Six Core Elements of Health Care Transition™ 3.0

An Implementation Guide

Transitioning Youth to an Adult Health Care Clinician

Core Element 4 - Transition Planning

I. Purpose, Objectives, and Considerations 2

II. Quality Improvement Considerations, Tools, and Measurement 5

III. Sample Transition Planning Tools 10

IV. Additional Resources 11

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I. Purpose, Objectives, and Considerations

Purpose

Transition planning is the fourth element in the Six Core Elements of Health Care Transition™ (HCT). Planning for transition should be accomplished in collaboration with youth and parents/caregivers beginning in early adolescence and continuing until the youth transfers out of pediatric care. Transition planning encompasses several ongoing activities that are intended to build health literacy and independent self-care skills; assist in preparing for changes that happen at age 18; and guide the timing of transfer and the selection of a new adult clinician, taking cultural preferences into account. In addition, addressing the legal issues of supported decision-making should be a part of this planning, if needed. *See sample transition plans of care and medical summary and emergency care plans in Section III.*

Objectives

Develop and regularly update the plan of care, including readiness assessment findings, youth's 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 an adult approach to care, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.

Determine need for decision-making supports for youth and make referrals to legal resources.

Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult care. If both primary and subspecialty care are involved, discuss optimal timing for each.

Assist youth in identifying an adult clinician(s) and provide linkages to insurance resources, self-care management information, and community support services.

Obtain consent from youth/parent/caregiver for release of medical information.

Take cultural preferences into account throughout transition planning.

Considerations

CONTENT

What information should be considered in developing a plan of care for transition?

Below are some questions and ideas to think about.

- *Does the practice already have a plan of care template and/or an HCT plan of care template? If the practice has a transition plan of care template, does it encompass some or all of the objectives listed above?*
- *At what age will the plan of care for transition be developed with youth and parents/caregivers and how often will it be updated?*

What issues should be considered in creating a medical summary and emergency care plan that is shared with youth and parents/caregivers?

Below are some questions and ideas to think about.

- *Does the practice have a medical summary template in its emergency medical records (EMR) or a way to create a medical summary within its EMR?*
- *Does the practice have an emergency care plan template available, or will the practice use another available template? (See Got Transition's template or those created by the American College of Physicians Subspecialty Society in Section III.)*
- *What is the key information needed in the medical summary and emergency care plan?*
- *Is the emergency care plan incorporated into the medical summary or is it a separate document, such as an asthma or sickle cell emergency care plan?*
- *Note: Include special non-medical information in the medical summary that the youth/parent/caregiver would want the new adult clinician to know about them (e.g., they are excellent at drawing or playing baseball). This information can assist new clinicians to make a connection and engage the young adult during the first visit.*

When does the practice begin offering time alone with the youth without the parents/caregivers present in the visit to foster independence in medical decision-making if supported decision-making documents are not needed?

Below are some questions and ideas to think about.

- *What does the practice offer youth and parents/caregivers to inform them of the timing and importance of time alone?*
- *Does the practice's approach and information shared align with the Bright Futures Guidelines from the American Academy of Pediatrics?*

What changes should the practice put in place to implement an adult model of care with their patients, starting at age 18?

Below are some questions and ideas to think about.

- *Does the practice explain to youth and parents/caregivers, prior to age 18, the changes that will take place in terms of privacy and consent at age 18? (See Got Transition's Turning 18: What It Means for Your Health in Section IV.)*
- *What safeguards are in place to ensure that patients, ages 18 and older, have sole access to their medical information unless they authorize otherwise?*
- *When and how does the practice discuss with youth and parents/caregivers the need for legal decision-making support, if needed?*
- *What does your practice offer to assist youth and parents/caregivers to consider if there is a need for supported decision-making and how to begin the legal process, if needed? For more information about resources, see the National Resource Center for Supported Decision-Making and The Arc.*
- *Does your practice have current information available to youth/parents/caregivers on adult primary and specialty care practices and other community support services for youth transferring out of pediatric care?*

PROCESS

What is the process to implement a transition plan of care?

Below are some questions and ideas to think about.

