Preparing Teens for Transition to Adult Health Care

10 STEPS TO SUCCESSFUL HEALTH CARE TRANSITION

November 2, 2019
Agenda

• What is health care transition (HCT)?
• Why is health care transition important?
• What steps can you take to ensure successful transition?
• How can Children’s Medical Services and FloridaHATS help youth and young adults transition successfully?
What is Health Care Transition?

Health Care Transition (HCT)

The purposeful, planned movement of adolescents and young adults, with and without special health care needs, 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

A discrete event.
Discharge from pediatrics and enrollment with an adult-oriented provider; Should occur between ages 18-21+

Successful Transition

Patients are engaged in and receive ongoing patient-centered adult care.
Why is Health Care Transition Important?

“A poor transition in health care can threaten health and undermine other transitions, for example in education, work, social relationships, and independent living.”

Institute of Medicine, 2007
Why is Health Care Transition Important?

• Without adequate support in moving from pediatric health care to adult care, youth and young adults may:
  • Experience loss/gaps in your health insurance
  • Have poor connections to the adult health care system
  • Lose support with medications and self-care regimens
  • Have increased ER visits & hospitalizations
  • Experience short term decline in health and poor 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.
Goals for a Successful Transition
Goals for Transition

- Be in charge of your own health
  - Medical decision-making
  - Disease self-management
  - Prevention, substance use, safety, sexuality
- Appropriately access adult primary care, specialists, therapies, equipment, supplies, etc.
- Have adequate and continuous health insurance
- Implement education and vocational goals

10 Steps to Successful Health Care Transition

1. Start early
2. Focus on responsibility for health care
3. Create a health summary
4. Create a health care transition plan
5. Maintain wellness
6. Integrate health care transition activities into the school setting
7. Know options for health insurance and public assistance programs
8. Find adult oriented providers
9. Learn about community services and supports
10. Include health in other areas of transition (school, work, independent living)
Step 1: Start Early

- Begin preparing for transition when 12 years old (or younger).
  - Assess your current knowledge of your health condition, your ability to use health care services and resources to manage your condition, and your ability to manage daily activities.

Moving from Dependent to Independent to Interdependent

Don’t know – know how?
Know you should learn more/learn how?
Are learning more/learning how?
Knowledgeable/skilled at doing?
Know when to ask questions – ask for help?
Taking responsibility for health care should be based on age and abilities. Step-by-step you can become more independent by learning important skills like talking to your doctor, asking questions, scheduling appointments, arranging transportation, filling prescriptions, and taking your medication on your own.
Self-Management Guides

SINCE YOU’RE NOT A KID ANYMORE

IT'S TIME TO BE MORE IN CHARGE OF YOUR HEALTH

Visit FloridaHATS.org

Health Care Transition Guide for Teens in Middle School

Now that you’re in High School...

IT’S TIME TO BE MORE IN CHARGE OF YOUR HEALTH

Visit FloridaHATS.org

Health Care Transition Guide for Teens in High School

When You’re 18

YOU ARE IN CHARGE OF YOUR HEALTH

Visit FloridaHATS.org

Health Care Transition Guide for Young Adults

For Youth & Families: FloridaHATS Information Guides
Self-Management Videos

Short videos with step-by-step instructions

For Youth & Families: FloridaHATS Information Guides
Self Management Smartphone Apps

Medisafe

MedCoach

Healthy Transition

carezone
Step 3: Create a Health Summary

Put important information about personal health in one place, including medications and plans for emergencies.
Medical Summary/Emergency Care Plan

Sample Medical Summary and Emergency Care Plan
Six Core Elements of Health Care Transition 2.0

This document should be shared with and carried by youth and families/caregivers.

