Health Care Transition & Title V Care Coordination Initiatives: Webinar Series

Webinar # 3 | April 26, 2018

TRANSFER TO ADULT CARE

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The National Alliance to Advance Adolescent Health
Disclosures and Funding Source

Karen Rundall, Lee Gordon, Kathy Rivers, and Peggy McManus have no financial disclosures or conflicts of interest.

Got Transition, a program of The National Alliance to Advance Adolescent Health, is funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, DHHS.
Got Transition’s Webinar Series Goals

• Support state Title V implementation and measurement of health care transition (HCT) in care coordination programs

• Guide care coordination improvements by sequentially building on the evidence-informed Six Core Elements

• Share promising practices from state Title V-supported care coordination programs (CC)

• 5-session webinar series on HCT and care coordination

• The webinars and handouts will be available following each session at www.gottransition.org
Webinar #3
Objectives

At the conclusion of Webinar 3, attendees will be able to...

- Identify ways for identifying adult primary and specialty providers
- Understand an adult model of care & Got Transition resources
- Understand contents of transfer package to send to adult provider
- Identify ways to communicate with and support adult practices (e.g., care coordination support)
- Learn how KY and MD CC programs plan and support transfer to adult care
1. Webinar #3 Slides
2. Got Transition’s Turning 18, Guardianship and Alternative for Decision-making Supports; Questions to Ask Your Doctor About HCT; YA Quiz
3. Kentucky’s transition policy & 18 year old birthday letter (parents & youth)
4. Coordinating Center’s Adult Provider Transfer Package, Adult Outreach Package, and Delineation of Roles Handout
Webinar #1 Review: Starting a Transition Improvement Process Using the Six Core Elements

- HCT clinical foundations: AAP/AAFP/ACP Clinical Report & Six Core Elements
- HCT performance measurement options
- Title V Care Coordination baseline results from Current Assessment of HCT
- Starting a HCT pilot using Quality Improvement and the Core Elements Processes; writing an aim statement
Webinar #2 Review: Transition Preparation

- Review of Six Core Elements: Transition Policy, Tracking, Readiness Assessment, Planning
- Options for Customizing HCT Tools/ACP HCT efforts
- DC’s Parent Navigator Program at Children’s National Health System’s customization and use of Six Core Elements
Transfer Success: Consumer, Provider, Researcher Perspectives

• “An easy transfer is associated with feeling ready and considering that coordination between teams is good.” (Suris et al, 2016)

• Success is:
  - Patient attending scheduled visits to adult care & not lost to follow-up
  - Patient building trusting relationship with adult provider
  - Patient receiving continued attention for self-management
  - Patient satisfied with transfer process (Sattoe et al, 2016)
Six Core Elements: Transfer of Care

• Plan with youth/family for optimal time for transfer
• Assist in identifying adult provider
• Complete transfer package and communicate with new adult provider
• Transfer when YA’s condition is stable
• Confirm pediatric provider's responsibility for care until YA is seen in adult practice
Adult Model of Care

• Preparing for adult model of care includes meeting with HCP alone, practicing independent self-care skills

• At age 18, youth becomes legal adult. Medical information cannot be shared unless permission given

• See: Got Transition Handouts: Turning 18, Guardianship & Alternatives for Decision-making Support, Questions to Ask Your Doctor about HCT, YA Quiz)
Adult Model of Care

• Patient-centered
• Care is self-directed
• Very limited resources for care coordination
• Role of adult primary care and specialty doctors often different than in pediatrics

“Leaving Never Never Land”
Transfer Package

- Transfer letter
- Final transition readiness assessment
- Plan of care, including transition goals and pending actions
- Updated medical summary and emergency care plan
- Guardianship or health proxy documents, if needed
- Condition fact sheet, if needed
- Evidence of communication with adult provider about transfer
The Kentucky Office for Children with Special Health Care Needs

Karen Rundall, RN, MSN, CCM
Division Director - Clinical & Augmentative Services

Lee Gordon, MPA
Transition Administrator
Title V Care Coordination

• In FY 2017 the CCSHCN provided 78,302 services to 9,148 unduplicated patients through specialty medical clinic programs and augmentative programs.

