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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Six Core Elements of Health Care Transition 2.0

Got Transition is pleased to share this updated package of the Six Core Elements of Health Care Transition for use by internal medicine, family medicine, and med-peds providers to benefit all young adults as they transition from pediatric to adult-centered health care. Consistent with the AAP/AAFP/ACP Clinical Report on Health Care Transition,1 transition consists of joint planning with young adults to foster development of self-care skills and active participation in decision-making. It also consists ensuring a smooth transfer to adult-centered care with current medical information.

Recognizing and responding to the diversity among young adults and their families is essential to the transition process. This diversity may include but is not limited to differences in culture, race, ethnicity, languages spoken, intellectual abilities, gender, sexual orientation, and age. Since implementation of the Six Core Elements depends so much on patient and provider communication, health plans and practices should use appropriate oral and written communications, including interpretation and translation services and health literacy supports as needed.2 In addition, engaging young adult and parents/caregivers from various cultural backgrounds in the development and evaluation of a transition quality improvement process is important.3

The Six Core Elements of Health Care Transition 2.0 define the basic components of health care transition support. The linked sample tools in this package provide tested means for integrating young adults into adult health care. Corresponding packages are available for 1) transitioning youth to adult health care providers and 2) transitioning to an adult approach to care without changing providers.4 Originally developed in 2009, this updated version incorporates the results of recent transition learning collaborative experiences in several states,5 an examination of transition innovations in the United States and abroad, and reviews by over 50 pediatric and adult health care professionals and youth and family experts.

To implement the Six Core Elements, a quality improvement approach is recommended. Plan-do-study-act (PDSA) cycles provide a useful way to incrementally adopt the Six Core Elements as a standard part of care for young adult and their families.6 The process begins with the creation of a collaborative pediatric and adult team that could include physicians, nurse practitioners, physician assistants, nurses, social workers, care coordinators, medical assistants, administrative staff, IT staff, and young adult/youth adults and families. Leadership support from the practice, plan, or academic department is critical as well. Oftentimes, practices decide to begin with a subset of young adult in order to pilot the pediatric and adult delivery system changes needed for transition. Sample tools that can be customized for use in primary and specialty care are available in this package and on www.GotTransition.org.

Got Transition has developed two different measurement approaches, described below, to assess the extent to which the Six Core Elements of Health Care Transition 2.0 are being incorporated into clinical processes. Both are aligned with the AAP/AAFP/ACP’s Clinical Report on Transition and the Six Core Elements.

1) Current Assessment of Health Care Transition Activities. This is a qualitative self-assessment method that allows individual providers, practices, or networks to determine the level of health care transition support currently available to young adults transitioning from pediatric to adult health care. It is intended to provide a current snapshot of how far along a practice is in implementing the Six Core Elements.

2) Health Care Transition Process Measurement Tool. This is an objective scoring method, with documentation specifications, that allows a practice or network to assess progress in implementing the Six Core Elements and, eventually, dissemination to all young adults ages 18 to 26. It is intended to be conducted at the start of a transition improvement initiative as a baseline measure and then repeated periodically to assess progress.

This tool package contains the Six Core Elements of Health Care Transition 2.0 side-by-side version followed by the Six Core Elements version for providers assisting young adult transitioning to a new adult provider and sample tools.

Got Transition welcomes your comments and feedback on the updated Six Core Elements of Health Care Transition 2.0. Please send your feedback to info@GotTransition.org. Thank you for your interest in the successful health care transitions of young adults from pediatric to adult-centered care.

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2Additional information can be found at: http://www.hhs.gov/ocr/civilrights/resources/specialtopics/lep/index.html and at: http://www.health.gov/communication/literacy/
3Additional information can be found at: www.thinkculturalhealth.hhs.gov
4To access all three transition packages, see www.GotTransition.org.
### Side-by-Side Version

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

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAP/F/AAP Clinical Report on Transition.1 Sample clinical tools and measurement resources are available for quality improvement purposes at [www.GotTransition.org](http://www.GotTransition.org).

<table>
<thead>
<tr>
<th>Transitioning Youth to Adult Health Care Providers</th>
<th>Transitioning to an Adult Approach to Health Care Without Changing Providers</th>
<th>Integrating Young Adults into Adult Health Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Pediatric, Family Medicine, and Med-Peds Providers)</td>
<td>(Family Medicine and Med-Peds Providers)</td>
<td>(Internal Medicine, Family Medicine, and Med-Peds Providers)</td>
</tr>
</tbody>
</table>

1. **Transition Policy**
   - Develop a transition policy/statement with input from youth and families that describes the practice’s approach to transition, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. **Transition Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning youth and enter their data into a registry.
   - Utilize individual flow sheet or registry to track youth’s transition progress and distinct roles of the *Six Core Elements*.
   - Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.

3. **Transition Readiness**
   - Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.
   - Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.

1. **Transition Policy**
   - Develop a transition policy/statement with input from youth/young adults and families that describes the practice’s approach to transitioning to an adult approach to care at age 18, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. **Transition Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry.
   - Utilize individual flow sheet or registry to track youth/young adults’ transition progress with the *Six Core Elements*.
   - Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.

3. **Transition Readiness**
   - Conduct regular transition readiness assessments, beginning at age 14, to identity and discuss with youth and parent/caregiver their needs and goals in self-care.
   - Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.

1. **Young Adult Transition and Care Policy**
   - Develop a transition policy/statement with input from young adults that describes the practice’s approach to accepting and partnering with young adults, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the *Six Core Elements* and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care.