- *Does the practice have a process to create and update a plan of care with HCT goals and action steps?*
- *Who will generate the HCT plan of care goals with the youth/parents/caregivers, utilizing the needed skills identified in the transition readiness assessment?*
- *Who will address the needed education on the identified skill gaps with the youth/parents/ caregivers?*
- *How will the education sessions be documented in the medical record?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

What is the process to implement a medical summary and emergency care plan?

Below are some questions and ideas to think about.

- *Is the medical summary and emergency care plan built from the EMR data or is it a template that needs to be completed? If the latter, who is responsible for adding it to the EMR?*
- *Who is responsible for completing the medical summary and emergency care plan and keeping it up to date?*
- *How will the practice share the medical summary and emergency care plan with youth and parents/caregivers (i.e., discuss at the visit or send it to the youth/parent/caregiver before an annual visit to review during the visit)?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

What is the process to implement key issues around confidentiality and legal decision-making?

Below are some questions and ideas to think about.

- *What process does the practice have in place to start offering youth time alone without the parent/caregiver present in the room to foster independence in medical decision-making, if supported decision-making is not needed?*
- *When and who will address the need for legal decision-making with the youth and parent/caregiver and offer resources, if needed?*
- *Who in the practice is responsible for explaining what an adult model of care is to the youth/ parents/caregivers before the youth turns 18?*
- *What processes will the practice implement to provide an adult model of care for youth, starting at age 18? For example, to demonstrate the changes that occur in confidentiality and consent, should all youth who do not need a legal decision-making document be asked to sign a HIPAA form if they come to the visit with their parent/caregiver when they are age 18 or older?*
- *Create a written document to describe the clinic approach to implement the process outlined above.*
- *Educate all team members/staff about the process.*

II. Quality Improvement Considerations, Tools, and Measurement

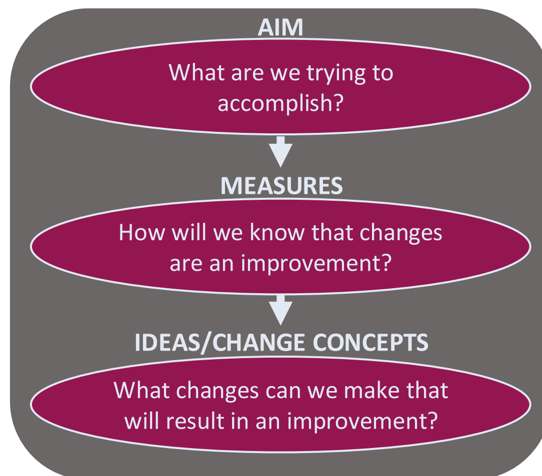
Quality Improvement Considerations

What should be thought about when forming a team? (See *Successful Teams* in the *QI Primer*)

- Include a representative from all areas of your practice
- Include a youth/parent/caregiver whenever possible
- Depending on what you are aiming to improve, consider any ad hoc members you might need (e.g., information services, lab, pharmacy, supply distribution, etc.)
- Schedule meetings or huddles

What is the Model for Improvement?

The Model for Improvement (see *Model for Improvement* in the *QI Primer*) is an approach to process improvement, developed by Associates in Process Improvement, which helps teams accelerate the adoption of proven and effective changes. The figure here illustrates the three questions that make up the Model for Improvement. This is a simple but robust model widely used for improvement in many industries, including health care.



Adapted from Langley GL, et al. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, 2nd ed. San Francisco: Jossey-Bass Publishers, 2009.

As you continue to work through this document and the Six Core Elements, you will find that the QI tools and other items below have been customized to each Element for each kind of practice. However, you will find the basic team considerations described above remain the same for most if not all of your QI work.

Quality Improvement Tools

The most important QI tools to guide a team's improvement work include ***Tools 1-5*** listed below. Using these tools in the following order will increase your chances of success, but teams can make modifications as needed. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

- ***Tool 1: An aim statement*** is a fundamental element of this model and answers the question of what you are trying to accomplish.
- ***Tool 2: Key driver diagrams*** allow teams to visualize the relationship between the project aim and contributing factors, helping them determine key actions necessary to meet this aim.
- ***Tool 3: Process flow maps*** can help you visualize the steps in your change process.
- ***Tool 4: The simplified failure mode and effects analysis*** form helps teams recognize what problems might arise in each step of the process and think of possible solutions.
- ***Tool 5: Plan-Do-Study-Act (PDSA) cycles*** allow teams to trial and learn from their process changes. Using Tools 1-4 before initiating a PDSA cycle helps teams assess root causes before jumping to solutions.

