New Directions in Health Care Transition Improvement

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

• Not just 500,000 youth with special needs transitioning to adult health care annually; it is ALL ADOLESCENTS who must transition from pediatric to adult-centered care

• There are an estimated 18 million adolescents, ages 18-21, about ¼ of whom have chronic conditions; many more millions if you count those 12-26.

• Majority of youth are ill-prepared for this change.

• Surveys of health care providers consistently show they lack a systematic way to provide transition support from pediatric to adult health.
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 lower and medical complications increased
- Youth and family worried

**Quality is compromised:**
- Youth, young adults, and families dissatisfied about lack of preparation, information about adult care, vetted adult providers, communication between pediatric and adult providers, and sharing of medical information.
- Discontinuity of care and lack of usual source of care common
- Medical errors reported

**Costs are increased:**
- Preventable ER and hospital use and duplicative tests widespread
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
# Six Core Elements of Health Care Transition (1.0)

<table>
<thead>
<tr>
<th>Pediatric Setting</th>
<th>Adult Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Transition Policy</td>
<td>Young Adult Privacy &amp; Consent Policy</td>
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<tr>
<td>2. Transitioning Youth Registry</td>
<td>Young Adult Registry</td>
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<td>3. Transition Preparation</td>
<td>Transition Preparation</td>
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<td>4. Planning</td>
<td>Transition Planning</td>
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<td>5. Transfer of Care</td>
<td>Transition and Transfer of Care</td>
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<tr>
<td>6. Transfer Completion</td>
<td>Transition Completion</td>
</tr>
</tbody>
</table>
Health Care Transition 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
• QI Team Leaders: Carl Cooley, Jeannie McAllister, Patience White, Mal Cyr, Laura Pickler, Eileen Forlenza
Results from DC Transition Learning Collaborative

- 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
- 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
Lessons Learned

• Feasible to implement Six Core Elements
• Involvement of pediatric, family medicine, and adult practices from outset was key
• Senior leadership engagement critical
• Team-based approach for QI clinical process necessary
• Family and young adult engagement critical, but challenging to sustain
• Need to consider young adults a special population in adult practice
• EHR customization and lack of financial incentives were major hurdles
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/tools needed refinement
• Measurement indices subject to variable interpretations
• Engagement of youth/young adults and families not strong enough
• Reading levels of samples/tools too high
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
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)
Samples/Tools: What’s New?

- 3 New Packages of Improved Samples and Tools
- Aligned with the Six Core Elements 2.0
- Currently available on [www.GotTransition.org](http://www.GotTransition.org)
- Customizable (using word version)
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)

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Six Core Elements of Health Care Transition 2.0
Integrating Young Adults into Adult Health Care
for use by Internal Medicine, Family Medicine, and Med-Peds Providers

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   Introduction to Each of the Six Core Elements
4. Core Element Samples
   1) Young Adult Transition and Care Policy
   2) Young Adult Tracking and Monitoring
   3) Individual Transition Flow Sheet
   4) Transition Timeline/Overview
   5) Sample Welcome and Orientation of New Young Adults
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Prepared by the Got Transition! Center for Health Care Transition Improvement project team, Megan McWhirt, Melissa Whitby, and Maggie Fie, with assistance from our research team, and others. The Got Transition! Center is a project of the Adolescent/Young Adult Health Care Transitions Project, funded by the Office of Juvenile Justice and Delinquency Prevention, Office of Justice Programs, U.S. Department of Justice, under award 2015-DN-BX-0017. It is operated through a cooperative agreement between the University of Rochester Medical Center and the National Initiative for Children's Healthcare Quality.
1. Young Adult Transition and Care Policy: What’s New?

- 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
Sample Young Adult Transition and Care Policy
Six Core Elements of Health Care Transition 2.0

[Adult Practice Name] welcomes young adults, including those with special health care needs, to our practice. We aim to provide high quality, comprehensive, and confidential health care to meet young adults’ unique needs.

