Transitions in Care
for Adolescents and Young Adults
with Special Health Care Needs

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Autism Speaks Transition Tool Kit

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- Background and Issues
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Terms
Developmental Disability

- A severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments

  - Is manifested before the individual attains age 22;
  - Likely to continue indefinitely;
  - Results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; economic self-sufficiency;
  - Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Source: 114 STAT. 1684 PUBLIC LAW 106-402 OCT. 30, 2000
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 on-going patient-centered adult care.
Background
Changing Epidemiology of Childhood/Congenital 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
Significance

Among youth ages 14-17 on SSI:

- 35-50% drop out of high school
- 32% in the Juvenile Justice system

Less likely to:

- finish high school
- pursue postsecondary education
- find a job
- live independently

3x more likely to live on income < $15,000

Source: USDHHS, 2001
What Can Happen?

Without adequate support in moving from pediatric to adult care, youth may:

- Experience gaps/loss in insurance coverage
- 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></th>
<th>EARLY (11-13)</th>
<th>MIDDLE (14-16)</th>
<th>LATE (17-21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concrete</td>
<td>Concrete thought</td>
<td>Abstraction</td>
<td>Established abstract thought</td>
</tr>
<tr>
<td>No future</td>
<td>No future perspective</td>
<td>Has future perspective; not always used</td>
<td>Future oriented</td>
</tr>
<tr>
<td>perspective</td>
<td></td>
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</table>
The Adolescent Brain

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

Emerging Adulthood 18-29

➢ Secular Changes
  • More youth pursuing higher education
    ▪ 1940’s: 14% post HS vs 2014: 68% of HS grads
    ▪ Mixed paths of education, vocation, independent living
  • Age of marriage is increasing
    ▪ 1940-1950’s: age 20 vs 2015: ages 26-30

➢ Increase in length of transition
  • Up to late 20’s, early 30’s

➢ Social class differences in transition to adulthood

## Culture Shock

- Professional culture and traditions

<table>
<thead>
<tr>
<th>Pediatricians</th>
<th>Adult Physicians</th>
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</thead>
<tbody>
<tr>
<td>Child-friendly</td>
<td>Cognitive</td>
</tr>
<tr>
<td>Family-centered</td>
<td>Patient-centered</td>
</tr>
<tr>
<td>Interact primarily with parents</td>
<td>Interact with patient</td>
</tr>
<tr>
<td>Nurturing</td>
<td>Empower individual</td>
</tr>
<tr>
<td>Prescription</td>
<td>Collaborative</td>
</tr>
<tr>
<td>Developmental Focus</td>
<td>Disease Focus</td>
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</table>
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 health care plans/services (private insurance, state Title V, SCHIP) at age 19 or 21

- Benefits in temporary jobs often limited, unavailable, or high premiums

- Increased salary may lower/eliminate public benefits

- Limited benefits provided in adult Medicaid package
Other Systemic Barriers

- Employment opportunities
- Transportation
- Limited assistance for adults with disabilities
  - Termination of childhood support systems
  - Fewer publicly funded programs
  - Stricter eligibility criteria
  - Increased financial burden
Discussion

How has the ACA impacted insurance coverage for adolescents and young adults?

What are the implications of expanded Medicaid coverage for adolescents and young adults?
How Are We Doing?
National Survey of Children with Special Health Care Needs

- Survey data from 2009-2010
  - Every 4 years
  - 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 Data

Nat’l Avg: 40%

Florida (#39): 37%

Range: 32% - 53%

Figure A. State Transition Performance* and Variance from National Mean

National mean: 42.6%

- More than 1.5 standard deviations (SD) above the mean
- Between 0.5 and 1.5 SD above the mean
- Between 0.5 SD above and 0.5 SD below the mean
- Between 0.5 and 1.5 SD below the mean
- More than 1.5 SD below the mean
Current Policies
MCHB
National Performance Measures

#1 Families will participate in decision-making and be satisfied with services.
#2 CSHCN will receive coordinated, comprehensive care within a medical home.
#3 Families will have adequate health insurance.
#4 CSHCN will be screened early and continuously.
#5 Services will be organized so that families can use them easily.
#6 YSHCN will receive the services necessary to make transitions to all aspects of adult life, including health care, work and independence.
Goals for Transition

- Manage their own health
  - Disease self-management
  - 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

Federal Initiatives (2000-Present)

- MCHB’s National Performance Measures
- Consensus Statements and Position Papers
  - American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians - American Society of Internal Medicine, Society of Adolescent Medicine
- Healthy People 2020
- 2011 Joint Clinical Report on Transitions
- Got Transition? National HCT Center
  - 6 Core Elements
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
Health Care Transition Planning Algorithm for All Youth and Young Adults Within a Medical Home Interaction