• Staff mix includes Registered Nurses, Social Workers, Administrative Support staff, Audiologists, Speech Language Pathologists, Dieticians and Family Support Parents in our larger offices.

• Registered nurses, social workers, support parents and providers collaborate with patients and families to create a plan of care.

• The multidisciplinary team at the CCSHCN assists with linking the patient/family with needed medical and social resources to assist with transition as well as overcoming financial, language and cultural barriers.
Specialty Medical Clinic Programs

- Autism Spectrum Disorder
- Cerebral Palsy
- Cleft lip & Palate
- Craniofacial Anomalies
- Ophthalmology
- Cardiology
- Neurology
- Orthopedics
- Otology
- Audiology
- Therapy Services

- The specialty clinics included currently fill gaps in medical care that exist in the regions where they are held.

- CCSHCN contracts with sub-specialists from University of Kentucky and University of Louisville who travel to our regional offices and provide clinical services to children enrolled in the CCSHCN program.

- Programs can be added if a gap in service is demonstrated and a provider is available.

- Programs can be removed if services become available in a region and a gap no longer exists.
Six Core Elements of Health Care Transition - KY

1. Transition Policy - Yes
   • CCSHCN developed a Transition policy utilizing the transition policy example on the
     Got Transition website.
   • Staff were informed about the policy and their role in the transition process.
   • The policy is posted in all 11 of our CCSHCN clinics.
   • The policy is mailed with a transition letter to all 14, 16 & 18 year old patients on
     their birthday.

2. Registry - Yes
   • CCSHCN uses an Electronic Health Record called CUP that all patient information is
     entered in.

3. Transition Readiness Assessment - Yes
   • The CCSHCN Transition Checklist is in CUP.
   • Staff enter transition progress notes to support the transition checklist as they meet
     with youth and families during the clinical process.
Six Core Elements of Health Care Transition - KY

4. Transition Planning - Yes
   • The CCSHCN Transition Checklist focuses on age appropriate transition questions for ages: (0-4, 5-11, 12-14, 15-17 & 18-21).
   • Prior to age 18, youth are informed about: The need to choose an adult health care provider when he/she turns 18; Be familiar with health insurance and how it works− i.e. insurance plans, deductibles, co-pays, etc.; and informed about the importance of organizing and keeping medical records and receipts.

5. Transfer of Care - Yes
   • Staff develop a portable medical summary that is given to patients to use upon transfer to an adult provider.
   • Staff inform patients about the FEMA emergency preparedness brochure titled “Preparing Makes Sense for People with Disabilities https://www.fema.gov/media-library/assets/documents/90360

6. Transfer Completion – Yes
   • Clinic surveys are completed by patients/family members during the clinic process.
   • Transition phone surveys are attempted with each CCSHCN patient after the patient turns 21 years old and ages out of the CCSHCN.
### Transition Standard: Transition to Adulthood

**Standard:** The CCSHCN will provide high quality transition support services to CYSHCN to assist them to make a successful transition to all aspects of adult life including health care, education, employment and independence to the full extent of their potential.

**Activities:**
- Information and patient education
- Linkage to needed services
- Facilitating access to service providers
- Advocacy and youth empowerment opportunities
- Support and encouragement
- Care Coordinators services for CYSHCN during transition to adult health care
- Youth Advisory Council

**Performance Evidence:**
- Patients and their families will attend clinics and be asked appropriate age group transition questions from the CCSHCN Transition Checklist in CUP. Patient and their family’s responses to the transition checklist questions will be documented in the medical record.
- Patient follow up on referral services will be documented in the medical record.
- All transition support services will be documented in the patient record.
- Parents will participate in satisfaction surveys.
Age Specific Information Timetable with Focus on Transition to Adult Care

The CCSHCN Transition Checklist focuses on age appropriate transition questions for ages: (0-4, 5-11, 12-14, 15-17 & 18-21). Beginning at age 12 questions are directed at the patient. Below are some questions targeted at preparing the youth to transition to adult health care.

