Youth with Special Health Care Needs:
Transition from Pediatric to Adult Health Care

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Agenda

Background
How Are We Doing?
Current Policy
Tools and Resources
How Can You Help?
Background
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.

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

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 ongoing patient-centered adult care.
Changing Epidemiology of Childhood 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

24.4% of youth aged 12-17 have SHCN

What Can Happen?

• Without adequate support in moving from pediatric to adult care, youth may:
  
  o Loss/gaps in insurance
  o Have poor connections to the adult health care system
  o Have decreased adherence with medicine, self-care
  o Increased ER visits, hospitalizations
  o 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; Dugueperoux et 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>EARLY (11-13)</th>
<th>MIDDLE (14-16)</th>
<th>LATE (17-21)</th>
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<tbody>
<tr>
<td>Concrete thought</td>
<td>Abstraction Has future perspective; not always used</td>
<td>Established abstract thought Future oriented</td>
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<tr>
<td>No future perspective</td>
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The Adolescent Brain

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

## Culture Shock

### Professional culture and traditions

<table>
<thead>
<tr>
<th>Pediatricians</th>
<th>Adult Physicians</th>
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<tbody>
<tr>
<td>- Child-friendly</td>
<td>- Cognitive</td>
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<tr>
<td>- Family-centered</td>
<td>- Patient-centered</td>
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<tr>
<td>- Interact primarily with parents</td>
<td>- Interact with patient</td>
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<tr>
<td>- Nurturing</td>
<td>- Empower individual</td>
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<tr>
<td>- Prescription</td>
<td>- Collaborative</td>
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<tr>
<td>- Developmental Focus</td>
<td>- Disease Focus</td>
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</tbody>
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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 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
Discussion

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?
How Are We Doing?
2016 National Survey of Children’s Health

- Starting in 2016, survey administered annually
- Web-based survey among parents of children aged 0-17
- Includes HCT measures for all youth aged 12-17, with and without SHCN
- Questions about anticipatory guidance from provider:
  - Discussed changing health care needs in adulthood
  - Talked about transitioning to adult care
  - Talked to youth privately
  - Worked with youth to gain self-management skills

Performance

YSHCN

Received services necessary to make transitions to adult health care
Children with special health care needs age 12-17 years

Nationwide

Non-YSHCN

Received services necessary to make transitions to adult health care
Children without special health care needs age 12-17 years

Nationwide

Current Policy
Goals for Transition

• Manage their own health
  o Disease self-management
  o 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

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?  
   Yes: STEP 1: Discuss Office Transitions Policy With Youth & Parents  
   No: 2b

2b. Is the Patient 14–15 Years of Age?  
   Yes: STEP 2: Ensure Step 1 Is Complete, Then Initiate a Jointly Developed Transition Plan With Youth & Parents  
   No: 2c

2c. Is the Patient 16–17 Years of Age?  
   Yes: STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care  
   No: 2d

2d. Is the Patient ≥ 18 Years of Age?  
   Yes: STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model  
   No: End

3a. Yes:  
   3b. Yes: Does Patient Have Special Health Care Needs?  
      Yes: 5a
      No: End

3b. Yes:  
   3c. Yes: Incorporate Transition Planning in Chronic Condition Management  
   No: End

3d. Yes:  
   3d. Yes: Have Age-Appropriate Transitions Issues Been Addressed?  
      Yes: 5b
      No: 5c

5a. Incorporate Transition Planning in Chronic Condition Management  
5b. Have Age-Appropriate Transitions Issues Been Addressed?  
   Yes: 5d
   No: Initiate Follow-up Interaction

5c. Initiate Follow-up Interaction  

6. Transitions Component of Interaction Complete  

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

The federal Maternal and Child Health Bureau defines children with special healthcare needs as: “Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” (McPherson K, Aarons G, Fox K, et al. A new definition of children with special healthcare needs. Pediatrics. 1995;96(1):115–123)

End
National Center for Health Care Transition Improvement

http://www.gottransition.org/
Six Core Elements of HCT
For Primary and Specialty Care

1. Develop Transition Policy
2. Establish Tracking and Monitoring
3. Assess Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transfer Completion
## Six Core Elements of Health Care Transition

Listed in the table below are PDFs of the sample tools used in the Six Core Elements of Health Care Transition. Complete packages are available to download and customize for your practice or plan.