Our practice places the young adult, ages 18 and older, in the center of his/her own health care, with the health care provider as a partner in supporting your health goals. This means that adult providers do not discuss any aspects of your care with anyone else unless you specifically ask that we do. We understand that some young adults involve family and close friends in their health care decisions and would like their provider to share information with those close to them. To allow others to be involved in your health care decisions requires that a signed consent form be completed, which is available at the clinic. For young adults unable to provide consent, we will need legal documentation about decision-making arrangements.

We ask that new patients transferring to our practice obtain from their previous provider(s) a medical summary or medical record and send it to us before the first appointment. We make every effort to coordinate the transfer of care with previous providers, including communicating with pediatric providers and assisting with transfer of specialty care, as needed. Having your medical information in advance helps to ensure greater continuity of care and a better experience for you.

Your health is important to us, and we look forward to having you as a new patient. If you have any questions or concerns, please feel free to contact us.
2. Young Adult 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 HER
- Excel registry to look at populations
Sample Individual Transition Flow Sheet
Six Core Elements of Health Care Transition 2.0

<table>
<thead>
<tr>
<th>Patient Name: ____________________</th>
<th>Date of Birth: ____________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Diagnosis:_______________</td>
<td>Transition Complexity: _______</td>
</tr>
</tbody>
</table>

Welcome and Orientation
- Contacted young adult before the first visit to welcome and answer questions  
  ________________________________ | Date _______________________ |
- Transfer package received from pediatric provider ____________________________ | Date ________________________ |
  - 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  
  - Additional provider records, if needed  
- Orientation material shared with young adult ____________________ | Date _______________________ |
- Practice policy on transition discussed/shared with young adult __________ | Date _______________________ |

Adult Model of Care
- Clarified adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication ____________________________ | Date ________________________ |
  - If needed and not previously addressed, discussed legal options for supported decision-making ___________________________ | Date _______________________ |

Self-Care Assessment
- Conducted self-care assessment ____________________ | Date | Date | Date |
  - Included self-care goals and prioritized actions in plan of care ____________________________ | Date | Date | Date |

Medical Summary and Emergency Care Plan
- Updated and shared medical summary and emergency care plan ____________________ | Date | Date | Date |

Transfer Completion
- Communicated with pediatric provider confirming transfer or care and arranging for consultation, if needed ___________________________ | Date _______________________ |
  - Elicited feedback from young adult about transition and experience with care ____________________ | Date _______________________ |
### Sample Transition Registry

**Six Core Elements of Health Care Transition 2.0**

#### Transition Registry

1/21/2014

<table>
<thead>
<tr>
<th>DOB</th>
<th>Age</th>
<th>Name</th>
<th>Primary Diagnosis</th>
<th>Transition Complexity*</th>
<th>First Appointment</th>
<th>Next Scheduled Appointment (Date or Blank)</th>
<th>Communicated with Pediatric Provider (Yes or Blank)</th>
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<tbody>
<tr>
<td>4/18/1990</td>
<td>23</td>
<td>David Crockett</td>
<td>well</td>
<td>1</td>
<td>12/22/2012</td>
<td>4/13/2014</td>
<td></td>
</tr>
<tr>
<td>4/2/1995</td>
<td>18</td>
<td>Tom Sawyer</td>
<td>ADHD</td>
<td>2</td>
<td>6/19/2014</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2/4/1987</td>
<td>26</td>
<td>Sasha Jones</td>
<td>well</td>
<td>1</td>
<td>4/16/2012</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2/3/1994</td>
<td>15</td>
<td>Enrique Montoya</td>
<td>well</td>
<td>1</td>
<td>5/13/2014</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Complexity Scoring
1 = Low Complexity
2 = Moderate Complexity
3 = High Complexity