2. **Young Adult Tracking and Monitoring**
   - Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry.
   - Utilize individual flow sheet or registry to track young adults’ completion of the *Six Core Elements*.
   - Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.

3. **Transition Readiness/Orientation to Adult Practice**
   - Identify and list adult providers within your practice interested in caring for young adults.
   - Establish a process to welcome and orient new young adults into practice, including a description of available services.
   - Provide youth-friendly online or written information about the practice and offer a “get-acquainted” appointment, if feasible.

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### Side-by-Side Version (continued)

#### 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>
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<th>Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)</th>
</tr>
</thead>
</table>
| **4. Transition Planning**
- Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.
- Prepare youth and parent/caregiver for adult approach to care at age 16, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
- Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
- Plan with youth/parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each.
- Obtain consent from youth/guardian for release of medical information.
- Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.
- Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports. | **4. Transition Planning/Integration into Adult Approach to Care**
- Develop and regularly update a plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents.
- Prepare youth and parent/caregiver for adult approach to care at age 16, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
- Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
- Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult specialty care.
- Obtain consent from youth/guardian for release of medical information.
- Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports. | **4. Transition Planning/Integration into Adult Practice**
- Communicate with young adult’s pediatric provider(s) and arrange for consultation assistance, if needed.
- Prior to first visit, ensure receipt of transfer package (final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.)
- Make pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences.
- Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports. |
| **5. Transfer of Care**
- Confirm date of first adult provider appointment.
- Transfer young adult when his/her condition is stable.
- Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.
- Prepare letter with transfer package, send to adult practice, and confirm adult practice’s receipt of transfer package.
- Confirm with adult provider the pediatric provider’s responsibility for care until young adult is seen in adult setting. | **5. Transfer to Adult Approach to Care**
- Address any concerns that young adult has about transferring to adult approach to care. Clarify adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.
- Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss needed self-care skills.
- Review young adult’s health priorities as part of ongoing plan of care.
- Continue to update and share portable medical summary and emergency care plan. | **5. Transfer of Care/Initial Visit**
- Prepare for initial visit by reviewing transfer package with appropriate team members.
- Address any concerns that young adult has about transferring to adult approach to care. Clarify approach to adult care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.
- Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss the young adult’s needs and goals in self-care.
- Review young adult’s health priorities as part of their plan of care.
- Update and share portable medical summary and emergency care plan. |
| **6. Transfer Completion**
- Contact young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process.
- Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed.
- Build ongoing and collaborative partnerships with adult primary and specialty care providers. | **6. Transfer Completion/Ongoing Care**
- Assist young adult to connect with adult specialists and other support services, as needed.
- Continue with ongoing care management tailored to each young adult.
- Elicit feedback from young adult to assess experience with adult health care.
- Build ongoing and collaborative partnerships with specialty care providers. | **6. Transfer Completion/Ongoing Care**
- Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed.
- Assist young adult to connect with adult specialists and other support services, as needed.
- Continue with ongoing care management tailored to each young adult.
- Elicit feedback from young adult to assess experience with adult health care.
- Build ongoing and collaborative partnerships with pediatric primary and specialty care providers. |
Integrating Young Adults into Adult Health Care

Six Core Elements of Health Care Transition 2.0

1. Young Adult Transition and Care Policy
   - Develop a transition policy/statement with input from young adults that describes the practice’s approach to accepting and partnering with new young adults, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care.

2. Young Adult Tracking and Monitoring
   - Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry.
   - Utilize individual flow sheet or registry to track young adults’ completion of Six Core Elements.
   - Incorporate Six Core Elements into clinical care process, using EHR if possible.

3. Transition Readiness/Orientation to Adult Practice
   - Identify and list adult providers within your practice interested in caring for young adults.
   - Establish a process to welcome and orient new young adults into practice, including a description of available services.
   - Provide young adult-friendly online or written information about the practice and offer a “get-acquainted” appointment, if feasible.

4. Transition Planning/Integration into Adult Practice
   - Communicate with young adult’s pediatric provider(s) and arrange for consultation assistance, if needed.
   - Prior to first visit, ensure receipt of transfer package (final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.)
   - Make pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences.
   - Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.

5. Transfer of Care/Initial Visit
   - Prepare for initial visit by reviewing transfer package with appropriate team members.
   - Address any concerns that young adult has about transferring to adult approach to care. Clarify adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.
   - Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss their needs and goals in self-care.
   - Review young adult’s health priorities as part of their plan of care.
   - Update and share portable medical summary and emergency care plan.

6. Transfer Completion/Ongoing Care
   - Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed.
   - Assist young adult to connect with adult specialists and other support services, as needed.
   - Continue with ongoing care management tailored to each young adult.
   - Elicit feedback from young adult to assess experience with adult health care.
   - Build ongoing and collaborative partnerships with pediatric primary and specialty care providers.
1. Young Adult Transition and Care Policy

Creating a written practice policy on transition is the first element in these health care transition quality recommendations. Developed by your practice or health system, with input from young adults, the policy provides consensus among the practice staff, mutual understanding of the process involved, and a structure for evaluation. The policy should include the practice’s approach to accepting and partnering with young adults. It should also explain the legal changes that take place in privacy and consent at age 18. The policy should be shared with young adults at their first visit and be publicly posted.