### Transferring Youth to Adult Health Care Providers
- **Pediatric, Family Medicine, and Med-Peds Providers**

<table>
<thead>
<tr>
<th>Complete Package</th>
<th>Transition Policy</th>
<th>Transition Tracking and Monitoring</th>
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<tbody>
<tr>
<td>Full Package</td>
<td></td>
<td>Individual Transition Flow Sheet</td>
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<tr>
<td>Editable Version</td>
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<td>Transition Registry</td>
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### Transitioning to an Adult Approach to Health Care Without Changing Providers
- **Family Medicine and Med-Peds Providers**

<table>
<thead>
<tr>
<th>Complete Package</th>
<th>Transition Policy</th>
<th>Transition Readiness</th>
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</thead>
<tbody>
<tr>
<td>Full Package</td>
<td></td>
<td>Transition Readiness Assessment for Youth</td>
</tr>
<tr>
<td>En Español</td>
<td></td>
<td>Transition Readiness Assessment for Parents/Caregivers</td>
</tr>
<tr>
<td>Editable Version</td>
<td></td>
<td>Welcome and Orientation of Young Adults</td>
</tr>
</tbody>
</table>

### Integrating Young Adults into Adult Health Care
- **Internal Medicine, Family Medicine, and Med-Peds Providers**

<table>
<thead>
<tr>
<th>Complete Package</th>
<th>Transition Policy</th>
<th>Transfer Care</th>
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<tbody>
<tr>
<td>Full Package</td>
<td></td>
<td>Health Care Transition Feedback Survey for Youth/Young Adults</td>
</tr>
<tr>
<td>En Español</td>
<td></td>
<td>Health Care Transition Feedback Survey for Parents/Caregivers</td>
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<tr>
<td>Editable Version</td>
<td></td>
<td>Health Care Transition Feedback Survey for Youth/Young Adults</td>
</tr>
</tbody>
</table>

### Summary of Six Core Elements

1. **Transferring Youth to an Adult Health Care Provider**
   - **Pediatric, Family Medicine, and Med-Peds Providers**

    | Complete Package          | Transition Policy | Transition Readiness |
    |---------------------------|-------------------|----------------------|
    | Full Package | | Transition Readiness Assessment for Youth | En Español |
    | En Español | | Transition Readiness Assessment for Parents/Caregivers | En Español |

2. **Transition Tracking and Monitoring**

    | Complete Package          | Transition Policy | Transition Readiness |
    |---------------------------|-------------------|----------------------|
    | Individual Transition Flow Sheet | | Transition Readiness Assessment for Youth | En Español |
    | En Español | | Transition Readiness Assessment for Parents/Caregivers | En Español |

3. **Transition Readiness**

    | Complete Package          | Transition Policy | Transition Readiness |
    |---------------------------|-------------------|----------------------|
    | Plan of Care | | Plan of Care | En Español |
    | Medical Summary and Emergency Care Plan | | Medical Summary and Emergency Care Plan | En Español |
    | Condition Fact Sheet | | Condition Fact Sheet | En Español |

4. **Transition Planning**

    | Complete Package          | Transition Policy | Transfer Care |
    |---------------------------|-------------------|---------------|
    | Health Care Transition Feedback Survey for Youth/Young Adults | | Health Care Transition Feedback Survey for Youth/Young Adults | En Español |
    | Health Care Transition Feedback Survey for Parents/Caregivers | | Health Care Transition Feedback Survey for Parents/Caregivers | En Español |

5. **Transfer of Care**

    | Complete Package          | Transition Policy | Transfer Care |
    |---------------------------|-------------------|---------------|
    | Health Care Transition Feedback Survey for Youth/Young Adults | | Health Care Transition Feedback Survey for Youth/Young Adults | En Español |
    | Health Care Transition Feedback Survey for Parents/Caregivers | | Health Care Transition Feedback Survey for Parents/Caregivers | En Español |

6. **Transfer Completion**

    | Complete Package          | Transition Policy | Transfer Care |
    |---------------------------|-------------------|---------------|
    | Health Care Transition Feedback Survey for Youth/Young Adults | | Health Care Transition Feedback Survey for Youth/Young Adults | En Español |
    | Health Care Transition Feedback Survey for Parents/Caregivers | | Health Care Transition Feedback Survey for Parents/Caregivers | En Español |
Resources for Florida Practitioners
Florida’s clearinghouse for HCT information

www.FloridaHATS.org
Florida Health and Transition Services

Welcome to the FloridaHATS Web site! FloridaHATS is a program of Florida Department of Health Children’s Medical Services Managed Care Plan (CMS Plan). Our mission is to ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health conditions or other special health care needs. To learn more about our program, visit About Us.