**Health 12 – 14**
I understand my diagnosis and can explain it.
I tell the doctor how I am doing and answer questions.
I take my medicine with or without supervision.

**Health 15 – 17**
I talk with my doctor/nurse/social worker about the need to choose an adult health care provider when I turn 18.
I am familiar with health insurance and how it works—i.e. insurance plans, deductibles, co-pays, etc.
I understand the importance of organizing and keeping my medical records and receipts.

**Health 18 – 21**
I have plans for adult health care providers (Primary Care, Specialty, Dental, DME, Pharmacy, Therapy and Mental Health) and have made initial appointments to establish care with them or are already seeing them.
Recruitment of Physicians

Types of Providers Available:
- Family Medicine Practices
- Parent’s adult PCP
- Federally Qualified Health Centers (FQHC)
- Medical Center Adult Health Care Clinics
- Adult Primary Care Provider

Process:
- CCSHCN staff perform regular outreach to area provider offices and FQHCs to provide information regarding transitioning youth with special health care need to adult care and the care coordination and assistance that can be provided to support until age 21 years.
- CCSHCN staff attend community partner meetings and community health fairs to learn about new area providers, stay in touch with current community providers and build relationships.
Portable Medical Summary

- Child’s Name
- Child’s Nickname
- DOB
- Health insurance
- Legal guardian
- Diagnosis
- Clinical summary
- Emergency Plan
- Allergies
- Medications

- Specialists
- Baseline Vitals (includes HT/WT)
- Problem List/Recommended Actions
- To be avoided
- Surgeries/procedures
- Labs/Diagnostics
- Equipment/Appliance/Assistive Technology provided
- Medical monitors provided
- School/Community Information
# Portable Medical Summary

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<th>Primary Care Provider Signature</th>
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<tr>
<th>Care Coordinator Signature</th>
<th>Special Circumstances/Comment/Family/Youth wants us to know:</th>
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<th>Date</th>
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Lessons Learned

- Call the physician’s practice for a good day and time to visit
- Try to connect with the physician’s nurse
- Try to establish a relationship with one contact person in the office
Introductory Remarks

Jed Miller, MD, MPH
Maryland Title V CSHCN Director
Health Care Transition & Title V Care Coordination Initiative
Transfer to Adult Care

Identifying and Partnering with Adult Health Care Providers at The Coordinating Center

Kathy Rivers MD
Got Transition Webinar #3
April 26, 2018 3 – 4 pm
The mission of The Coordinating Center is to partner with people of all ages and abilities and those who support them in the community to achieve their aspirations for independence, health and meaningful community life.
Rare and Expensive Case Management (REM) and Model Waiver Programs

• **REM**
  - Provides integrated coordination of services for people with specialized health care needs that are defined as rare in occurrence and expensive to treat
  - Serves 4,200 individuals
  - 75% younger than 18

• **Model Waiver**
  - 200 children with complex medical needs at risk for long-term hospitalization without necessary in-home services
  - Under 22, not eligible for other Medicaid programs

• **Funded by Maryland Medicaid**

“One of the greatest challenges we face is the need to prepare youth and families for transition to adulthood, including health care transition.”
Transition Connection Initiative (TCI)
Funded by a systems development grant from the MD Dept of Health’s Office of Genetics and People with Special Health Care Needs (Title V)

Goal: Improve HCT for YSHCN, their families and their providers

• Implement the 6 Core Elements model of HCT at The Coordinating Center
• Customize HCT tools for the REM/MW population
• Care coordination model with staff training and support
• Provider outreach, education, and support
• Recruitment of adult primary care providers
TCI Baseline Client Assessment

- Only 21% of respondents received assistance identifying a new adult PCP
- Most transfers occurred between 18 and 21
- 1/3 of clients over age 22 had pediatric PCPs
- Families want advance notice about HCT policies and to be part of transfer planning
TCI Provider Surveys

• Providers want training, communication, support and resources
  • childhood-onset complex chronic illness management
  • adult health challenges facing long-term survivors

• Pediatricians
  • List of adult PCP’s willing to accept YSHCN

• Adult Providers
  • More communication from pediatric providers to improve transfer and ongoing care
  • A plan of care for the next year
  • Information about adult disability resources
REM Adult Provider Survey Comments

• “Why do I need a policy for integration of YA with SHCN? I accept new adult patients all the time.”

