Six Core Elements of Health Care Transition 2.0
Transitioning Youth to an Adult Health Care Provider
for use by Pediatric, Family Medicine, and Med-Peds Providers

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Prepared by the Got Transition/Center for Health Care Transition Improvement project team, Margaret McManus, Patience White, and Megan Prior, with assistance from our cabinet executive team, Jeanne McAllister, Carl Cooley, Eileen Fortenza, Laura Pickler, Mallory Cyr, Nienke Dosa, Teresa Nguyen, Tawara Goode, and Wendy Jones, and our federal Maternal and Child Health Bureau project officer, Marie Mann. Special thanks to Corinne Dreskin and Daniel Beck of The National Alliance to Advance Adolescent Health. This work is funded through a cooperative agreement from the Maternal and Child Health Bureau, Health Resources and Services Administration (U39MC25729).
Got Transition is pleased to share this updated package of the Six Core Elements of Health Care Transition for use by pediatric, family medicine, and med-peds providers to benefit all youth, including those with special needs, as they transition from pediatric to adult-centered health care. Consistent with the AAP/AAFP/ACP Clinical Report on Health Care Transition, the transition consists of joint planning with youth and parents/caregivers to foster development of self-care skills and active participation in decision-making. It also consists of assistance in identifying adult providers and ensuring a smooth transfer to adult-centered care with current medical information.

Recognizing and responding to the diversity among youth, 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. In addition, engaging youth and parents/caregivers from various cultural backgrounds in the development and evaluation of a transition quality improvement process is important.

The Six Core Elements of Health Care Transition 2.0 define the basic components of health care transition support and the linked sample tools in this package provide tested means for transitioning youth to adult health care providers. Corresponding packages are available for 1) transitioning to an adult approach to care without changing providers and 2) integrating young adults into adult health care. Originally developed in 2009, this updated version incorporates the results of recent transition learning collaborative experiences in several states, 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 youth and their families.

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 youth/young 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 youth 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 youth and families 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 youth ages 12 and over. 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.

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

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2 Additional information can be found at: http://www.hhs.gov/ocr/officials/resources/specialtopics/fep/index.html and at: http://www.health.gov/communication/literacy/
3 Additional information can be found at www.thinkculturalhealth.hhs.gov
4 To access all three transition packages, see www.GotTransition.org.
5 White, PH, McManus MA, McAlister JII, Cooling WC. A primary care quality improvement approach to health care transition. Pediatric Annals. 2012: 41; S.
## 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/AAFP/ACP 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).

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

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 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 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.

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

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 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.

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### Integrating Young Adults into Adult Health Care
(Internal Medicine, Family Medicine, and Med-Peds Providers)

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 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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### Six Core Elements of Health Care Transition 2.0

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

**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 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
- Determine need for decision-making supports for youth with intellectual challenges.
- Plan with youth/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.

**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.
- 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).
- 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.

**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.

#### Integrating Young Adults into Adult Health Care
(Pediatric, Family Medicine, and Med-Peds Providers)

**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 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/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.
Transitioning Youth to An Adult Health Care Provider
Six Core Elements of Health Care Transition 2.0

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 with the Six Core Elements.
   - Incorporate 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.

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 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
   - Determine 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. 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.

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.

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.
Introduction to Each of the Six Core Elements

Six Core Elements of Health Care Transition 2.0

1. **Transition 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 youth and families, the policy provides consensus among the practice staff, mutual understanding of the process involved, and a structure for evaluation. The policy should include a transition time frame (When are youth expected to leave your practice?) and an explanation of the practice’s transition approach (What will your practice offer youth and families to assist them in transition?). It should also explain the legal changes that take place in privacy and consent at age 18, even if the youth has not left your practice. The policy should be shared with youth and families beginning at ages 12 to 14 and publicly posted.

2. **Transition Tracking and Monitoring**

Establishing a mechanism to track progress of each youth 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 youth with chronic conditions. The long-term goal is to track health care transition progress among all youth ages 12 and older, with and without chronic conditions.

3. **Transition Readiness**

Assessing youth’s transition readiness and self-care skills is the third element in these health care transition quality recommendations. Use of a standardized transition assessment tool is helpful in engaging youth and families in setting health priorities, addressing self-care needs to prepare them for an adult approach to care at age 18, and navigating the adult health care system, including health insurance. Providers can use the results to jointly develop a plan of care with youth and families. Transition readiness assessment should begin at age 14 and continue through adolescence and young adulthood, as needed.

