Health Literacy, Communication, & Self-Management:

Critical Pathways to Adulthood
Presenter

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...What and Why?
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Success in school, at work, & in the community requires that you stay healthy!

- The best ways to stay healthy are to
  - understand your own health
  - receive age-appropriate health services
  - participate in health care decision-making
Health Care Transition

Health Care Transition (HCT)
The purposeful, planned movement of adolescents and young adults 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.
After turning age 18:

- Doctors and other health care providers must:
  - Get informed consent from adult patients to carry out a medical procedure
  - Have the patient’s written permission to share health information with others

- BUT…. Patients can ask family members or friends to help answer questions and fill out forms
Adult patients should be able to:

- Name chronic medical conditions or allergies
- Know the correct names of medications, when to take them, and why
- Take medications independently
- Order medications when needed
- Call to make doctor appointments
- Know what to do in case of an emergency
- Know what to do to stay healthy, and do it without being reminded

If teens can’t do these things, they need to learn!
How are we doing?

MCHB Core Outcome #6: CSHCN age 12-17 years who receive services needed for transition to adult health care, work and independence

CSHCN age 12-17 years only

Nationwide

2009-2010 National Survey of Children with Special Health Care Needs
Pediatric vs Adult Care

- 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

- Between adult provider and youth

- Among providers

- Pediatric knowledge of adult system physicians, resources and services

- Lack of systematic transfer of records and co-management of care during transition
Adult System of Care

- Provider capacity and training

- Lack of adult physicians who are
  - Trained in pediatric onset/developmental 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 (state Title V, SCHIP) at age 19 or 21
  - ACA: Can stay on parents’ family plans up to age 26

- 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
HCT Improvement Programs

- Got Transition/ National Center for Health Care Transition Improvement
  - Website, webinars, resources
  - Clinical Practice Learning Collaboratives

- Medical and Nursing Education

- FloridaHATS
  - State strategic plan for HCT
  - Clearinghouse of HCT information for consumers, educators, and providers
  - Regional coalitions
  - Health Service Directory for Young Adults
What YOU can do: Take charge of your health care!

- Use the GLADD approach when talking to doctors or nurses and in managing health care:
  - **G**ive information
  - **L**isten and learn
  - **A**sk questions
  - **D**ecide on a plan
  - **D**o your part

- Teach your child how to use GLADD!
Give Information
Communicate how you are feeling

- Be HONEST in giving complete, detailed information
- Describe how your condition affects your every day life
- Describe symptoms
  - Handy High 5: Who, what, when, where, why
  - Keep a medical diary
- Use visual aids if needed
  - Pain Scales
  - Health Pictures, Communication Boards
Tools to Assist

PAIN MEASUREMENT SCALE

0
No Hurt

2
Hurts Little Bit

4
Hurts Little More

6
Hurts Even More

8
Hurts Whole Lot

10
Hurts Worst

No Pain
Mild
Moderate
Severe
Worst Pain Imaginable
Tools to Assist
GLADD

Listen and Learn
Practice good listening skills

- Listening includes UNDERSTANDING

- Pay attention to body language

  **SLANT**

  - Sit up
  - Lean in
  - Ask questions
  - Nod
  - Track the speaker
Remember what is said

- Write down information
  - Take notes in a health diary
- Use a voice recorder to enhance information recall and understanding
  - Free iphone recording apps
  - Always ask for permission before recording
  - Practice before you go to the doctor’s office
Learn more about your condition

- Read books

- Explore the Internet
  - Ask your doctor/nurse for recommended web sites

- Considerations for your job
  - Environment
  - Special dietary or medication needs
  - Accessibility
  - Stamina and strength issues

- Talk to people who have the same or a similar condition
GLADD

Ask Questions
Prepare questions ahead of time

- Be prepared with questions and issues to discuss at office visits
  - Write questions on paper
  - Record them on a voice recorder
- If you don’t understand what you’re being told:
  - Let your doctor/nurse know
  - Ask them to explain in a different way
  - Ask for written instructions or materials to take home
  - Keep asking until you understand
- There’s no such thing as a DUMB question!
Tools to Assist

Ask Me 3

Ask Your Doctor, Nurse, or Pharmacist:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Good Questions for Your Good Health

AHRQ Question Builder
HillsboroughHATS Post Card

ASK THEM 3!
All teens and their families should ask their pediatric doctors these 3 questions:

1. When should I/my child transfer to adult primary and specialty care physicians?
2. Who should I/my child go to for adult primary and specialty care?
3. Will you help with the transfer of care by communicating my/my child’s needs and providing a transfer summary?