Tool 1: Aim Statement

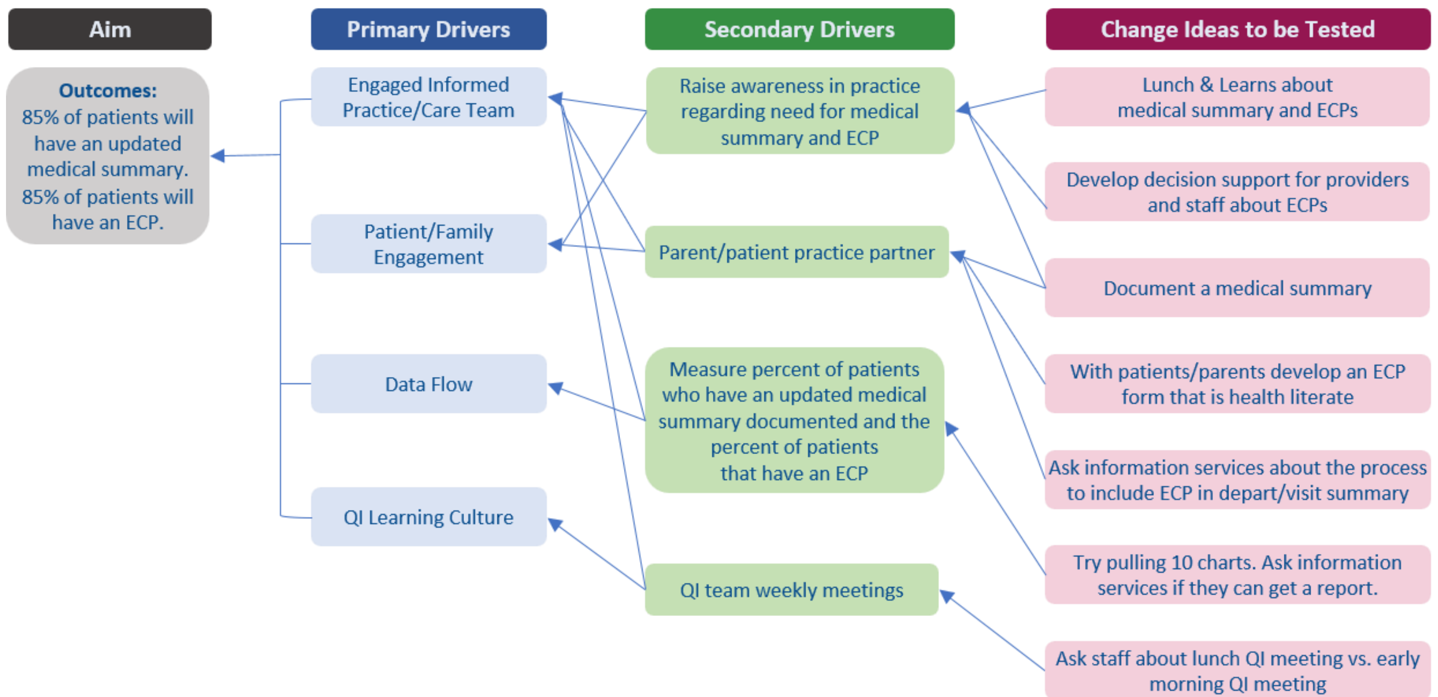
The aim statement is a written statement that describes the improvement effort and includes the rationale for doing the work, the target population, the time period of the work, and measurable numeric goals. For more information and examples, see *Model for Improvement* in the QI Primer.

Example Aim Statement

We aim to improve care for patients with sickle cell disease by creating a transition plan. By [insert date], 85% of patients will have an updated medical summary and 85% of patients will have an emergency care plan.

Tool 2: Key Driver Diagram

Key driver diagrams (KDDs) require teams to identify their theories or "key drivers" which lead to outcomes. They help teams see relationships and organize work, especially in complex systems. They are frequently used for analysis, organization, and communication to direct improvement work. For more information and examples, see *Tools for Improvement* in the QI Primer.



