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

Webinar #1 | February 28, 2018

STARTING A TRANSITION IMPROVEMENT PROCESS USING THE SIX CORE ELEMENTS

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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
• 5-session webinar series on HCT and care coordination
• The webinars and handouts will be available following each session at www.gottransition.org
Webinar #1: Objectives

At the conclusion of Webinar 1, attendees will be able to...

- Discuss HCT clinical foundations & evidence of effectiveness
- Discuss HCT measurement options & results from the National Survey of Children's Health
- Discuss Title V care coordination baseline results on implementing Six Core Elements of HCT
- Have an approach to initiate a HCT pilot to achieve measurable improvements in Six Core Elements
Webinar #1 Handouts

1. Webinar #1 Slideshow
2. Supporting HCT from Adolescence to Adulthood in Medical Home (AAP/AAFP/ACP Clinical Report)
3. Side-by-Side Version of Six Core Elements HCT
4. Baseline Assessment of HCT Implementation in Title V Care Coordination Programs (Got Transition Report)
5. Current Assessment of HCT Activities in Care Coordination Programs (customized Got Transition tool)
Opening Remarks

Susan Chacon, MSW
AMCHP, President
New Mexico Title V CSHCN Director
2011 AAP/AAFP/ACP HCT Clinical Report

- Update, expected in coming months
- Expert opinion/consensus recommendations
- Algorithm for standardizing HCT process

Six Core Elements of HCT

- Aligned with Clinical Report
- Define basic components of HCT support with linked tools and measurement resources
AAP/AAFP/ACP Clinical Report on HCT (Handout)

<table>
<thead>
<tr>
<th>Age 12</th>
<th>Youth and family aware of transition policy</th>
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<tbody>
<tr>
<td>Age 14</td>
<td>Health care transition planning initiated</td>
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<tr>
<td>Age 16</td>
<td>Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care</td>
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<tr>
<td>Age 18</td>
<td>Transition to adult approach to care</td>
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<tr>
<td>Age 18-22</td>
<td>Transfer of care to adult medical home and specialists with transfer package</td>
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- In 2011, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- Targets all youth, beginning at age 12
- Algorithmic structure with:
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
- Extends through transfer and establishment of care to adult medical home and adult specialists
- Clinical Report recently renewed by the AAP
Six Core Elements of HCT: Transitioning Youth to an Adult Provider (Handout)

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer/Integration into Adult-Centered Care
6. Transition Completion/Ongoing Care

Discuss transition policy
Track progress
Assess skills
Develop HCT plan, incl. medical summary
• Transfer to adult-centered care
• Integration into adult practice
• Confirm transfer completion
• Elicit consumer feedback

AGE 12-14
AGE 14-18
AGE 14-18
AGE 18-21
AGE 18-26
Article:

Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review


Click here for Gabriel article
Systematic Evidence Review of Structured HCT Interventions

Statistically Significant Positive Impacts:

**Population Health**
- Adherence to care
- Patient-reported health & quality of life
- Self care skills – disease specific knowledge, self-management of medications, higher transition readiness scores, carrying important information

**Experience of Care**
- Satisfaction – with transition, with transfer, with life and health goals, helpfulness of tools, autonomy, time alone with provider

**Utilization and Costs of Care**
- Service utilization - increase in adult visit rates; reductions in ER visits and hospitalizations, decrease in time between last pediatric and first adult visit
- Improved process of care
- Costs of care seldom examined
Two Important Sources

1. National Survey of Children’s Health (NSCH)
2. Current Assessment of HCT Activities in Care Coordination Programs
HCT Performance Measurement for YSHCN

National Survey of Children’s Health

• Conducted annually
• Parent survey of youth ages 12 through 17 (with and without special needs)
• HCT Questions:
  • Chance to speak with the MD or health care provider (HCP) privately at last preventive visit
  • MD/HCP actively worked with youth to gain skills to manage health care
  • MD/HCP actively worked with youth to understand changes in health care that happen at age 18 (e.g., privacy, consent)
  • MD/HCP talked about eventually seeing doctors or other HCPs who treat adults
• Only 17% of YSHCN met national transition measure
• State results available at www.childhealthdata.org
HCT Performance Measurement for YSHCN