#### Transition Registry

1/21/2014

<table>
<thead>
<tr>
<th>Name</th>
<th>Transfer Package Received</th>
<th>Contacted Young Adult Before First Visit (Date or Blank)</th>
<th>Policy Shared with Young Adult (Yes or Blank)</th>
<th>Self-Care Assessment Administered (Date or Blank)</th>
<th>Plan of Care Updated and Shared with Young Adult (Date or Blank)</th>
<th>Medical Summary and Emergency Care Plan Updated and Shared with Young Adult (Date or Blank)</th>
<th>Elicited Feedback from Young Adult about Transition and Experience with Care (Yes or Blank)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan Cox</td>
<td>Yes</td>
<td>6/1/2012</td>
<td>Yes</td>
<td>7/9/2012</td>
<td>7/9/2012</td>
<td>7/9/2012</td>
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<tr>
<td>Terence Train</td>
<td>Yes</td>
<td></td>
<td></td>
<td>8/16/2013</td>
<td>8/16/2013</td>
<td>8/16/2013</td>
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<tr>
<td>Devin Carn</td>
<td>Yes</td>
<td></td>
<td></td>
<td>9/20/2013</td>
<td>9/20/2013</td>
<td>9/20/2013</td>
<td></td>
</tr>
<tr>
<td>Jen Lawrence</td>
<td>Yes</td>
<td></td>
<td></td>
<td>9/20/2012</td>
<td>9/20/2012</td>
<td>9/20/2012</td>
<td></td>
</tr>
<tr>
<td>Sasha Jones</td>
<td>Yes</td>
<td></td>
<td></td>
<td>4/13/2012</td>
<td>4/13/2012</td>
<td>4/13/2012</td>
<td></td>
</tr>
</tbody>
</table>
3. Transition Readiness/Orientation to the Adult Practice: What’s New?

- New suggestion to identify adult providers interested in caring for young adults
- New Welcome and Orientation material with FAQs
[Adult Practice Name] is pleased to welcome you into our practice. Our practice places young adults in the center of their own health care. This means that our providers do not discuss your care with anyone else unless you ask that we do. We understand that some young adults involve family and close friends in their health care decisions. To allow others to be involved in your health care decisions you will need to complete a signed consent. These forms are available at the clinic. For young adults unable to provide consent, we will need legal documentation about decision-making arrangements.

At our practice, you have the right to:

- Be treated in a caring way
- Make your own decisions
- Talk to your health care provider alone
- Have things explained in a way that you understand
- Have access to your medical information

In turn, you are responsible for:

- Keeping appointments and cancelling appointments in advance
- Telling us about your current symptoms and health history to help us treat you
- Following treatment plans that you develop with your health provider
- Asking questions about your care
- Knowing what your insurance covers

Below is a list of frequently asked questions and answers about our practice. If you have a question that is not listed below, feel free to ask any of our staff. We look forward to having you in our practice.

Q: What services does the practice provide (including preventive, acute and chronic illness care, and, if offered, sexual health, mental/behavioral health, wellness programs, and other specialty care)?
A: 

Q: Are services confidential?
A:

Q: Where is the office located (including map and nearest public transportation)?
A:

Q: What providers are available to care for young adults?
A:

Q: What are the office hours (including walk-in options, if available)?
A:

Q: Are there after-hours call-in options?
A:

Q: How do I schedule, reschedule, or cancel an appointment?
A:

Q: What insurance is accepted?
A:

Q: How much do visits cost?
A:

Q: What should I bring for my first appointment?
A:

Q: What resources are available to assist me to learn about wellness and self-care (e.g., nutrition and fitness classes, support groups, special apps or websites, local community resources)?
A:
4. Transition Planning/Integration into the Adult Practice: What’s New?

• Updated transfer package
  – New template for plan of care that incorporates health into young adult’s overall priorities
  – New combined medical summary and emergency care plan
  – New sample condition fact sheet

• Suggestion make pre-visit welcome and reminder call
Sample Plan of Care
Six Core Elements of Health Care Transition 2.0

Instructions: This sample plan of care is a written document developed jointly with the young adult to establish priorities and a course of action that integrates health and personal goals. Motivational interviewing and strength-based counseling are key approaches in developing a collaborative process and shared decision-making. Information from the self-care assessment can be used to guide the development of health goals. The plan of care should be dynamic and updated regularly.

Name: ___________________________  Date of Birth: ___________________________
Primary Diagnosis: ___________________________  Secondary Diagnosis: ___________________________

What matters most to you as an adult? How can learning more about your health condition and how to use health care support your goals?