Tool Box

Our health care transition tool box contains documents and links to a variety of local, state and national resources. Materials for youth, families and professionals are organized in these categories:

- For Health Care Practitioners
- Independent Living

- For Youth & Families
- Decision-Making & Guardianship

- Education & Training for Professionals
- Service Delivery & Models of Care

- Health Insurance & Financing
- Advocacy

- Secondary & Post-Secondary Education
- Juvenile Justice

Some Resources

- Understanding Florida Medicaid Managed Care: From Family Network on Disabilities (2016)

- My Health Care A classroom curriculum to improve health literacy, communication and self-advocacy skills

Some Materials for Youth and Families

- Just the Facts: The 411 on Health Insurance for Young Adults Ages 18-36 in Florida (2015)

- Transition 2 Go: International Briefs On Florida Guardianship: Employment, Social Security, and

Some Tools for Providers

- Condition-Specific Tools for Subspecialists From the American College of Physicians; tools are now available for the following subspecialties: general internal medicine, geriatric medicine, endocrinology, physical medicine and rehabilitation, and mental health

Need Training?

- Health Care Transition Training for Health Care Professionals. This course is appropriate for all practitioners and support staff involved in the care of adolescents and young adults.

- Illinois Transition Care Project Offers
Health Care Transition Preparation for Youth and Young Adults with Special Health Care Needs in Florida

Is patient 12-14 years?  
Yes  
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.

No  
Is patient 15-17 years?  
Yes  
Step 2  
Ensure Step 1. Assess transition readiness (TRAG or other tool). Explore post-high school options, identify decision making needs. Establish timeline for transfer to adult primary and subspecialty care.

No  
Is patient 18-21 years?  
Yes  
Step 3  
Ensure Steps 1 and 2. Identify insurance coverage, adult service and employment needs. Transfer to adult primary and subspecialty care.

No  
Is patient eligible for MedWaver program?  
No  
Does patient have ID?  
No  
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.

Yes  
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.

Is patient eligible for VR?  
No  
Needs help with decision-making?  
No  
Insurance patient will have as adult?  
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  
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).

Yes  
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 Centers for Independent Living for additional guidance. (handout).

Is patient eligible for VR?  
No  
Needs help with decision-making?  
Yes  
Determine Services Needed

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
TRAG-5.0: Transition Readiness Questionnaire 5.0 (or use other checklist)
VR: Vocational Rehabilitation Program

*Handouts are available in English, Spanish and Haitian Creole at www.Fl溯源 destinaté.org
# Health Summary & Emergency Care Plan

## Health Care Transition Summary

<table>
<thead>
<tr>
<th>Name</th>
<th>DOB</th>
<th>SS#</th>
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<tr>
<th>Emergency Contact</th>
<th>Relationship</th>
<th>Cell Phone</th>
<th>Home Phone</th>
<th>Email</th>
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<th>Health Insurance Plan</th>
<th>Group and P P</th>
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<thead>
<tr>
<th>Health Care Transition Summary Details and Recommendations</th>
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<tbody>
<tr>
<td>Primary Insurance:</td>
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<tr>
<td>Secondary Insurance:</td>
</tr>
<tr>
<td>Allergies: (meds &amp; food):</td>
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<tr>
<td>Recent Lab X-ray Findings:</td>
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<tr>
<td>Height:           Weight:</td>
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<tr>
<td>Primary Care Provider:</td>
</tr>
<tr>
<td>Address: Street, City, State</td>
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<th>Current Medications</th>
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<th>Current Therapies</th>
<th>Frequency</th>
<th>Provider</th>
<th>Contact Information</th>
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**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: _____________________

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/extra support is needed)

[Signature]

[Stamp]
## 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 transfer package along with the latest transition readiness assessment, medical summary, and emergency care plan, and, if needed, a condition fact sheet and legal documents.

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of Birth:</th>
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<tbody>
<tr>
<td>Primary Diagnosis:</td>
<td>Secondary Diagnosis:</td>
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</table>

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: ____________________

© Get Transition™ Center for Health Care Transition Improvement, 01/2014  Get Transition™ is a program of The National Alliance to Advance Adolescent Health supported by U39HC57293HSA/6MC18  www.GetTransition.org
Self-Management Videos

Short Videos with step-by-step instructions
• 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
Transition for Students with Disabilities
How Parents Can Be Effective Advocates in the IEP Meeting

If you're a parent of one of the 5 million children with disabilities in the U.S., you're probably aware of the Individual Educational Plan (IEP) meeting. Under the Individuals with Disabilities Education Act (IDEA), parents of a child who receives special education services must meet at least once a year with representatives of the local school district to prepare their child's IEP - a detailed, written description of the child's educational program. You don't need to be a special education expert to be an effective advocate for your child in the IEP process. What you must do is be prepared and plan ahead. Every parent - whether it's their first or their 10th IEP meeting - will benefit from reviewing these 10 Steps in advance of the meeting.

