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

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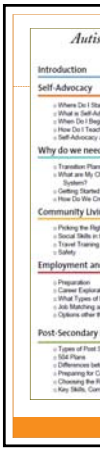
March 22, 2017



Autism Speaks Transition Tool Kit
Table of Contents

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Agenda

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- Background and issues
- How are we doing?
- Current policies
- Tools and resources
- How can you help?

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Terms

Developmental disability

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- 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

CYSHCN

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- 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, Nor/July 1998

Disability criteria in adulthood

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- 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

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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

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Changing epidemiology of childhood/congenital conditions

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- 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 (2016)
Tolsi et al. (2009). Adults with cerebral palsy: a workshop to define the challenges of treating and preventing secondary musculoskeletal and neuromuscular complications in this rapidly growing population, Developmental Medicine and Child Neurology, http://onlinelibrary.wiley.co m/enhanced/doi/10.1111/j.1469-8749.2009.03462.x

Prevalence

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- 17% of youth have SHCN
- 7-10% have significant physical or mental health condition (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

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- 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?

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- 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; Dugneperoscet al. 2008; White 2002; Williams 2009.

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" 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."

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What are the issues?

Cognitive development: Piaget's formal operational thought

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

The adolescent brain

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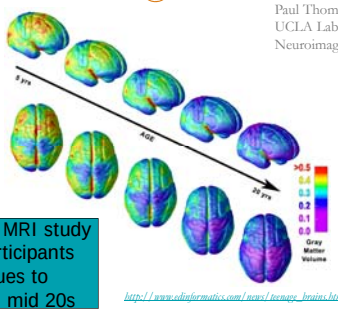
Paul Thompson, Ph.D.
UCLA Laboratory of Neuroimaging



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

http://www.edinformatics.com/news/teenage_brains.htm

Emerging adulthood, ages18-29

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- 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

Sources: U.S. Census Bureau, 1940 – 2015, www.census.gov/hhes/families/files/graphics/MS-2.pdf
U.S. Bureau of Labor Statistics, www.bls.gov/news.release/hsgec.nr0.htm

Culture shock

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- Professional culture and traditions

Pediatricians	Adult Physicians
Child- friendly	*Cognitive*
Family-centered	*Patient-centered*
Interact primarily with parents	*Interact with patient*
Nurturing	*Empower individual*
Prescription	*Collaborative*
Developmental focus	*Disease focus*

Communication gaps

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- 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

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- 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

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- Aging out of health care plans/services (private insurance, Medicaid, 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

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- 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

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Think about how your personal experience with health insurance as a young adult - or the experience of a young adult whom you know - has been impacted by federal and/or state level policies. Have they been positive or negative experiences?

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Current policies

MCHB
National performance measures

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#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

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- 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 independent living, education and vocational goals

Scal, et. Al. Pediatrics 2002
Lotstein DS, et. al J Adol Med. 2008;43:23-29

Federal initiatives (2000-Present)

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- 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 Center for HCT Improvement
  - Six Core Elements
- Condition-Specific HCT Tools for Subspecialists

Joint clinical report on transitions

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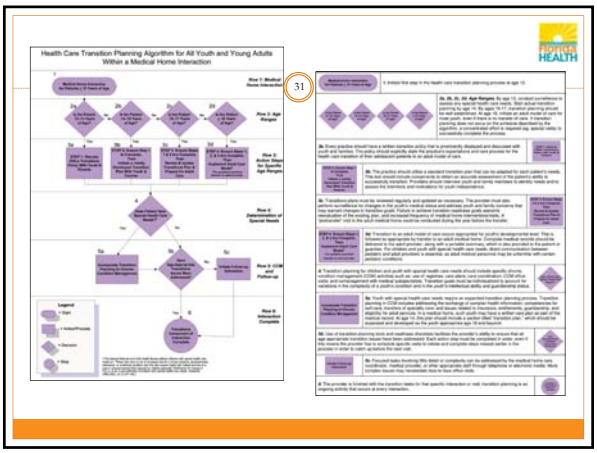
- Published in *Pediatrics,* July 2011
  - Joint report from AAP /AAFP/ACP
- Provides framework for developmentally appropriate transition services:
  - For ***all*** youth starting at ages 12-14
  - Enhanced planning activities for YSHCN
  - Move from pediatric to adult model of care at age 18, even if there is no transfer (e.g., Family Medicine, Med Peds practice)
  - Within context of a medical home



Six core elements of HCT

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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

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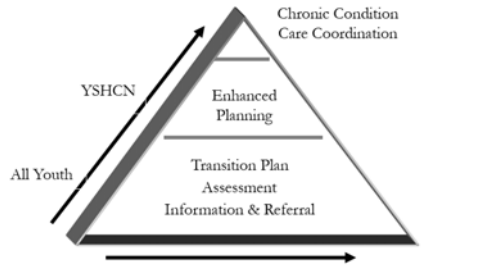

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How are we doing?

