New Directions in Health Care Transition Improvement

CAAI Webinar: Autism Spectrum Disorder and Transition
April 30, 2014

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Got Transition/Center for Health Care Transition Improvement
The National Alliance to Advance Adolescent Health
Disclosures

• None
Presentation Overview

• Making the case for transition improvements
• Background leading to development of Six Core Elements 1.0
• Updated Six Core Elements 2.0
  – New clinical tools/packages
  – Measurement options
• Next Steps
Making the Case for Transition Improvements

**Health is diminished:**
- Youth often unable to name their health condition, relevant medical history, prescriptions, insurance source
- Adherence to care is lower and medical complications are increased
- Youth and family are worried

**Quality is compromised:**
- Youth, young adults, and families are dissatisfied about lack of preparation, information about adult care, vetted adult providers, communication between pediatric and adult providers, and sharing of medical information.
- Many surveys of adult and pediatric providers have outlined the barriers to a successful transition
- Discontinuity of care and lack of usual source of care is common
- Medical errors reported

**Costs are increased:**
- Increased ER, hospital use, and duplicative tests result
AAP/AAFP/ACP Clinical Report on Health Care Transition

- 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 of care to adult medical home and adult specialists

**Age 12** – Youth and family aware of transition policy

**Age 14** – Health care transition planning initiated

**Age 16** – Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care

**Age 18** – Transition to adult approach to care

**Age 18-22** – Transfer of care to adult medical home and specialists with transfer package

“Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home” (Pediatrics, July 2011)
Six Core Elements of Health Care Transition (1.0)

• MCHB’s National Health Care Transition Center (*Got Transition*, led by Carl Cooley and Jeannie McAllister)

• Created:
  – Six Core Elements as quality improvement (QI) strategy aligned with Clinical Report algorithm
  – Corresponding set of sample tools
  – Health Care Transition Indices
    • Pediatric and Adult Versions
    • Modeled after Medical Home Index, developed by Center for Medical Home Improvement

• HCT Learning Collaboratives
  – Conducted between 2010-2012 in DC, Boston, Denver, New Hampshire, Minnesota, Wisconsin
  – Purpose: to determine if Six Core Elements were feasible and resulted in improvements
Results from DC Transition Learning Collaborative (18 month project)

- All met the goal of at least 30% improvement on the 6 core elements measured by the HCT index
- All pediatric, family medicine, and internal medicine practices created practice-wide policies on transition
- All created a method for tracking transitioning youth with chronic conditions (Registry of DC Medicaid HSCSN members)
- Transition readiness assessments conducted with patients in their registry
- Transition plans developed for 1/3 of youth and 45% of young adults
- Of the 350 youth (14 and older) in LC registries, 50 were transferred to adult practices by 18 months (more since then)
Lessons Learned

• Feasible to implement Six Core Elements
• Involvement -- from the outset -- of pediatric, family medicine, and adult practices was key
• Senior leadership engagement critical
• Team-based approach for QI clinical process necessary
• Family and young adult engagement critical, and challenging to sustain
• Adult practices realized the need to consider young adults a special population in adult practice
• EHR customization and lack of financial incentives were major hurdles that now are being addressed
• Multiple models of transfer depending on provider availability
Models of Care Transfer

Pediatric diseases where there are few adult subspecialty providers available e.g. congenital heart disease

Pediatric  |  Adult Medicine
Primary Care  |  Primary Care
Subspecialty Care  |  Subspecialty Care
Models of Care Transfer
Pediatric Disease where adult primary care manages some of pediatric subspecialty e.g. pediatric type II diabetes, pediatric leukemia
Models of Care Transfer

Pediatric diseases where there are both pediatric and adult subspecialty providers available e.g. pediatric rheumatology

Pediatric                      Adult Medicine
Primary Care ←→ Primary Care
Subspecialty Care ←→ Subspecialty Care
Additional Feedback on Six Core Elements (1.0)

- More focus on role and responsibilities of adult providers receiving transitioning youth
- Greater clarity of family medicine/med-peds multiple roles in transition process, including when youth do not transfer
- Samples for use in clinical sites needed refinement
- Measurement HCT indices subject to variable interpretations
- Engagement of youth/young adults and families not strong enough
- Reading levels of tools too high
State of Health Care Transition from Pediatric to Adult Health Care
Fast Forward to Got Transition
Center for Health Care Transition Improvement

• MCHB’s new Got Transition grantee: The National Alliance to Advance Adolescent Health (Peggy McManus and Patience White, Co-Directors)

• Project Team: Megan Prior, Dan Beck, Corinne Dreskin

• Cabinet Executive Team: Carl Cooley, Jeanne McAllister, Mal Cyr, Eileen Forlenza, Laura Pickler, Teresa Nguyen, Nienke Dosa, Tawara Goode, and Wendy Jones