4. **Transition Planning**

Planning for transition as a collaborative and continuous process with youth and families is the fourth element in these health care transition recommendations. It encompasses several activities. To begin with, it is important to develop and regularly update a plan of care that identifies the transitioning youth’s priorities and addresses how learning about health and health care can support their priorities. In addition, to further youth’s independence, developing and sharing a medical summary and emergency care plan, and establishing linkages to community-based supports is also important. Starting at about age 16, providers should assist youth and families in preparing for changes in decision-making when youth legally become adults at age 18. For some youth and families this may require referring them to legal resources about supported decision-making, and for others it may require obtaining their consent to involve parents/caregivers. Finally, transition planning involves inquiring about youth’s preferences for transferring to an adult provider and assisting them in this process. An up-to-date and vetted list of adult primary and specialty care providers interested in care for young adults should be shared with youth and families.

5. **Transfer of Care**

Creating a transfer of care checklist for the practice, preparing a transfer package for youth leaving the practice, and communicating with the new adult provider is the fifth element in these health care transition quality recommendations. The
transfer package contains a transfer letter along with the final transition readiness assessment, transition goals and actions accomplished or yet to be achieved, a medical summary and emergency care plan, and, if needed, legal documents. If the youth’s condition is one that adult providers do not routinely encounter, adding a condition fact sheet to the transfer package is helpful. A telephone conversation with the adult provider may be warranted for transitioning youth with more complex health and psychosocial needs. Transfer to an adult provider is recommended before the age of 22.

6. Transfer Completion

Confirming transfer completion, arranging for pediatric consultation (as needed), and assessing youth and family experience with transition support are all part of the sixth element in these health care transition quality recommendations. Communicating with the adult provider about the pediatric provider’s residual responsibility for care until the first visit is completed and the young adult selects the adult provider as his/her primary care medical home is necessary. Until the young adult has made and kept an appointment establishing care in the new medical home, the pediatric provider should expect to have some residual responsibility for care. Examples may include medication refills or acute care visits. In addition, communicating with the adult practice about available pediatric consultation assistance is also important. To evaluate the success of the transition process, having a mechanism to obtain and incorporate the feedback from youth and families will improve the practice’s approach to transition. Such a survey can be done three to six months after transfer.
[Pediatric Practice Name] is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.
Patient Name: ___________________  Date of Birth: ____________

Primary Diagnosis: _______________  Transition Complexity: _______________

- **Transition Policy**
  - Practice policy on transition discussed/shared with youth and parent caregiver

- **Transition Readiness Assessment**
  - Conducted transition readiness assessment
  - Included transition goals and prioritized actions in plan of care

- **Medical Summary and Emergency Plan**
  - Updated and shared medical summary and emergency plan

- **Adult Model of Care**
  - Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver
  - Timing of transfer discussed with youth and parent/caregiver
  - Selected Adult Provider

- **Transfer of Care**
  - Prepared transfer package including:
    - Transfer letter, including effective date of transfer of care to adult provider
    - Final transition readiness assessment
    - Plan of care, including goals and actions
    - Updated medical summary and emergency care plan
    - Legal documents, if needed
    - Condition fact sheet, if needed
    - Additional provider records, if needed

  - Sent transfer package
  - Communicated with adult provider about transfer
  - Elicited feedback from young adult after transfer from pediatric care

