Transitions in Care for Young Adults with Disabilities

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Agenda

• Background
• How Are We Doing?
• Current Policy
• Resources for Florida Practitioners
Background
Children and youth with special health care needs (CYSHCN) are those who “have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition who also require health and related services of a type or amount beyond that required by children generally.”

Source: Pediatrics; Volume 102, Nov/July 1998
Health Care Transition (HCT)

The purposeful, planned movement of adolescents and young adults, with and without SHCN, from child-centered to adult-oriented health care systems.

- **Preparation**
  Increased responsibility for health care self-management; understanding and planning for changes in health needs, insurance, and providers in adulthood; should occur across ages 12-21+

- **Transfer of Care**
  Discrete event, physical transfer from a pediatric to an adult provider; should occur between ages 18-21+

- **Successful Transition**
  Patients are engaged in and receive ongoing patient-centered adult care.
Changing Epidemiology of Childhood Conditions

- Congenital Heart Disease
  - ~1,000,000 adults in the U.S. have CHD
  - Slightly more adults than children

- Cerebral Palsy
  - Up to ~1,000,000 people in U.S. have CP
  - Lifespan approaching that of general population

Sources: Centers for Disease Control and Prevention, [www.cdc.gov/ncbddd/heartdefects/data.html](http://www.cdc.gov/ncbddd/heartdefects/data.html) (2016)
Sickle Cell Disease

24.4% of youth aged 12-17 have SHCN

What Can Happen?

• Without adequate support in moving from pediatric to adult care, youth may:
  o Loss/gaps in insurance
  o Have poor connections to the adult health care system
  o Have decreased adherence with medicine, self-care
  o Increased ER visits, hospitalizations
  o Experience short term deterioration in health and worse long term outcomes

Institute of Medicine, 2007; Boyle et al. 2001; Callahan et al. 2001; Betz 2003; Freyer et al. 2008; Tuchman et al. 2008), Watson 2000; Annunziato et al. 2007; Gurvitz et al. 2007; Dugueperoux et al. 2008; White 2002; Williams 2009.
“When we left pediatric care, it was as if someone flipped the switch and turned the lights off.”

- parent of child with developmental disability
“It’s like taking 18 years to build a fine canoe and then riding it over a waterfall.”
What Are the Issues?
# Cognitive Development: Piaget’s Formal Operational Thought

**EARLY** (11-13)  |  **MIDDLE** (14-16)  |  **LATE** (17-21)
---|---|---
Concrete thought | Abstraction | Established abstract thought |
No future perspective | Has future perspective; not always used | Future oriented
The Adolescent Brain

- 10-year NIH MRI study
- 5-20 y.o. participants
- Brain continues to change until mid 20s

# Culture Shock

## Professional culture and traditions

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Communication Gaps

Among providers

Pediatric knowledge of adult system physicians, resources and services

Lack of systematic transfer of records and co-management of care during transition

Between adult provider and youth
Adult System of Care

- Provider capacity and training

- Lack of physicians who are
  - Trained in pediatric onset conditions
  - Willing to take primary responsibility for care

- Service fragmentation
  - Minimal case management in adult practices
  - Lack of linkages to community-based adult services

- Low Medicaid reimbursement rates
Adequate Insurance Coverage

- Aging out of childhood health insurance plans can create gaps/loss in coverage
- Benefits in temporary jobs often limited, unavailable, or have high premiums
- Increased salary may lower/eliminate public benefits
- Limited benefits provided in adult Medicaid package
How Are We Doing?
2016 National Survey of Children’s Health

- Starting in 2016, survey administered annually
- Survey among parents of children aged 0-17
- Includes HCT measures for all youth aged 12-17, with and without SHCN
- Questions about anticipatory guidance from provider:
  - Discussed changing health care needs in adulthood
  - Talked about transitioning to adult care
  - Talked to youth privately
  - Worked with youth to gain self-management skills

Performance

YSHCN

Received services necessary to make transitions to adult health care
Children with special health care needs age 12-17 years

Non-YSHCN

Received services necessary to make transitions to adult health care
Children without special health care needs age 12-17 years

Current Policy
Goals for Transition

• Manage their own health
  o Disease self-management
  o Prevention, substance use, safety, sexuality

• Appropriately access adult primary care, specialists, therapies, equipment, supplies, etc.