National survey of children with special health care needs

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- Parent Survey
  - 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

National survey of children with special health care needs

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- 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 that includes HCT measures
  - Combines National Survey of Children's Health and NS-CSHCN
  - First report due in 2017

Source: 2009-2010 National Survey of Children with Special Health Care Needs, http://childhealthdata.org

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HCT tools for Florida practitioners

FloridaHATS

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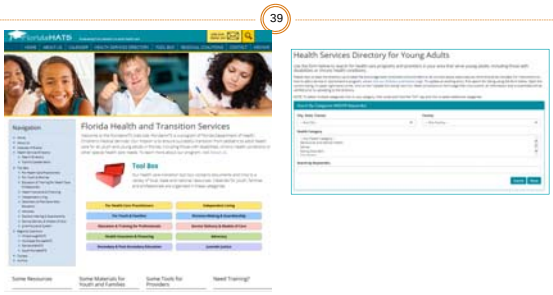
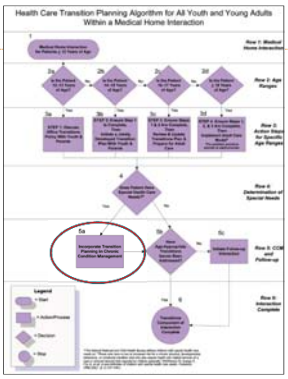


Florida's clearinghouse for HCT information
www.FloridaHATS.org



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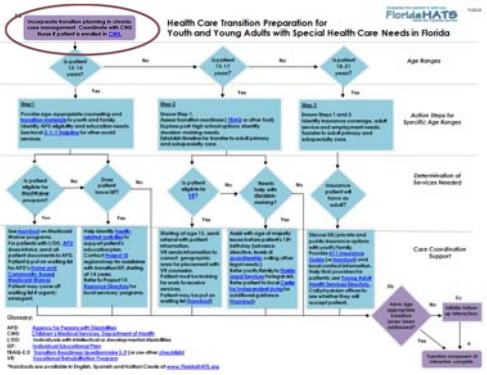

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Ages 12-14:
Agency for Persons with Disabilities

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- 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

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- 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.project 10.info) is Florida Department of Education's statewide transition initiative
  - Includes employment training, post-secondary education and independent living resources

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Classroom Curriculum

Parent/Student Handouts

Lesson Plans

Ages 12+: Self-advocacy guides

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www.floridahats.org/?page_id=616

Ages 12+: Self-management videos

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Short Videos
with step-by-step instructions

Ages 12+: Health summary

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Ages 15-17: VR

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

Ages 15-17: Sexual health

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- High incidence of sexual abuse among persons with intellectual and developmental disabilities
  - 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

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- Legal responsibilities
  - Financial
  - Decision-Making
  - Florida Bar's #JustAdulting Legal Survival Guide for new adults

    www.justadulting.com/
- Disability benefits determined by ability to work

By age 18: Decision-making

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https://youtu.be/CpvIyfiRjRM

By age 18: Decision-making

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- 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

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- Redetermination at age 18
- Stricter eligibility requirements

By age 18: Health insurance

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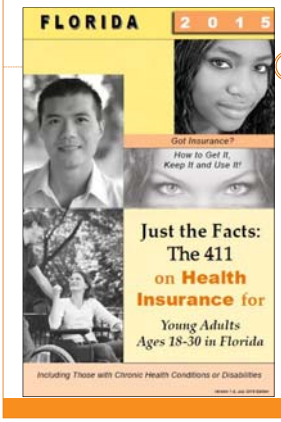
- Plan for change in insurance coverage
  - Medicaid
  - Parents' plan
  - Employer-based
  - Marketplace plans



Ages 18-21: Transfer of care

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- Transfer of care
  - Primary Care
  - Specialty Care

Other transition resources

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- 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

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How you can support transitioning adolescents and young adults

HCT training for health care professionals

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- 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

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- 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

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- 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

Summing it up

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Contact

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