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### 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>Date Last Seen</th>
<th>Next Scheduled Appointment (Date or Blank)</th>
<th>Date of first appointment with adult provider (Date or Blank)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3/4/1995</td>
<td>18 Y</td>
<td>Mary Smith</td>
<td>seizure disorder</td>
<td>3</td>
<td>12/13/2013</td>
<td>1/30/2014</td>
<td>Highlighted if no apt</td>
</tr>
<tr>
<td>9/2/1996</td>
<td>17 Y</td>
<td>Billy Jones</td>
<td>asthma</td>
<td>1</td>
<td>6/23/2013</td>
<td>12/22/2014</td>
<td>Highlighted if not done by 22</td>
</tr>
<tr>
<td>12/25/1997</td>
<td>16 Y</td>
<td>Susan Cue</td>
<td>congenital heart disease</td>
<td>1</td>
<td>7/6/2013</td>
<td>8/6/2014</td>
<td></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>6/7/2014</td>
<td></td>
</tr>
<tr>
<td>4/18/1996</td>
<td>17 Y</td>
<td>David Crockett</td>
<td>well</td>
<td>1</td>
<td>12/22/2012</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1/3/1990</td>
<td>24 Y</td>
<td>Jen Lawrence</td>
<td>cerebral palsy</td>
<td>3</td>
<td>1/14/2014</td>
<td>2/20/2014</td>
<td></td>
</tr>
<tr>
<td>2/14/1999</td>
<td>14 Y</td>
<td>Sasha Jones</td>
<td>well</td>
<td>1</td>
<td>4/16/2012</td>
<td></td>
<td></td>
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<tr>
<td>2/3/1994</td>
<td>19 Y</td>
<td>Enrique Montoya</td>
<td>well</td>
<td>1</td>
<td>5/13/2013</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>Policy Shared with Youth/Family (Yes or Blank)</th>
<th>Readiness Assessment Administered (Date or Blank)</th>
<th>Plan of Care Updated and Shared with Youth/Family (Date or Blank)</th>
<th>Medical Summary and Emergency Care Plan Updated and Shared with Youth/Family (Date or Blank)</th>
<th>Adult Provider Identified (Yes or Blank)</th>
<th>Transfer Package Sent to Adult Provider (Yes or Blank)</th>
<th>Communicated with Adult Provider (Yes or Blank)</th>
<th>Elicited Feedback about Transition from Youth and Family (Yes or Blank)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary Smith</td>
<td>Yes</td>
<td>8/13/2013</td>
<td>8/13/2013</td>
<td>8/13/2013</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Susan Cue</td>
<td>Yes</td>
<td>7/6/2013</td>
<td>7/6/2013</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
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<td>8/16/2013</td>
<td>8/16/2013</td>
<td>8/16/2013</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</tr>
<tr>
<td>Devin Carn</td>
<td>Yes</td>
<td>12/22/2012</td>
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<td></td>
<td></td>
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<tr>
<td>Tom Sawyer</td>
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<td>9/14/2013</td>
<td>9/14/2013</td>
<td>9/14/2013</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
<td></td>
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<tr>
<td>Jen Lawrence</td>
<td>Yes</td>
<td>5/13/2013</td>
<td>5/13/2013</td>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
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<tr>
<td>Sasha Jones</td>
<td>Yes</td>
<td>5/13/2013</td>
<td>5/13/2013</td>
<td></td>
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<td></td>
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<tr>
<td>Enrique Montoya</td>
<td>Yes</td>
<td>5/13/2013</td>
<td>5/13/2013</td>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date: 

Name: 

Date of Birth: 

### Transition Importance and Confidence

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

| How important is it to you to prepare for/change to an adult doctor before age 22? |
|----------------------------------|---|---|---|---|---|---|---|---|---|---|
| 0 (not)                          | 1  | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  | 10 (very) |

| How confident do you feel about your ability to prepare for/change to an adult doctor? |
|----------------------------------|---|---|---|---|---|---|---|---|---|---|
| 0 (not)                          | 1  | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  | 10 (very) |

### My Health

Please check the box that applies to you right now.

- Yes, I know this
- I need to learn
- Someone needs to do this… Who?

<table>
<thead>
<tr>
<th>I know my medical needs.</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I can explain my medical needs to others.</td>
<td></td>
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<tr>
<td>I know my symptoms including ones that I quickly need to see a doctor for.</td>
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<tr>
<td>I know what to do in case I have a medical emergency.</td>
<td></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>
<td></td>
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</tr>
<tr>
<td>I know my allergies to medicines and medicines I should not take.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I carry important health information with me every day. (e.g. insurance card, allergies, medications, emergency contact information, medical summary)</td>
<td></td>
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</tr>
<tr>
<td>I understand how health care privacy changes at age 18 when legally an adult.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Using Health Care

<table>
<thead>
<tr>
<th>I know or I can find my doctor’s phone number.</th>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>I make my own doctor appointments.</td>
<td></td>
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<tr>
<td>Before a visit, I think about questions to ask.</td>
<td></td>
<td></td>
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<tr>
<td>I have a way to get to my doctor’s office.</td>
<td></td>
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<tr>
<td>I know 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>
<td></td>
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<tr>
<td>I have a copy of my current plan of care.</td>
<td></td>
<td></td>
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<tr>
<td>I know how to fill out medical forms.</td>
<td></td>
<td></td>
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<tr>
<td>I know how to get referrals to other providers.</td>
<td></td>
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<tr>
<td>I know where my pharmacy is and how to refill my medicines.</td>
<td></td>
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<tr>
<td>I know where to get blood work or x-rays if my doctor orders them.</td>
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<tr>
<td>I have a plan so I can keep my health insurance after 18 or older.</td>
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</tr>
<tr>
<td>My family and I have discussed my ability to make my own health care decisions at age 18.</td>
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</tbody>
</table>
Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child’s health care skills.