2. Young Adult Tracking and Monitoring

Establishing a mechanism to track progress of each young adult as they receive the Six Core Elements is the second element in these health care transition quality recommendations. An individual flow sheet within the chart can be used to track individual patient progress with the Six Core Elements. Information from an individual flow sheet can be used to populate a registry and help to monitor the transition progress within a larger population. Practices may elect to start monitoring transition progress with a subset of young adults with chronic conditions. The long-term goal is to track health care transition progress among all young adults ages 18-26, with and without chronic conditions.

3. Transition Readiness/Orientation to the Adult Practice

Orienting young adults to the adult practice is the third element in these health care transition quality recommendations. To begin with, the practice should identify those providers interested in taking on new young adult patients. The names of these providers should be shared with front desk staff and with partnering pediatric practices. Because young adults are relatively new health care consumers, an orientation to the adult practice is important. Establishing a process and designating staff members to welcome young adults will ensure that orientation is an integral component of the clinic workflow. The practice should provide young adult-friendly welcome materials that describe confidentiality, services offered, and the logistics of obtaining care. Offering get-acquainted appointments, if feasible can be a useful option for some prospective young adult patients.

4. Transition Planning/Integration into the Adult Practice

Planning with the pediatric provider for the transition of young adults is the fourth element in these health care transition recommendations. Adult practices should ensure receipt of the young adult’s transfer package from the pediatric practice. A transfer package should include a final transition readiness assessment, plan of care, medical summary and emergency care plan, and, if needed, legal documents, a condition fact sheet and subspecialist records. The adult practice must communicate with the pediatric practice about their residual responsibility for care until the first visit to the adult provider is completed. Until the young adult has gone to the first appointment and established care in the new medical home, the pediatric provider has some residual responsibility for care (e.g. medication refills or acute care visits). In the case of young adults with complicated health or psychosocial needs, direct provider communication is encouraged. Adult providers can also establish a plan for further consultation with the pediatric provider should the need arise. After all records are obtained and the pediatric practice is contacted, the adult practice should make a pre-visit call to welcome the patient, remind them of their upcoming appointment, and identify any special needs or preferences. Community resource information on insurance, self-care management, and culturally appropriate supports can be helpful to young adults.
5. Transfer of Care/Initial Visit

Welcoming and orienting the new young adult into the adult practice is the fifth element in these health care transition quality recommendations. Following review of the transfer package, the initial appointment should address any concerns that the young adult may have in transferring to a new adult provider and distinctions between pediatric and adult care. Specifically, it is important to discuss confidentiality, access to information, and shared decision-making and to elicit how to best communicate with the young adult. Over the next few visits, the provider should work with the young adult to assess and strengthen self-care skills. Use of a standardized self-care assessment tool can be helpful in engaging young adults in their care and assisting them in navigating the adult health care system, including health insurance. Providers can use the results of this assessment to develop a plan of care with the young adults. Finally, updating and sharing a medical summary and emergency care plan helps to further engage young adults in their own care.

6. Transfer Completion/Ongoing Care

Confirming transfer completion, coordinating transfer to adult specialists, and assessing young adult’s experience with transition support are all part of the sixth element in these health care transition quality recommendations. Confirming with the pediatric practice that the adult provider has taken on responsibility for the young adult’s health care is necessary. Since many young adults may transfer to an adult primary care provider first, helping them to select new adult specialist providers may be necessary. To evaluate the success of the transition process and the young adult’s experience with care, having a mechanism to obtain and incorporate the feedback six months after the first visit will improve the practice’s approach to integrating young adults into the practice.
[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.
### 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>
</tr>
</thead>
<tbody>
<tr>
<td>12/25/1992</td>
<td>21 Y</td>
<td>Susan Cue</td>
<td>major depressive disorder</td>
<td>2</td>
<td>7/6/2012</td>
<td>2/7/2014</td>
<td>Yes</td>
</tr>
<tr>
<td>1/17/1993</td>
<td>21 Y</td>
<td>Terrence Train</td>
<td>JRA</td>
<td>2</td>
<td>8/16/2013</td>
<td>4/23/2014</td>
<td>Yes</td>
</tr>
<tr>
<td>4/18/1990</td>
<td>23 Y</td>
<td>David Crockett</td>
<td>well</td>
<td>1</td>
<td>12/22/2012</td>
<td>4/13/2014</td>
<td>Yes</td>
</tr>
<tr>
<td>4/2/1995</td>
<td>18 Y</td>
<td>Tom Sawyer</td>
<td>ADHD</td>
<td>2</td>
<td>6/19/2014</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1/3/1989</td>
<td>25 Y</td>
<td>Jen Lawrence</td>
<td>cerebral palsy</td>
<td>3</td>
<td>9/14/2012</td>
<td>2/19/2014</td>
<td>Yes</td>
</tr>
<tr>
<td>2/14/1987</td>
<td>26 Y</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>19 Y</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 (Yes or Blank)</th>
<th>Plan of Care Updated and Shared with Young Adult (Yes or Blank)</th>
<th>Medical Summary and Emergency Care Plan Updated and Shared with Young Adult (Yes or Blank)</th>
<th>Ellicited Feedback from Young Adult about Transition and Experience with Care (Yes or Blank)</th>
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<tbody>
<tr>
<td>Mary Smith</td>
<td>Yes</td>
<td>10/2/2013</td>
<td>Yes</td>
<td>12/3/2013</td>
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<tr>
<td>Susan Cue</td>
<td>Yes</td>
<td>6/1/2012</td>
<td>Yes</td>
<td>7/9/2013</td>
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<tr>
<td>Terrence Train</td>
<td>Yes</td>
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<td></td>
<td>8/16/2013</td>
<td>8/16/2013</td>
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<tr>
<td>Devin Carn</td>
<td>Yes</td>
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<td>Tom Sawyer</td>
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<td>8/16/2013</td>
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<td>8/16/2013</td>
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<td>8/16/2013</td>
<td></td>
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</tr>
</tbody>
</table>
[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:
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.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of Birth:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Diagnosis:</td>
<td>Secondary Diagnosis:</td>
</tr>
</tbody>
</table>