Current Assessment of HCT Activities in Care Coordination Programs (Handout)

- Customized from Got Transition’s Current Assessment of HCT Activities
- A qualitative self-assessment that provides a snapshot of how far along CC program is with implementing Six Core Elements
- The self assessment scores CC program’s level of implementation related to 7 HCT elements
- Conducted in May 2017, to be repeated in May 2018 by Got Transition
- 27 of 32 states that selected HCT as national performance measure responded
2017 Baseline Assessment of HCT Implementation in Title V Care Coordination (CC) Programs: Results (Handout)

1. Transition Policy
2. Transition Tracking
3. Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transition Completion
7. Youth and Family Engagement
**Baseline Assessment: Results**

**TRANSITION POLICY**
Average Level: 2.7

- **5 states at Level 4**
- **13 states at Level 3**
- **6 states at Level 2**
- **3 states at Level 1**

**Level 1:** CC program has no uniform approach or written policy shared with YSHCN and families.

**Level 2:** CCs follow a similar, but not a written policy that it shares with YSHCN and families on HCT.

**Level 3:** The CC program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at age 18, and the age when Title V eligibility ends. The HCT policy is not consistently shared with youth and families.

**Level 4:** CC program has written HCT policy describing its HCT approach, legal changes that take place in privacy and consent at age 18, and age when Title V eligibility ends. CCs consistently share and discuss HCT policy with all YSHCN and families beginning at ages 12-14. Policy is publicly posted and used by all CCs.
Baseline Assessment: Results

**TRANSITION TRACKING**
Average Level: 2.3

- **Level 1:** CCs vary in the identification of transition-age YSHCN, but most wait close to the age of transfer to prepare youth for HCT.

- **Level 2:** CCs use patient records to document certain relevant HCT information (e.g., adult doctor information, date of transfer to adult doctor).

- **Level 3:** The CC program uses an individual transition flow sheet or registry for identifying and tracking a subset of transition-age YSHCN, ages 14 and older, as they complete some but not all of the Six Core Elements of HCT.

- **Level 4:** The CC program uses an individual transition flow sheet or registry for identifying and tracking all transition-age YSHCN, ages 14 and older, as they progress/complete all of the Six Core Elements of HCT, using an EHR if possible.
**Level 1:** CCs vary in whether they assess HCT readiness/self-care skills.

**Level 2:** CCs assess HCT readiness/self-care skills, but do not consistently use a HCT readiness assessment tool.

**Level 3:** CCs assess HCT readiness/self-care skills using a HCT readiness/self-care skill assessment tool.

**Level 4:** CCs consistently assess and re-assess each year HCT readiness/self-care skills beginning at ages 14 to 16, using a transition readiness/self-care assessment tool.
**Baseline Assessment: Results**

**TRANSITION PLANNING**

Average Level: 1.9

- **12 states at Level 1**
- **8 states at Level 2**
- **4 states at Level 3**
- **3 states at Level 4**

**Level 1:** CCs vary in whether they include goals and action steps related to HCT in the plan of care for YSHCN.

**Level 2:** CCs consistently include goals and action steps related to HCT for YSHCN, but vary in addressing privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care.

**Level 3:** CCs consistently include goals and action steps related to HCT for YSHCN based on the results from a HCT readiness/self-care assessment tool. CCs consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. This plan of care is regularly updated.

**Level 4:** The care coordination program has incorporated HCT into its plan of care template for all YSHCN. CCs consistently include YSHCN goals and action steps related to HCT based on results from HCT readiness/self-care assessment tool. CCs consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. This plan of care is regularly updated and shared with YSHCN and families.
Baseline Assessment: Results

TRANSFER OF CARE
Average Level: 1.7

- **Level 1:** CCs vary in whether they give YSHCN and families a list of adult providers. They rarely share plans of care with HCT information to adult providers for their transitioning YSHCN.

