Health Literacy, Communication, & Self-Management

Critical Pathways to Adulthood
Presenter

- Janet Hess, DrPH, MPH
  Assistant Professor
  Project Director, FloridaHATS
  University of South Florida College of Medicine
  Department of Pediatrics, Adolescent Medicine
  jhess@health.usf.edu, (813) 259-8604
Acknowledgments

- John Reiss, PhD, University of Florida
- Pat Slaski, Educational Consultant
- Laurie James, Educational Consultant
- Randy Miller, Educational Media Specialist
- Florida Department of Health, Children’s Medical Services
- Florida Developmental Disabilities Council, Inc.
Agenda

- What is Health Care Transition?

- Using the GLADD Approach

- Tools to Assist
Health Care Transition
...What and Why?
JA Transition Toolkit

Your future is on its way.
www.janstoolbox.org

Young people with rheumatic diseases have to take on new responsibilities as they enter the world of adult medical care. The Arthritis Foundation Transition Toolkit is designed to help you and your families develop the skills they need to successfully make the leap to independence. Take a health care skills assessment and create a customized Transition Toolkit that meets YOUR needs. Or check the resource library to learn more about: communicating with your doctors, organizing your health care, going to college with arthritis, managing stress, eating well, and much more!

Create your transition toolkit at www.JAtransition.org.

Build Your Toolkit

What skills do you want to work on today?

- College Tips for Young Adults with Juvenile Arthritis
- Communicating with my doctors
- Making appointments
- Finding and Using Adult Health Care
- Managing health insurance
- Managing health information
- Planning your future: school and work
- Nutrition and Arthritis
- Rheumatic Diseases and Planning for College
- Refilling prescriptions
- Taking medications
- Understanding Lab Tests
- Working with Arthritis
- What is Juvenile Idiopathic Arthritis (JIA)?
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 (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:
  - Give information
  - Listen and learn
  - Ask questions
  - Decide on a plan
  - Do your part

- Teach your child how to use GLADD!
Give Information

GLADD
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

Picture Communication Aid

Ask me questions if you need to, but please wait patiently for my replies.

I will point to where I hurt.
GLADD

Listen and Learn
Practice good listening skills

- Listening includes UNDERSTANDING

- Pay attention to body language

- **S**it up
- **L**ean in
- **A**sk questions
- **N**od
- **T**rack 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

Doctor, what you say during our visit is very important to me. Recording this visit would be helpful with remembering what you tell me, and what to do. May I have your permission to record this session?
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?

Ask Me 3

Good Questions for Your Good Health

AHRQ Question Builder

Questions Are the Answer

Step 1: Choose the kind of appointment you need

- To talk about a health problem
- To get or change a medicine
- To get medical tests
- To talk about surgery

Next >>
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?

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
JA Transition Toolkit & Resource Library

- Communicating with friends and families about your disease
- Communicating with your Doctor and Scheduling Appointments
- Depression and Anxiety
- Finding an Adult Rheumatologist
- Getting a Job
- Getting Organized and Creating a Health Summary
- Going to College
- Health Insurance
- Juvenile Dermatomyositis
- Juvenile Idiopathic Arthritis
- Juvenile Scleroderma
- Lupus
- Managing Stress
- Medications
- Mixed Connective Tissue Disease
- Nutrition
- Other Rheumatic Diseases
- Preparing for Transition: Videos
- Reproductive Health
- Scholarships
- Transition Overviews and Guides
- Transition Tools and Checklists
- Vasculitis
Got Transition

Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

**Health Care Providers**
Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.

**Youth & Families**
Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.

**Researchers & Policymakers**
Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.
FloridaHATS Tool Box & Service Directory

Health Services Directory for Young Adults

Use the form below to search for health care programs and providers that are specifically tailored to meeting the needs of 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 130’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-Wide Florida Resource Directory
- ONS Provider Search
- 2-1-1 Helplines in Florida
- WaiverProvider.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
School Resources

What’s HEALTH Got To Do with TRANSITION? CURRICULUM

Moving from Pediatric to Adult Health Care

Scheduling an appointment
- Scheduling a Medical Appointment
- Scheduling Transportation
- Paperwork at the Sign In Desk
- Is the doctor’s office accessible?

Getting health insurance
- Are Therapies Covered?
- Beware of Timetables.
- Insurance Options Before Age 18.

School Resources
- Classroom Curriculum
- Links to Lesson Plans
- Parent/Student Handouts
Medicaid Waiver Programs

Vocational Rehabilitation

Transition 2 Go

in Florida

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 services 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 ensure 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/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.unf.edu or (813) 259-8604
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 choices 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 in 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 fear 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 several rights of the individual to another person (such as a parent) without declaring them incapacitated (see www.centerforguardianadvocacy.com). For a full list of options for people with ID/DD, visit www.fccflorida.org/devdss/guardian/qa_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 uses 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 Hess at jjness@health.ufl.edu, (813) 259-8604.

Issue no. 4
December 2012

Supplemental Security Income

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

- The answer is – it depends, you need to re-apply
- Social Security will review your case
- Since you are not a child anymore, you will need medical evidence to prove that you are disabled as an adult
- Yes, you can work:
- For every $2 you earn, Social Security will deduct about $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 22, and regularly attending school, Social Security won’t count up to $3500 of earnings before deducting from your benefit check
- Social Security will let you save money for college or training, or 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 of 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 Program or your state. The contact information can be found on the Social Security website by clicking on the Service Provider Directory link at https://secure.ssa.gov/appsl/coe/appsl/providers.nsf/ByState.

Visit us online at http://labs.umassmed.edu/transitionsRTC/
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

Now that you’re in High School...

Health Care Transition Guide for Teens in High School

When You’re 18

Health Care Transition Guide for Young Adults
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
Tools to Assist

My Health Passport

If you are a health care professional that 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)

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—also note procedures never experienced before or in recent years)

I am allergic to the following:

If I am in pain, I know it by:

My mobility needs are:

When drinking, you may assist me by:

My favorite foods and drink are:

I do not like to eat or drink the following:

My mobility needs are:

When I am in pain, I know it by:

My favorite foods and drink are:

I do not like to eat or drink the following:

I am very sensitive to: (e.g. spices, eggs, dairy, nuts, monosodium glutamate, etc.) that may cause allergic reactions.

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

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

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

For more information, please visit: https://www.uscedh.org/treatme.png
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

Free medication schedules, reminders, and NEW Health Tracker

Thousands of patients and caregivers use MyMedSchedule to manage meds and labs on the go, set reminders, and make it easier to communicate with their healthcare providers. Now MyMedSchedule includes My Health Tracker and lets you record all your lab results and vital signs.

Take the right dose at the right time
- Print schedules that are easy to create, read, and update
- Keep track of all your medications
- Bring your pill schedule to all your medical and dental appointments
- Print schedules in English or Spanish

My Health Tracker
- Keep a list of all your lab results and vital signs
- Graph results to track progress
- Set personal goals and compare them to your actual results

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

- Got Transition, [www.gottransition.org/youthfamilies](http://www.gottransition.org/youthfamilies)
- FloridaHATS, [www.floridahats.org](http://www.floridahats.org)
- 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)
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 (try 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 (lots of online resources!)
7. Practice negotiating skills (self-advocacy guides)
8. Carry a health summary with you (use a template)
9. Learn how to schedule and navigate doctor’s visits (watch videos and practice)
10. Manage your medications (MyMedSchedule.com)