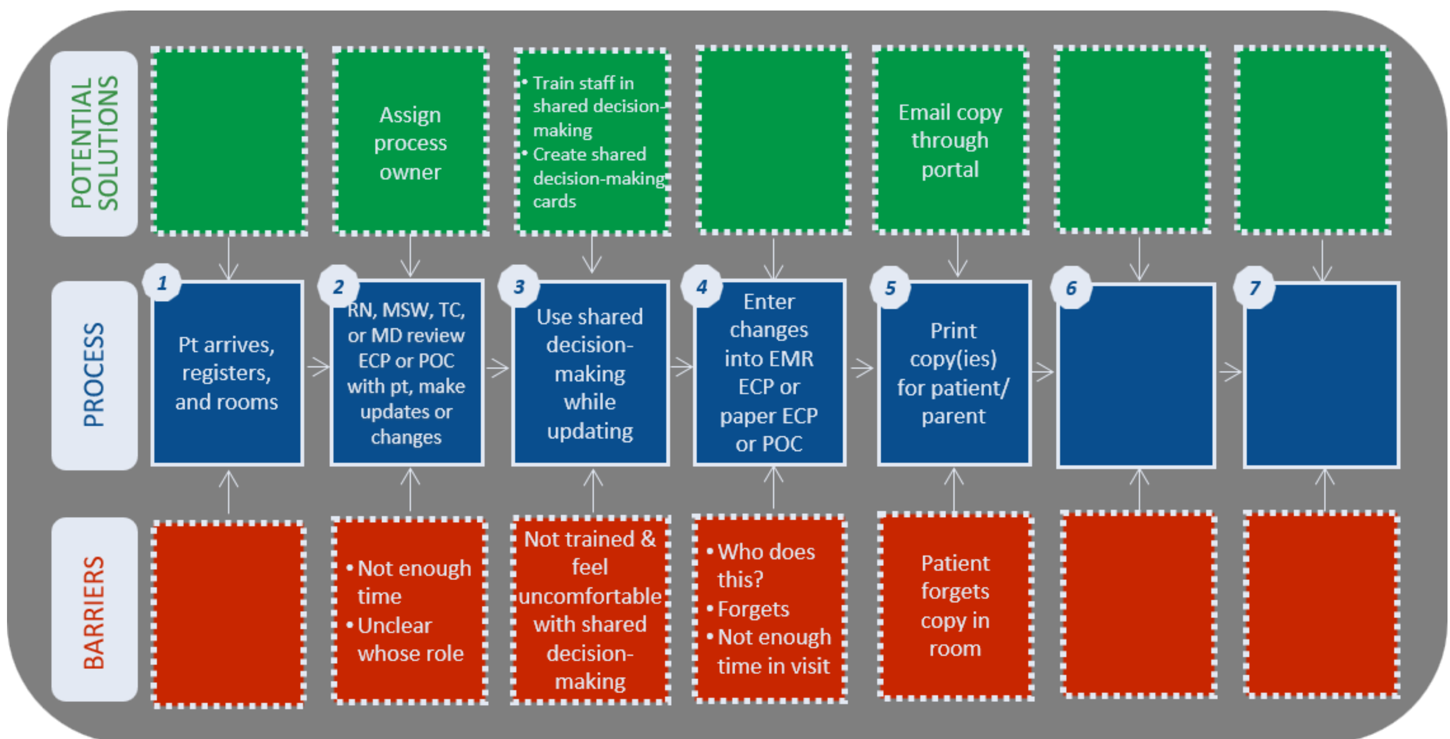
Adapted from ST3P UP, a collaborative sponsored by Patient Centered Outcomes Research Institute® (PCORI) Award MCSC-1608-35861 Titled A Comparative Effectiveness of Peer Mentoring Versus Structured Education Based Transition Programming For The Management Of Care Transitions In Emerging Adults With Sickle Cell Disease.

Tool 3: Process Flow Map

A flow map is a visual display of the separate steps in a process placed in sequential order. It is extremely helpful in documenting different views of the same process. It can show the sequence of actions, materials/inputs entering and leaving the process, decision points, and people involved. Flow maps can be used to document steps in the process of either how things are or how things could be. Posting the flow map gives staff an opportunity to clarify the steps in the process and can uncover conflicting understandings. For more information and examples, see *Tools for Improvement* in the *QI Primer*.

