Improving Health Care Transitions from Pediatric to Adult Care Settings: The Six Core Elements of Health Care Transition

Funded by a cooperative agreement between CMHI and MCHB/HRSA

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Disclosure

- We have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and / or provider(s) of commercial services discussed in this CME activity

Objectives

- Participants will be able to:
  - Recognize importance of planned, proactive transitions from pediatric to adult health care
  - Describe the Six Core Elements of Health Care Transition
  - Consider ways to improve health care transition process for youth and young adults

Agenda

- Welcome and introductions
- Transitions are real life events
- Background
  - Evidence of a problem
  - HCT Clinical Report (2011)

Agenda

- Six Core Elements of Health Care Transition
- GotTransition Learning Collaboratives
- Q and A

What Were Your HCT Experiences?

- How did your transition from pediatric to adult care go? Was it planned?
- Do you have adolescent or young adult children? What's happened with their transition to adult care?

Evidence that HCT Services Need Improvement

- Surveys of families indicate that needed supports are lacking
- Surveys of pediatricians demonstrate low levels of HCT policy in place, limited preparation of youth, late planning, and difficulty transferring complex patients

Evidence that HCT Services Need Improvement

- Surveys of adult health care providers indicate young adult patients are ill-prepared for self-management, physician anxiety about unfamiliar conditions, worries about time and reimbursement

Evidence that HCT Services Need Improvement

- Limited studies of young adult outcomes suggest increased costs/utilization, decreased adherence to treatment, and increased mortality in some conditions

Health Care Transition Clinical Report: A Road Map

- Published in Pediatrics, July 2011
- Developed by an expert authoring group
- Jointly authored by AAP, AAFP, and ACP

Health Care Transition Clinical Report: A Road Map

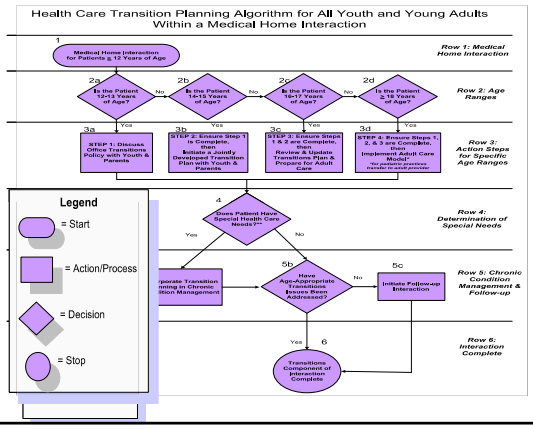
- Reviewed by large and diverse constituency
- Funded with support from the U.S. MCHB

Health Care Transition Clinical Report

- Targets all youth
- Algorithmic structure provides logical framework
  - Branching for youth with special health care needs
  - Provides framework for future condition or specialty specific applications

Health Care Transition Clinical Report

- Explicit guidance about practice structure and process beginning at the 12 year check-up
- Extends through the transfer of care to an adult medical home and adult specialists



GotTransition: The National Health Care Transition Center

- Funded by the U.S. MCHB
- Engage and build leadership among youth and young adults
- Demonstrate the implementation of improved health care transition supports

GotTransition: The National Health Care Transition Center

- Develop and test processes and tools that health care providers, youth, and families can use

GotTransition: Six Core Elements of Health Care Transition

- **Translate the "clinical report" into a series of steps that health care settings can implement**
- **Focus on preparation and planning**
- **Focus on "warm handshakes" rather than blind handoffs**
- **Focus on seamless, successful, safe outcomes**

Six Core Elements of Health Care Transition
Pediatric Health Care Setting – *Prepare Well*
Adult Focused Setting – *Ready to Receive*

1) Transition Policy/Approach	
2) Transitioning Youth Registry	
3) Transition Preparation - HCT Readiness assessment	
4) Transition Planning **- Integrated care plan (medical summary, guidance for emergencies, condition action plan and HCT "next steps" (addresses goals)**	
5) Transition and Transfer of Care - HCT summary & transfer of care checklist	
6) Transition Completion **-** HCT-PASS An assessment of HCT Success	

Six Core Elements of Health Care Transition
Pediatric Health Care Setting – *Prepare Well*
Adult Focused Setting – *Ready to Receive*