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>
</table>

Initial Date of Plan: ______________ Last Updated: ______________ Young Adult Signature: ______________

Clinician Signature: ______________ Care Staff Contact: ______________

Care Staff Phone: ______________
This document should be shared with and carried by the young adult.

<table>
<thead>
<tr>
<th>Date Completed:</th>
<th>Date Revised:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Form completed by:</td>
<td></td>
</tr>
<tr>
<td>Contact Information</td>
<td></td>
</tr>
<tr>
<td>Name:</td>
<td>Nickname:</td>
</tr>
<tr>
<td>DOB:</td>
<td>Preferred Language:</td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Cell #:</td>
<td>Home #:</td>
</tr>
<tr>
<td>E-Mail:</td>
<td>Best Way to Reach:</td>
</tr>
<tr>
<td>Health Insurance/Plan:</td>
<td>Group and ID #:</td>
</tr>
</tbody>
</table>

### Emergency Care Plan

<table>
<thead>
<tr>
<th>Emergency Contact:</th>
<th>Relationship:</th>
<th>Phone:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferred Emergency Care Location:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Common Emergent Presenting Problems

<table>
<thead>
<tr>
<th>Suggested Tests</th>
<th>Treatment Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Special Concerns for Disaster:

### Allergies and Procedures to be Avoided

#### Allergies

#### Reactions

To be avoided | Why?
---|---

#### Medical Procedures:

#### Medications:

### Diagnoses and Current Problems

<table>
<thead>
<tr>
<th>Problem</th>
<th>Details and Recommendations</th>
</tr>
</thead>
</table>

#### Primary Diagnosis

#### Secondary Diagnosis

#### Behavioral

#### Communication

#### Feed & Swallowing

#### Hearing/Vision

#### Learning

#### Orthopedic/Musculoskeletal

#### Physical Anomalies

#### Respiratory

#### Sensory

#### Stamina/Fatigue

#### Other
## Sample Medical Summary and Emergency Care Plan

### Six Core Elements of Health Care Transition 2.0

---

### Medications

<table>
<thead>
<tr>
<th>Medications</th>
<th>Dose</th>
<th>Frequency</th>
<th>Medications</th>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

### Health Care Providers

<table>
<thead>
<tr>
<th>Provider</th>
<th>Primary and Specialty</th>
<th>Clinic or Hospital</th>
<th>Phone</th>
<th>Fax</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

### Prior Surgeries, Procedures, and Hospitalizations

<table>
<thead>
<tr>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
</tr>
</thead>
</table>

### Baseline

**Baseline Vital Signs:**

- **Ht**
- **Wt**
- **RR**
- **HR**
- **BP**

**Baseline Neurological Status:**

### Most Recent Labs and Radiology

<table>
<thead>
<tr>
<th>Test</th>
<th>Date</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

**Tests:**

- **EEG**
- **EKG**
- **X-Ray**
- **C-Spine**
- **MRI/CT**
- **Other**

### Equipment, Appliances, and Assistive Technology

- **Gastrostomy**
- **Tracheostomy**
- **Suctions**
- **Nebulizer**
- **Other**

- **Adaptive Seating**
- **Communication Device**
- **Monitors:**
- **Apnea**
- **O2**
- **Cardiac**
- **Wheelchair**
- **Orthotics**
- **Crutches**
- **Walker**
- **Other**

---

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School, Work and Community Information

<table>
<thead>
<tr>
<th>Agency/School</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
</tbody>
</table>

Special information that the patient wants health care professionals to know

<table>
<thead>
<tr>
<th>Patient/Guardian Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Primary Care Provider Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Care Coordinator Signature</th>
<th>Print Name</th>
<th>Phone Number</th>
<th>Date</th>
</tr>
</thead>
</table>

Please attach the immunization record to this form.
Summary of Spina Bifida for Health Care Professionals

Spina Bifida (SB) is a neural tube defect in which there is failure of the neural tube to close very early in pregnancy, resulting in a spinal cord defect usually visible at birth. The most common form of SB in which there is an open lesion is myelomeningocele (MM), but other types of SB exist, including occult dysraphism where lipomas may be present. The MM subtype is associated with varying degrees of lower extremity paralysis and sensory loss, hydrocephalus, Chiari II malformation, syringomyelia, tethered cord, bowel and bladder dysfunction, and some learning disabilities. Conditions such as hydrocephalus, Chiari II, and syringomyelia, are not generally seen in those with lipomas and other forms of occult dysraphism. SB is generally not felt to be a progressive condition, and any deterioration in adulthood should prompt a search for a treatable condition.