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

2a. Is the Patient 12–13 Years of Age?
No

2b. Is the Patient 14–15 Years of Age?
No

2c. Is the Patient 16–17 Years of Age?
No

2d. Is the Patient ≥ 18 Years of Age?
Yes

Row 2: Age Ranges

3a. Is the Patient 10–11 Years of Age?
Yes

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

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

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

Row 3: Action Steps for Specific Age Ranges

4. Does Patient Have Special Health Care Needs?

5a. In a Consultation Setting, Discuss Needs & Transition Planning

5b. Review & Update Transitions Plan

Row 4: Determination of Special Needs

5c. Initiate Follow-up Interaction

Row 5: CCM and Follow-up

6. Transitions Component of Interaction Complete

Legend:
- Start
- Action/Process
- Decision
- Stop

1. Initiate first step in the health care transition planning process at age 12.

2a, 2b, 2c, 2d. Age Ranges. By age 12, conduct surveillance to assess any special care needs. Start actual transition planning by age 14. By ages 16-17, transition planning should be well established. At age 18, initiate an adult mode of care for most youth, even if there is no transfer of care. If transition planning does not occur on the schedule described by the algorithm, a concentrated effort is required (eg, special visits) to successfully complete the process.

3a. Every practice should have a written transition policy that is prominently displayed and discussed with youth and families. The policy should explicitly state the practice’s expectations and care process for the health care transition of their adolescent patients to an adult care model.

3b. The practice should utilize a standard transition plan that can be adopted for each patient’s needs. The tool should include components to obtain an accurate assessment of the patient’s ability to successfully transition. Providers should interview youth and family members to identify needs and to assess the intentions and motivations for youth independence.

3c. Transitions plans must be reviewed regularly and updated as necessary. The provider must also perform surveillance for changes in the youth’s medical status and address youth and family concerns that may warrant changes in transition plans. Failure to achieve transition readiness goals warrants reevaluation of the existing plan, and increased frequency of medical home interventions/visits. A “pretransfer” visit to the adult medical home could be conducted during the year before the transfer.

3d. Transition to an adult model of care occurs appropriate for youth’s developmental level. This is followed as appropriate by transfer to an adult medical home. Complete medical records should be delivered to the adult provider, along with a portable summary, which is also provided to the patient or guardian. For children and youth with special health care needs, direct communication between pediatric and adult providers is essential, as adult medical personnel may be unfamiliar with certain pediatric conditions.

4. Transition planning for children and youth with special health care needs should include specific chronic condition management (CCM) activities such as: use of registries; care plans; care coordination; CCM office visits; and arrangement with medical sub-specialists. Transition goals must be individualized to account for variations in the complexity of a youth’s condition and in the youth’s intellectual ability and guardianship status.

5a. Youth with special health care needs require an expanded transition planning process. Transition planning in CCM includes addressing the exchange of complex health information, companionship for self-care, transfers of specialty care, and issues related to insurance, entitlement, guardianship, and eligibility for adult services. In a medical home, such youth may have a written care plan as part of the medical record. At age 14, this plan should include a section titled “transition plan,” which should be expanded and developed as the youth approaches age 18 and beyond.

5b. Use of transition planning tools and readiness checklists facilitate the provider’s ability to ensure that all age-appropriate transition issues have been addressed. Each action step must be completed in order, even if the means the provider has to achieve specific visits to initiate and complete steps missed earlier in the process in order to catch up before the next visit.

5c. Focused tasks involving little detail or complexity can be addressed by the medical home care coordinator, medical provider, or other appropriate staff through telephone or electronic media. More complex issues may necessitate face-to-face office visits.

6. The provider is finished with the transition tasks for that specific interaction or visit; transition planning is an ongoing activity that occurs at every interaction.
6 Core Elements of HCT

1. Develop Transition Policy
2. Establish Tracking and Monitoring
3. Assess Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transfer Completion
Population Model of HCT

Chronic Condition Care Coordination

Enhanced Planning

Transition Plan Assessment Information & Referral

YSHCN

All Youth

Pediatric Care System

Adult Care System
HCT Tools for Florida Practitioners
Florida’s clearinghouse for HCT information
www.FloridaHATS.org
Incorporate transition planning in chronic care management. Coordinate with CMS Nurse if patient is enrolled in CMS.

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

**Step 2**
Ensure Step 1. Assess transition readiness (TRAQ 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.

**Determination of Services Needed**

- **Is patient eligible for MedWaiver 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.
    - 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
    - **Does patient have IEP?**
      - Yes
        - Starting at age 15, send referral with patient information. VR sends information to correct geographic area for placement with VR counselor. Patient must be looking for work to receive services. Patient may be put on waiting list (handout).
        - Assist with age of majority issues before patient’s 18th birthday (advance directive, levels of guardianship, voting, other legal needs). Refer youth/family to Florida Legal Services for legal aid. Refer patient to local Center for Independent Living for additional guidance. (handout).
      - No
        - **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
            - **Needs help with decision-making?**
              - Yes
                - Continue with steps above.
              - No
                - **Insurance patient will have as adult?**
                  - Yes
                    - Continue with steps above.
                  - No
                    - **Have age appropriate transition issues been addressed?**
                      - No
                        - Initiate follow-up interaction.
                      - Yes
                        - 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
- TRAQ-5.0: Transition Readiness Questionnaire 5.0 (or use other checklists)
- VR: Vocational Rehabilitation Program

*Handouts are available in English, Spanish and Haitian Creole at www.FloridaHATS.org*
Ages 12-14: Agency for Persons with Disabilities

- Individuals with a developmental disability should apply to APD as early as age 3
- Don’t wait to get on the Home and Community –Based Waiver Waiting List (called iBudget)
Ages 12-14: School

- Incorporate self-advocacy and self-management skills in school IEP

- Transition IEPs, which are introduced at age 14 in Florida, should outline a pathway to post-secondary independent living

- Project 10 (www.project10.info) is Florida Department of Education’s statewide transition initiative
  - Includes employment training, post-secondary education and independent living resources
What's HEALTH Got To Do with TRANSITION?

