Empowering pediatric patients for transitions of care

Brandon Abbott DO, MPH
Internal Medicine–Pediatrics
North Country HealthCare
Adjunct Faculty, ATSU–SOMA
None
#Learning Objectives

Learners will be able to:

- Identify barriers to effective transitions of care
- Identify tools they can use to ease and organize transitions of care
- Identify how to assess readiness and efforts in transition
#Introduction

¼ of adolescents 18-21yo have chronic medical conditions

“With reasonable biological certainty, most adolescents transition to adulthood”

Two (and a half) scenarios of transition:

- From pediatrician to adult care provider
- From your practice as a pediatric patient to an adult patient (family medicine or med-peds)
- From the universe to adult care provider (immaculate transition)
#Problem

Despite multi-organizational focus (AAP, AAFP, ACP, ASIM) in 2002, widespread awareness lacking, even today

Outcomes research shows no progress

Most pediatric practices do not have plans for transition
# Barriers

Limited staff training
Lack of responsible staff person identified
Financial barriers
Inadequate payment models
Lack of time
Anxiety of parent or patient
Limited availability of adult providers
-- workforce shortages with the aging population
-- knowledge gap of adult providers to pediatric conditions
# A Good Transition

Builds empowerment

Ensures treatment and goals are continued

Likely reduces costs

Is unambiguous
#Challenges

NOT one-size-fits-all

Team based

Must be tailored to your population and patient individually

Needs based assessment required

Interpretation/translation, health literacy assessment, culturally aware engagement
# Algorithm Close-up

1. Medical Home Interaction for Patients ≥ 12 Years of Age

   2a. Is the Patient 12–13 Years of Age? (Yes → 3a, No → 2b)

   2b. Is the Patient 14–15 Years of Age? (Yes → 3b, No → 2c)

   2c. Is the Patient 16–17 Years of Age? (Yes → 3c, No → 2d)

   2d. Is the Patient ≥18 Years of Age? (Yes → 3d)

   Row 2: Age Ranges

3a. STEP 1: Discuss Office Transitions Policy With Youth & Parents

3b. STEP 2: Ensure Step 1 Is Complete, Then Initiate a Jointly Developed Transition Plan With Youth & Parents

3c. STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care

3d. STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model

Row 3: Action Steps for Specific Age Ranges
#Algorithm Close-up

Row 4: Determination of Special Needs

- 4
  - Does Patient Have Special Health Care Needs?
    - Yes
      - 5a
        - Incorporate Transition Planning in Chronic Condition Management
    - No
      - 5b
        - Have Age-Appropriate Transitions Issues Been Addressed?
          - No
            - 5c
              - Initiate Follow-up Interaction
          - Yes
            - 6
              - Transition Component of Interaction Complete

Row 5: CCM and Follow-up

Row 6: Interaction Complete

Legend
- Start
- Action/Process
- Decision
- Stop
#Six Core Elements of Health Care Transition 2.0

- Transition policy
- Tracking and Monitoring
- Transition Readiness
- Transition Planning
- Transfer of Care
- Transfer Complete
- Bonus: Measuring Transition
#Transition Policy

Involve patients and families

First inquire what your current approach is

Educate staff about new approach/formalized policy, 6 core elements to transition

Post policy and deliver PRIOR to 12 year old appointment for EVERYONE
#Transition Policy

Transition time frame: explicit start and stop

Explanation of approach

Responsibilities: will address process during subsequent visits

Stress parents are to be included but part of visits will require teen without parent present

Explain legal changes at 18 yo (privacy, consent) – “adult model”
#Transition Policy
#Tracking and Monitoring

Utilize a registry!

Use EHR flags!

Define criteria and process for identifying upcoming transitions

Document progress!
If your EHR doesn’t support developing registries, consider excel spreadsheet (use of patient ID’s doesn’t violate HIPAA)

---

And there is always good-ol’ paper.
#Transition Readiness

Ongoing process

Start at 14 yo

Must view youth as the driver in the process

Consider using a questionnaire and help tailor approach and re-visit it yearly

Empowers development of self management skills

Assess parent and youth individually
#Transition Readiness

Can you explain your condition in your words?

Do who you know other people who have the same condition?

When was the last time you forgot to take your treatment?

Why do you need treatment?