Most individuals with MM have hydrocephalus, which is most commonly treated with a ventriculoperitoneal shunt. Shunt malfunction is a common problem in patients with MM and can present with a wide range of symptoms including headache, nausea, vomiting, blurred vision, as well as subtle symptoms like deterioration in sensorimotor function, changes in bladder function, back pain, or changes in school performance, cognition, or memory. In most cases of shunt malfunction, the ventricles will appear enlarged on CT compared with a baseline CT done when the patient is asymptomatic; however, up to 15% of patients with MM can have a shunt malfunction with no significant change in ventricular size. Therefore if symptoms of shunt malfunction are present, consultation with an experienced neurosurgeon is recommended regardless of CT findings. Most cases of shunt malfunction will require shunt revision, although in rare cases, shunt malfunction may be caused by constipation which puts pressure on the distal end of the shunt.

The Chiari II malformation is seen in almost all patients with MM, although only 10-15% become symptomatic, and the majority of these present during infancy. In the Chiari II malformation, the cerebellar tonsils, vermis, and brainstem descend through the foramen magnum to a variable degree. Surgical intervention may become necessary for symptomatic patients with swallowing difficulties, breathing difficulties or stridor, severe sleep apnea, increasing sensorimotor dysfunction, headache and/or neck pain. These symptoms should prompt a referral to a neurosurgeon. The most common cause of Chiari symptoms in adults is a shunt malfunction; rarely symptoms may require decompression surgery. Associated syringomyelia - an accumulation of cerebrospinal fluid within the spinal cord – may often be present with the Chiari malformation but requires treatment only 15-35% of the time, usually due to back or limb pain, or sensorimotor loss.

Tethered cord occurs when the spinal cord becomes progressively stretched due to its attachment to the distal end of the spinal canal. Tethering is a universal radiographic finding but symptoms from spinal cord tethering – referred to as tethered cord syndrome – occurs in only about 1/3 of patients, and even less frequently in adults. Tethered cord syndrome is manifested by worsening scoliosis, back or leg pain, sensorimotor changes, spasticity, and worsening bladder or bowel function, and may require neurosurgical evaluation and untethering of the spinal cord.

Neurogenic bladder dysfunction occurs in over 90% of patients with SB and can be manifested across a spectrum ranging from small, hypertensive bladders to large, flaccid bladders. The goals of urologic management are preservation of renal function, reduction in urinary tract infection, and attainment of continence, if so desired by the patients. Elevated bladder pressures due to hypertensive or poorly compliant bladders can result in renal damage and, eventually, failure. Anticholinergic medications, such as oxybutynin, are used in many patients to keep bladder pressure low and are combined with bladder catheterization to attain continence. Some patients have had bladder augmentation surgery to improve bladder volumes and/or reduce pressures, and some have an abdominal wall or umbilical siroma (Mitrofanoff) through which to catheterize the bladder avoiding the urethra. Some also require bladder neck surgery to attain continence. Approximately two-thirds of all patients self-catheterize to empty their bladders, so bacteriuria is often present but does not necessarily indicate infection nor require treatment. Symptoms of infection (abdominal pain, fever, malaise, or urinary changes such as increasing incontinence) suggest a bladder infection and require treatment, but it is not recommended to check urine in asymptomatic patients or treat bacteriuria alone. Individuals with thoracic level SB may lack the usual signs of dysuria or flank pain. Patients with MM are at increased risk for bladder and renal stones, as well

www.spinabifidaassociation.org • 4590 MacArthur Boulevard NW, Suite 250, Washington, DC 20007 • 800-621-3141

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as bladder cancer. A yearly urology visit is recommended. Routine annual renal and bladder ultrasound and GFR/creatinine are important. Proteinuria may indicate early renal problems. Those with augmented bladder may need to undergo regular serum chemistry assessment due to risk of metabolic acidosis and periodic cystoscopy due to increased risk of malignancy.

Neurogenic bowel problems generally result in constipation and/or incontinence. Most patients are on an oral bowel regimen, timed toileting program, and/or enema program. Some patients have an operation to bring the appendix to the skin in a continent manner to allow an antegrade enema to completely evacuate the colon, typically every 1-3 days. This operation is called an antegrade colonic enema (ACE) or MACE (Malone ACE), and a cecostomy tube or button may be used in patients without a suitable appendix.

Orthopedic issues include shoulder pain from rotator cuff problems, carpal tunnel syndrome, scoliosis, and a variety of hip, knee, ankle and foot deformities. Many patients require lower limb bracing in order to walk or transfer. Early onset osteoporosis is also common. Physiatrists and Orthopedic surgeons play an important role in preserving functional independence with the goal of maximizing function in society. For many, that will involve a combination of walking and use of a wheeled mobility device. Some will be full time wheelchair users.

Skin integrity is vital as skin breakdown in areas of insensitive skin is common and can lead to osteomyelitis or sepsis. Patients should check their skin daily and perform weight shifts regularly throughout the day. Prevention and treatment strategies are aimed at reducing pressure and shear (cushions, properly fitting braces), improving nutrition, and eliminating or minimizing incontinence. Lymphedema is also very common and must be distinguished from other forms of edema. Referral to a Lymphedema treatment center may be necessary.

Latex allergy is common in this group, and universally applied latex precautions should be taken.

Restrictive lung disease in those with higher level lesions due to scoliosis and muscle weakness may require pulmonology evaluation. Obstructive and central sleep apnea may also contribute to pulmonary dysfunction and can contribute to sudden death in adults if left untreated.

Learning disabilities often include difficulties with “executive function” in which impairments of organization, inference, and insight are common. Many have had difficulties with reading comprehension and math. Depression, unemployment and social isolation are common.