• Evaluation Consultants: Henry Ireys and KaraAnn Clouse

• MCHB Project Officer: Marie Mann
Got Transition Goals: 2014-2018

1. Transition Quality Improvement Spread
   • Update Six Core Elements and new package of clinical tools and measurement options
   • Collaborate with new transition learning networks in large integrated care systems to promote transition spread
2. Transition Education and Training
3. Young Adult and Family Engagement
4. Transition Policy Interventions
5. Transition Information Dissemination
Process for Updating the Six Core Elements

- Used best ideas/samples from state and national transition QI efforts
- Reviewed QI transition, medical home, and consumer engagement literature
- Obtained extensive feedback from leaders in field
- Actively involved Cabinet and MCHB Project Officer in updating process
Samples/Tools: What’s New?

- 3 New Packages of Improved Samples and Tools
- Aligned with the Clinical report and Six Core Elements 1.0
- Currently available on www.GotTransition.org
- Customizable (using word version)
Six Core Elements 2.0: What’s New?

- Transitioning Youth to Adult Health Care Providers
  (Pediatric, Family Medicine, and Med-Peds Providers)

- Transitioning to an Adult Approach to Health Care Without Changing Providers
  (Family Medicine and Med-Peds Providers)

- Integrating Young Adults into Adult Health Care
  (Internal Medicine, Family Medicine, and Med-Peds Providers)
## Six Core Elements of Health Care Transition (2.0)

<table>
<thead>
<tr>
<th>Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)</th>
<th>Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)</th>
<th>Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Transition Policy</td>
<td>Transition Policy</td>
<td>Young Adult Transition and Care Policy</td>
</tr>
<tr>
<td>2. Transition Tracking and Monitoring</td>
<td>Transition Tracking and Monitoring</td>
<td>Young Adult Tracking and Monitoring</td>
</tr>
<tr>
<td>3. Transition Readiness</td>
<td>Transition Readiness</td>
<td>Transition Readiness/Orientation to Adult Practice</td>
</tr>
<tr>
<td>4. Transition Planning</td>
<td>Transition Planning/Integration into Adult Approach to Care</td>
<td>Transition Planning/Integration into Adult Practice</td>
</tr>
<tr>
<td>5. Transfer of Care</td>
<td>Transfer to Adult Approach to Care</td>
<td>Transfer of Care/Initial Visit</td>
</tr>
<tr>
<td>6. Transfer Completion</td>
<td>Transfer Completion/Ongoing Care</td>
<td>Transfer Completion/Ongoing Care</td>
</tr>
</tbody>
</table>
A further look...

Transitioning Youth to Adult Health Care Providers
(Pediatric, Family Medicine, and Med-Peds Providers)

Transitioning to an Adult Approach to Health Care Without Changing Providers
(Family Medicine and Med-Peds Providers)

Integrating Young Adults into Adult Health Care
(Internal Medicine, Family Medicine, and Med-Peds Providers)
1. Transition Policy: What’s New?

TURN TO PAGE 7 IN PEDIATRIC PACKAGE

- Distinctive policy issues in the 3 packages
- Greater emphasis on adult approach to care and legal changes at age 18, including options for supported decision-making
- More clarity about ages
2. Tracking and Monitoring: What’s New?

- Distinctive tracking issues in 3 packages
- Need for tracking options for those with and without electronic health records
- Individual Transition Flow Sheet for use in paper chart or EHR
- Registry set up as an excel file
3. Transition Readiness/Orientation to the Adult Practice: What’s New?

TURN TO PAGES 10 & 11

- Lowered literacy level (now 5.7)
- New validated questions on importance and confidence
- Young adult’s readiness assessment called self-care assessment and part of initial adult visit (core element #5)
- New young adult welcome and orientation information, with FAQs
4. Transition Planning/Integration into Adult Approach to Care/Integration into Adult Practice: What’s New?

TURN TO PAGES 12, 13, & 16

- New template for plan of care that incorporates health into youth and young adult’s overall priorities
- New combined medical summary and emergency care plan
- New sample condition fact sheet
# Sample Medical Summary and Emergency Care Plan

Six Core Elements of Health Care Transition 2.0

This document should be shared with and carried by youth and families/caregivers.