Tool 4: Simplified Failure Mode and Effects Analysis (sFMEA)

Simplified Failure Mode and Effects Analysis (sFMEA) is a proactive method for evaluating a process to identify where and how it might fail and to assess the relative impact of different failures, in order to identify the parts of the process that are most in need of change and help generate ideas to prevent those possible failures. This is a good companion to the flow map – a flow map lets you see the process as it is, and the sFMEA helps you look more closely to identify breakdowns. The example below has a few solutions filled in, to illustrate how teams might start completing an sFMEA. For more information and examples, see *Tools for Improvement* in the *QI Primer*.



Adapted from the copyrighted Simplified Failure Mode Effects Analysis Worksheet (sFMEA) from Cincinnati Children's Hospital Medical Center. This version of the sFMEA has been modified and has been reprinted with permission.

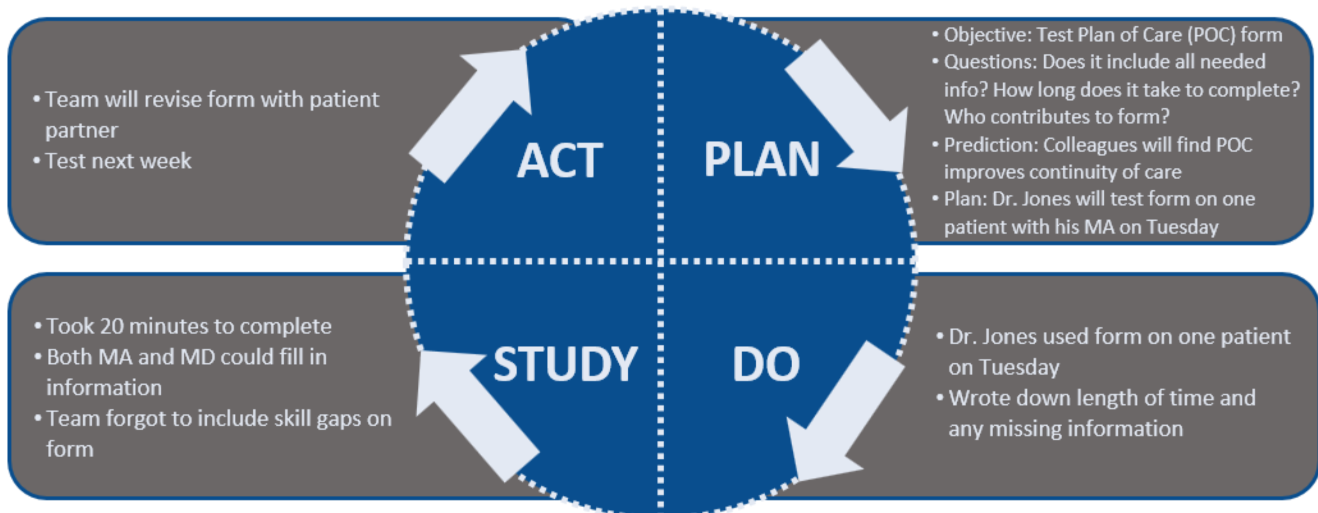
Tool 5: PDSA Cycles

PDSA cycles are a structured test of a process change. These are meant to be done rapidly, for example one patient, one afternoon, with one doctor. To accelerate learning and improvement, small tests with reflection allow for change ideas to be adapted, adopted, or abandoned easily within busy healthcare settings. Learning to do rapid cycle testing is key to keeping the momentum going; it is not necessary to schedule a full separate meeting, just a quick huddle allows teams to plan the next cycle. For more detailed explanation and a blank form, see *Model for Improvement* in the *QI Primer*. This effort includes:

- **Plan** the test: who, what, where, when;
- **Do** try the change and observe what happens;
- **Study** reflect on what was learned from the test; and
- **Act** decide next steps based on the reflection.

Examples of Ideas to Test

- Test the plan of care form (content) on one patient
- Make a mock portable medical summary and test on one patient
- Test an informational flyer about the adult approach to care at age 18 on one patient



Adapted from AHEC QI 101, a Quality Improvement course sponsored by Charlotte Area Health Education Center.