Women with SB are generally fertile, and they are capable of becoming pregnant. Pregnant women may have worsening gait, bladder control, or shunt problems with pregnancy, consult with a high risk OB/GYN is recommended. Women who have SB or who have already had a child with SB and who want to conceive should take 4mg of Folic Acid daily (rather than the recommended RDA of 400 mcg in those without SB) for one month prior to conception until the end of the first trimester to prevent neural tube defects in the baby. It is also recommended for wives of men with SB to do the same; however studies to support this recommendation are lacking. Although many men with SB can achieve and sustain an erection, pre-treatment before intercourse with drugs can improve the ability to maintain an erection. Many men with SB are fertile, but sperm counts can be decreased. Ejaculation may occur retrograde into the bladder.

In addition to the specific challenges related to SB, adults with SB should undergo routine medical care and screening that would be provided to individuals without such a disability. Obesity, diabetes, and cardiovascular risk factors are prevalent in this population. Renal etiology for hypertension should be considered in this population. Increased risk factors for breast, uterine and ovarian cancer may be due to early menarche, nulliparity, and obesity.

Although the exact life expectancy for adults with SB is not known, patients are now living into their 7th and 8th decades. It is of utmost important to be proactive in the care of these individuals in order to prevent secondary medical complications that can reduce independence and quality of life.
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>How important is it to you to manage your own health care?</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 confident do you feel about your ability to manage your own health care?</td>
<td>0 (not)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10 (very)</td>
</tr>
</tbody>
</table>

My Health  Please check the box that applies to you right now.

| I know my medical needs. | ☐ | ☐ | ☐ |
| I can explain my medical needs to others. | ☐ | ☐ | ☐ |
| I know my symptoms including ones that I quickly need to see a doctor for. | ☐ | ☐ | ☐ |
| I know what to do in case I have a medical emergency. | ☐ | ☐ | ☐ |
| I know my own medicines, what they are for, and when I need to take them. | ☐ | ☐ | ☐ |
| I know my allergies to medicines and the medicines I should not take. | ☐ | ☐ | ☐ |
| I can explain to others how my customs and beliefs affect my health care decisions and medical treatment. | ☐ | ☐ | ☐ |

Using Health Care

| I know or I can find my doctor’s phone number. | ☐ | ☐ | ☐ |
| I make my own doctor appointments. | ☐ | ☐ | ☐ |
| Before a visit, I think about questions to ask. | ☐ | ☐ | ☐ |
| I have a way to get to my doctor’s office. | ☐ | ☐ | ☐ |
| I know I need to show up 15 minutes before the visit to check in. | ☐ | ☐ | ☐ |
| I know where to go to get medical care when the doctor’s office is closed. | ☐ | ☐ | ☐ |
| I have a file at home for my medical information. | ☐ | ☐ | ☐ |
| I know how to fill out medical forms. | ☐ | ☐ | ☐ |
| I know how to get referrals to other providers. | ☐ | ☐ | ☐ |
| I know where my pharmacy is and how to refill my medicines. | ☐ | ☐ | ☐ |
| I know where to get blood work or x-rays done if my doctor orders them. | ☐ | ☐ | ☐ |
| I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary). | ☐ | ☐ | ☐ |
| I understand how health care privacy changes at age 18 when legally an adult. | ☐ | ☐ | ☐ |
| I have a plan so I can keep my health insurance after 18 or older. | ☐ | ☐ | ☐ |
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 provider/practice 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 18?
   - 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. Does your adult health care provider update and share a current medical summary and emergency care plan 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 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 his/her practice?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

*Adapted from the National Survey of Children's Health
Current Assessment of Health Care Transition Activities for Integrating Young Adults into Adult Health Care
Six Core Elements of Health Care Transition 2.0

Introduction
Got Transition has developed two different measurement approaches, described below, to assess the extent to which the Six Core Elements of Health Care Transition 2.0 are being incorporated into clinical processes. Both are aligned with the AAP/AAFP/ACP’s Clinical Report on Transition and the Six Core Elements. These instruments are available at www.GotTransition.org.

Current Assessment of Health Care Transition Activities
This is a qualitative self-assessment method that allows individual providers, practices, or networks to determine the level of health care transition support currently available to young adults transitioning from pediatric to adult health care. It is intended to provide a current snapshot of how far along a practice is in implementing the Six Core Elements.

Health Care Transition Process Measurement Tool
This is an objective scoring method, with documentation specifications, that allows a practice or network to assess progress in implementing the Six Core Elements and, eventually, dissemination to all young adults ages 18–26. It is intended to be conducted at the start of a transition improvement initiative as a baseline measure and then repeated periodically to assess progress.