Date Completed: [__] Date Accessed: [__]”

Health Care Transition Summary

Name: [__]
Address: [__]
DOB: [__]
SS#: [__]

Emergency Contact: [__]
Relationship: [__]
Phone: [__]
Guardian/Health Surrogate: [__]
Relationship: [__]
Phone: [__]

Unique Communication/Cultural Needs:

Strengths/Assets:

Assistive Technology:

Primary Insurance: [__]
Policy #: [__]
Case Manager: [__]
Phone: [__]

Secondary Insurance: [__]
Policy #: [__]
Case Manager: [__]
Phone: [__]

Allergies (meds & food): [__]

Medications:

Diagnosis and Current Problems:

Program:

Primary Diagnoses:

Secondary Diagnoses:

Behavioral:

Communication:

Nutrition:

Sleep:

Orthopedic/Musculoskeletal:

Physical Activity:

Respiratory:

Sensory:

Genitourinary:

Other:

Details and Recommendations:

Current Medications:

Current Treatments:

Frequency:

Provider:

Contact Information:

My Health Passport

If you are a health care professional who will be helping me, PLEASE READ THIS

before you try to 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)
Step 4: Create a Health Care Transition Plan

Work with your current health care team (e.g., primary care provider, specialists, nurse care coordinator, social worker) to develop a written transition plan that includes your future roles and responsibilities, services that will be needed, who will provide the services and how will the services be paid for.
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 transition 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?

<table>
<thead>
<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>
</tr>
</thead>
</table>

Initial Date of Plan: ______________ Last Updated: ______________ Parent/Caregiver Signature: ______________

Clinician Signature: ______________ Care Staff Contact: ______________ Care Staff Phone: ______________

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Step 5: Maintain Wellness

Establish healthy habits that will continue into your adulthood. Learn about and talk with adults you trust and your health care providers about risky behaviors, such as alcohol use, smoking, and sex and about building healthy relationships.

\textit{Remember: Youth should spend time alone with their doctor at every office visit.}
Resources

Coach.me Mobile App

Checkmark Goals Mobile App
Step 6: Integrate HCT Activities at School

- Include HCT readiness, goals, and activities in your other future planning activities:
  - IEP (Individualized Education Program; specialized instruction & services)
  - 504 Plan (accommodations)

- HCT Resources for Educators
  - FloridaHATS
  - CPALMS: My Health Care
Transition IEP factors

- Understanding own needs and required accommodations
- Medication, medical supplies, and equipment
- Volunteer experiences and recreational activities to develop work and social skills
- Self-determination, self-advocacy
- Health care management skills, self-care, and knowledge of health insurance
- Many more factors to consider
Step 7: Know Health Insurance & Public Assistance Options

**Health Insurance**
- Types of insurance plans
- Eligibility requirements
- Financial requirements

**Public Assistance**
- Financial
- Work
- Housing
- Medical (equipment, respite care, home health)
Health Insurance

- Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
Health Insurance After Age 18

- 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
School to Work Transition Vocational Rehabilitation

Most teens and young adults look forward to having a job and being independent. For young Floridians with disabilities, whose goals include employment, the Florida Department of Education’s Division of Vocational Rehabilitation (VR) can provide critical support services. This federal-state program works with people who have physical or mental disabilities to prepare for, gain, and/or retain employment.

Transition planning for individuals whose health conditions interfere with their ability to work should address eligibility for an array of VR programs, including the School to Work Transition program. The School to Work Transition program specifically helps students ages 16-22 prepare for employment and adult life. VR transition activities can help students enter training, continue education, and/or find a job after leaving high school.

Any student with a disability may be eligible for VR services if the student receives special education services, is enrolled in a public secondary school, has been in school for at least one year, and is 16 or older. VR services may also be provided to students who are not enrolled in a public secondary school but who are enrolled at an institution of higher education and who are between the ages of 16 and 21. VR services may be provided to students who are not enrolled in a public secondary school or institution of higher education but who are 16 or older and who are engaged in a self-employment activity or an activity that is related to their vocational interest, and who are working part-time in such an activity or that is related to their vocational interest, and who are working part-time in such an activity.

Students who may benefit from VR services should apply at least 6 months before graduation from high school. VR services may be provided to students who are not enrolled in a public secondary school or institution of higher education but who are 16 or older and who are engaged in a self-employment activity or an activity that is related to their vocational interest, and who are working part-time in such an activity. VR referrals can be made by anyone by contacting the local VR office or by calling 1-800-342-5663.

Home and Community-Based Living Medicaid Waivers

Home and Community-Based Services (HCBS) Waivers are Medicaid programs that provide services in the home for persons who would otherwise require institutional care in a hospital or nursing facility. Without waiver services being delivered in the community, some adolescents and young adults might not be able to live at home or receive needed supports in the workplace.