Step 1: Understand your child's legal rights to special education.
You must know the language of IDEA to give your advocate of special education rights, regulations, and policies. Read carefully. Keep in mind that under the law, parents are equal partners with school representatives in decision-making. You are just as important as anyone else at the IEP meeting.

Step 2: Obtain a copy of your school district's IEP form.
Become familiar with the sections you will be filling out at the IEP meeting, which typically include:
- **Program or Class** - the appropriate learning environment for your child, such as a regular classroom for all or part of the school day, a special class, or a private school
- **Goals and Objectives** - the general academic, social, communication, vocational, cognitive, self-help, and other goals you have for your child, such as reading or math skills, healthy peer relationships, or independent living skills. The specific step is the key to meeting these goals.
- **Related Services** - developmental, corrective or other services necessary to support your child's placement in a regular class or to allow your child to benefit from special education. Examples include a one-to-one aide in the classroom, speech therapy, or transportation and from school.

For children age 14 and older that will help them meet postsecondary educational, employment, and independent living. Transition services for those for whom it is appropriate.

1. Prior and other school representatives, and gather information about the child's educational performance and their needs. Figure out what each item means and think about what you need for a particular program or service.

2. And services within your school district (as well as those outside of those outside of school) to your child's teacher, professionals who have evaluated your child, and other parents. Visit many of these programs as you can.

In the IEP, it's a good idea for you to put together a blueprint you want beforehand. This will not only help you learn your materials, but also demonstrate that your child needs the educational help you want for
• Plan for change in insurance coverage
  ○ Medicaid
  ○ Parents’ plan
  ○ Employer-based
  ○ Marketplace plans
  ○ Plan for change in insurance coverage
Sexual Health

- 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
• 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)
Age of Majority

- 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
• Consider decision making options, such as guardian advocacy

• Explore long-term financial planning options, such as a special needs trust
• Redetermination at age 18
• Stricter eligibility requirements
Employment

- Apply to Division of Vocational Rehabilitation 2 years before leaving high school
- Can help pay for post-secondary education and job training programs
- Assists in job placement
Transfer of Care

➢ Transfer of care
  ○ Primary Care
  ○ Specialty Care

www.floridahats.org/service-directory/search-service-directory
College Students with Disabilities

Secondary & Post-Secondary Education

College Resources for Students with Disabilities

- Scholarships and Financial Aid for Students with Disabilities, from accreditedschoolsonline.org
- Study Tips for College Students with Dyslexia and Dysgraphia
- Studying with ADHD
- Going to College with ASD
- Thriving in Trade School with a Disability
- Heading for College with Special Health Care Needs (YouTube video)
  Dr. Kitty O’Hare of Boston Children’s Hospital, provides practical considerations for a student’s health care transition, in preparation for a successful adjustment to college life, prepared by Got Transition.
- Radio Episodes from Got Transition
  - Radio Episode 2
    Healthcare Transition & College- It Doesn’t Have to be Learned the Hard Way!
  - Radio Episode 3
    Healthcare Transition & College- It Doesn’t Have to be Learned the Hard Way! Part 2
- Transitioning from High School to Post-Secondary Education, article by Dr. Marilyn Bartlett, Texas A&M
- Resources for College Students from BestColleges.com, including information on disability, mental health, academics and college life

Other Transition Resources

- Assistive Technology and Equipment: FAAST
- Independent Living: Centers for Independent Living
- Transportation: Access to Florida’s Transportation Disadvantaged Program for Individuals with Disabilities
How Can You Help?
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
Regional Coalitions

Background

Four regions – Tampa/Hillsborough County, Panama City/Panhandle area, Jacksonville/Duval County, and South Florida – have used the MAPP community-based planning approach to begin building local systems that support health care transition.

The coalitions were organized with assistance from local MAPP facilitators, and used our Strategic Planning Guide for Health Care Transition Coalitions to help guide them in the process. Here is a presentation that highlights background and history of coalition development. Links to scheduled meetings and meeting minutes for each coalition are listed below.

- HillsboroughHATS
- Northeast FloridaHATS
- PanhandleHATS
- South FloridaHATS
Web-Based Training for Professionals

• Cross-disciplinary training for practitioners in the clinical setting
  o 10 modules, 15-20 minutes each
  o Free CME/CE for physicians, physician assistants, LPNs, RNs, and other allied health professionals, through Florida AHEC Network at www.aheceducation.com
  o Modules also posted on www.FloridaHATS.org

• Training for teachers, school nurses and other professionals in the school setting
  o Available at www.FloridaHATS.org
Summing It Up
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