Instructions for completing the Current Assessment of Health Care Transition Activities
Each of the Six Core Elements can be scored between 1 (basic) and 4 (comprehensive).
If the level is partially but not fully completed, scoring should be at the lower level.
A table to total scores is available on the final page of this tool.
<table>
<thead>
<tr>
<th><strong>Element</strong></th>
<th><strong>Level 1</strong></th>
<th><strong>Level 2</strong></th>
<th><strong>Level 3</strong></th>
<th><strong>Level 4</strong></th>
<th><strong>Score</strong></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>
<td></td>
</tr>
<tr>
<td><strong>4. Transition Planning/Integration into Adult Practice</strong></td>
<td>Clinicians vary in whether they request previous records before seeing a new young adult patient.</td>
<td>Clinicians receive and review previous records prior to seeing new young adult patients and determine if any special accommodations are needed.</td>
<td>The practice ensures receipt of complete transfer package (including final readiness assessment, medical summary, emergency plan, and, if needed, legal documents, and condition fact sheet) for each transitioning young adult patient and determines if special accommodations are needed.</td>
<td>Prior to the first visit, the care team makes a pre-visit call to all new young adult patients, reviews the transfer package (including final readiness assessment, medical summary, emergency plan, and, if needed, legal documents, and condition fact sheet) and communicates with the pediatric practice.</td>
<td></td>
</tr>
</tbody>
</table>
## Current Assessment of Health Care Transition Activities for Integrating Young Adults into Adult Health Care (continued)

### 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>
</tr>
</thead>
<tbody>
<tr>
<td>5. Transfer of Care/Initial Visit</td>
<td>Clinicians vary in addressing self-care needs and health priorities among new young adult patients.</td>
<td>Clinicians discuss young adults’ concerns about transferring to a new adult provider, the distinctions in adult-centered care from pediatric care, and self-care needs and health priorities.</td>
<td>Prior to the first visit, clinicians review young adult’s transfer package (including final transition readiness assessment, medical summary, emergency plan, legal documents, and condition fact sheet), and during the first visit, partner with the young adult patient in reviewing self-care needs and priorities, unique aspects of adult-centered care, and concerns about changing from pediatric to adult care.</td>
<td>The practice uses a standardized self-care assessment tool and incorporates self-care assessment into a plan of care template in its EHR. Clinicians partner with young adults in updating their plan of care, reviewing unique aspects of adult-centered care, and concerns about changing from pediatric to adult care. The young adult’s plan of care is accessible to them.</td>
</tr>
<tr>
<td>6. Transfer Completion/Ongoing Care</td>
<td>Clinicians rarely communicate with and/or seek consultation assistance from pediatric providers after transfer.</td>
<td>Clinicians are responsive to pediatric transfer requests, but generally do not follow-up for consultation assistance. Adult providers assist new young adult patients in identifying adult specialty providers.</td>
<td>The practice has an organized process to ensure that adult clinicians receive consultation support or training for childhood-onset conditions. Adult providers assist new young adult patients in identifying adult specialty providers.</td>
<td>The practice consistently works with pediatric practices to consult and co-manage care of young adults with complex conditions and assists new young adult patients in connecting with adult specialists and community resources. The practice also elicits feedback about young adults’ experience with care.</td>
</tr>
<tr>
<td>Young Adult Feedback</td>
<td>The practice has no formal process to obtain feedback from young adults about transition support/assistance.</td>
<td>The practice obtains feedback from young adults using a transition feedback survey.</td>
<td>The practice involves young adults in developing or reviewing the transition feedback survey.</td>
<td>The practice involves young adults in developing strategies to address areas of concern identified by the transition feedback survey.</td>
</tr>
<tr>
<td>Young Adult Leadership</td>
<td>Clinicians provide young adults with tools and information about the adult approach to health care.</td>
<td>The practice involves young adults in creating and implementing education programs for practice staff related to the care of young adults.</td>
<td>The practice includes young adults as active members of a young adult advisory council or a quality improvement team.</td>
<td>The practice involves young adults in strategic planning related to the care of young adults.</td>
</tr>
</tbody>
</table>

The table at right can be used to total the number of points that your practice obtained on the adult version of the Current Assessment of Health Care Transition Activities.

---

**This form is being completed to assess:**

- [ ] An Individual Provider
- [ ] An Individual Practice
- [ ] A Practice Network

---

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Health Care Transition Process Measurement Tool for Integrating Young Adults into Adult Health Care
Six Core Elements of Health Care Transition 2.0

Introduction
Got Transition has developed two different measurement approaches, described below, to assess the extent to which the Six Core Elements of Health Care Transition 2.0 are being incorporated into clinical processes. Both are aligned with the AAP/AAFP/ACP’s Clinical Report on Transition and the Six Core Elements. These instruments are available at www.GotTransition.org.

Current Assessment of Health Care Transition Activities
This is a qualitative self-assessment method that allows individual providers, practices, or networks to determine the level of health care transition support currently available to young adults transitioning from pediatric to adult health care. It is intended to provide a current snapshot of how far along a practice is in implementing the Six Core Elements.

Health Care Transition Process Measurement Tool
This is an objective scoring method, with documentation specifications, that allows a practice or network to assess progress in implementing the Six Core Elements and, eventually, dissemination to all young adults ages 18–26. It is intended to be conducted at the start of a transition improvement initiative as a baseline measure and then repeated periodically to assess progress.

Instructions for completing the Health Care Transition Process Measurement Tool
Each of the Six Core Elements can be scored according to whether some or all of the implementation steps have been completed. Scores for each step vary depending on complexity or importance. For example, developing a written transition policy has a score of 4; that is, if this step is completed, a practice or network would receive a score of 4. If it is not completed, the score is 0. Posting the transition policy has a score of 2, and similarly, not posting it would be a 0.

In addition to evaluating implementation and young adult engagement, this measurement tool assesses dissemination to all eligible young adults, ages 18 to 26, within a practice or network. That is, if a practice or plan starts with a subset of young adults with special needs, they would likely be reaching 10% or less of eligible patients for a score of 1 point. If they are implementing the Six Core Elements for all eligible young adults with and without chronic conditions, they would score at the maximum level of 5 points.