- **Level 2:** CCs consistently give YSHCN and families a list of adult providers and share the plan of care, including HCT information to the adult provider(s) for transitioning YSHCN.

- **Level 3:** The CC program is actively involved in outreach to identify potential adult providers for transitioning YSHCN. Care coordinators share the plan of care with HCT information to the adult provider(s) for their transitioning YSHCN.

- **Level 4:** The CC program is actively involved in outreach to identify potential adult providers for transitioning YSHCN. CCs consistently share the plan of care with HCT information for YSHCN transferring to the adult provider(s). In addition, care coordinators routinely communicate with adult providers to ensure information was received and transfer was completed.
Level 1: CCs vary in whether they follow-up with YSHCN and parents/caregivers to provide feedback about the HCT support provided by the CC program.

Level 2: CCs consistently encourage YSHCN and parents/caregivers to provide feedback about the HCT support provided by the care coordination program, but do not use a specific HCT feedback survey.

Level 3: CCs consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey.

Level 4: The CC program uses the results from its HCT feedback survey as part of its transition performance measurement for the Title V block grant reporting.
**Baseline Assessment: Results**

**YOUTH & FAMILY ENGAGEMENT**

Average Level: 1.6

- **16 states at Level 1**
- **9 states at Level 2**
- **2 states at Level 4**

**Level 1:** The CC program offers general information about HCT to YSHCN and parents/caregivers, but has limited involvement of YSHCN and parents/caregivers in Title V HCT program development and evaluation.

**Level 2:** The CC program, in addition to its HCT education efforts with YSHCN and parents/caregivers, has trained YSHCN and parents leaders about the Six Core Elements of HCT.

**Level 3:** The CC program offers HCT education to YSHCN and parents/caregivers, has trained YSHCN and parent leaders about the Six Core Elements, and involves them in Title V program development and evaluation on HCT.

**Level 4:** The CC program offers HCT education to YSHCN and parents/caregivers and involves YSHCN/parent HCT leaders, knowledgeable about the Six Core Elements in statewide efforts to advance HCT improvements.
What to do? Where to start?
Starting a HCT Pilot to Achieve Measurable Improvements

Goal:
Maximize HCT supports for YSHCN by increasing Title V CC implementation of Six Core Elements

Use qualitative improvement (QI) methods:
- Gain leadership support
- Form HCT QI improvement team
- Create AIM statement/definition of success
- Clarify measurement
- Specify activities/actions needed for HCT improvement
- Test change (plan, do, study, act/PDSA cycle)
- Implement pilot
Leadership Support and QI Team

Obtain senior Title V leadership support for HCT improvement process

Form HCT QI Team:
• Leaders with enough authority to test and implement change (including CC managers, both pediatric and adult clinicians, and office staff)
• Family and YSHCN
• Day-to-day leader who understands CC operations and effects of changes and works effectively with others
• Administrative expert who can assist with tracking progress and information system updates/EMR modifications
• HCT QI sponsor (e.g., CYSHCN director) with connection to senior management and can overcome barriers of team (involved not as a regular team member, but to review/learn about progress)
Aim Statement Example

**Aim: By May 2018, 80% of youth (with selected conditions), ages 14-21, will complete a standardized Transition Readiness Assessment, and their transition skill needs will be incorporated into a plan of care that is jointly developed with YSHCN and families.**

- This aim intends to reach Level 3 on Transition Readiness and Transition Planning core elements
- Aim could focus on other core elements
- Aim should include date, population, target, and specific HCT element(s)
- Important to align aim statement with what success should look like and to reach a specific level of HCT implementation
Ways to Measure Aim Statement

Aim: By May 2018, 80% of youth (with selected conditions), ages 14-21, will complete a standardized Transition Readiness Assessment, and their transition skill needs will be incorporated into a plan of care that is jointly developed with YSHCN and families.

