Transitions in Care for Adolescents and Young Adults with Disabilities

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Agenda

- Terms
- Background
- Current Policy and Tools
- USF and Statewide 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)
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

Sources: 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; 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?
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
Current Policy and Tools for Practitioners
Why Do Adolescents Need a Structured Health Care Transition Process?

• Evidence of need for transition services
  ○ 2016 National Survey of Children’s Health shows that, nationally, only 16.5% of youth with special health care needs, and 14.2% without special health care needs, received the services necessary to make transitions to adult care
  ○ Florida is below national average: 7.5% of youth with special health care needs, and 7.0% without special health care needs, received the necessary services

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

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

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

<table>
<thead>
<tr>
<th>Age</th>
<th>Description</th>
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<tbody>
<tr>
<td>12</td>
<td>Youth and family aware of transition policy</td>
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<tr>
<td>14</td>
<td>Health care transition planning initiated</td>
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<tr>
<td>16</td>
<td>Preparation of youth/parents for adult approach to care; discussion of preferences and timing for transfer to adult health care</td>
</tr>
<tr>
<td>18</td>
<td>Transition to adult approach to care</td>
</tr>
<tr>
<td>18-22</td>
<td>Transfer of care to adult medical home and specialists with transfer package</td>
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*Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home (Pediatrics, July 2011)
National Center for Health Care Transition Improvement

http://www.gottransition.org/
Six Core Elements Approach to Health Care Transition

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer/Integration into Adult-Centered Care
6. Transition Completion and Ongoing Care

Ages 12-14:
Discuss Transition Policy

Ages 14-18:
Track progress
Assess skills annually
Develop transition plan, including medical summary

Ages 14-18:
• Transfer to adult-centered care
• Integration into adult practice

Ages 18-21:
• Confirm transfer completion
• Elicit consumer feedback

Ages 18-26:

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer/Integration into Adult-Centered Care
6. Transition Completion and Ongoing Care
Youth and Parent Transition Readiness Assessments

- Many validated tools are available, such as Got Transition and the TRAQ
- There are also readiness tools for youth with ID/DD and their families at www.gottransition.org/resources/index.cfm#developmentaldisabilitiesandtransition
## Planning tasks

Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents. Documents could also be utilized by client/caregiver to create their own medical binder.

Prepare youth and parent/caregiver for adult approach to care at age 18, including changes in decision-making and privacy and consent, self-advocacy, and access to information.

Determine level of need for decision-making supports for youth with intellectual challenges; make referrals to legal resources.

Plan with youth/guardian for optimal timing of transfer.

Obtain consent from youth/guardian for release of medical information.

Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.

Provide linkages to insurance resources, self-care management information and culturally appropriate community supports.
Sample Transfer of Care Checklist
Six Core Elements of Health Care Transition 2.0

Patient Name: ________________ Date of Birth: ________________

Primary Diagnosis: ________________ Transition Complexity: ________________
Low, moderate, or high

-Prepared transfer package including:
  □ Transfer letter, including effective of date of transfer of care to adult provider
  □ Final transition readiness assessment
  □ Plan of care, including transition goals and pending actions
  □ Updated medical summary and emergency care plan
  □ Guardianship or health proxy documents, if needed
  □ Condition fact sheet, if needed
  □ Additional provider records, if needed

-Sent transfer package __________ Date

-Communicated with adult provider about transfer __________ Date
How Can You Ensure a Smooth Transition to the New Adult Care Provider?

One of the most effective transition tools is physician-to-physician communication.

Sample Transfer Letter
Six Core Elements of Health Care Transition 2.0

Dear Adult Provider,

_Name_ is an _age_ year-old patient of our pediatric practice who will be transferring to your care on _date_ of this year. _His or her_ primary chronic condition is _condition_, and _his or her_ secondary conditions are _conditions_. _Name’s_ related medications and specialists are outlined in the enclosed transfer package that includes _his or her_ medical summary and emergency care plan, _plan of care_, and _transition readiness assessment_. _Name_ acts as _his or her_ own guardian, and is insured under _insurance plan_ until age _age_

_I have had_ _name_ as a patient since _age_ and am very familiar with _his or her_ health condition, medical history, and specialists. I would be happy to provide any consultation assistance to you during the initial phases of _name’s_ transition to adult health care. Please do not hesitate to contact me by phone or email if you have further questions.

Thank you very much for your willingness to assume the care of this young _man or woman_.

Sincerely,
Is There a Way to Bill for Transition Services?

Got Transition and the American Academy of Pediatrics developed a transition payment tip sheet to support the delivery of recommended transition services in pediatric and adult primary and specialty care settings.

The 2017 tip sheet provides a comprehensive listing of transition-related CPT codes, corresponding Medicare fees and several clinical vignettes.

In response to popular requests for use of the Six Core Elements for PCMH certification, Got Transition completed a series of key informant interviews with clinical and administrative leaders in the health field and developed a tip sheet.

This resource includes an easy-to-use chart displaying specific NCQA criteria and guidance with links to related Six Core Elements tools.

http://gottransition.org/resourceGet.cfm?id=444
USF and Statewide Resources
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

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]
Florida’s clearinghouse for HCT information
**www.FloridaHATS.org**
FloridaHATS offers many resources for both practitioners and consumers, including a Tool Box and Health Services Directory for Young Adults.

Direct patients and caregivers to the site for downloadable educational materials.
Self-Advocacy Guides

www.floridahats.org/?page_id=616
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)

www.floridahats.org/service-directory/search-service-directory
Web-based training is available to everyone; appropriate for clinical support staff, graduate students in health-related fields, medical and nursing school students, etc.

Up to 4 free continuing education contact hours for Florida physicians, physician assistants, nurses, nurse practitioners, social workers, mental health counselors and allied health professionals are available through the Florida AHEC Network.

www.floridahats.org/education-training-for-health-care-professionals
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