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@doh.state.fl.us
Decide on a Plan of Care
Participate in developing a plan of care

- With your doctor or nurse, decide:
  - What medical services will be needed
  - Who will provide them
  - How will they be paid for

- With your health care team and circle of support, set longer term goals for health, education, work and independent living

- Explore community resources that can help you reach your goals
  - Your doctor may need to provide documentation of medical condition/disability to meet program eligibility guidelines
Tools to Assist

FloridaHATS Information Guides

- FloridaHATS Brochure (English) (Spanish) (Haitian Creole)
- 10 Steps to Successful Health Care Transition (English/Spanish) (English/Haitian Creole)
- Algorithm for YSHCN in Florida (decision-making tree for preparation for transition to an adult model of care)

From the Institute for Child Health Policy at the University of Florida:

- Since You’re Not a Kid Anymore (English) (Spanish)
- Now That You’re in High School (English) (Spanish)
- When You’re 18 (English) (Spanish)
- Envisioning My Future (English) (Spanish)

Transition Toolkit

An easy-to-use, interactive Transition Toolkit for physicians, families and youth, case managers, and teachers. Through a series of questions, the toolkit helps you determine which resources may be most useful (depending on your role) to support the transition process. Developed by the JacksonvilleHATS Coalition, the Toolkit incorporates instruments and resources that have been adapted for Floridians but can be used by anyone. Get started here!

Transition 2 Go

A series of informational briefs with transition-related tips and resources for consumers and health care providers in Florida:

- T2G: Health Insurance (English) (Spanish) (Haitian Creole)
- T2G: Employment (English) (Spanish) (Haitian Creole)
- T2G: Medicaid Waiver Programs (English) (Spanish) (Haitian Creole)
- T2G: Guardianship (English) (Spanish) (Haitian Creole)

Skill-Building Curricula and Videos

- Health Care Self-Management videos from Jacksonville and Healthy Transitions (short vignettes with step-by-step instructions for scheduling medical appointments, arranging for transportation, accessing medications, and more)
Service Directory

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.

Related Service Directories in Florida:
- Project 10’s Florida District Resource Directory
- Florida Community Health Centers
- Agency for Persons with Disabilities Resource Directory
- Family Network on Disabilities
- Mental Health Access Line/CLEAR
- Healthy Athletes Resource Directory
- Find-a-Ride Florida Resource Directory
- CMS Provider Search
- 2-1-1 Helplines in Florida
- WeaveProvider.com
- Where To Find Help in Florida
- Adult Primary Care Providers in Hillsborough County

Search By: Categories AND/OR Keyword(s)

City, State, County: [Any City]
County: [Any County]

Health Category:
- Behavioral and Mental Health
- Dental
- Eating Disorders

Search by Keyword(s):

[Submit Query] [Reset]
Information Guides

- Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
APD/ iBudget

Transition 2 Go in Florida

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 over 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. Enrolment is typically capped; once enrolment reaches a specified number or dollar threshold, waiting lists are created. The waiting lists for Florida Medicaid Waivers are often years.

There are currently 15 HCBS waivers in Florida. The largest one is for individuals with developmental disabilities ages 3 and older. Medicaid 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 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 require determination of medical necessity. For more information about the program and applying for services at one of APD’s 14 area offices, visit http://adpcareinfo.org. Families should also visit the Florida Family Care Council website at www.fccflorida.org.

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 a potential source of services and supports, and provide required 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://ahca.myflorida.com/Medicaid/HCBS/2012-2013-Summary-of-Services-final-121031.pdf.

For more information about this topic, contact Janet Hess at jhess@health.usf.edu or (813) 259-8604.

Issue no: 3 December 2012

Transition 2 Go

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 program 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 starting at age 16. For students who receive special education services, schools often take the lead in referral to VR as part of the student’s transition Individualized Education Plan (IEP). However, having an IEP is not a VR eligibility requirement. Health care professionals can help assure that all young people with disabilities and their families are aware of VR as a potential source of services and supports, and facilitate access by making referrals as needed.

Students who may benefit from VR services should apply at least 2 years before leaving high school, e.g., apply at age 16 if leaving high school at age 18. VR can also assist students with community work experience while they are still in high school.

Applications can be downloaded at http://rehabworks.org/docs/vr/VRApplication.pdf.