1) Transition Policy/Approach	**1) Readiness to Receive/Welcome**
2) Transitioning Youth Registry	**2) Young adults enrolled in patient registry**
3) Transition Preparation - HCT Readiness assessment	**3) Young adult patient approach** **Preventive, acute, and chronic condition care** **-Patient activation and empowerment** **- Assessment and intervention**
4) Transition Planning **- Integrated care plan (medical summary, guidance for emergencies, condition action plan and HCT "next steps" (addresses goals)**	**4) Well/Health and Chronic Care Management** **- Integrated care plan: (medical summary, guidance for emergencies, condition action plan, and "next steps" (addresses goals)**
5) Transition and Transfer of Care - HCT summary & transfer of care checklist	**5) Patient-Centered Medical Home** **-Care coordination** **-Adult oriented health system transitions**
6) Transition Completion **-** HCT-PASS An assessment of HCT Success	**6) Continuous, longitudinal care across the lifespan**

Health Care Transition Policy / Approach

- **What do we mean?**
  - **. . . an explicit office policy that describes the practice's approach to health care transition, including the age and process at which youth shift to adult focused care**

Health Care Transition Policy / Approach

- **Visible**
- **Clear**
- **Drives education of youth, families, and staff**

How Are Primary Care Practices Using and Learning from This Element?

- **Our practice will:**
  - **Introduce the concept of transition in early adolescence at well visits and sometimes at sick visits**

How Are Primary Care Practices Using and Learning from This Element?

- Provide support and suggestions as to how adolescents can gradually achieve more health care independence

How Are Primary Care Practices Using and Learning from This Element?

- See the adolescents individually for portions of their visits so they learn how to communicate effectively with their providers
- Help provide information about choosing an adult health care provider

How Are Primary Care Practices Using and Learning from This Element?

- Transition should be a gradual process of preparation and growth towards the eventual goal of increasing independence with health care, based on each individual's ability to achieve these goals

Through the Eyes of Patients: POLICY

- This can set the tone for the way youth and families feel about the practice
- Gets consumers thinking about the future so it doesn't come as a shock

Through the Eyes of Patients: POLICY

- Use accessible language, so youth and families can understand
  - But find a time to go over it with them as well

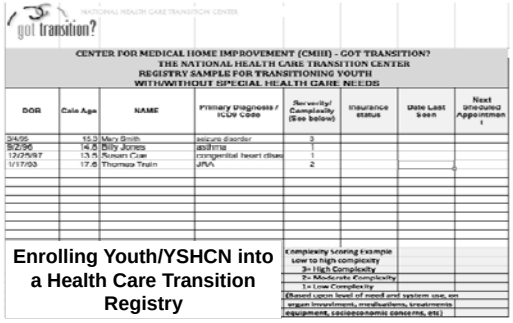
Through the Eyes of Patients: POLICY

- I got a phone call when I was 18
  - They said I had to leave, and they could not refer me to any other providers

Transitioning Youth Registry

- **What do we mean?**
  - **A registry is a spreadsheet, database, or other paper or electronic tool that stores health information in a way that supports pro-active, planned, and coordinated care**

Practice Use and Lessons Learned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CENTER FOR MEDICAL HOME IMPROVEMENT (CMHI) - GOT TRANSITION?
THE NATIONAL HEALTH CARE TRANSITION CENTER
REGISTRY SAMPLE FOR TRANSITIONING YOUTH
WITH/WITHOUT SPECIAL HEALTH CARE NEEDS

DOB	Calc Age	NAME	Primary Diagnosis / ICD9 Code	Severity/ Complexity (See below)	Insurance status	Date Last Seen	Next Inhouse Appointment
3/4/95	15.3	Mary Smith	seizure disorder	3			
8/2/96	14.8	Billy Jones	asthma	1			
12/25/97	13.5	Susan Cain	congenital heart disease	1			
1/17/03	17.6	Thomas Train	JRA	2			

Enrolling Youth/YSHCN into a Health Care Transition Registry

Complexity Scoring Example
Low to high complexity
3= High Complexity
2= Moderate Complexity
1= Low Complexity
(Based upon level of need and system use, en
organ involvement, medications, treatments
equipment, socioeconomic concerns, etc)

Transition Preparation

- **Using a Readiness Assessment: What Do We Mean?**
  - **Guiding youth / families to repeatedly assess their readiness for increasing independence in their care, as appropriate**

Transition Preparation

- **A readiness assessment helps the health care team to help youth and families learn and practice adult health care skills**

Transition Preparation Using a Readiness Assessment: How Are Practices Using and Learning from These?