For parents: what are you afraid of happening if you give the responsibility of the care to your adolescent?
#SAMPLE READINESS ASSESSMENT
#Shared Management

##Shared Management Overview

<table>
<thead>
<tr>
<th>Role of Parent</th>
<th>Youth Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent is <strong>PROVIDER</strong></td>
<td>Youth <strong>receives</strong> care</td>
</tr>
<tr>
<td>Parent becomes <strong>MANAGER</strong> of care</td>
<td>Youth <strong>provides</strong> some self-care</td>
</tr>
<tr>
<td>Parent becomes <strong>SUPERVISOR</strong> of care</td>
<td>Youth becomes <strong>manager</strong> of care</td>
</tr>
<tr>
<td>Parent becomes <strong>CONSULTANT</strong> to youth</td>
<td>Youth becomes <strong>supervisor</strong> of care</td>
</tr>
<tr>
<td></td>
<td>Youth becomes <strong>CEO</strong> of care</td>
</tr>
</tbody>
</table>
#Steps to Independence

Steps to Independence:

- Parental effectiveness
- Early autonomy
- Promotion of developmental potential
- Prevention of secondary disability and dysfunction
- Good health habits
- Self-responsibility
- Self-efficacy & mastery
- Self-esteem
- Sense of identity
- Independence!!
#Transition Planning

Formalize a plan

Written plan assessing current readiness for self-management and steps needed

Not once-size-fits-all

Re-visit each year
Identify adult care provider/medical home
--Arguably the most important task
--Develop your network

Develop and share a medical summary and action oriented care plan
--Many chronic conditions have standardized/fill-in-the-blank care plans available
--Linkages to community resources

Prepare for changes in decision-making
--May necessitate legal resources (special needs)
#Transition Planning - Sample Transition Plan

Main goal

Who is responsible for coordinating?

Timeline

Skills required

Family/caregiver role?

---

**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.

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>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Initial Date of Plan: ___________________________ Last Updated: ___________________________ Parent/Caregiver Signature: ___________________________

Clinician Signature: ___________________________ Care Staff Contact: ___________________________ Care Staff Phone: ___________________________
#Action PLANS

A lot of chronic medical conditions have specific action plans available for download and implementation

Asthma
Cystic Fibrosis
Epilepsy
#Portable Health Summary Examples
# Further considerations

Assistance securing health insurance coverage

Connecting with community resources
--Family voices, The Arc, lawyers experienced in disability issues
# Transfer of Care

Create checklist

Prepare transfer package: medical record and patient summary/letter!

Consider adult provider’s knowledge of condition
--consider condition fact sheet
--encourage a phone call for more complex conditions/psychosocial needs

Consider pre-transfer visit
#SAMPLE CHECKLIST
Transfer of care - Patient summary

Many standardized patient summaries, your EHR may have one

For special needs:

Baseline functional/neurological status

Formal test results and dates

Condition-specific emergency treatments and contacts

Patient’s health education history

Assessment of understanding of management and prognosis

Advanced directives/health care proxy

Special accommodations: ESL, interpreter, augmented communication device
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,
#Transfer Complete

Confirm that transfer was successful

Expect some residual responsibilities until fully established: medication refills, acute care visits

Get feedback: ideally 3-6 months after transfer
#BONUS: MEASURING TRANSITION

Use results to tailor future transition activities

QI!

---

**Sample Health Care Transition Feedback Survey for Youth**

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

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

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?
Alright, we covered all the vague theoretical stuff...now what?
#GOTTRANSITION.ORG

Step-by-step actions with sample tools (policy, readiness, planning)

Gold standard reference for developing transition practices in your practice

Helpful even for family medicine and med-peds and internists
#Let’s Put It To Work!

Fabulous practical, quick resource: University of Florida Jacksonville -- JAXHATS

https://hscj.ufl.edu/jaxhats
#Register: https://hscj.ufl.edu/jaxhats
#Register: https://hscj.ufl.edu/jaxhats
Medical Provider

Question 1

Do you have a Transition Policy established in your practice or facility?  ○ Yes  ○ No

Organization Name:  North Country HealthCare

Patient's age at which the transition process will begin:  12

Patient's age at which they will be transferred to an adult medical provider or medical home:  18

Please select a Transition Policy below:

○ Policy 1

North Country HealthCare models its transition policy upon the guidelines provided by the American Academy of Pediatrics' joint clinical report on transition and by Bright Futures. We believe that a smooth transition from adolescence to young adulthood includes the explicit transition from a pediatric to an adult health care model and the eventual transfer of health care to adult providers. This process requires joint planning, preparation, and implementation to begin by age 18. At age 12, most youth in our practice will transition to an adult model of care with modifications as needed for youth with intellectual disabilities though the actual transfer of care to adult providers may take place later. We honor the preferences of the youth and family regarding the eventual transfer of care to an adult primary care medical home, but we generally expect this to occur at sometime between 18 and 21 years of age.