1. Transition Registry (of population group ages 14-21)
   - Name, DOB, Age
   - Transition Readiness Assessment administered (date)
   - Plan of Care with HCT skill action steps (date)

2. Current Assessment of HCT Activities in CC programs
   - Baseline collected in May 2017
   - To be repeated in May 2018 by Got Transition
Activities Needed for HCT Improvement

1. Select pilot population
2. Select/customize Transition Readiness Assessment (RA) tools involving CCs and youth and families (Got Transition, ACP, TRAQ)
3. Decide at what age RA to be given
4. Decide if youth/parent will complete RA on their own or CC will administer RA with youth/parent
5. Decide how RA skill needs and action steps will be jointly identified with youth/parents

6. Clarify roles in terms of who will provide needed self-care education (CC, clinician, family depending on skill needed)

7. Decide how identified RA skills and action steps will be included in plan of care

8. Decide how often to repeat RA and offer self-care education

9. Decide how CC program will track date when YSHCN received RA and plan of care was updated with HCT skill needs and action steps
Testing HCT Activities Using PDSA Cycles

**Transition Readiness Assessment**
- Pilot with small group of youth (e.g., from different age groups, conditions/complexities, family backgrounds). What questions or words were problematic? Were important questions missing? Is the reading level/language appropriate?
- Pilot using different processes to administer RA by YSHCN on their own or by CCs/clinician office
- Pilot using different processes to provide self-care education

**Transition Plan**
- Pilot within small group of YSHCN (e.g., from different age groups, conditions/complexity, family backgrounds)
- Pilot updating plan of care with CCs

**Tracking**
- Pilot tracking method with CC and administrative staff

**Refine and Re-test**
Implementing Changes That Will Result in HCT Improvement

Aim: By May 2018, 80% of youth (with selected conditions), ages 14-21, will complete a standardized Transition Readiness Assessment, and their transition skill needs will be incorporated into a plan of care that is jointly developed with YSHCN and Families.

- After testing changes on small scale and refining, HCT change process is ready for implementation to broader pilot population.
- Consider a planned launch with education for CCs.
- Measure progress from tracking method(s) and provide ongoing feedback to CCs and senior leadership.
- Keep track of lessons learned, including sequencing of tasks, effective ways of working with youth and families, etc.
Lessons Learned in Implementing Six Core Elements Pilots

- Choose your pilot wisely. Rest of CC program is watching. Try not to transition the most complex patients until HCT processes are in place.
- Without leadership support and continued buy-in, sustainability is impossible.
- Outline measurement strategies up front so that everyone knows what “success looks like.”
- Success in implementing Six Core Elements is about putting a fail-safe process in place that is integrated into routine CC functions. It is not about hiring a CC to make it all happen.
- Clear delineation of the distinctive and collaborative roles of CCs and pediatric and adult clinicians in HCT process is important.
- HCT progress is rewarding and youth and families appreciate and benefit from these recommended HCT supports!
Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

**News & Announcements**

- **New Got Transition Webinar Series**
  Registration is open for Got Transition’s new webinar series, “Health Care Transition & Title V Care Coordination Initiatives.”

- **AAP Transition ECHO**
  The American Academy of Pediatrics Transition ECHO offers a standardized curriculum on health care transition.

- **New Transition of Care Video Series for Neurology**
  The Child Neurology Foundation has released a new Transition of Care Video Series that shares the journeys of patients transitioning to adult neurologists and showcases perspectives of national transition experts.

- **Take Our Quiz!**

**Health Care Providers**
Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.

**Youth & Families**
Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.

**Researchers & Policymakers**
Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.

**Customize the Six Core Elements of Health Care Transition to meet your patients’**

**Turning 18: What it Means for Your Health**

**NEW Got Transition Webinar Series**
Questions?

• About writing a HCT Aim statement?

• About selecting HCT activities to achieve improvement?

• About measuring HCT improvement?

• About CC baseline results?

• About clinical foundations?
Upcoming Title V Care Coordination Webinars

Transition Preparation
March 28, 3-4 pm ET

Transfer to Adult Care
April 26, 3-4 pm ET

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 News & Announcements (www.gottransition.org)
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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