Health Transitions

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Transition Best Practices

- **Developmentally appropriate, asset-oriented** framework for services
- **Adolescents are partners** in decision-making
- **Support for families** to cope with adolescent role changes during the transition process
- **Transfer processing** includes medical summary (primary, preventive and specialty care)

(AAP, 2000; AAP, AAFP, ACP-ASIM, 2002; SAM,Rosen et al., 2003; Blum et al. 1993; NAPNAP, 2001; HRTW, MCHB, DCSHCN)

Transition Best Practices

- **Client education** to teach ASHCN to learn self-management
- **Service Coordination** managed by health care professional
- **Referrals** to employment, educational, rehabilitation, community living and disability community services (including identification of **health-related accommodations**)

(AAP, 2000; AAP, AAFP, ACP-ASIM, 2002; SAM,Rosen et al., 2003; Blum et al. 1993; NAPNAP, 2001; HRTW, MCHB, DCSHCN)

Features of Transition Best Practices

- Continuous
- Coordinated
- Comprehensive
- Integrated
- Culturally Competent
- Youth/Young Adult/Family Centered

(AAP, 2000; AAP, AAFP, ACP-ASIM, 2002; SAM,Rosen et al., 2003; Blum et al. 1993; NAPNAP, 2001; HRTW, MCHB, DCSHCN)

Holistic Goals of Health Care Transition Planning

- Enrollment in adult health insurance plan
- Access to adult specialty and primary health care services
- Adopts healthy lifestyle
- Achieves self management skills
- Obtains needed health-related accommodations and modifications needed for education, training and employment
- Able to advocate for self

Factors Associated with Successful Transition

- Family, youth/young adult and healthcare provider have future orientation
- Transition is initiated early
- Family members/providers foster personal and medical independence
- Futures planning occurs
- Youth/young adult has dreams and goals for the future
- Service reimbursement is not interrupted
- Pediatric providers continue to be involved in care in adult settings
- Continue to receive services within same system of care

(Reiss & Gibson, 2002)

When Transition Begins

- Begins at Diagnosis
- Lifelong Process
  - Future-orientation
  - Survival into Adulthood is Reality
  - Dreams and Visions for Adulthood
- Formalized Transition begins at 14 years

(AAP, AAFP, ACP, ASIM, 2002; Betz, 1998, 2004; Blum et al.,1993; McDonagh, 2005; Olsen & Swigonski, 2004; Reiss, Gibson, & Walker 2005; Scal, Evans, Blozis, Okinow, & Blum, 1999).

Transition Readiness-The Issues

Research findings demonstrate

- ***Youth have had minimal experience in SHCN self management***
- ***Youth are more confident than parents/providers about transitioning***
- ***Youth/Families have different priorities/goals***
- ***Youth/Families are ill prepared***
- ***Youth/Families are uncertain***

(Betz, 2004; Betz & Redcay,2003; Boyle et al., 2001; Hauser & Dorn, 1999; Madge & Byron, 2002; Patterson & Lanier, 1999; Scal & Ireland, 2005)

Transition Readiness

- Lack of evidence as to what constitutes “transition readiness”
- No studies have reported a planned approach to determining readiness
- Criteria used include:
  - Age-most frequently used
    - 16 years to 22 years

(Betz, 2004)

Evidence for Health Care Transition Planning

- Lack of empirical evidence related to effective models to effect improved outcomes

- Models described in the literature have not been rigorously tested using valid and reliable tools

Evidence for Health Care Transition Planning

- Most outcomes reported have narrowly focused on *transfer* outcomes
  - Follow-up appointments
  - Biochemical measurements
  - Adherence
- Outcomes focused on service processes rather than youth perspectives
- Time and setting for data collection
- Proxy approach
  - Parents
  - Administrative data

(Appleton, Chadwick, & Sweeney, 1997; Kipps, Bahu, Ong, Ackland, Brown, Fox, et al., 2002; Reid et al., 2004; Rettig & Athreya, 1991

Evidence for Health Care Transition Planning

- Lack of theoretical frameworks
- Lack of coherence related to concepts measured between studies
- Concepts not operationalized for measurement

(Anderson & Wolpert, 2004; Bell et al., 2008; Capelli et al., 1989; Jordan & McDonagh, 2007; McLaughlin et al. 2008)

Evidence for Health Care Transition Planning

- Reconsider developmental approach for measuring outcomes
  - Emerging adulthood

- Lack of youth perspective with research design and methodology

(Appleton, Chadwick, & Sweeney, 1997; Kipps, Bahu, Ong, Ackland, Brown, Fox, et al., 2002; Lyon, Kuehl, & McCarter, 2006; Reid et al., 2004; Rettig & Athreya, 1991; Roisman, Masten, Coatsworth & Tellegan, 2004)

Finding a Health Care Professional

- Primary Care MD
- Specialty Care MD
- Dentist and Dental Hygienist
- Therapists
  - Mental Health
  - Physical Therapy
  - Occupational Therapy