<table>
<thead>
<tr>
<th>Prioritized Goals</th>
<th>Issues or Concerns</th>
<th>Actions</th>
<th>Person Responsible</th>
<th>Target Date</th>
<th>Date Complete</th>
</tr>
</thead>
<tbody>
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</table>

Initial Date of Plan: _______________  Last Updated: _______________  Young Adult Signature: _______________
Clinician Signature: _______________  Care Staff Contact: _______________  Care Staff Phone: _______________
**Sample Medical Summary and Emergency Care Plan**

**Six Core Elements of Health Care Transition 2.0**

<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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<tr>
<th>DOB:</th>
<th>Preferred Language:</th>
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<table>
<thead>
<tr>
<th>Address:</th>
<th>Relationship:</th>
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<table>
<thead>
<tr>
<th>Cell #:</th>
<th>Home #:</th>
<th>Best Time to Reach:</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Text     Phone     Email</td>
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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>Emergency Contact</th>
<th>Relationship</th>
<th>Phone:</th>
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</table>

**Preferred Emergency Care Location:**

<table>
<thead>
<tr>
<th>Common Emergent Presenting Problems</th>
<th>Suggested Tests</th>
<th>Treatment Considerations</th>
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**Special Concerns for Disaster:**

**Allergies and Procedures to be Avoided**

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<tr>
<th>Allergies</th>
<th>Reactions</th>
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**To be avoided**

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<tr>
<th>Medical Procedures</th>
<th>Why?</th>
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**Diagnoses and Current Problems**

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<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>Stomach/Fatigue</th>
<th>Other</th>
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**Secondary Diagnosis**

<table>
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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>Stomach/Fatigue</th>
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</table>
5. Transfer of Care/Initial Visit: What’s New?

• Now title readiness assessment “self-care assessment” for young adults
  – Updated versions for youth and families
  – Lowered literacy level (now 5.7)
  – New validated questions on importance and confidence

• New guidance on transferring to an adult approach to care
  – Shared-decision making
  – Privacy and consent
  – Access to information
  – Adherence to care
  – Methods of communication
  – Health literacy
# Sample Self-Care Assessment for Young Adults

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health, using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

**Date:**

**Name:**

**Date of Birth:**

## Transition and Self-Care Importance and Confidence

*On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

<table>
<thead>
<tr>
<th>Importance</th>
<th>0 (not)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 (very)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is it to you to manage your own health care?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>How confident do you feel about your ability to manage your own health care?</td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

## My Health

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes, I know this</th>
<th>I need to learn</th>
<th>Someone needs to do this...</th>
<th>Who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know my medical needs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can explain my medical needs to others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know my symptoms including ones that quickly need to see a doctor for.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I know what to do in case I have a medical emergency.</td>
<td></td>
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</tr>
<tr>
<td>I know my own medicines, what they are for, and when I need to take them.</td>
<td></td>
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<tr>
<td>I know my allergies to medicines and the medicines I should not take.</td>
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</tr>
<tr>
<td>I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

## Using Health Care

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes, I know this</th>
<th>I need to learn</th>
<th>Someone needs to do this...</th>
<th>Who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know or I can find my doctor’s phone number.</td>
<td></td>
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</tr>
<tr>
<td>I make my own doctor appointments.</td>
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<tr>
<td>Before a visit, I think about questions to ask.</td>
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<tr>
<td>I have a way to get to my doctor’s office.</td>
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<tr>
<td>I know I need to show up 15 minutes before the visit to check in.</td>
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<tr>
<td>I know where to go to get medical care when the doctor’s office is closed.</td>
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<tr>
<td>I have a file at home for my medical information.</td>
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<td></td>
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<tr>
<td>I know how to fill out medical forms.</td>
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<tr>
<td>I know how to get referrals to other providers.</td>
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<tr>
<td>I know where my pharmacy is and how to refill my medicines.</td>
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</tr>
<tr>
<td>I know where to get blood work or x-rays done if my doctor orders them.</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I carry important health information with me every day, i.e., insurance card, allergies, medications, emergency contact information, medical summary.</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>I understand how health care privacy changes at age 18 when legally an adult.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I have a plan so I can keep my health insurance after 18 or older.</td>
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</tr>
</tbody>
</table>
6. Transfer Completion/Ongoing Care: What’s New?