GotTransition? Health Care Transitions (HCT) and Changing Roles for Youth

Transition Readiness Assessment — NA – if non applicable

Health & Wellness 101 The Basics:	Yes I do this	I want to do this	I need To learn	Someone else will have to do this - *Who?* /NA
1. I understand my health care needs and or disability				
2. I can explain my needs to others.				
3. I can explain to others how our family's customs/beliefs might affect health care decisions and/or treatments.				
4. I carry my health insurance card everyday				
5. I know and pay attention to my health and wellness baseline (pulse, respiration rate, elimination habits)				
6. I make and track my own appointments				

Readiness Assessment: A Conversation Starter

- **Creates the foundation of the transition process for youth and families**
- **CRITICAL how it is presented, filled out, and followed up**

Readiness Assessment: A Conversation Starter

- I didn't realize some of these things I could be doing on my own with little trouble
  - Small tangible steps that make youth / family feel like they are in the transition "process"

Readiness Assessment: A Conversation Starter

- Be willing and open to meet youth and family "where they're at," learn why there may be hesitation to take steps toward independence or try new things
  - Previous negative experience?

Transition Planning: What Do We Mean?

McAllister, Presler, Turchi &Antonelli; Achieving Effective Care Coordination in the Medical Home. Pediatric Annals, September 2009.

Transition Planning: What Do We Mean?

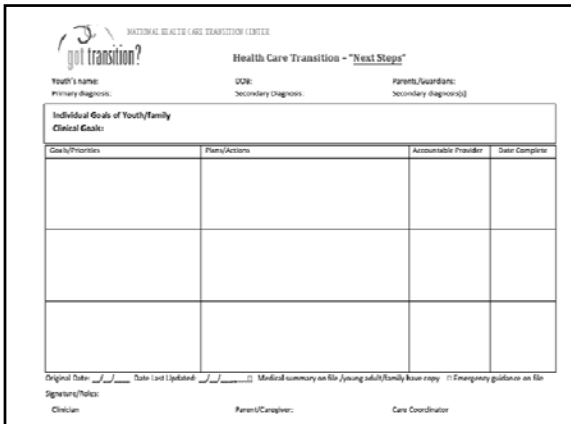
- Using an integrated care plan to address "next steps"
  - Next steps include the dynamic elements of care planning
  - What are the goals?
  - What is agreed as partners to achieve them

Transition Planning: What Do We Mean?

- Who is responsible, for what, by when
  - Team reflects back what they hear from youth and families
  - Youth / family "teach back" acquired steps and skills

Transition Planning: What Do We Mean?

- Shared, accessible
- Future – follows the person



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Health Care Transition – "Next Steps"

Youth's name: DOB: Parents/Guardians:
Primary diagnosis: Secondary Diagnosis: Secondary diagnosis(s)

Individual Goals of Youth/Family
Clinical Goals:

Goals/Priorities	Plans/Actions	Accountable Provider	Date Complete

Original Date: __/__/____ Date Last Updated: __/__/____ ☐ Medical summary on file /young adult/family have copy ☐ Emergency guidance on file
Signature/Notes:
Clinician: Parent/Caregiver: Care Coordinator

Care Planning: Keeping it Youth Centered

- Having a medical summary / integrated care plan proves valuable in many phases of transition
  - School, ER visits, relationships

Care Planning: Keeping it Youth Centered

- Young adults will be more accountable for plans they help create
  - "WIIFM" (what's in it for me?)
  - Youth need to see health care transition as having a positive effect on their day-to-day life

Care Planning: Keeping it Youth Centered

- Take time for conversations around what is important to them, what they want to achieve
  - What are their goals?
    - Then break down in terms of health care steps needed

Care Planning: Keeping it Youth Centered

- Build compromise between what you want for them and what they want for themselves

Transition or Transfer of Care: What Do We Mean?

- Transfer of care is a "hand off requiring a handshake" and more
- It is a risky moment in the health care transition process helped by:
  - Exchange of information
  - Agreement about timing

Transition or Transfer of Care: What Do We Mean?

- Agreement about roles
- Communication
  - Multi-directional, on-going

Transition or Transfer of Care: What Do We Mean?

- Transfer package contains the information most useful to the new adult clinician
  - Transfer or cover letter, date of transfer / adult appointment
  - Most recent readiness assessment

Transition or Transfer of Care: What Do We Mean?

- Integrated care plan
  - Summary, emergency, condition action plan, and latest transition "next steps"
- Name and contact information of pediatric team / adult team

Transition or Transfer of Care: What Do We Mean?