<table>
<thead>
<tr>
<th>Date:</th>
<th>Name:</th>
<th>Date of Birth:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Importance and Confidence</td>
<td>On a scale of 0 to 10, please circle the number that best describes how you feel right now.</td>
<td></td>
</tr>
<tr>
<td>How important is it for your child to prepare for/change to an adult doctor before age 22?</td>
<td>0 (not)  1  2  3  4  5  6  7  8  9  10 (very)</td>
<td></td>
</tr>
<tr>
<td>How confident do you feel about your child’s ability to prepare for/change to an adult doctor?</td>
<td>0 (not)  1  2  3  4  5  6  7  8  9  10 (very)</td>
<td></td>
</tr>
</tbody>
</table>

**My Health**

Please check the box that applies to your child right now.

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<thead>
<tr>
<th>Yes, he/she knows this</th>
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<tbody>
<tr>
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<td>☐</td>
</tr>
<tr>
<td>My child knows he/she can see a doctor alone as I wait in the waiting room.</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child understands how health care privacy changes at age 18.</td>
<td>☐</td>
<td>☐</td>
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<tr>
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<td>☐</td>
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<td>☐</td>
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<tr>
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<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child and I have discussed a plan for supported decision-making, if needed.</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
**Instructions:** This sample plan of care is a written document developed jointly with the transitioning youth 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 transition readiness assessment can be used to guide the development of health goals. The plan of care should be dynamic and updated regularly and sent to the new adult provider as part of the transfer package along with the latest transition readiness assessment, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.

Name: ___________________________ Date of Birth: ___________________________

Primary Diagnosis: __________________ Secondary Diagnosis: __________________

What matters most to you as you become 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: ___________________________ Parent/Caregiver Signature: ___________________________

Clinician Signature: ___________________________ Care Staff Contact: ___________________________ Care Staff Phone: ___________________________
<table>
<thead>
<tr>
<th>Date Completed:</th>
<th>Date Revised:</th>
</tr>
</thead>
</table>

**Contact Information**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Nickname:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOB:</td>
<td>Preferred Language:</td>
</tr>
<tr>
<td>Parent (Caregiver):</td>
<td>Relationship:</td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cell #:</th>
<th>Home #:</th>
<th>Best Time to Reach:</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-Mail:</td>
<td></td>
<td>Best Way to Reach:</td>
</tr>
</tbody>
</table>

| Health Insurance/Plan: | Group and ID #: |

**Emergency Care Plan**

<table>
<thead>
<tr>
<th>Emergency Contact:</th>
<th>Relationship:</th>
<th>Phone:</th>
</tr>
</thead>
</table>

**Preferred Emergency Care Location:**

**Common Emergent Presenting Problems**

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

**Special Concerns for Disaster:**

**Allergies and Procedures to be Avoided**

<table>
<thead>
<tr>
<th>Allergies</th>
<th>Reactions</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>To be avoided</th>
<th>Why?</th>
</tr>
</thead>
</table>

- [ ] 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
### Medications

<table>
<thead>
<tr>
<th>Medications</th>
<th>Dose</th>
<th>Frequency</th>
<th>Medications</th>
<th>Dose</th>
<th>Frequency</th>
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</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>
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<tbody>
<tr>
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### Prior Surgeries, Procedures, and Hospitalizations

<table>
<thead>
<tr>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
<th>Date</th>
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### 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>
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<tr>
<td>EEG</td>
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<tr>
<td>EKG</td>
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<tr>
<td>X-Ray</td>
<td></td>
<td></td>
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<tr>
<td>C-Spine</td>
<td></td>
<td></td>
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<tr>
<td>MRI/CT</td>
<td></td>
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<tr>
<td>Other</td>
<td></td>
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</tbody>
</table>

### Equipment, Appliances, and Assistive Technology

- Gastrostomy
- Adaptive Seating
- Wheelchair
- Tracheostomy
- Communication Device
- Orthotics
- Suctions
- Monitors:
- Crutches
- Nebulizer
- Apnea
- O2
- Walker
- Cardiac
- Glucose
- Other
**School 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>
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<td>Phone:</td>
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<tr>
<td></td>
<td>Contact Person:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
</tbody>
</table>

**Special information that the youth or family wants health care professionals to know**

Youth signature  Print Name  Phone Number  Date

Parent/Caregiver  Print Name  Phone Number  Date

Primary Care Provider Signature  Print Name  Phone Number  Date

Care Coordinator Signature  Print Name  Phone Number  Date

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 – occur 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, hyperreflexic 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 hyperreflexive 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 stoma (Mitrafanoff) 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 as bladder and kidney infections.

