Six Core Elements of Health Care Transition: Planning, Transfer of Care, and Completion

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Agenda

- Review Six Core Elements
- Core Element #4: Planning
- Updating Health Services Directory
- Core Element #5: Transfer of Care
- Core Element #6: Completion
Six Core Elements
Health Care Transition

• Goals
  ○ To improve the ability of youth and young adults to manage their own health and effectively use health services
  ○ To ensure an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care and integration into adult-centered care

• TRANSITION ≠ TRANSFER

• Transition is an explicit process and includes:
  ○ Planning
  ○ Transfer
  ○ Integration into adult health care
Why Do Adolescents Need a Structured Health Care Transition Process?

- Evidence of need for transition services
  - 2017-18 National Survey of Children’s Health shows that, nationally, only **18.9%** of youth with special health care needs, and **14.2%** without special health care needs, received the services necessary to make transitions to adult care
  - Florida is below national average: **6.4%** of youth with special health care needs, and **6.8%** without special health care needs, received the necessary services

- Evidence of improved outcomes with a structured approach
  - Evaluation studies indicate improvement in population health (adherence to care, perceived health and quality of life, self-care); increased patient and family satisfaction; decreased barriers to care; improved utilization of ambulatory care in adult settings; reduced hospitalizations

Gabriel et al. *J Pediatr* 2017Sep;188:263-269
AAP/AAFP/ACP Clinical Report on Health Care Transition*

- In 2011, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- Targets all youth, beginning at age 12
- Algorithmic structure with:
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
- Extends through transfer of care to adult medical home and adult specialists
- CR reaffirmed by AAP /AAFP/ACP in 2018

<table>
<thead>
<tr>
<th>Age 12</th>
<th>Youth and family aware of transition policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 14</td>
<td>Health care transition planning initiated</td>
</tr>
<tr>
<td>Age 16</td>
<td>Preparation of youth/parents for adult approach to care; discussion of preferences and timing for transfer to adult health care</td>
</tr>
<tr>
<td>Age 18</td>
<td>Transition to adult approach to care</td>
</tr>
<tr>
<td>Age 18-22</td>
<td>Transfer of care to adult medical home and specialists with transfer package</td>
</tr>
</tbody>
</table>

*Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home (*Pediatrics*, July 2011)
Six Core Elements Approach to Health Care Transition

1. **Transition Policy**
   - Ages 12-14: Discuss Transition Policy

2. **Transition Tracking and Monitoring**
   - Ages 14-18: Track progress

3. **Transition Readiness**
   - Ages 14-18: Assess skills annually

4. **Transition Planning**
   - Ages 14-18: Develop transition plan, including medical summary

5. **Transfer/Integration into Adult-Centered Care**
   - Ages 14-18: • Transfer to adult-centered care
     • Integration into adult practice
   - Ages 18-21: • Confirm transfer completion
     • Elicit consumer feedback

6. **Transition Completion and Ongoing Care**
   - Ages 18-26
### Six Core Elements Packages

See [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>
Current Assessment of Health Care Transition Activities
for Transitioning Youth to Adult Health Care Providers
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 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.

https://www.gottransition.org/providers/leaving-measure.cfm
*Tools also available in Spanish
# Current Level Self-Assessment

**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><strong>1. Transition Policy</strong></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><strong>2. Transition Tracking and Monitoring</strong></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 all “Six Core Elements of Health Care Transition 2.0,” using HHIE if possible.</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 “Six Core Elements of Health Care Transition 2.0,” using HHIE if possible.</td>
<td></td>
</tr>
<tr>
<td><strong>3. Transition Readiness</strong></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><strong>4. Transition Planning</strong></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 weighted list of adult providers and assists youth in identifying adult providers.</td>
<td></td>
</tr>
</tbody>
</table>
## Current Level Self-Assessment

### 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 solicits 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

### Transition Activities

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

### Health Care Transition Process Measurement Tool for Transitioning Youth to Adult Health Care Providers

#### 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></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>
<tr>
<td><strong>Transition Policy Subtotal:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2. Transition Tracking and Monitoring</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<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>
<tr>
<td><strong>Transition Tracking and Monitoring Subtotal:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3. Transition Readiness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<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>
<tr>
<td><strong>Transition Readiness Subtotal:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4. Transition Planning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<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>
<tr>
<td><strong>Transition Planning Subtotal:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5. Transfer of Care</strong></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 = 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>
<tr>
<td><strong>Transfer of Care Subtotal:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>6. Transfer Completion</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<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>
<tr>
<td><strong>Transfer Completion Subtotal:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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## QI Process Measurement Tool