• Access to adequate and continuous health insurance

• Implement education and vocational goals

Joint Clinical Report on Transitions

Published in *Pediatrics*, July 2011
- Joint report from AAP / AAFP / ACP

Provides framework for developmentally appropriate transition services:
- For all youth starting at ages 12-14
- Enhanced planning activities for YSHCN
- Move from pediatric to adult model of care at age 18, even if there is no transfer (e.g., Family Medicine, Med Peds practice)
- Within context of a medical home
Population Model of HCT

- Chronic Condition Care Coordination
- Enhanced Planning
- Transition Plan
- Assessment Information & Referral

YSHCN
All Youth

Pediatric Care System
Adult Care System
National Center for Health Care Transition Improvement

http://www.gottransition.org/
Six Core Elements of HCT
For Primary and Specialty Care

1. Develop Transition Policy
2. Establish Tracking and Monitoring
3. Assess Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transfer Completion
# Six Core Elements of Health Care Transition

Listed in the table below are PDFs of the sample tools used in the Six Core Elements of Health Care Transition. Complete packages are available to download and customize for your practice or plan.

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Readiness Assessment Tools

Sample Transition Readiness Assessment for Youth

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health 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/guardian.

Date:

Name:

Date of Birth:

Transition Importance and Confidence

Directions to Youth and Young Adults: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level.

Check here if you are a parent/guardian completing this form.

Managing Medications

1. Do you fill a prescription if you need to?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

   2. Do you know what to do if you are having a bad reaction to your medications?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

   3. Do you take medications correctly and on your own?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

   4. Do you reorder medications before they run out?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

Appointment Keeping

5. Do you call the doctor’s office to make an appointment?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

6. Do you follow up on any referral for tests, check-ups, or labs?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

7. Do you arrange for your ride to medical appointments?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

8. Do you call the doctor about unusual changes in your health (for example: Allergic reactions)?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

9. Do you apply for health insurance if you lose your current coverage?
   - No
   - No, but I want to learn
   - No, but I am learning to do this
   - Yes, I have started doing this
   - Yes, I always do this when I need to

10. Do you know what your health insurance covers?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

11. Do you manage your money and budget household expenses (for example: use checking/debit card)?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

Tracking Health Issues

12. Do you fill out the medical history form, including all of your allergies?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

13. Do you keep a calendar list of medical and other appointments?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

14. Do you make a list of questions before the doctor’s visit?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

15. Do you get financial help with school or work?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

Talking with Providers

16. Do you tell the doctor or nurse what you are feeling?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

Managing Daily Activities

18. Do you help plan or prepare meals/food?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

19. Do you keep your home/clean or clean up after meals?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to

20. Do you use neighborhood stores and services (e.g. grocery stores and pharmacy stores)?
    - No
    - No, but I want to learn
    - No, but I am learning to do this
    - Yes, I have started doing this
    - Yes, I always do this when I need to
Plan of Care

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?

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<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>
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</table>

Initial Date of Plan: ___________________________ Last Updated: ___________________________
Clinician Signature: ___________________________ Care Staff Contact: ___________________________

Parent/Caregiver Signature: ___________________________ Care Staff Phone: ___________________________

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Condition-Specific Tools

The ACP Pediatric to Adult Care Transitions Toolkit contains disease-specific tools that are critical for the young adult in transition to be aware of and understand in order to successfully achieve optimal self-care as an emerging adult.

Each set of tools was required to include at least the three minimum elements described below, which have been customized to include disease-condition-specific elements that are an important part of the transition process for emerging adults in learning self-care. Practices utilizing these tools should also consider incorporating some of the generic tools from the Got Transition Six Core Elements in establishing a process and procedures for pediatric to adult care. The condition-specific tools found below on this page contain the following customized elements, at a minimum:

- Transition Readiness Assessment - an assessment tool intended to be utilized by the pediatric care team or other clinicians serving for youth to begin the conversation about the youth’s needed skills to manage their health and health care. The tool is used to evaluate the youth’s current knowledge about and ability to manage their health condition. This tool indicates the elements specifically related to the clinic condition that should be assessed and documented by the transferring pediatric practice. This tool can be revisited and utilized as a teaching and training aid to ensure that these tasks have been mastered by the time the young adult is ready to transition to adult care.
- Medical Summary/Transfer Record – a summary of the key medical record elements that contain the essential information needed for communication between pediatric and adult clinicians for the specific patient including pertinent disease-specific information. This tool is to be completed by the pediatric or other sending clinician, shared with the youth and family and sent to the receiving adult clinicians.
- Self-Care Assessment - an assessment tool to be utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the patient’s condition(s).