Quality Improvement Measurement

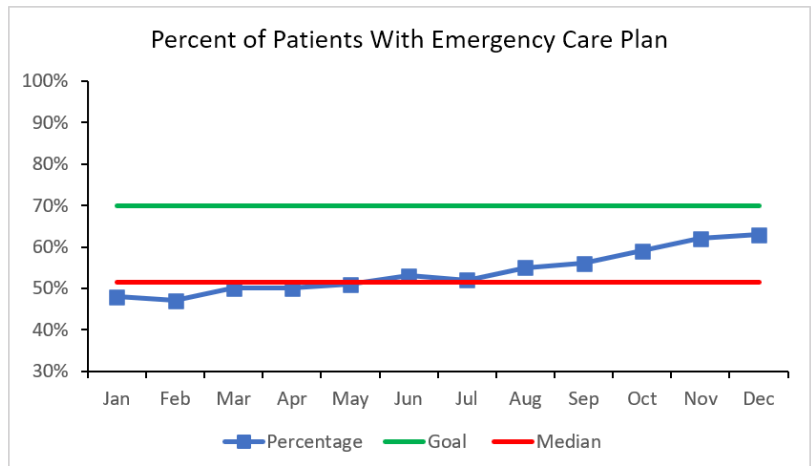
This step will sometimes be informal, while other situations will require a more formal process. Tracking your progress can be as simple as using a check sheet for a short period of time or a more formal use of a run chart which displays improvement over time. Specifically, the Current Assessment of HCT Activities or the HCT Process Measurement Tool in the Six Core Elements package can be used by teams to track progress of specific core elements or the overall HCT process. For more information and examples, see *Measuring for Improvement* in the *QI Primer*.

Example Data Collection Check Sheet

- ☐ Track for 1 week the number of patients given a plan of care or emergency care plan.
- ☐ Track the number of documents left in the room or found in the trash.
- ☐ Call 5 patients and ask if they have used the emergency care plan and if so, in what setting.

	Mon	**Tues**	**Wed**	**Thurs**	**Fri**
# pts given Care Plan	||	||||	|||	|	||
# forms left in trash		|	|		|
# pts confirm ECP use	|	||		|	

Data display is important for teams to assess the impact of the changes they are making. In QI, run charts are most often used. Run charts are a dynamic display of data over time. They require no statistical calculations and should be easily understood. Use a clear title. Data points are plotted around a median line. When possible, adding annotations to the chart to explain when certain changes were introduced can make the chart more informative and robust.



Sustain & Spread

For strategies on how to sustain and spread your work, please see Steps 6 and 7 in *How to Implement the Six Core Elements of Health Care Transition*.

III. Sample Transition Planning Tools

Sample Transition Planning Tools from the Six Core Elements of HCT™

- Sample plan of care from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*
- Sample medical summary and emergency care plan from Got Transition's "Transitioning Youth to an Adult Health Care Clinician" *(click here)*

Sample Wellness Plan for School Health Settings

- Sample wellness plan from Mary's Center's school mental health program *(click here)*

Sample Transition Planning Tools for Youth with Specific Conditions

- Sickle Cell Disease SMART Phrase resource for incorporating a medical summary into a transfer letter (*click here*)
- Additional condition-specific medical summaries from the American College of Physicians (*click here*)

IV. Additional Resources

- Turning 18: What It Means for Your Health (*click* *here*)
- Health Care Transition Timeline for Youth and Young Adults (*click* *here*)
- Health Care Transition Timeline for Parents/Caregivers (*click* *here*)
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  (*click* *here*)
- Add your health information into your smartphone (*click* *here*)
- Questions for youth/young adults to ask their doctor about transitioning to adult health care (*click* *here*)
- Questions for parents/caregivers to ask their child's doctor about transitioning to adult health care (*click* *here*)
- System Differences Between Pediatric and Adult Health Care *(click* *here)*
- Planning to Move from Pediatric to Adult Care? Here's How They Can Differ *(click* *here)*
- A Family Toolkit: Pediatric-to-Adult Health Care Transition (*click* *here*)

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