Transitions in Care for Adolescents and Young Adults with Disabilities

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Agenda

- Background
- How Are We Doing?
- Current Policy
- Resources
Terms
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
Disability Criteria in Adulthood

• The inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

Source: Social Security Administration web site: www.ssa.gov/disability/professionals/bluebook/general-info.htm
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.
Background
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

Prevalence

• 17% of youth have SHCN

• 7-10% have significant physical or mental health conditions (or both)
  ○ 4-5% youth have disabling SHCN
    ✷ Complex physical health conditions
    ✷ Developmental disabilities
  ○ 4-5% have serious mental illness
  ○ 1-2% on SSI

Source: 2009-10 National Survey of CSHCN; USDHHS, 2001
What Can Happen?

• Without adequate support in moving from pediatric to adult care, youth may:
  – Loss/gaps in insurance
  – Have poor connections to the adult health care system
  – Have decreased adherence with medicine, self-care
  – Increased ER visits, hospitalizations
  – 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; Dugueperouxet 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

<table>
<thead>
<tr>
<th>EARLY</th>
<th>MIDDLE</th>
<th>LATE</th>
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<tr>
<td>(11-13)</td>
<td>(14-16)</td>
<td>(17-21)</td>
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<tr>
<td>Concrete thought</td>
<td>Abstraction</td>
<td>Established abstract thought</td>
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<tr>
<td>No future perspective</td>
<td>Has future perspective; not always used</td>
<td>Future oriented</td>
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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

**Pediatricians**
- Child-friendly
- Family-centered
- Interact primarily with parents
- Nurturing
- Prescription
- Developmental Focus

**Adult Physicians**
- Cognitive
- Patient-centered
- Interact with patient
- Empower individual
- Collaborative
- Disease Focus
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?
National Survey of Children with Special Health Care Needs

- Telephone survey every 4 years
- Parents of YSHCN ages 12-17
- State and National level reporting
- 4 questions about anticipatory guidance:
  - Changing health needs in adulthood
  - Transition to adult health provider
  - Insurance needs in adulthood
  - Youth encouraged to take increased responsibility for care
Performance

Outcome: YSHCN who receive the services they need to make appropriate transitions to adult health care, work, and independence.

- Data from 2009-2010 NS-CSHCN
  - National average: 40% met HCT criteria
  - States range: 32% - 53% met criteria
  - Florida (ranked #39): 37% met criteria

- Starting in 2016, new annual survey
  - Combines National Survey of Children’s Health and NS-CSHCN
  - Includes HCT measures for all youth, with and without SHCN
  - First report due late 2017

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
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
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.
USF Pediatrics

HCT Preparation Tool in EMR

- Prompts to discuss patient readiness/planning
- Adolescent well child visits
- Age-delineated: 11-14, 15-17, 18-21 years

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**Health Care Self Management/Transition: 15-17 years**

- Patient can describe how his/her chronic conditions (if any) impact their health. *(yes/needs help/no)*
- Patient can describe how his/her medications (if any) impact their health. *(yes/needs help/no)*
- Patient can take his/her medications (if any) without supervision. *(yes/needs help/no)*
- Patient has tried to refill a medication *(yes/needs help/no)*
- Patient has scheduled a doctor’s appointment on his/her own *(yes/needs help/no)*
- Patient meets with provider without parents/caregivers present (for part of visit) *(yes/no)*
- Patient is keeping his/her own health care summary *(yes/needs help/no)*
- Patient knows source of own medical insurance *(yes/needs help/no)*
- Patient/family are investigating adult doctors for both primary and specialty care *(yes/needs help/no)*
- Patient/family are investigating secondary education or vocational opportunities *(yes/no)*
- Patient has received “10 Steps to Successful Health Care Transition” handout *(yes/no)*

**For YSHCN:**

- Family has begun Voc Rehab application *(yes/no/NA)*
- Family has begun guardianship applications (by age 17) *(yes/no/NA)*
- Transition IEP includes health care transition goals/activities, such as health care self-management *(yes/no/NA)*
- Patient has applied for APD/ Medicaid Home and Community-Based Waiver *(yes/no/NA)*

Subspeciality Provider Contacts: [type text here]
Tools for Florida Practitioners
Florida’s clearinghouse for HCT information

www.FloridaHATS.org
Health Care Transition Preparation for Youth and Young Adults with Special Health Care Needs in Florida

**Step 1:** Provide age-appropriate counseling and transition materials to youth and family. Identify APD eligibility and education needs. See local 2-1-1 Help line for other social services.

**Step 2:** Ensure Step 1. Assess transition readiness (TRAG or other tool). Explore post-high school options, identify decision making needs. Establish timeline for transfer to adult primary and subspecialty care.

**Step 3:** Ensure Steps 1 and 2. Identify insurance coverage, adult service and employment needs. Transfer to adult primary and subspecialty care.

**Is patient 12-14 years?**
- Yes: Provide age-appropriate counseling and transition materials to youth and family. Identify APD eligibility and education needs. See local 2-1-1 Help line for other social services.
- No: Proceed to next step.

**Is patient 15-17 years?**
- Yes: Ensure Step 1. Assess transition readiness (TRAG or other tool). Explore post-high school options, identify decision making needs. Establish timeline for transfer to adult primary and subspecialty care.
- No: Proceed to next step.