A table to total implementation, young adult engagement, and dissemination scores is available on the final page of this tool. Practices and plans may elect to just score implementation and engagement at the outset of a transition quality improvement initiative and score dissemination after the Six Core Elements have been incorporated into ongoing clinical processes.
## 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></td>
<td></td>
<td></td>
<td></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>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

<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>2. Transition Tracking and Monitoring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established criteria and process for identifying transitioning target population to enter into registry or individual transition flow sheet</td>
<td>Yes = 3</td>
<td></td>
<td></td>
<td>Screenshot or copy of registry/list</td>
</tr>
<tr>
<td>Incorporated transition core elements into clinical processes (e.g. EHR templates, progress notes, care plans)</td>
<td>Yes = 4</td>
<td></td>
<td></td>
<td>Screenshot or copy of chart</td>
</tr>
</tbody>
</table>

**Tracking and Monitoring Implementation Subtotal:** 7

<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>3. Transition Readiness/Orientation to the Adult Practice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identified providers in practice interested in caring for young adults</td>
<td>Yes = 2</td>
<td></td>
<td></td>
<td>List of providers</td>
</tr>
<tr>
<td>Established a process to orient new young adults into practice</td>
<td>Yes = 2</td>
<td></td>
<td></td>
<td>Welcome letter/materials</td>
</tr>
</tbody>
</table>

**Transition Readiness Implementation Subtotal:** 4

<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>4. Transition Planning/Integration into Adult Practice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established a process to ensure receipt of transfer package from pediatric providers before first visit</td>
<td>Yes = 2</td>
<td></td>
<td></td>
<td>Sample plan of care</td>
</tr>
<tr>
<td>Made available list of community support resources</td>
<td>Yes = 2</td>
<td></td>
<td></td>
<td>List of resources</td>
</tr>
</tbody>
</table>

**Transition Planning Implementation Subtotal:** 4

<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>5. Transfer of Care/Initial Visit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adopted a self-care assessment tool for use in practice</td>
<td>Yes = 3</td>
<td></td>
<td></td>
<td>Self-care assessment</td>
</tr>
<tr>
<td>Developed a plan of care template that incorporates transition readiness assessment findings, goals, and prioritized actions</td>
<td>Yes = 3</td>
<td></td>
<td></td>
<td>Sample plan of care</td>
</tr>
<tr>
<td>Developed a medical summary and emergency care plan templates</td>
<td>Yes = 3</td>
<td></td>
<td></td>
<td>Portable medical summary</td>
</tr>
</tbody>
</table>

**Transfer of Care Implementation Subtotal:** 9

<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>6. Transfer Completion/Ongoing Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have mechanism to systematically obtain feedback from young adults about experience with adult care</td>
<td>Yes = 3</td>
<td></td>
<td></td>
<td>Survey or interview questions</td>
</tr>
</tbody>
</table>

**Transfer Completion Implementation Subtotal:** 3

*Continued*
### Health Care Transition Process Measurement Tool

#### for Integrating Young Adults into Adult Health Care (continued)

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

<table>
<thead>
<tr>
<th>B) Young Adult Engagement 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>
<tr>
<td>Included input from young adults in developing or reviewing health care transition feedback survey</td>
<td>Yes = 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involved young adults in the implementation of staff education on young adult care</td>
<td>Yes = 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Included young adults as active members of the advisory council or quality improvement team</td>
<td>Yes = 3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Youth and Family Engagement Subtotal:**

<table>
<thead>
<tr>
<th>C) Dissemination Requirement</th>
<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>
<th>Possible</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score Points:</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Transition Policy</td>
<td>Sharing policy with young adults, ages 18–25 (letter or visit)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0 to 5</td>
<td></td>
</tr>
</tbody>
</table>

**Transition Policy Dissemination Subtotal:**

2. Transition Tracking and Monitoring

Percentage of young adults in practice tracked in registry/list

**Transition Tracking and Monitoring Dissemination Subtotal:**

3. Transition Readiness/Orientation into Adult Practice

Administering transition readiness assessment tool periodically to patients ages 18–26

**Transition Readiness Dissemination Subtotal:**

4. Transition Planning/Integration into Adult Practice

Updating and sharing medical summary and emergency care plan regularly

Updating and sharing plan of care including readiness assessment findings, goals, and prioritized actions regularly

**Transition Planning Dissemination Subtotal:**

5. Transfer of Care/Initial Visit

Administering self-care assessment tool

Updating and sharing medical summary and emergency care plan

Updating and sharing plan of care including self-care assessment findings, goals, and prioritized actions

**Transfer of Care Dissemination Subtotal:**

6. Transfer Completion/Ongoing Care

Eliciting feedback from new young adult patients six months after the first visit

Communicating with pediatric practices to confirm transfer or care responsibilities

**Transfer Completion Dissemination Subtotal:**

**DISSEMINATION SUBTOTAL:**

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The table below can be used to total the number of points that your practice obtained in implementation of the *Six Care Elements*, young adult engagement, and dissemination.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Implementation in Practice/Network</strong></td>
<td>14/7</td>
<td>4/4</td>
<td>9/3</td>
<td>41</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Youth and Family Feedback and Leadership</strong></td>
<td>—/—</td>
<td>—/—</td>
<td>—/—</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Dissemination in Practice/Network</strong></td>
<td>5/5</td>
<td>5/5</td>
<td>10/15</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19/12</td>
<td>9/14</td>
<td>24/13</td>
<td>100</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>