VR referrals can be made by anyone by contacting the local VR office at www.rehabworks.org (click on VR Office Directory). To learn more about the School to Work Transition program, visit www.rehabworks.org/docs/SchoolsToWork.pdf.

For more information about this topic, contact Janet Hess at jhess@health.usf.edu or (813) 259-8604.

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Vocational Rehabilitation
Guardianship and Other Decision-Making Alternatives

Reaching the age of majority – 18 years old in Florida – means an individual is no longer a “minor.” As such, the person has the right and responsibility to make certain legal decisions that adults make. For some young adults with intellectual disabilities, this may be an exciting opportunity for increased independence. But there may also be family concerns about how to best support that person’s self-determination in making life decisions such as for health care or financial management.

Many parents and caregivers are surprised to learn that when their child turns 18, they may not be able to direct or participate in their child’s medical treatment, except as a proxy during an emergency. Further, banks and government agencies have neither the duty nor the authority to discuss an 18 year old’s benefits or financial issues with parents. Families often ignore the problem, fearing the expense or complexity of court, and carry on with only minor difficulty until confronted by an emergency. But when an emergency finally occurs, their fears of expense and complication may be realized.

There are several levels of healthcare and financial decision-making assistance available to Floridians, ranging from informal “shared” responsibilities with a trusted friend or family member, to health care surrogacy, durable power of attorney or guardianship. State law requires, whenever possible, the use of the least restrictive alternative to protect persons incapable of fully caring for themselves or managing their affairs. Some families may find that “guardian advocacy” is a good option for individuals with an intellectual or developmental disability. This process delegates rights of the individual to another person (such as a parent) without declaring them incapacitated (see www.centreforguardianadvocacy.com). For a full list of options for people with ID/DD, visit www.lcflorida.org/adevalis/guardian/a_main.htm.

Certainly, cost for legal services – which can exceed $3,000 for guardianship – is a concern for most families. However, income-eligible consumers may qualify for pro bono or reduced-fee services through Florida Legal Services, a statewide network of organizations that provides legal assistance based on need (http://floridalegalhelp.org). The Center for Guardian Advocacy also offers a sliding fee scale. The Florida Bar operates a lawyer referral service at www.floridabar.org.

Families should plan to address decision-making alternatives prior to their child’s 18th birthday. After age 18, the process becomes more complex and, often, more expensive.

For more information about this topic, visit the Tool Box at www.FloridaHATS.com or contact Janet Haas at thess@health.wust.edu, (813) 259-8604.

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Transition Toolkit

Youth and Caregiver

Transition Toolkit

These tools and resources will be most helpful for youth transitioning from pediatric to adult health care. Many changes are happening all at once and these resources will help you make appropriate decisions when it comes to your health care.

- SSI Information
  - Information about changes to SSI when someone turns 18.
  - SSI Tip Sheet (PDF)
  - Apply for SSI

- Health Care Provider
  - Jacksonville AHEC is a local resource in NE Florida, a health and transition clinic for youth with special health care needs in transition.
  - FloridaHATS
    - A clearinghouse for information and resources regarding health care transition across the state. FloridaHATS is a collaborative program of the Florida Department of Health, Children’s Medical Services Network, Florida Developmental Disabilities Council, and other partners throughout the state.

- Guardianship Information
  - Powers of Attorney explained (PDF)
  - Find out the Guardianship options (PDF)
  - (Right to Decide) Health Care Advanced Directives

- Self-Advocacy
  - Know how to advocate for yourself and your health care needs.
  - Find the caption in you... watch this informative and empowering video as two teens explore what Self-Advocacy really means.
  - Advocating for Yourself in Middle School and High School (PDF)
  - GLADD Tool
    - Learn about the GLADD approach to talking with health care professionals.

- Dental
  - Medicaid only covers some dental services up until the age of 21. After 21, you may apply for insurance through an exchange. Individual dental plans start as low as $10.00/month. Just be sure to check out the network and be aware of the services needed and services covered in NE Florida.
  - UF Health Tadache Dental Clinic provides dental services to adults with developmental disabilities.

- Health Insurance
  - Know what your insurance covers, when it may expire, and how to apply for coverage.
  - Medicaid
Practice negotiating skills

- It is important to provide feedback to the physician about your treatment plan
  - Can you follow the plan? If not, why not?
  - Are there alternative treatment options?