**Is patient 18-21 years?**
- Yes: Ensure Steps 1 and 2. Identify insurance coverage, adult service and employment needs. Transfer to adult primary and subspecialty care.
- No: Proceed to next step.

**Is patient eligible for Medicaid Waiver program?**
- Yes: See handout on Medicaid Waiver programs. For patients with I/DD, APD does intake; send all patient documents to APD. Patient is put on waiting list for APD’s Home and Community-Based Medicaid Waiver. Patient may come off waiting list if urgent/emergent.
- No: Proceed to next step.

**Does patient have ID?**
- Yes: Help identify health-related activities to support patient’s education plan. Contact Project 10 regional rep for assistance with transition IEP, starting at 14 years. Refer to Project 10 Resource Directory for local services/programs.
- No: Assist with age-appropriate transition issues before patient’s 17th birthday (advance directive, levels of guardianship, voting, other legal needs). Referral youth/family to Florida Legal Services for legal aid. Refer patient to local Center for Independent Living for additional guidance.

**Is patient eligible for VR?**
- Yes: Discuss SSI/private and public insurance options with youth/family. Provide 411 Insurance Guide (or handout) and local contact information. Help find providers for patients; see Young Adult Health Services Directory. Call physician offices to see whether they will accept patient.
- No: Proceed to next step.

**Needs help with decision-making?**
- Yes: Assist with age-appropriate transition issues before patient’s 18th birthday (advance directive, levels of guardianship, voting, other legal needs). Referral youth/family to Florida Legal Services for legal aid. Refer patient to local Center for Independent Living for additional guidance.
- No: Proceed to next step.

**Insurance patient will have as adult?**
- Yes: Assist with age-appropriate transition issues before patient’s 18th birthday (advance directive, levels of guardianship, voting, other legal needs). Referral youth/family to Florida Legal Services for legal aid. Refer patient to local Center for Independent Living for additional guidance. (Handout)
- No: Proceed to next step.

**Are age-appropriate transition issues been addressed?**
- Yes: Initiate follow-up interaction.
- No: Proceed to next step.

**Care Coordination Support**

**5b** Have age-appropriate transition issues been addressed?
- Yes: Initiate follow-up interaction.
- No: Proceed to next step.

**5c** Transition component of interaction complete.

**Glossary**
- **APD:** Agency for Persons with Disabilities
- **CMS:** Children’s Medical Services, Department of Health
- **I/DD:** Individuals with intellectual or developmental disabilities
- **IEP:** Individual Educational Plan
- **TRAG-5.0** Transition Readiness Questionnaire 5.0 (or use other checklist)
- **VR:** Vocational Rehabilitation Program

*Handouts are available in English, Spanish and Haitian Creole at [www.FloridaHATS.org](http://www.FloridaHATS.org)*
Florida Health and Transition Services

Welcome to the FloridaHATS Web site! FloridaHATS is a program of 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
- Decision-Making & Guardianship
- Service Delivery & Models of Care
- Juvenile Justice System

For Youth & Families
- Education & Training for Professionals
- Health Insurance & Financing
- Secondary & Post-Secondary Education
- Advocacy
- Decision Making & Guardianship
- Service Delivery & Models of Care

Secondary & Post-Secondary Education
- Advocacy
- Juvenile Justice

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

Some Materials for Youth and Families
- Just the Facts: The 411 on Health Insurance for Young Adults Ages 18-30 in Florida (2015)
- Transition 2 Go: International Briefs on Florida Guardianship, Education, Social Security and Employment

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, geriatrics, developmental disabilities and physical disabilities

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

- Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
Self-Advocacy Guides

www.floridahats.org/?page_id=616
Employment

- Apply to Division of Vocational Rehabilitation 2 years before leaving high school.
Guardianship

- Consider decision making alternatives, such as including guardianship or guardian advocacy.
- Explore long-term financial planning options, such as a special needs trust.
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 --

Health Category

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

County

-- Any County --

Search by Keyword(s)

www.floridahats.org/service-directory/search-service-directory
2017 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care

Margaret McManna, MPH
Patience White, MD, MPH
Chris Harwood, Ed.
The National Alliance to Advance Adolescent Health

Richard Meltzer, MD
David Kanter, MD
Tati Sami, MPA
American Academy of Pediatrics

New in 2017:
- Code 99420 has been replaced with codes 90150 and 90161, which can be used for reporting administration and scoring of a patient/caregiver transition readiness or self-care assessment using a standardized, scoratable 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 “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.
Use Tools and Resources

- **Encourage independence in managing care**
  - Fill prescriptions, take medication, schedule appointments
  - Talk to youth independently for portion of visit

- **Help youth access adult primary and specialty care providers**
  - Establish relationships with adult providers
  - Initiate transfer of care and be available for consultation

- **Maintain an up-to-date health care summary for youth that is portable and accessible**
Use Tools and Resources (cont’d)

- Help youth identify and access adult health insurance coverage
- Coordinate linkages to community-based adult services
- Work with schools to include HCT goals and activities in IEP and 504 Plans
- Review legal rights and responsibilities at 18
- Discuss guardianship or decision-making options, if needed
HCT Training
for Health Care Professionals

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