Sets of tools are currently available for the following subspecialties and diseases (with more to be added over time):

1. General Internal Medicine
2. Cardiology
3. Endocrinology
4. Gastroenterology
5. Hematology
6. Nephrology
7. Rheumatology
USF Pediatrics

Transition of Care Policy for Teens and Young Adults

USF Pediatrics works with each patient and family to prepare for a smooth transition to adult care. We believe this process requires gradual transition from a pediatric to an adult health care model, and eventual transfer of care to adult providers. Successful transition also requires that patients, as developmentally able, learn to manage their health care independently with the assistance of a provider, and that responsibility for care gradually shifts from the family to the young adult.

Our staff works closely with patients and families throughout this process, which requires joint planning, preparation and implementation. Our office endorses and follows the policies below to prepare our patients for adult care and adulthood:

- With most patients, transition planning and preparation begins at ages 12-14.
- By age 21, most patients will be fully transitioned to an adult care model and/or transferred to an adult medical provider.
- The transition process is tailored for individuals, as needed.
- At the patient’s last visit, a transfer summary will be provided for the new physician.

Our approach to the care of young adults age 18 and older meets HIPPA and state privacy consent requirements. These requirements make the young adult the sole decision-maker about their care, and allow the young adult to direct the sharing of their personal health information. Exceptions to this 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.

This USF Pediatrics policy is in accordance with guidelines provided by the American Academy of Pediatrics’ joint clinical report on transition and Bright Futures initiative.
Prompts to discuss patient readiness/planning
Adolescent well child visits
Age-delineated: 11-14, 15-17, 18-21 years
Resources for Florida Practitioners
Florida’s clearinghouse for HCT information

www.FloridaHATS.org
Florida Health and Transition Services
Welcome to the Florida HATS website! Florida HATS is a program of the Florida Department of Health, Children’s Medical Services Managed Care Plan (CMS Plan). Our mission is to ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health conditions or other special health care needs. To learn more about our program, visit About Us.

Tool Box
Our health care transition tool box contains documents and links to a variety of local, state and national resources. Materials for youth, families and professionals are organized in these categories:

- For Health Care Practitioners
- Independent Living
- For Youth & Families
- Decision-Making & Guardianship
- Education & Training for Professionals
- Service Delivery & Models of Care
- Health Insurance & Financing
- Advocacy
- Secondary & Post-Secondary Education
- Juvenile Justice System

Some Resources
- Understanding Florida Medicaid Managed Care: From Family Network on Disabilities (2014)
- My Health Care: A classroom curriculum to improve health literacy, communication and self-advocacy skills
- Just the Facts: The 411 on Health Insurance for Young Adults Ages 16-30 in Florida (2015)
- Transition 26 (International Briefs on Florida Guardianship, Employment, Social Security, and

Some Materials for Youth and Families

Some Tools for Providers
- Condition-Specific Tools for Subspecialists from the American College of Physicians. Tools are now available for the following subspecialties: general internal medicine, general pediatrics, disabilities and physical disabilities.

Need Training?
- Health Care Transition Training for Health Care Professionals. This course is appropriate for all practitioners and supports individuals involved in the care of adolescents and young adults.
- Illinois Transition Care Program Offers
Health Insurance

- Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
  - Plan for change in insurance coverage
Employment

- Apply to Division of Vocational Rehabilitation 2 years before leaving high school
• Consider decision making options, such as guardian advocacy

• Explore long-term financial planning options, such as a special needs trust
2017 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care

Margaret McManus, MHS
Patience White, MD, MA
Chris Harwood, RA
The National Alliance to Advance Adolescent Health
Richard Molteni, MD
David Kanter, MD
Teri Salas, MPA
American Academy of Pediatrics

New In 2017
- Code 99420 has been replaced with codes 96160 and 96161, which can be used for reporting administration and scoring of a patient/caregiver transition readiness or self-care assessment using a standardized, scoreable tool.
- New clinical vignettes have been added with recommended coding suggestions.

Improving transition from pediatric to adult health care is a national priority, a medical home standard, and a meaningful use requirement for electronic health records. Health care transition involves increasing youth’s ability to manage their own health and effectively use health services. It also involves ensuring an organized clinical process to prepare youth and families for adult-centered care, transfer to a new adult provider, and integration into adult health care.

In 2011, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians published a clinical report on transition that represents expert opinion and consensus on practice-based implementation of transition for all youth, beginning early in adolescence and continuing through young adulthood. These joint recommendations were subsequently translated into a set of clinical tools, called the “Six Core Elements of Health Care Transition.” These tested tools were updated in 2014 and are available at no cost from Got Transition, the national resource center on health care transition (www.gottransition.org).

To support the delivery of recommended transition services in pediatric and adult primary and specialty care settings, Got Transition and the American Academy of Pediatrics partnered to develop this transition payment tip sheet. It begins with a listing of transition-related CPT codes and corresponding Medicare fees and relative value units (RVUs), effective as of 2017. It also includes a set of clinical vignettes with recommended CPT and ICD coding and CPT coding descriptions for transition-related services with selected coding tips.