- New transition feedback surveys for young adults
- Several questions adapted from new questions under development for National Survey of Children’s Health
Sample Health Care Transition Feedback Survey
for Young Adults
Six Core Elements of Health Care Transition 2.0

This is a survey about your experience with your new adult health care provider. You may choose to answer this survey or not. Your responses to this survey are confidential.

1. Does your adult health care provider explain things in a way that is easy to understand?
   - Yes
   - No

2. Does your adult health care provider listen carefully to you?
   - Yes
   - No

3. Does your adult health care provider respect how your customs or beliefs affect your care?
   - Yes
   - No
   - Not applicable

4. Did your adult health care provider discuss with you or have an office policy that explained their approach to accepting and partnering with young adult patients?
   - Yes
   - No

5. Did your adult health care provider provide written or online information describing their hours and services?
   - Yes
   - No

6. Does your adult health care provider actively work with you to improve skills to manage your own health and health care (e.g., know your medications and their side effects, know what to do in an emergency)?
   - A lot
   - Some
   - A little
   - Not at all

7. Does your adult health care provider actively work with you to plan for the future (e.g., take time to discuss future plans about education, work relationships, and development of independent living skills)?
   - A lot
   - Some
   - A little
   - Not at all

8. Did your adult health care provider address any of your concerns about transferring to a new practice/provider?
   - Yes
   - No

9. Did your adult health care provider explain the legal changes in privacy, decision-making, and consent that take place at age 19?
   - Yes
   - No

10. Does your adult health care provider actively work with you to create a written plan of care to meet your health goals and needs?
    - Yes
    - No

11. Did your adult health care provider update and share a current medical summary with you?
    - Yes
    - No

12. Does your adult health care provider assist you in identifying adult specialists, if needed?
    - Yes
    - No
    - Not needed

13. Do you know how to find information about health insurance options, if needed?
    - Yes
    - No
    - Not needed

14. Does your adult health care provider have information about community resources?
    - Yes
    - No

15. At what age did you change to an adult health care provider?
    Age __________

16. How can your adult health care provider improve your experience of care in this/this practice?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

*Adapted from the National Survey of Children’s Health
Measurement Options

1. Current Assessment of Health Care Transition Activities
   - 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
# Current Assessment of Health Care Transition Activities for Integrating Young Adults into Adult Health Care

## Six Core Elements of Health Care Transition 2.0

<table>
<thead>
<tr>
<th>Element</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>1. Young Adult Transition and Care Policy</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>2. Tracking and Monitoring</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>3. Transition Readiness/Orientation to Adult Practice</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>
<td></td>
</tr>
</tbody>
</table>
Measurement Options

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 Tool: 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>1. Young Adult Transition and Care Policy</td>
<td>Yes = 4</td>
<td></td>
<td></td>
<td>Transition policy</td>
</tr>
<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></td>
<td></td>
<td></td>
<td></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>Data(s) of program</td>
</tr>
<tr>
<td>Designated practice staff to incorporate <em>Six Core Elements</em> 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 Requirement

<table>
<thead>
<tr>
<th>Percent of Patients in Practice Receiving Transition Elements:</th>
<th>1–10%</th>
<th>11–25%</th>
<th>26–50%</th>
<th>51–75%</th>
<th>76–100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score Points:</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>1. Transition Policy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing policy with young adults, ages 18–26 (letter or visit)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

**Transition Policy Dissemination Subtotal:**

| 5 |
Next Steps: Dissemination of Six Core Elements Packages

- New Six Core Elements Packages now available for:
  - 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)

- Launch of new website with interactive health professional page in spring
- Spanish and low literacy 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
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 the forefront
- Transition support is a need for all youth, and especially those with chronic conditions
- Transition is a concern of many providers, but not yet a common standard of primary and specialty care practices
- We hope the updated version of the Six Core Elements and the 3 new packages of clinical samples/tools will accelerate quality improvements in health care transition