Transition to Adult Life: The Essential Role of the School Nurse

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Health Care Transition

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.

Population Model

Chronic Condition Care Coordination

Enhanced Planning

Transition Plan
Preparation
Assessment
Information & Referral

YSHCN

All Youth

Pediatric Care System

Adult Care System

What Can Happen?

Without adequate support in moving from pediatric to adult health care, youth may:

- Lose insurance
- Have poor connections to the adult health care system
- Have decreased adherence with medicine, self-care
- Increased ER visits, hospitalizations
- Experience short-term deterioration in health and worse long-term outcomes

Did You Know...

➢ The National Association of School Nurses recommends school nurses take the lead in planning for transition from school to post-secondary life for students with chronic conditions.

Transition to Adult Life: Health Care Transition of the School Nurse

Discrete event, physical transfer from a pediatric to an adult health care system for students with chronic health conditions.

School to Post-Secondary Life for Students with Chronic Health Conditions.

School Nurses take the lead in self-care from a pediatric to an adult population model.

Increased ER visits, hospitalizations, and urgent care visits have been noted in youth who have transitioned from pediatric to adult health care systems.

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“When we left pediatric care it was as if someone flipped the switch and turned the lights off.”
— parent of child with developmental disability

“It’s like taking 18 years to build a fine canoe and then riding it over a waterfall.”

Goals for Transition

- Manage their own health
  - Disease self-management
  - Prevention, substance use, safety, sexuality
- Appropriately access adult primary care, specialists, therapies, equipment, supplies, etc.
- Access to adequate and continuous health insurance
- Implement education and vocational goals

HCT and the School Setting

- Opportunity for synergy with mandated transition IEP process
  - Transition IEPs, which are introduced at age 14 in Florida, should outline a pathway to post-secondary independent living
  - Incorporate self-advocacy and self-management skills in school IEP
- Project 10 ([www.project 10.info](http://www.project 10.info)) is FDOE’s statewide transition initiative
  - Includes employment training, post-secondary education and independent living resources

Role of School Nurses

- Provide linkage between pediatric and adult health systems
- Help students/families to understand, identify, and access adult services and resources
- Encourage self-management activities and skills
- Collaboration with community-based providers and other school staff on HCT issues
- Proactive consideration of health-related factors in development of transition IEPs

Transition IEP Factors

- Understanding own needs and required accommodations
- Accessibility, such as entrances, school activity areas, transportation, emergency evacuation
- Stamina and strength issues, such as carrying heavy books, scheduling classes
- Medication, medical supplies, and equipment
- Volunteer experiences and recreational activities to develop work and social skills
Transition IEP Factors

- Self-determination, self-advocacy
- Vocational training that won’t conflict with health needs
- Modifications to physical education program
- Classroom seating, such as avoiding being next to windows because of allergies or noise
- Health care management skills, self-care, and knowledge of health insurance
- Special dietary needs

FloridaHATS Activities

- Web Site/Electronic Media
- Educational Materials
- Training Programs
- Transition Toolkit
- Health Services Directory for Young Adults
- Outreach and dissemination
- Legislative Advocacy
- Regional Coalitions
  - HillsboroughHATS web page

Transition Toolkit

- Visit www.jaxhats.ufl.edu or www.FloridaHATS.org
- Account Set Up
  - Email address
- Which position best describes you?
  - Medical Provider
  - Youth and/or Caregiver
  - Case Manager
  - Teacher
Starting at Age 12

APD/Waiver

- Apply to APD if haven’t already
- Don’t wait to get on the Home and Community-Based Waiver Waiting List (now called iBudget)

School Resources

Classroom Curriculum

Parent/Student Handouts

Self-Advocacy Guides

School Resources

Classroom Curriculum

Links to Lesson Plans
Self-Management Videos

Short Videos with step-by-step instructions

Health Summary

Ages 15-17: VR
- Apply to Division of Vocational Rehabilitation 2 years before leaving high school

Ages 15-17: Sexual Health
- High incidence of sexual abuse among persons with I/DD
  - Most abusers are service providers
  - Lack of education about how to properly act on urges can cause major issues
  - Unacceptable public displays
  - Unwarranted sexual harassment
- Sexuality & Developmental Disabilities Across the Lifespan:
  - Helps educators and family members assist with exploration of self and sexuality

Turning 18: Age of Majority
- Legal responsibilities
  - Financial
  - Decision-Making
  - Legal Guide for New Adults
    [www.floridabar.org/tfb/TFBConsum.nsf/48e76203493b82ad852567090070c9b9/34557641d4c2f7c885256b2f006c5753?OpenDocument]
- Disability benefits determined by ability to work

By Age 18: Decision-Making
- Consider decision-making alternatives, such as including guardianship or guardian advocacy
- Explore long-term financial planning options, such as a special needs trust
By Age 18: SSI
- Redetermination at age 18
- Stricter eligibility requirements

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

Ages 18-21
- Transfer of care
  - Primary Care
  - Specialty Care

Other Transition Resources
- Assistive Technology and Equipment
  - FAAST
- Independent Living
  - Centers for Independent Living
- Housing
  - Housing in Florida: A Resource Guide for Individuals with Developmental Disabilities
- Transportation
  - Access to Florida’s Transportation Disadvantaged Program for Individuals with Disabilities

HCT Training for Health Care Professionals
- Web-based cross-disciplinary training for professionals
  - 10 modules, 15-20 minutes each
  - Free CME/CE for physicians, PAs, RNs, LPNs, ARNPs, social workers
  - CME/CE available through Gulfcoast AHEC at www.aheceducation.com
  - Modules also posted on www.FloridaHATS.org

Training Course Modules
Part I:
1. Introduction
2. Adolescent Development
3. Working with Caregivers
4. Assessing Transition Readiness
5. Patient Skill Development

Part 2:
6. Financial/Legal Considerations
7. Insurance
8. Working with Adult Medicine
9. Care Transfer
10. Conclusion
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