LETTER TEMPLATE TO PAYERS REGARDING RECOGNITION OF CODES RELATED TO PEDIATRIC TO ADULT TRANSITION SERVICES

Address to Insurance Carrier Claims Review Dept. and Address or Insurance Carrier Medical Director

Dear (to be individually addressed on practice or chapter letter head):

I am writing to object to [Carrier Name] policy of [select as appropriate either not covering or bundling, or inadequately paying for] CPT codes related to transition from pediatric to adult care. Transition services are intended to be part of routine preventive, primary, and chronic care for all adolescents and young adults. Our physicians and their clinical staff are appropriately reporting CPT codes even though the services may otherwise be denied by the payer. The specific CPT codes listed below are necessary to report the additional time and work for transition services and should be paid appropriately.

These transition-related codes align with the pediatric and adult patient-centered medical home model of care and the AAP/AAPA/ACP Clinical Report on Transition to Adulthood, which calls for a structured transition process beginning early in adolescence and continuing through transfer to adult care. Recognizing these codes would enable physicians and their clinical staff to provide the recommended transition planning, transfer assistance, and effective integration of into adult care. Evidence shows that a structured transition to adult care improves adherence to care, consumer satisfaction, and use of adult ambulatory care services. A complete list of transition codes with corresponding Medicare fees, relative value units, and clinical vignettes was published in 2017.

The CPT codes related to transition that are at issue include the following: [please select those codes that the practice is addressing (in listing of CPT codes related to transition are attached for the practice’s reference)].

We urge you to recognize and pay appropriately for these services related to transition from pediatric to adult care. We look forward to your response on your coverage and payment policy for these health care transition-related CPT codes. If you have any questions or need additional information, please contact [include contact information].

Sincerely,

X
Health Services Directory for Young Adults

Use the form below to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

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 or recommend a program, please visit our directory submission page. To update an existing entry, first search for listing using the form below. 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 By: Categories AND/OR Keyword(s)

City, State, County

-- Any City --

County

-- Any County --

Health Category

-- Any Health Category --
Behavioral and Mental Health
Dental
Eating Disorders

Search by Keyword(s)

Submit  Reset

www.floridahats.org/service-directory/search-service-directory
College Students with Disabilities

Second Primary & Post-Secondary Education

College Resources for Students with Disabilities

- Scholarships and Financial Aid for Students with Disabilities, from accreditedschoolsonline.org
- Study Tips for College Students with Dyslexia and Dysgraphia
- Studying with ADHD
- Going to College with ASD
- Thriving in Trade School with a Disability
- Heading for College with Special Health Care Needs (YouTube video)
  
  Dr. Kitty O’Hare of Boston Children’s Hospital, provides practical considerations for a student’s health care transition, in preparation for a successful adjustment to college life, prepared by Got Transition.

- Radio Episodes from Got Transition
  - Radio Episode 2
    - Healthcare Transition & College- It Doesn’t Have to be Learned the Hard Way!
  - Radio Episode 3
    - Healthcare Transition & College- It Doesn’t Have to be Learned the Hard Way! Part 2

- Transitioning from High School to Post-Secondary Education, article by Dr. Marilyn Bartlett, Texas A&M
- Resources for College Students from BestColleges.com, including information on disability, mental health, academics and college life

College Health Services

- Barriers to health care transition in the college setting
  - Lack of continuity, tracking and follow up over time
  - When possible, students should concurrently continue receiving care in their non-campus medical home, where transition can be more fully addressed

- BUT, college health services play an important role!

- Encourage independence in managing care
  - Fill prescriptions, take medication, schedule appointments

- Encourage self-advocacy in the classroom
College Health Services (cont’d)

- Maintain an up-to-date health care summary for student that is portable and accessible
- Help student access specialty care providers
  - Initiate referral and be available for consultation
- Help student identify and access adult health insurance coverage
- Coordinate linkages to public benefits and services
- Review legal rights and responsibilities at 18
- Discuss decision-making options, if needed
HCT Training
for Health Care Professionals

• Web-based cross-disciplinary training for professionals
  o 10 modules, 15-20 minutes each
  o Free CME/CE for physicians, physician assistants, LPNs, RNs, and other allied health professionals
  o CME/CE available through Gulfcoast AHEC at www.aheceducation.com
  o Modules also posted on www.FloridaHATS.org
  o Highlighted as a key resource for new Adolescent Medicine Resident Curriculum developed by Society for Adolescent Health and Medicine
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