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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 insensate 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; consultation 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.

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Sample Transfer of Care Checklist
Six Core Elements of Health Care Transition 2.0

Patient Name: ____________________ Date of Birth: __________

Primary Diagnosis: ____________________ Transition Complexity: _________________
Low, moderate, or high

-Prepared transfer package including:
  □ Transfer letter, including effective of date of transfer of care to adult provider
  □ 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

-Sent transfer package __________
  Date

-Communicated with adult provider about transfer __________
  Date
Dear Adult Provider,

_Name_ is an _age_ year-old patient of our pediatric practice who will be transferring to your care on _date_ of this year. _His or her_ primary chronic condition is _condition_, and _his or her_ secondary conditions are _conditions_. _Name’s_ related medications and specialists are outlined in the enclosed transfer package that includes _his or her_ medical summary and emergency care plan, plan of care, and transition readiness assessment. _Name_ acts as _his or her_ own guardian, and is insured under _insurance plan_ until age _age_.

I have had _name_ as a patient since _age_ and am very familiar with _his or her_ health condition, medical history, and specialists. I would be happy to provide any consultation assistance to you during the initial phases of _name’s_ transition to adult health care. Please do not hesitate to contact me by phone or email if you have further questions.

Thank you very much for your willingness to assume the care of this young _man or woman_.

Sincerely,
This is a survey about your experience changing from pediatric to adult health care. You may choose to answer this survey or not. Your responses to this survey are confidential.

1. How often did your previous health care provider explain things in a way that was easy to understand?
   - Always
   - Usually
   - Sometimes
   - Never

2. How often did your previous health care provider listen carefully to you?
   - Always
   - Usually
   - Sometimes
   - Never

3. Did your previous health care provider respect how your customs or beliefs affect your care?
   - A lot
   - Some
   - A little
   - Not at all

4. Did your previous health care provider discuss with you or have an office policy that informed you at what age you may need to change to a new provider who treats mostly adults?
   - Yes
   - No

5. Did you talk with your previous health care provider without your parent or guardian in the room?
   - Yes
   - No

6. Did your previous health care provider actively work with you to gain 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. Did your previous health care provider actively work with you to think about and 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. How often did you schedule your own appointments with your previous health care provider?
   - Never
   - Sometimes
   - Usually
   - Always

9. Did your previous health care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?
   - Yes
   - No

10. Did your previous health care provider actively work with you to create a written plan to meet your health goals and needs?*
    - Yes
    - No

11. Did your previous health care provider create and share with you your medical summary?
    - Yes
    - No

12. Did your previous health care provider have information about community resources?
    - Yes
    - No

13. Do you know how you will be insured as you become an adult?*
    - Yes
    - No

*Continued*
14. Did your previous health care provider assist you in identifying a new adult provider to transfer to?
☐ Yes
☐ No

15. Did your adult health care provider have your medical records before your first visit?
☐ Yes
☐ No
☐ Don’t Know
☐ Have not had first visit yet

16. Did you feel prepared to change to an adult health care provider?
☐ Very prepared
☐ Somewhat prepared
☐ Not prepared

17. At what age did you change to an adult health care provider?
Age ______

18. How could your pediatric health care provider have made your move to an adult health care provider better?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

*Adapted from the National Survey of Children’s Health

Thank you.
Sample Health Care Transition Feedback Survey
for Parents/Caregivers
Six Core Elements of Health Care Transition 2.0

This is an optional survey about your experience changing from pediatric to adult health care. If you choose to, please answer each question by marking the box to the left of the answer. Your responses to this survey are confidential.