Waivers provide specific services to and above those in the general Medicaid adult benefits package and are targeted to persons who demonstrate the need for a high level of care. Enrollment is typically capped; once enrollment reaches a specified number or dollar threshold, waiting lists are created.

As of December, there were currently 16 HCBS waivers in Florida. The largest one is for individuals with developmental disabilities ages 3 and older, administered by the Agency for Persons with Disabilities (APD). APD offers a broad range of supports and services to assist persons with developmental disabilities, defined in Florida as those who have autism, cerebral palsy, Down syndrome, intellectual disabilities, Prader-Willi syndrome or certain familial forms of spina bifida. Services may include personal care assistance, companion services, transportation, therapy, behavioral support, skilled nursing, durable medical equipment, and supported employment services. All services are subject to eligibility, and are provided to individuals when needed.

For more information about the program and applying for services, visit the APD website at http://medicaid.apd.state.fl.us/ and call the APD Help Line at 1-800-335-4494.

Health care professionals can help assure that young people with disabilities, especially those with developmental disabilities, and their families are aware of Medicaid waiver programs as potential sources of services and supports, and provide requested documentation, as needed. Due to long waiting lists, it is important for families to apply early, even before services might be needed.

For full list of waiver programs and descriptions, see Florida Medicaid Summary of Services at http://medicaid choisefl.org/Medicaid/Providers/2012-2013-Summary-of-Services.html.

For more information about this topic, contact Janet Hess or jhess@health.state.fl.us or (813) 259-4604.

Supplemental Security Income: What Happens to My SSI When I Turn 18?

Tip Sheet 3

Transition 2 Go

April 2011

Can I keep my SSI?

Yes, you can work.

For every $2 you earn, Social Security will deduct $1 from your SSI check.

If you earn enough so that there is no money left to deduct from your SSI check, you may still be able to keep your Medicaid (depending on how much you earn).

Yes, Social Security has other ways to help you keep more of your SSI check if you are earning money.

If you are under age 18 and regularly attending school, Social Security will count up to $4,000 in earnings before deducting from your SSI check.

Social Security will let you save money for college or training, a computer, and other expenses by helping you write a plan to achieve self-support (PASS Plan).

There are other deductions and programs to help you, too.

Appeal your case

You may continue getting your SSI check if:

- Social Security has approved your participation in a vocational rehabilitation or similar program.
- You have told Social Security that you are currently participating in an individualized education program (IEP)

You must participate in these programs before Social Security turns you down, and at least 2 months afterwards.

For help, contact the Work Incentives Planning and Assistance (WIPA) Program in your state. The contact information can be found on the Social Security website by clicking on the Provider Directory link at http://secure.ssa.gov/apps11/osp/providers.aspx?state=FL.

Visit us online at http://sbhr.unmc.edu/transition/RTC

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Florida Department of Education, Division of Vocational Rehabilitation

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Employment

Apply to Division of Vocational Rehabilitation 2 years before leaving high school
Step 8: Find Adult Providers

If still in the care of pediatric providers, identify a primary care physician and specialist who provide care for adults.
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
Emotional

Search by Keyword(s)
Step 9: Learn about Community Services & Support for Adults with Special Needs and Abilities

- Be knowledgeable about your rights and responsibilities at age 18.
- Discuss guardianship and decision-making options, as needed.
- Join community support groups.
Decision-Making

- Consider options, such as power of attorney (POA), supported decision-making guardianship, guardian advocacy

- Explore long-term financial planning strategies, such as a special needs trust
Step 10: Include Health in Other Areas of Transition

Ask your primary care physician to provide documentation of your medical conditions and health care needs for other programs and agencies.
How to get Involved in Your Community

HillsboroughHATS
Visit FloridaHATS.org

Health Services Directory for Young Adults
Search for services and programs by community, county, key word or type of service.

For additional information and assistance with resources in Hillsborough County that support transition from pediatric to adult health care, please contact:

Joane White, Family Support Worker
Children’s Medical Services
(813) 396-9772
joane.white@flhealth.gov

www.floridahats.org/hillsborough-hats/
Florida’s clearinghouse for HCT information

www.FloridaHATS.org
National Center for Health Care Transition Improvement

http://www.gottransition.org/
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