Our approach to the care of young adults age 18 and older meets HIPAA and state privacy and consent requirements making the young adult the sole decision-maker about care and about the sharing of personal health information. Exceptions to this approach require legal authority through the signed consent of the young adult, legally valid custodial care or power of attorney documentation, or an adjudicated guardianship arrangement.

○ Policy 2

As recommended by the American Academy of Pediatrics we at North Country HealthCare...
As recommended by the American Academy of Pediatrics we at North Country HealthCare
want to support your smooth transition from our practice to adult-oriented care. Our office
endorses and follows the policies below to help you (and your parents) prepare you for adult
care and adulthood.

- Transition planning, preparation, and transition will be done 2 years before age 18.
- At age 18, unless there are additional circumstances, you will be transitioned to an
  adult medical provider or medical home.
- All youth will be provided with a health summary at his or her last visit to take to your
  adult physician.
- A letter which includes past medical history and any additional recommendations will
  be sent to your adult physician.

Question 2
Do you have a checklist or method that helps patients through the transition process?  Yes No

Question 3
Do you currently provide your patients with a portable health summary after each visit?  Yes No

Click on the links below to review each Portable Health Summary (PHS) as a PDF. Then select which PHS you would
like to use.

- H.L Doc. (PDF)
- My Health Passport (PDF)
- Health and Transition Summary (PDF)

Question 4
What are the age range of your patients?

- 12-14
- 15-17
- 18 and older

Question 5
Do you maintain a Transition registry to track and monitor patients through transition?  Yes No

Question 6
For Pediatric providers and practices: Do you use a transfer letter?  Yes No N/A

Question 7
#JAXHATS -- https://hscj.ufl.edu/jaxhats

## Your Transition Toolkit

Change your answers

<table>
<thead>
<tr>
<th>#</th>
<th>Question</th>
<th>Answer</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do you have a Transition Policy established in your practice or facility?</td>
<td>No</td>
<td>Transition Policy [link]</td>
</tr>
<tr>
<td>2</td>
<td>Do you have a checklist or method that helps patients through the transition process?</td>
<td>No</td>
<td>Transition Checklist for Providers [link]</td>
</tr>
<tr>
<td>3</td>
<td>Do you currently provide your patients with a portable health summary after each visit?</td>
<td>No</td>
<td>My Health Passport [link]</td>
</tr>
<tr>
<td>4</td>
<td>Age range of patients?</td>
<td>15-17</td>
<td>Health and Transition Checklist for Ages 15-17 [link]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Now That You're In High School (English) [link]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Spanish) [link]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>For additional resources, visit:</td>
</tr>
<tr>
<td>5</td>
<td>Do you maintain a Transition registry to track and monitor patients through transition?</td>
<td>No</td>
<td>Transition Registry [link]</td>
</tr>
<tr>
<td>6</td>
<td>For Pediatric providers and practices: Do you use a transfer letter?</td>
<td>No</td>
<td>Transfer Letter [link]</td>
</tr>
<tr>
<td>7</td>
<td>For Pediatric providers and practices transferring youth out: Do you have a way to elicit patient feedback after transfer?</td>
<td>No</td>
<td>Feedback Survey - Youth [link]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Feedback Survey - Parents/Caregivers [link]</td>
</tr>
</tbody>
</table>
#JAXHATS -- https://hscj.ufl.edu/jaxhats

## Health Care Transition Checklist

### Ages 12-14

<table>
<thead>
<tr>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop knowledge of your health care needs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You should be able to:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ describe medical condition(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ name medication(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ manage routine medical tasks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explore appropriate work and volunteer opportunities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answer questions during a health care visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If eligible, sign up for Agency for Persons with Disabilities Med Waiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continue self-advocacy skills, especially with health care providers and teachers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Ages 15-17

<table>
<thead>
<tr>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take responsibility for making medical appointments and getting prescriptions refilled</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talk to medical providers during visits about age-appropriate information regarding physical, emotional, and sexual development</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Begin thinking and talking about transition from pediatric to adult health care providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss pediatrician’s discharge age and plan for transition and transfer to adult care accordingly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keep a health record, including all medical paperwork</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Youth spend the majority of health care visits alone with the doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check in annually with AEP regarding the waiver waitlist status</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Prior to 18th Birthday