1. How often did your child’s health care provider explain things in a way that was easy to understand?
   - [ ] Always
   - [ ] Usually
   - [ ] Sometimes
   - [ ] Never

2. How often did your child’s health care provider listen carefully to you?
   - [ ] Always
   - [ ] Usually
   - [ ] Sometimes
   - [ ] Never

3. Did your child’s health care provider respect how your customs or beliefs affect your care?
   - [ ] A lot
   - [ ] Some
   - [ ] A little
   - [ ] Not at all

4. Did your child’s health care provider discuss with you or have an office policy that informed you at what age your child may need to change to a new provider who treats mostly adults?
   - [ ] Yes
   - [ ] No

5. Did your child talk with your health care provider alone while you waited in the waiting room?
   - [ ] Yes
   - [ ] No
   - [ ] Not applicable (if child has significant intellectual disabilities)

6. Did your child’s health care provider actively work with your child to gain skills to manage his/her own health and health care (e.g., know his/her medications and their side effects, know what to do in an emergency)?
   - [ ] A lot
   - [ ] Some
   - [ ] A little
   - [ ] Not at all

7. Did your child’s health care provider actively work with your child to think about and 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. How often did your child schedule his/her own appointments with his/her previous health care provider?
   - [ ] Never
   - [ ] Sometimes
   - [ ] Usually
   - [ ] Always
   - [ ] Not applicable

9. Did your child’s health care provider explain legal changes in privacy, decision-making, and consent that take place at age 18?
   - [ ] Yes
   - [ ] No

10. Did your child’s health care provider actively work with your child and you to create a written plan to meet his/her health goals and needs?
    - [ ] Yes
    - [ ] No

11. Did your child’s health care provider create and share his/her medical summary with your child and you?
    - [ ] Yes
    - [ ] No

12. Did your child’s health care provider have information about community resources?
    - [ ] Yes
    - [ ] No

Continued »
13. Do you know how your child will be insured as he/she becomes an adult?*
   ☐ Yes
   ☐ No

14. Did your child’s health care provider assist in identifying a new adult provider to transfer to?
   ☐ Yes
   ☐ No

15. Did your child’s adult health care provider have his/her medical records before the first visit?
   ☐ Yes
   ☐ No
   ☐ Don’t Know
   ☐ Have not had first visit yet

16. Did your child feel prepared to change to an adult health care provider?
   ☐ Very prepared
   ☐ Somewhat prepared
   ☐ Not prepared
   ☐ Not applicable

17. At what age did your child change to an adult health care provider?
   Age ______

18. How could your child’s health care provider have made the move to an adult health care provider better for you and your child?
   _______________________________________________
   _______________________________________________
   _______________________________________________
   _______________________________________________
   _______________________________________________
   _______________________________________________
   _______________________________________________
   _______________________________________________

*Adapted from the National Survey of Children’s Health

Thank you.
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 youth and families 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 youth ages 12 and over. 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.
### Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers

**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. Transition Policy</td>
<td>Clinicians vary in their approach to health care transition, including the appropriate age for transfer to adult providers.</td>
<td>Clinicians follow a uniform but not a written policy about the age for transfer. The approach for transition planning differs among clinicians.</td>
<td>The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information and addresses the practice’s transition approach and age of transfer. The policy is not consistently shared with youth and families.</td>
<td>The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice’s approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12 to 14. The policy is publicly posted and familiar to all staff.</td>
<td></td>
</tr>
<tr>
<td>2. Transition Tracking and Monitoring</td>
<td>Clinicians vary in the identification of transitioning youth, but most wait until close to the age of transfer to identify and prepare youth.</td>
<td>Clinicians use patient records to document certain relevant transition information (e.g., future provider information, date of transfer).</td>
<td>The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth 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 transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete all &quot;Six Core Elements of Health Care Transition 2.0,&quot; using EHR if possible.</td>
<td></td>
</tr>
<tr>
<td>3. Transition Readiness</td>
<td>Clinicians vary in terms of the age when youth begin to have time alone during preventive visits without the parent/caregiver present. Transition readiness is seldom assessed.</td>
<td>Clinicians consistently offer time alone for youth after age 14 during preventive visits without the parent/caregiver present. They usually wait to assess transition readiness/self-care skills close to the time of transfer.</td>
<td>The practice consistently offers clinician time alone with youth after age 14 with clinicians during preventive visits, and clinicians discuss transition readiness/self-care skills and changes in adult-centered care beginning at ages 14 to 16, but no formal assessment tool is used.</td>
<td>The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool. Self-care needs and goals are incorporated into the youth’s plan of care beginning at ages 14 to 16.</td>
<td></td>
</tr>
<tr>
<td>4. Transition Planning</td>
<td>Clinicians vary in addressing health care transition needs and goals. They seldom make available a plan of care (including medical summary and emergency care plan and transition goals and action steps) or a list of adult providers.</td>
<td>Clinicians consistently address transition needs and goals as part of the plan of care. They usually provide a list of adult providers close to the time of transfer.</td>
<td>The practice partners with youth and families in developing and updating their plan of care with prioritized transition goals and preferences for securing an adult provider. This plan of care is regularly updated and accessible to youth and families.</td>
<td>The practice has incorporated transition into its plan of care template for all patients. All clinicians are encouraged to partner with youth and families in developing transition goals and updating and sharing the plan of care. Clinicians address needs for decision-making supports prior to age 18. The practice has a vetted list of adult providers and assists youth in identifying adult providers.</td>
<td></td>
</tr>
</tbody>
</table>