- Tips for negotiating
  - Know what you want and why
  - Plan what you will say
  - Be truthful
  - Be assertive
Self-Advocacy Guides

Health Care Transition Guide for Teens in Middle School

Health Care Transition Guide for Teens in High School

When You’re 18

Health Care Transition Guide for Young Adults
GLADD

Do Your Part
Carry a health summary with you

- Put personal health information in one place and keep it updated
  - Medical history and medications
  - Equipment and supply needs
  - Physician, hospital, emergency contacts
  - Health insurance

- Be able to access it easily
  - Paper copy
  - Thumb drive
  - Electronic Patient Portal
Tools to Assist

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: ______________________

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: __________________________ 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 medical history: Include other conditions (e.g. vision impairment, hearing impairment, diabetes, epilepsy, post operative, illnesses, and other medical issues)

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, IV’s, physical examinations, X-rays, oxygen therapy—also note procedures never experienced before or in recent years)

I am allergic to the following:

If I am in pain, I know it right away (please put in box)

My mobility needs are:

My favorite foods and drinks are:

When drinking, you may assist me by:

I do not like to eat or drink the following:

I am very sensitive to (list specific: light, sound, sharp objects, etc.) that may cause me discomfort (e.g. fluorescent light, automobiles, bleach, or treatment)

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

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

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I like to do this to help pass the time:

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

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

I like to do this to help pass the time:
Learn how to schedule and navigate doctor’s visits

- Practice scheduling your doctor’s appointment
- Arrange for transportation
- Fill out paperwork at the doctor’s office
  - Medical history
  - Insurance
  - Consent to Treat
  - HIPAA Privacy form
- Ask questions if you don’t understand, and don’t be afraid to ask for help!
Tools to Assist

Short Videos with step-by-step instructions
Manage your medications

- Learn the correct names of your medicines, when you take them, and why
- Be able to read prescription labels
- Be able to refill your prescriptions
- Bring a list of your medications to doctor visits
- Keep a chart with times you need to take medicine and dosage
- If you take several medications, a pill organizer can help
Tools to Assist

Using MyMedSchedule.com

This video will demonstrate how you can use MyMedSchedule.com, an electronic reminder tool that can help you manage your medication regimen.

View Video
Resource Handout

- FloridaHATS, [www.floridahats.org](http://www.floridahats.org)
- Health Care Transitions, [http://hctransitions.ichp.ufl.edu](http://hctransitions.ichp.ufl.edu)
- JaxHATS Clinic, [http://hscj.ufl.edu/jaxhats](http://hscj.ufl.edu/jaxhats)
- Healthy Transitions, [www.healthytransitionsny.org](http://www.healthytransitionsny.org)
- Ask Me 3, [www.npsf.org/for-healthcare-professionals/programs/ask-me-3](http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3)
- AHRQ Question Builder, [www.ahrq.gov/legacy/questions/qb](http://www.ahrq.gov/legacy/questions/qb)
- My Health Passport, [http://flfcic.fmhi.usf.edu/program-areas/health.html](http://flfcic.fmhi.usf.edu/program-areas/health.html)
- MyMedSchedule.com, [www.mymedschedule.com](http://www.mymedschedule.com)
Initiatives: Health Literacy, Communications, and Self-Management
My Health Care

- A health literacy and communications training program sponsored by FDDC

- 22-hour curriculum
  - Designed for classroom of learners
  - PPT presentations with imbedded videos
  - Interactive role play, modeling, games
  - Implement in 2-3 hour blocks over 9 weeks
  - Step-by-step Instructor’s Guide and accompanying video

- Available online in 2015
Hillsborough HATS

- Regional HCT coalition of providers, youth and families

- Local action plan to improve HCT
  - Outreach, education and advocacy

- Visit [www.floridahats.org](http://www.floridahats.org), go to Regional Coalitions

- Next meeting:
  - Tuesday, November 18
  - 8:30 AM
  - St. Joseph’s Hospital, Command Center
Take Charge Now!

**Give – Listen – Ask – Decide – Do**

1. Communicate how you are feeling (Handy High 5)
2. Practice good listening skills (SLANT)
3. Remember what your doctors/nurses say (use a voice recorder!)
4. Learn more about your condition (books, web site)
5. Prepare questions ahead of time (Ask Me 3)
6. Participate in developing a plan of care (FloridaHATS resources)
7. Practice negotiating skills (self-advocacy guides)
8. Carry a health summary with you (My Health Passport)
9. Learn how to schedule and navigate doctor’s visits (watch videos and practice!)
10. Manage your medications (MyMedSchedule.com)
Contacts

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