- Guardianship, custodianship, powers of attorney – if appropriate
- Plans, if any, for transfer of specialty care
- Preferred or planned means of interim communication

How Are Practices Doing and What Are They Learning from These?

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Health Care Transition Transfer of Care Checklist (Pediatric)

<Patient Name> <Date of Birth>	
	Date
☐ Transfer of care policy discussed with youth and family	
☐ Transfer of care options discussed with youth and family	
○ Timing of transfer of primary care discussed with youth and family	
○ Option of using the family's existing adult primary care provider(s)	
○ Review of the practice's list of available adult primary care providers	
○ Options and timing for transfer of specialty care discussed	

The Send Off!

- It can be difficult for parents, youth, and provider to let go
  - It's OK to acknowledge this

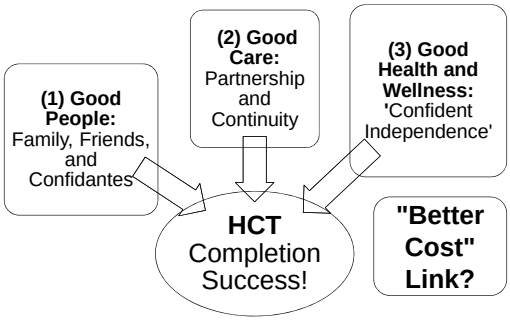
The Send Off!

- **How firmly you "close the door" depends on the young adult and their condition**
  - **For me and my size, there are times I am treated in a pediatric setting for safety reasons, but my adult providers still manage my care**

The Send Off!

- **All about relationships and being willing to be a resource to new providers**

Transition Complete: What Do We Mean?



Transition Is Complete! Or Is It . . .?

- **Transition is a very cyclical process**
- **Example**
  - **In transitioning to graduate school, I contacted many providers trying to access record; at send off maybe even share how long this info is available, or how to access**

Transition Is Complete! Or Is It . . .?

- **New providers may still need support**
  - **Have a method of communication that works for you**

Learning Collaborative Sites

Washington, DC	**2011 - 2012**
Denver, Colorado	**2011 - 2012**
Boston, Massachusetts	**2011- 2012**
New Hampshire	**2012 (ended 12/12)**
Minnesota	**2012 - 2013**
Pennsylvania	**2012 - 2013**
Wisconsin	**2012 - 2013**

Measuring Health Care Transition in Practices

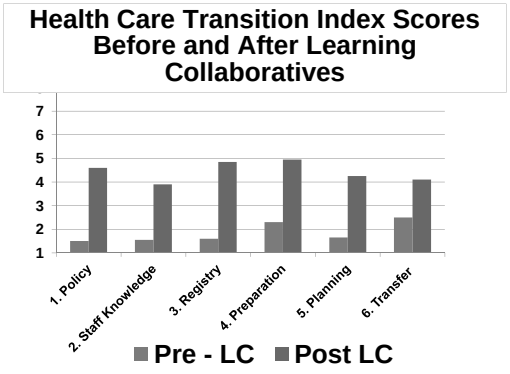
- Health Care Transition Index
  - Provides a numerical score for HCT implementation
  - Modeled after the Medical Home Index
  - Pediatric setting version and adult setting version

Measuring Health Care Transition in Practices

- Tracking implementation goals in practices
  - Written transition policy in place
    - % of practices
  - Number of youth enrolled in registry prospectively

Measuring Health Care Transition in Practices

- Number of readiness assessments completed
- Number of transition plans in place
- Number of transfers of care to adult settings



Learning Collaborative Core Measures – 3 Collaboratives: DC, CO, NH

Practices with Health Care Transition Policy	19 / 19
Patients in Transition Registries	751
Patients Assessed for Readiness	418
Patients with Transition Care Plan	265
Patients Transferring to Adult Care	119

Lessons of the Collaboratives

- Health care transition has been seen primarily from the pediatric perspective – adult role is unclear at first
  - Role seen as passive reception of transfers

Lessons of the Collaboratives

- Twenty-somethings are a special population unrecognized as such in the adult health care system
  - Completely new to the adult system of care
  - Health or health care are not first priorities

Lessons of the Collaboratives

- Variability in developmental readiness

Contact Information

- www.gottransition.org
  - Join the National Health Care Transition Center on Facebook
    - Search GotTransition
- cooley@cmf.org
- mhcyr@bu.edu

References

- AAP, AAFP, ACP: A Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs. Pediatrics, 2002, 110:6, 1304
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