CURRICULUM

D DD FLORIDA DEVELOPMENTAL DISABILITIES

HILLSBOROUGH COUNTY PUBLIC SCHOOLS

Hillsborough County Excellence in Education

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Classroom Curriculum

Links to Lesson Plans

Parent/Student Handouts
Age 12+
Self-Advocacy Guides

Health Care Transition Guide for Teens in Middle School
Health Care Transition Guide for Teens in High School
Health Care Transition Guide for Young Adults
Ages 12+
Self-Management Videos

Short Videos with step-by-step instructions
Ages 12+
Health Summary

My Health Passport

If you are a health care professional that will be helping me, PLEASE READ THIS before you try help me with my care or treatment.

My full name is: ____________________________
I like to be called: __________________________
Date of birth: ______/____/____
My primary care physician: _______________________
Physician’s phone number: _______________________

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic. Please keep this with my other notes, and where it may be easily referenced.

My signature: ____________________________ Date completed: ______/____/____
You can talk to this person about my health: __________________________
Phone number: ____________________________ Relationship: ____________________________

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

My current medications are:

When I take my medications, I prefer to take it (e.g. with water, with food)

How I cope with medical procedures: (e.g. how I usually react to injections, IVs, physical examinations, x-rays, oxygen therapy—Note: note procedures never experienced before or in recent years)

I am allergic to:

If I am in pain, I know it by:

My mobility needs are:
(e.g. walker, wheelchair, cane, need long-term care plan, need help getting on/off plane)

My favorite foods and drinks are:

I do not like to eat or drink the following:

When drinking, you may assist me by:

Things I like to do that will help pass the time:

How to make future/follow-up appointments easier for me:

Ages 15-17: VR

- Apply to Division of Vocational Rehabilitation 2 years before leaving high school
Ages 15-17: Sexual Health

- High incidence of sexual abuse among persons with I/DD
  - Most abusers are service providers
- Lack of education about how to properly act on urges can cause major issues
  - Unacceptable public displays
  - Unwarranted sexual harassment
- Sexuality & Developmental Disabilities Across the Lifespan:
  - Helps educators and family members assist with exploration of self and sexuality
Turning 18: Age of Majority

- Legal responsibilities
  - Financial
  - Decision-Making
  - Florida Bar’s #JustAdulting Legal Survival Guide for new adults
    - [www.justadulting.com/](http://www.justadulting.com/)

- Disability benefits determined by ability to work
By Age 18: Decision Making

Becoming an Adult:
Legal and Financial Planning

https://youtu.be/CpvlyfiRjRM
Consider decision making alternatives, such as including guardianship or guardian advocacy.

Explore long-term financial planning options, such as a special needs trust.
By Age 18: SSI

- Redetermination at age 18
- Stricter eligibility requirements
By Age 18: Health Insurance

- Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
Transfer of care

- Primary Care
- Specialty Care

Ages 18-21

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, update an existing entry, or recommend a program, please visit our Submission Instructions page.

Disclaimer: A listing in this directory does not imply an endorsement from FloridaHATS, Children's Medical Services, or Florida Department of Health. The information is solely for your convenience in locating services from those available in your area. Individuals should perform their own research of any organization they choose. If the service is covered on an insurance plan, first check the plan’s provider network. However, if you believe a particular listing in this directory does not meet our criteria of serving young adults with chronic health conditions or disabilities, please contact us here.
Other Transition Resources

- Assistive Technology and Equipment
  - FAAST

- Independent Living
  - Centers for Independent Living

- Housing
  - Housing in Florida: A Resource Guide for Individuals with Developmental Disabilities

- Transportation
  - Access to Florida’s Transportation Disadvantaged Program for Individuals with Disabilities
How You Can Support Transitioning Adolescents and Young Adults
HCT Training for Health Care Professionals

- Web-based cross-disciplinary training for professionals
  - 10 modules, 15-20 minutes each
  - Free CME/CE for physicians, nurses, social workers, dieticians, psychologists, mental health workers, respiratory therapists, dentists
  - CME/CE available through Gulfcoast AHEC at www.aheceducation.com
  - Modules also posted on www.FloridaHATS.org
What You Can Do

- Establish *practice* policies for transition to adult care: post them in waiting rooms!

- Encourage independence in managing care
  - Fill prescriptions, take medication, schedule appointments
  - Talk directly to YSHCN first, then to caregiver as needed

- Help YSHCN 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 YSHCN that is portable and accessible
What You Can Do

- Help YSHCN 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
Contact

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