<table>
<thead>
<tr>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finalize adult health care coverage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reapply for Medicaid benefits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reapply for SI benefits (17 years and 11 months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make decisions about Power of Attorney or other Guardianship options</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Age 18+

<table>
<thead>
<tr>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transfer medical care from pediatric providers to adult providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reapply for Medicaid Benefits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact Vocational/Rehabilitation to explore vocational assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explore living arrangements, education, and employment opportunities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make decisions regarding Power of Attorney or Guardianship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check in annually with APO regarding waiver waitlist status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer medications to local pharmacy (if moving or going away to school)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If going to college, learn about health care coverage and health services provided on campus</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Sample Individual Transition Flow Sheet

<table>
<thead>
<tr>
<th>Six Core Elements of Health Care Transition 2.0</th>
<th>Date of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Name</td>
<td></td>
</tr>
<tr>
<td>Primary Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Transition Complexity</td>
<td>(low, moderate, or high)</td>
</tr>
<tr>
<td>Transition Timeline</td>
<td></td>
</tr>
<tr>
<td>- Final transition timeline</td>
<td></td>
</tr>
<tr>
<td>- Initial transition timeline</td>
<td></td>
</tr>
<tr>
<td>Transition Readiness Assessment</td>
<td></td>
</tr>
<tr>
<td>Medical Summary and Emergency Plan</td>
<td></td>
</tr>
<tr>
<td>- Updated and transferred medical summary and emergency plan</td>
<td></td>
</tr>
<tr>
<td>Adult Model of Care</td>
<td></td>
</tr>
<tr>
<td>- Decision-making, privacy, and consent in adult care discussed with youth and parent/caregiver if needed, discussed plans for supported decision-making</td>
<td></td>
</tr>
<tr>
<td>- Timing of transfer discussed with youth and parent/caregiver</td>
<td></td>
</tr>
<tr>
<td>- Selected Adult Provider</td>
<td></td>
</tr>
<tr>
<td>Transfer of Care</td>
<td></td>
</tr>
<tr>
<td>- Prepared transfer package including:</td>
<td></td>
</tr>
<tr>
<td>- Transfer letter, including effective date of transfer of care to adult provider</td>
<td></td>
</tr>
<tr>
<td>- Final transition timeline assessment</td>
<td></td>
</tr>
<tr>
<td>- Place of care, including goals and actions</td>
<td></td>
</tr>
<tr>
<td>- Updated medical summary and emergency care plan</td>
<td></td>
</tr>
<tr>
<td>- Legal document, if needed</td>
<td></td>
</tr>
<tr>
<td>- Additional provider records, if needed</td>
<td></td>
</tr>
<tr>
<td>- Send transfer package</td>
<td></td>
</tr>
<tr>
<td>- Communicated with adult provider about transfer</td>
<td></td>
</tr>
<tr>
<td>- Elected feedback from young adult after transfer from pediatric care</td>
<td></td>
</tr>
</tbody>
</table>
Videos

Take Charge of Your Health

Acknowledge Your Circle of Support
Learn about the circle of support and how they may participate in your health care.
View Video

Bringing Medications to Your Medical Appointment
This video demonstrates how you can actively participate in the proper management of your health care by bringing all of your medications to every medical appointment.
View Video

JaxHATS Health Care Notebook
Learn how to organize and prioritize all of your health care information.
View Video
#JAXHATS - MORE INFO

Opportunity for further training and 4 CME credits free through their AHEC
# University of Washington AHTP Project

depts.washington.edu/healthtr

Not plug-and-play like JAXHATS

Plenty of helpful resources and directions to further resources:

- Multilingual health history forms
- Resources for adolescents (readiness resources): how to make the most of health care appointment, talking with your doctor, what is a health advocate?
#Future opportunities

Studies show increased utilization of transition practices in those who were exposed during residency -- Encorp during GME

Leverage GME to help develop best practices and disseminate in community

Future research needed: best practices, cost-effectiveness

Enhanced payment for transition services
#Resources


Colwill JM, Cultice JM, Kruse RL. Will generalist physician supply meet demands of an increasing and aging population? Health Aff. 2008;72(3):w232-241

Got Transition. The National Alliance to Advance Adolescent Health. www.gottransition.org