### Health Care Transition Process Measurement Tool for Transitioning Youth to Adult Health Care Providers (continued)

#### B) Youth and Family Feedback and Leadership

<table>
<thead>
<tr>
<th>Score Points</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possible Subtotal</td>
<td>| | | | |</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Actual Subtotal</td>
<td>| | | | |</td>
<td></td>
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</tr>
</tbody>
</table>

- Included youth and families in developing policy: Yes = 2
- Included youth and families in developing or reviewing health care transition feedback survey: Yes = 2
- Involved youth and families in transition staff education: Yes = 2
- Included youth and families as active members of transition quality improvement team: Yes = 3

**Youth and Family Engagement Subtotal:** 9

#### C) Dissemination in Practice/Network

<table>
<thead>
<tr>
<th>Score Points</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
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<tr>
<td>Possible Subtotal</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Actual Subtotal</td>
<td>| | | | |</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Transition Policy
- Sharing policy with families and youth ages 12–21 (letter or visit): 0 to 5

2. Transition Tracking and Monitoring
- Percentage of youth, ages 12–21, in practice tracked with individual transition flow sheet or registry: 0 to 5

3. Transition Readiness
- Administering transition readiness assessment tool periodically to patients ages 14–21: 0 to 5

4. Transition Planning
- Updating and sharing medical summary and emergency care plan regularly: 0 to 5
- Updating and sharing plan of care including readiness assessment findings, goals, and prioritized actions regularly: 0 to 5

5. Transfer of Care
- Preparing and sending a transfer package for transferring youth: 0 to 5

6. Transfer Completion
- Contacting transitioned young adults for feedback: 0 to 5
- Communicating with adult providers to confirm transfer and offer consultation 3 to 6 months following last pediatric visit: 0 to 5

**Continued...**
# QI Process Measurement Tool

## Health Care Transition Process Measurement Tool for Transitioning Youth to Adult Health Care Providers (continued)

### Six Core Elements of Health Care Transition 2.0

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>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Implementation in Practice/Network</strong></td>
<td><strong>14</strong></td>
<td><strong>7</strong></td>
<td><strong>7</strong></td>
<td><strong>14</strong></td>
<td><strong>6</strong></td>
<td><strong>3</strong></td>
<td><strong>51</strong></td>
</tr>
<tr>
<td><strong>Youth and Family Feedback and Leadership</strong></td>
<td><strong>---</strong></td>
<td><strong>---</strong></td>
<td><strong>---</strong></td>
<td><strong>---</strong></td>
<td><strong>---</strong></td>
<td><strong>---</strong></td>
<td><strong>9</strong></td>
</tr>
<tr>
<td><strong>Dissemination in Practice/Network</strong></td>
<td><strong>5</strong></td>
<td><strong>5</strong></td>
<td><strong>5</strong></td>
<td><strong>10</strong></td>
<td><strong>5</strong></td>
<td><strong>10</strong></td>
<td><strong>40</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>19</strong></td>
<td><strong>12</strong></td>
<td><strong>12</strong></td>
<td><strong>24</strong></td>
<td><strong>11</strong></td>
<td><strong>13</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>
Provider Communication Strategies

• Target practices include primary and specialty care, pediatric and adult providers – with a focus on pediatric providers

• Emphasize the role of CMS/Title V staff in supporting transition activities and as a resource for practices

• Reach out to nursing staff and office managers
  ○ Serve as link to provider

• Request time for face-to-face meeting
  ○ Explore presentation to practice groups, such as regularly scheduled nurse and/office staff meetings
  ○ Keep presentation short and concise
Provider Follow-Up Strategies

- Document notes on provider outreach activities, e.g., difficulties, challenges, feedback from practices, what worked well

- Follow up with practice contact after initial communication to answer questions, provide further assistance, check on progress

- Identify additional support that would be helpful from Dr. Hess or Central Office
Core Element #4: Planning for Health Care Transition

Source: Got Transition’s Title V Care Coordination initiative Webinar Series, https://www.gottransition.org/webinars/index.cfm; see presentation handouts
Developing a Plan of Care

• Purpose
  ○ Establish agreement between youth and provider about a set of actions to address priorities and access current medical information

• Content
  ○ Identify what is important to youth in becoming adult beyond health goals (education, career, relationships, living situation, etc.)
  ○ Define how learning about health and health care supports these goals
    ▪ Add readiness assessment skills needed
  ○ Complete health summary and emergency care plan
    ▪ Include pertinent non-medical information for provider
Challenges

• How can Title V staff support providers, youth and families in completing a medical summary and emergency care plan?

