 2019
 - <https://www.healthcare.gov/>



Healthcare Transition Resources

- Got Transition?
 - <http://www.gottransition.org/index.cfm>
 - 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/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/>
 - <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>