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### Current Assessment of Health Care Transition Activities for Transitioning Youth to Adult Health Care Providers (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>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Transfer of Care</td>
<td>Clinicians usually send medical records to adult providers in response to transitioning patient requests.</td>
<td>Clinicians consistently send medical records to adult providers for their transitioning patients.</td>
<td>The practice sends a transfer package that includes the plan of care (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet).</td>
<td>The practice sends a complete transfer package (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet), and pediatric clinicians communicate with adult clinicians, confirming pediatric provider’s responsibility for care until young adult is seen in the adult practice.</td>
<td></td>
</tr>
<tr>
<td>6. Transfer Completion</td>
<td>Clinicians have no formal process for follow-up with patients who have transferred to new adult providers.</td>
<td>Clinicians encourage patients to let them know whether or not the transfer to new adult provider went smoothly.</td>
<td>The pediatric practice communicates with the adult practice confirming completion of transfer first appointment and offering consultation assistance, if needed.</td>
<td>The practice confirms transfer completion, need for consultation assistance, and elicits feedback from patients regarding the transition experience.</td>
<td></td>
</tr>
<tr>
<td>Youth and Family Feedback</td>
<td>The practice has no formal process to obtain feedback from youth and families about transition support.</td>
<td>The practice obtains feedback from youth and families using a transition survey.</td>
<td>The practice involves youth and families in developing or reviewing the transition survey and conducts the survey with eligible youth and families.</td>
<td>The practice involves youth and families in developing or reviewing the transition survey, conducts the survey with eligible youth and families, and involves youth and families in developing strategies to address areas of concern identified by the transition survey.</td>
<td></td>
</tr>
<tr>
<td>Youth and Family Leadership</td>
<td>Clinicians provide youth and families with tools and information about health care transition.</td>
<td>The practice involves youth and families in creating and implementing education programs for practice staff related to transition.</td>
<td>The practice includes youth and families as active members of a youth advisory council for transition or a transition quality improvement team.</td>
<td>The practice ensures equal representation of youth and families in strategic planning related to health care transition.</td>
<td></td>
</tr>
</tbody>
</table>

The table at right can be used to total the number of points that your practice obtained on the pediatric 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

<table>
<thead>
<tr>
<th>Transition Activities</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Policy</td>
<td>4</td>
</tr>
<tr>
<td>Tracking and Monitoring</td>
<td>4</td>
</tr>
<tr>
<td>Transition Readiness</td>
<td>4</td>
</tr>
<tr>
<td>Transition Planning</td>
<td>4</td>
</tr>
<tr>
<td>Transfer of Care</td>
<td>4</td>
</tr>
<tr>
<td>Transfer Completion</td>
<td>4</td>
</tr>
<tr>
<td>Youth and Family Feedback</td>
<td>4</td>
</tr>
<tr>
<td>Youth and Family Leadership</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32</strong></td>
</tr>
</tbody>
</table>
Introduction

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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 has 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 youth and family engagement, this measurement tool assesses dissemination to all eligible youth, ages 12 and older, within a practice or network. That is, if a practice or plan starts with a subset of youth 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 youth with and without chronic conditions, they would score at the maximum level of 5 points.