• Who will provide the needed self-care education for the youth?
### Sample Plan of Care

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

Instructions: This sample plan of care is a written document developed jointly with the 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.

<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 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: ________________

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**Health Care Transition**

**Planning Guide**

- Ages 12 - 14
- Ages 15 - 17
- Ages 18

*Florida HEALTH*

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Self-Advocacy Guides

www.floridahats.org/?page_id=616
Self-Management Videos

Short Videos with step-by-step instructions
Example: Parent Navigator Program at Goldberg Center, D.C.

Transition Planning

Six Core Element National Standard
- 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 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.
- 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.

Navigator’s Role
- Prepare youth and parent/caregiver for adult approach to care at age 18. Start the discussion around Power of Attorney versus Guardianship.
- Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
- Dissemination of guardian decision making and guardianship brochure.
- Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.
  - PN provides family an adult provider list
- Provide linkages to insurance resources, self-care management information and culturally appropriate community resources.
Updating FloridaHATS
Health Services Directory
Health Services Directory

The Health Services Directory will help you to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

- Search the Health Services Directory
- Submit a new entry
- Recommend a program or provider
- Update an existing entry
- Find related service directories in Florida

Please help us keep the directory up-to-date! We encourage both consumers and providers to let us know about resources you think should be included. For instructions on how to add a service, update an existing entry, or recommend a program, please visit our Directory Submission Page.

Disclaimer: A listing in this directory does not imply an endorsement from FloridaHATS, Children's Medical Services, or Florida Department of Health. The information is solely for your convenience in locating services from those available in your area. Individuals should perform their own research of any organization they choose. If the service is covered on an insurance plan, first check the plan's provider network. However, if you believe a particular listing in this directory does not meet our criteria of serving young adults with chronic health conditions or disabilities, please contact us here.

Related Service Directories in Florida:
- Project 44 Florida District Resource Directory

www.floridahats.org/service-directory/search-service-directory
Submission Process for New/Updated Services Programs

Health Services Directory Submissions

Submission Instructions
If you know of a provider or program that should be included in the directory, you may complete the form below or contact a FloridaHATS representative. Please include as much detail as possible about the program in the “Service Description” field, such as type of insurance accepted and/or fee structure, eligibility criteria (e.g., age parameters, type of condition), population served (e.g., developmental disabilities, technology-dependent, non-ambulatory). A comprehensive description will result in a better match between patient need and services. There also is a field for a web site address. All information that is submitted will be verified prior to uploading to the directory.

Update Existing Entry
To update an existing entry, first search for listing using the Health Service Directory Search Feature. Open the current listing. In upper right-hand corner, click on the “Update this listing” text link. Make corrections on form page then click submit. All information that is submitted will be verified prior to uploading to the directory.

Search the Directory
To search the Health Service Directory, please visit this page.

Contact FloridaHATS
If you have questions about submitting the online form, would like to recommend a new listing, or would like to talk to a representative about a service, please contact Florida HATS.

Disclaimer: Please help us keep the directory up-to-date by letting us know about resources you think should be included, however, please note that a listing in this directory does not imply an endorsement from FloridaHATS, Florida Department of Health, or Children’s Medical Services. These resources are listed solely for your convenience in locating services from those available in your area. Individuals should perform their own research of any agency they choose. If the service is covered on an insurance plan, first check the plan’s provider network.
# Provider Submission Form

**Organization Name**: 

**Business 1**: 

**Business 2**: 

**Address 1**: 

**Address 2**: 

**City, State, County**: 

- **Please Select**: 

**Zip**: 

**Fax**: (example: 123-456-7890) 

**Email**: 

**Web Site**: (example: http://www.example.com) 

**Health Categories**: 

<table>
<thead>
<tr>
<th>Health Category</th>
<th>Additional Health Category 1st</th>
<th>Additional Health Category 2nd</th>
<th>Additional Health Category 3rd</th>
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<tbody>
<tr>
<td>- <strong>Please Select</strong> -</td>
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<td>- <strong>Please Select</strong> -</td>
<td>- <strong>Please Select</strong> -</td>
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**Age range of patients/demographics served**: 