<table>
<thead>
<tr>
<th>Date Completed:</th>
<th>Date Revised:</th>
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## Contact Information

<table>
<thead>
<tr>
<th>Name:</th>
<th>Nickname:</th>
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<table>
<thead>
<tr>
<th>DOB:</th>
<th>Preferred Language:</th>
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<table>
<thead>
<tr>
<th>Parent (Caregiver):</th>
<th>Relationship:</th>
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<table>
<thead>
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<table>
<thead>
<tr>
<th>Cell #:</th>
<th>Home #:</th>
<th>Best Time to Reach:</th>
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<tr>
<th>E-Mail:</th>
<th>Best Way to Reach:</th>
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<thead>
<tr>
<th>Health Insurance/Plan:</th>
<th>Group and ID #:</th>
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## Emergency Care Plan

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<tr>
<th>Preferred Emergency Care Location:</th>
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</table>

## Common Emergent Presenting Problems

<table>
<thead>
<tr>
<th>Suggested Tests</th>
<th>Treatment Considerations</th>
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## Special Concerns for Disaster:

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## Allergies and Procedures to be Avoided

<table>
<thead>
<tr>
<th>Allergies</th>
<th>Reactions</th>
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## To be avoided

<table>
<thead>
<tr>
<th>Medical Procedures:</th>
<th>Why?</th>
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<table>
<thead>
<tr>
<th>Medications:</th>
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## Diagnoses and Current Problems

<table>
<thead>
<tr>
<th>Problem</th>
<th>Details and Recommendations</th>
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## Primary Diagnosis

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<tr>
<th>Behavioral</th>
<th>Communication</th>
<th>Feed &amp; Swallowing</th>
<th>Hearing/Vision</th>
<th>Learning</th>
<th>Orthopedic/Musculoskeletal</th>
<th>Physical Anomalies</th>
<th>Respiratory</th>
<th>Sensory</th>
<th>Stamina/Fatigue</th>
<th>Other</th>
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## Secondary Diagnosis

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<thead>
<tr>
<th>Behavioral</th>
<th>Communication</th>
<th>Feed &amp; Swallowing</th>
<th>Hearing/Vision</th>
<th>Learning</th>
<th>Orthopedic/Musculoskeletal</th>
<th>Physical Anomalies</th>
<th>Respiratory</th>
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</table>
5. Transfer of Care/Transfer to Adult Approach to Care/Initial Visit: What’s New?

- New sample transfer letter
- In package for young adults integrating into adult health care, new guidance on what should occur prior to and during initial visit:
  - Pre-visit call recommended
  - At first visit, discussion about
    - Transfer concerns
    - Orientation to adult care/practice
    - Partnership with adult provider
  - Final transition readiness/self-care assessment form, medical summary, and plan of care reviewed and updated
6. Transfer Completion/ Ongoing Care: What’s New?

Turn to page 20

- New transition feedback surveys
- Several questions adapted from new questions under development for National Survey of Children’s Health
Measurement Options

1. Initial Health Care Transition Assessment

TURN TO PAGE 25

• Qualitative self-assessment tool modeled after index
• Provides a snapshot of where practice is in implementing transition processes
• New questions on consumer feedback and leadership
<table>
<thead>
<tr>
<th>Transition Activity</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Young Adult Transition and Care Policy</strong></td>
<td>Clinicians vary in their approach to new young adult patients, and most often approach new young adults as any new patient group, requesting that they complete new patient information forms.</td>
<td>Clinicians follow a uniform, but not a written health care transition policy about the practice’s approach for accepting new young adults, assisting them in gaining knowledge of the adult health care system.</td>
<td>The practice has a written health care transition and care policy or approach, developed with input from young adults, which describes the practice’s approach for partnering with new young adult patients and explains privacy and consent in understandable language.</td>
<td>The practice has a written health care transition and care policy or approach, developed with input from young adults, and it is publicly displayed and discussed with new young adult patients. All staff are familiar with the policy.</td>
<td></td>
</tr>
<tr>
<td><strong>2. Tracking and Monitoring</strong></td>
<td>Clinicians have no mechanism to identify new young adults in the practice and their level of self-care skills.</td>
<td>Clinicians use patient charts to record certain relevant transition information (e.g., medical summary, self-care assessment).</td>
<td>The practice has an individual transition flow sheet or transition registry for identifying and tracking new young adult patients, or a subgroup of young adults with chronic conditions, as they progress through and complete some but not all transition processes.</td>
<td>The practice has an individual transition flow sheet or registry for identifying and tracking new young adult patients, or a subgroup of young adults with chronic conditions, as they progress through and complete all Six Core Elements of Health Care Transition, using EHR if possible.</td>
<td></td>
</tr>
<tr>
<td><strong>3. Transition Readiness/Orientation to Adult Practice</strong></td>
<td>Clinicians have no welcome process tailored to new young adult patients, and there is no organized process within the practice to identify clinicians interested in caring for young adults.</td>
<td>Clinicians within the practice have self-selected to accept new young adult patients, and the practice makes available general introductory information for all new patients of all ages.</td>
<td>The practice has a list of providers interested in caring for young adults that it shares with new young adult patients and pediatric practices. It also makes available general introductory information for all new patients.</td>
<td>The practice has a packet of materials tailored to young adults orienting them to the practice and including a list of providers interested in caring for young adults. The practice offers get-acquainted appointments, if feasible.</td>
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</tbody>
</table>
2. Health Care Transition Process Measurement Tool