A table to total implementation, family engagement, and dissemination scores is available on the final page of this tool. Practices and plans may elect to just score implementation and family 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 Transitioning Youth to Adult Health Care Providers (continued)

Six Core Elements of Health Care Transition 2.0

<table>
<thead>
<tr>
<th>A) Implementation in Practice/Network</th>
<th>Yes or No</th>
<th>Possible</th>
<th>Actual</th>
<th>Possible Documentation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Transition Policy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developed a written transition policy/statement that describes the practice's approach to transition</td>
<td>Yes = 4</td>
<td>Transition policy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Included information about privacy and consent at age 18 in transition policy/statement</td>
<td>Yes = 2</td>
<td>Transition policy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Posted policy/statement (public clinic spaces, practice website etc.)</td>
<td>Yes = 2</td>
<td>Photo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated staff about transition policy/statement and their role in transition process</td>
<td>Yes = 2</td>
<td>Date(s) of program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Designated practice staff to incorporate Six Core Elements into clinical processes</td>
<td>Yes = 4</td>
<td>Job description</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Transition Policy Subtotal:** 14

<table>
<thead>
<tr>
<th><strong>2. Transition Tracking and Monitoring</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Established criteria and process for identifying transitioning target population and entering into individual transition flow sheet or registry</td>
<td>Yes = 3</td>
<td>Screenshot or copy of registry/list</td>
<td></td>
<td></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>Screenshot or copy of chart</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Tracking and Monitoring Subtotal:** 7

<table>
<thead>
<tr>
<th><strong>3. Transition Readiness</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Adopted transition readiness assessment tool for use in practice</td>
<td>Yes = 4</td>
<td>Readiness assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incorporated transition readiness assessment into clinical processes</td>
<td>Yes = 3</td>
<td>Clinical process flow sheet</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Transition Readiness Subtotal:** 7

<table>
<thead>
<tr>
<th><strong>4. Transition Planning</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Developed a plan of care template that incorporates transition readiness assessment findings, goals, and prioritized actions</td>
<td>Yes = 4</td>
<td>Sample plan of care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established clinical process to assess need for decision-making support before age 18</td>
<td>Yes = 2</td>
<td>Practice policy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developed a medical summary and emergency care plan</td>
<td>Yes = 4</td>
<td>Portable medical summary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Made available list of community support resources</td>
<td>Yes = 2</td>
<td>List of resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established process to match and communicate with selected adult provider</td>
<td>Yes = 2</td>
<td>Practice policy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Transition Planning Subtotal:** 14

<table>
<thead>
<tr>
<th><strong>5. Transfer of Care</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Adopted a self-care assessment tool for use in practice</td>
<td>Yes = 4</td>
<td>Transfer package checklist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developed a medical summary and emergency care plan templates</td>
<td>Yes = 2</td>
<td>Transfer letter</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Transfer of Care Subtotal:** 6

<table>
<thead>
<tr>
<th><strong>6. Transfer Completion</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Have mechanism to systematically obtain feedback from young adult about transition process</td>
<td>Yes = 3</td>
<td>Survey or interview questions</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Transfer Completion Subtotal:** 3

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### C) Dissemination in Practice/Network

<table>
<thead>
<tr>
<th>Percent of Patients in Practice Receiving Transition Elements:</th>
<th>Possible</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–10%</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

#### 1. Transition Policy
- Sharing policy with families and youth ages 12–21 (letter or visit)  
  - Transition Policy Subtotal: 5

#### 2. Transition Tracking and Monitoring
- Percentage of youth, ages 12–21, in practice tracked with individual transition flow sheet or registry  
  - Transition Tracking and Monitoring Subtotal: 5

#### 3. Transition Readiness
- Administering transition readiness assessment tool periodically to patients ages 14–21  
  - Transition Readiness Subtotal: 5

#### 4. Transition Planning
- Updating and sharing medical summary and emergency care plan regularly  
  - Transition Planning Subtotal: 10
- Updating and sharing plan of care including readiness assessment findings, goals, and prioritized actions regularly  
  - Transition Planning Subtotal: 10

#### 5. Transfer of Care
- Preparing and sending a transfer package for transferring youth  
  - Transfer of Care Subtotal: 5

#### 6. Transfer Completion
- Contacting transitioned young adults for feedback  
  - Transfer Completion Subtotal: 5
- Communicating with adult providers to confirm transfer and offer consultation 3 to 6 months following last pediatric visit  
  - Transfer Completion Subtotal: 10
The table below can be used to total the number of points that your practice obtained in implementation of the *Six Core Elements*, youth and family 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>Implementation in Practice/Network</td>
<td>14</td>
<td>7</td>
<td>7</td>
<td>14</td>
<td>6</td>
<td>3</td>
<td>51</td>
</tr>
<tr>
<td>Youth and Family Feedback and Leadership</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Dissemination in Practice/Network</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>10</td>
<td>5</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>12</td>
<td>12</td>
<td>24</td>
<td>11</td>
<td>13</td>
<td>100</td>
</tr>
</tbody>
</table>