- Years 

**Do you accept Medicaid for your services?**

- Yes 
- No 

**Services are provided in these languages**: 

- **Spanish** 
- **Haitian Creole** 
- **Other** 

**Special populations served**: 

- **Developmental disabilities** 
- **Technology dependent** 
- **Non Ambulatory** 
- **Other** 

**Organization Contact**: 

<table>
<thead>
<tr>
<th>Organization Contact First Name</th>
<th>Organization Contact Last Name</th>
<th>Organization Contact Job Title</th>
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**Please provide your information below. Your name, email and phone number are for our records only and will remain private.** 

**Your Name**: 

**Your Email**: 

**Your Phone**: 

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Core Element #5: Transfer of Care

Source: Got Transition’s Title V Care Coordination initiative Webinar Series, https://www.gottransition.org/webinars/index.cfm; see presentation handouts
Transfer of Care

- Plan with youth/family for optimal time for transfer
- Assist in identifying adult provider
- Complete transfer package and communicate with new adult provider
- Transfer when YA’s condition is stable
- Confirm pediatric provider’s responsibility for care until YA is seen in adult practice
Transfer Package

• 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
• Evidence of communication with adult provider about transfer
Sample Transfer Letter
Six Core Elements of Health Care Transition 2.0

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

Patient Name: ______________   Date of Birth: ____________

Primary Diagnosis: ______________   Transition Complexity: ______________

-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

Florida HEALTH
Example: Parent Navigator Program at Goldberg Center, D.C.

Transfer of Care

**Six Core Element National Standard**
- Confirm date of first adult provider appointment.
- Transfer young adults 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.

**Navigator’s Role**
- Navigator assists family with scheduling the initial adult primary care visit.
- Assists family with getting a copy of the medical visit summary and an immunization record.
Core Element #6: Completion and Integration into Adult Care

Source: Got Transition’s Title V Care Coordination initiative Webinar Series, https://www.gottransition.org/webinars/index.cfm; see presentation handouts
Pediatric Provider Responsibilities

- Send reminder to the YA to contact new provider office
- Assure YA and Adult Clinician that Peds will cover their care until 1st adult clinician visit
- Follow up to learn if the young adult went to first appt and have a plan to follow up if the YA did not come to the 1st appt
- Follow up with YA to obtain feedback on the process after first Adult Clinician appt
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>1. Does your adult health care provider explain things in a way that is easy to understand?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>2. Does your adult health care provider listen carefully to you?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>3. Does your adult health care provider respect how your customs or beliefs affect your care?</td>
<td>Yes, No, Not applicable</td>
</tr>
<tr>
<td>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?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>5. Did your adult provider/practice provide written or online information describing their hours and services?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>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)?</td>
<td>A lot, Some, A little, Not at all</td>
</tr>
<tr>
<td>7. Does your adult health care provider actively work with you to plan for the future (e.g., talk time to discuss future plans about education, work, relationships, and development of independent living skills)?</td>
<td>A lot, Some, A little, Not at all</td>
</tr>
<tr>
<td>8. Did your adult health care provider address any of your concerns about transitioning to a new practice/provider?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>9. Did your adult health care provider explain the legal changes in privacy, decision-making, and consent that take place at age 18?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>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?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>11. Does your adult health care provider update and share a current medical summary and emergency care plan with you?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>12. Does your adult health care provider assist you in identifying adult specialists, if needed?</td>
<td>Yes, No, Not needed</td>
</tr>
<tr>
<td>13. Do you know how to find information about health insurance options, if needed?</td>
<td>Yes, No, Not needed</td>
</tr>
<tr>
<td>14. Does your adult provider have information about community resources?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>15. At what age did you change to an adult health care provider?</td>
<td>Age ________</td>
</tr>
<tr>
<td>16. How can your adult health care provider improve your experience of care in his/her practice?</td>
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*Adapted from the National Survey of Vital Signs health
Adult Provider Responsibilities

- Adult office nurse calls YA to schedule first appointment and identify needs for accommodations
- Send welcome letter to YA
  - Explanation of adult model of care
  - Privacy and consent information; if needed legal information about decision making support
  - Medical information needed to be sent to the adult clinician’s office before 1st appointment
Sample Welcome and Orientation of New Young Adults
Six Core Elements of Health Care Transition 2.0

[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:
Example: Parent Navigator Program at Goldberg Center, D.C.

Transfer Completion

Six Core Element National Standard

- 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.

Navigator’s Role

- Navigators contacts families approximately 2 wks. after the appt. to verify attendance.
Questions and Discussion