- Objective scoring method with documentation requirements
- Measures implementation of Six Core Elements, consumer feedback and leadership, and dissemination
- Intended to be conducted at start of QI initiative as baseline measure and repeated to assess progress
# Measurement: Policy Example

## Health Care Transition Process Measurement Tool for Integrating Young Adults into Adult Health Care

### Six Core Elements of Health Care Transition 2.0

#### A) Implementation Requirement

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Yes or No</th>
<th>Possible</th>
<th>Actual</th>
<th>Possible Documentation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developed a written transition and care policy that describes the practice’s approach to accepting and partnering with new young adults</td>
<td>Yes = 4</td>
<td></td>
<td></td>
<td>Transition policy</td>
</tr>
<tr>
<td>Included information about privacy and consent in transition policy</td>
<td>Yes = 2</td>
<td></td>
<td></td>
<td>Transition policy</td>
</tr>
<tr>
<td>Posted policy in public clinic spaces</td>
<td>Yes = 2</td>
<td></td>
<td></td>
<td>Photo</td>
</tr>
<tr>
<td>Educated staff about transition policy and their role in transition process</td>
<td>Yes = 2</td>
<td></td>
<td></td>
<td>Date(s) of program</td>
</tr>
<tr>
<td>Designated practice staff to incorporate Six Core Elements into clinical processes</td>
<td>Yes = 4</td>
<td></td>
<td></td>
<td>Job description</td>
</tr>
</tbody>
</table>

**Transition Policy Implementation Subtotal:** 14

#### B) Young Adult Engagement Requirement

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Yes or No</th>
<th>Possible</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Included input from young adults in developing policy</td>
<td>Yes = 2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### C) Dissemination in Practice/Network

<table>
<thead>
<tr>
<th>Percent of Patients in Practice:</th>
<th>1–10%</th>
<th>11–25%</th>
<th>26–50%</th>
<th>51–75%</th>
<th>76–100%</th>
<th>Possible</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Score Points:</strong></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. **Transition Policy**

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Possible</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing policy with young adults, ages 18–26 (letter or visit)</td>
<td>0 to 5</td>
<td>5</td>
</tr>
</tbody>
</table>

**Transition Policy Dissemination Subtotal:** 5
Next Steps: Dissemination of Six Core Elements Packages

- New Six Core Elements Packages now available in PDF or Word for customization at www.gottransition.org:
  - Transitioning youth to an adult provider (for pediatric, family medicine, and med-peds providers)
  - Transitioning to an adult approach to health care without changing providers (for family medicine and med-peds providers)
  - Integrating young adults into adult health care (for internal medicine, family medicine, and med-peds providers)
- Launch of new website with family and youth FAQs, resources, and a policy sections in June 2014
- Spanish versions of packages available in summer
- Feedback welcome: info@gottransition.org
Next Steps: Transition Learning Networks with 4 Large Integrated Care Systems

• Kaiser Northern California – primary care
• Health Partners (MN) – primary care
• Henry Ford Health System (MI) – primary care
• Walter Reed National Military Medical Center (MD) – specialty care

  – Partnership in implementing and evaluating new Six Core Elements Packages
  – Pediatric and adult teams participating
  – Coaching support to networks by Got Transition
  – Goal: to learn about spread of transition QI and ROI Working with Mathematica as an evaluator)
Next Steps: State Title V Transition Planning Group

• CSHCN Directors and Adolescent Coordinators from MD, OH, OR, RI, TX, and WI
  – Goal: to expand leadership development with implementation and evaluation of updated Six Core Elements packages
    • Building partnerships between pediatric and adult providers/systems of care and engaging state public health adolescent health and chronic disease programs
    • Expanding youth/young adult/family leadership in transition quality improvement
Conclusion

• Time is now to bring transition from pediatric to adult health care to forefront
• Transition support is a need for all youth, and especially those with complex chronic conditions like autism
• Transition is a concern of many providers, but not yet a common standard of primary and specialty practices
• The updated 2.0 version of the Six Core Elements in the 3 new packages with clinical samples/tools can accelerate quality improvements in health care transition
Thank you and Questions

• pwhite@thenationalalliance.org

• Please visit [www.gottransition.org](http://www.gottransition.org) (see link to new Transition CME sponsored by HSCSN) and download the other 6 core elements 2.0