• “The young adult is an unreliable historian and comes with no or insufficient medical records.”

• “I need (but never get) a concise medical summary and a plan of care for the next year. Then I could implement the plan while I get to know the patient instead of having to start from scratch at the first visit.”

• “No one at Peds talked to the family about advance directives and the discussion is clearly needed, but if I raise the issue early in our relationship I look like the grim reaper.”

• “The structure of my clinic doesn’t support the extra time these patients need. Also I’m willing to see them but my staff gets upset about time spent, extra paperwork, office schedule disrupted and extra care needed.”
TCI Action Plan for Adult Provider Recruitment

• Identification
• Engagement
• Education
• Support
• Increase capacity
REM Program Examples - Identify Adult Providers

Who – starting “the list”
• Internal database of adult PCPs already seeing REM clients
  • Existing connection with ASHCN
  • Add other providers in their office/network
  • Providers accepting new patients
• Parents’ adult PCPs
• Pediatrician’s referral list

• Med-Peds!
• Geriatricians
• Educational outreach/CME attendees
• AAFP, ACP
• Networking contacts
• The Office Manager
• “But I don’t want my name on a list!”
Adult Provider Engagement

What – make a connection
• Outreach
• HCT educational event
• Provider packet

Where
• In person
  • Provider office
  • Group home
  • Provider event
• Remote – call, email, ECHO

When
• Whenever it is most convenient for the adult PCP
  • After office hours

How
• Survey
• Phone call
• Email
• Fax
• Letter
• Website
• Social media
Adult PCP HCT Education

• Outreach - Meet with PCPs and their staff to discuss
  • The importance of HCT/transfer for YSHCN
  • The 6 Core Elements Approach to HCT
  • Current office HCT policy
  • Practice issues with and needs for HCT planning
  • Consider adding HCT to Medical Home efforts

• Presentations
  • Staff meetings
  • CME events
  • Partner with provider organizations (AAP, ACP, AAFP); sponsor joint events
Adult Provider Training Requests

- Adult consequences of pediatric-onset chronic diseases
  - Care of Adults with Chronic Childhood Conditions: A Practical Guide by Pilapil, M et al. (Eds) Springer Nov 2016 (436 pp)
    http://www.springer.com/978-3-319-43825-2
    - Chapter 1 Facilitating the Transition from Pediatric-Oriented to Adult-Oriented Primary Care by Patience H. White and Margaret McManus

- Management of neurodevelopmental disorders
- Mental/behavioral health disorders management
- Medical technology needs
- YA development, complicated by chronic disease
REM Program Adult Provider Support

- Care coordination assistance
  - REM/MW youth and families ready by age 22 for adult model of care
  - Client support for integration into adult practice
  - Adult subspecialty provider resources
  - Local/state/national adult disability resources

- Transfer packages
  - Most recent transition readiness assessment
  - Medical summary and emergency care plan
  - Care management plan
  - Plan of care for the next year
  - Legal decision-making supports documentation, if needed

- Link to pediatric provider for information/consultation
Increase Number of Adult Providers Caring for YASHCN

• Identify, engage, educate, support to increase system capacity - grow “the list”
  • Obtain feedback (client, provider) to inform program change
  • Collect data performance measures
  • Collaborate with state transition leaders for systems change
  • Share resources
  • Start early - HCT education in medical curriculum
Questions?

• About identifying adult providers?
• About preparing a transfer package?
• About ways to support adult practices in integrating young adults into their practice?
• About KY’s approach?
• About MD’s approach?
Upcoming Title V Care Coordination Webinars

Integration into Adult Care
May 31, 3-4 pm ET

Youth, Young Adult, & Parent Engagement
June 28, 3-4 pm ET

To register, please visit Got Transition’s website under Webinars (www.gottransition.org/webinars)
Thank You!

WEBSITE
www.gottransition.org
See link to new transition news and articles and download the *Six Core Elements 2.0* packages to start making HCT quality improvements in your practice

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