Strategies to Finding a Health Care Professional

Be proactive and start early

- Pediatric specialty team referral
- Pediatric medical home
- School nurses
- HMO medical transfer program
- “Pockets of Excellence” transition programs
- Title V CSHCN Programs
- Referral lists compiled by disability agencies
- Disability community
- Vocational rehabilitation

Transition Resource Referrals: Health Insurance Plans and Services

Adolescent Coverage

- State Child Health Insurance Programs (SCHIP)
- EPDST
- Department of Mental Health
- Parent's health insurance coverage
- Employer-based health insurance plan

Transition Resource Referrals: Health Insurance Plans and Services

Adult Coverage

- Medicare
- State Medicaid
- State-specific health insurance plan programs
- Title V SHCN Programs
- Planned Parenthood
- Department of Mental Health
- College Student Health Services
- Parent's health insurance coverage
- Employer-Based health insurance plan

Health Insurance Plans

- Start early with gathering information
- Talk to knowledgeable resources
  - Employee benefits representative
  - Social worker
  - Health insurance advocate in community
  - Independent Living Center representative
  - WIA One Stop counselor

Assessing the Health Care Plan

What is type of services does the plan cover?

- Primary care
- Type of health screenings (cholesterol screening, colorectal cancer tests, mammograms, Pap smears, etc.)
- Hospitalizations and emergency care
- Vision, dental and mental health care
- Ongoing care for chronic diseases, conditions or disabilities

Adapted from

Agency for Health Care Research and Quality. (2002). Choosing and Using a Health Plan. accessed on January 7, 2004 from http://www.ahcpr.gov/consumer/hlthpln1.htm

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Assessing the Health Care Plan

What is type of services does the plan cover?

- Physical therapy and other rehabilitative care
- Home health, nursing home and hospice care
- Alternative health care, such as acupuncture
- Type of preventive care offered (Immunizations, prophylactic antibiotics, hearing exams/hearing aids))
- Inpatient/outpatient prescription medications

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Transition Self Management

Medical Condition as it relates to knowledge of:

- Underlying physiology
- Medications/treatments
- Past medical history
- Report current illnesses/functional status
- Decision-making skills related to health care

(Cappelli et al., 1989; Hauser & Dorn, 1999; Scal, 2002)

Transition Self Management

Demonstrates ability to adhere to:

- Treatment regimen at home, school and community settings
- Taking medications appropriately
- Keeping appointments with MD, therapists
- Engaging in preventive health behaviors
- Seeking care when problems arise

(Burkhart & Dunbar-Jacob, 2002; Kyngas, 2000; Ledlie, 2006)

Transition Self Management

Self-advocacy

- Demonstrates knowledge of medical system
- Demonstrates navigation skills
- Understands rights, protections and responsibilities

(DHHS, 2002, 2005; Ledlie, 2006; Scal et al., 1999)

Health Promotion and Disease Prevention

Has understanding of what are daily healthy choices:

- Diet
- Exercise
- Sleep
- Infection control
- Avoidance of at-risk behaviors
- Health maintenance behaviors

The *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities (DHHS, 2005)*

Health Promotion Guidelines

- American Cancer Society Guidelines (2008)
  - Early detection of breast, colon and rectal, cervical, endometrial, and prostate cancer
- National Institutes of Health Guidelines (DHHS, 2008)
  - Asthma, high blood cholesterol, high blood pressure, overweight/obesity and sickle cell disease
- American Heart Association Guidelines (2008)
  - Blood pressure
- Centers for Disease Control and Prevention Recommendations (DHHS, 2007)
  - Immunization schedules
- American College of Obstetricians and Gynecologists (ACOG, 2003) recommends
  - Pelvic exams, quadrivalent human papillomavirus (HPV) vaccine

Health Promotion

- Health promotion extends to personal safety
- Safety instruction includes:
  - Violence prevention
  - Abuse prevention
  - At risk situations such as parties when drugs and alcohol are used
  - Unsafe driving
  - Concerts and outdoor events wherein smoking/use of illicit substances occurs
  - Skin exposure
  - Ingestion of herbal supplements

Down Syndrome Associated Conditions

- Alzheimer (nearly 40% of individuals are affected)
- Dementia due to brain function and CNS changes
- IQ and Short term memory decreases, social skills decrease
- Behavioral issues become apparent during adolescence (18% to 40% prevalence)
  - Aggression, depression, hyperactivity, and inattention
- Congestive heart disease
- Autoimmune diseases
- Orthopedic problems
- Hearing loss worsens
- Obesity
- Diabetes 2
- Periodontal disease
- Increased dental caries
- Skin problems

(Ailey, 2005 Capone, Capone Goyal, Ares, & Lannigan, 2006; Capone, Grados, Kaufmann, Bernad-Ripoll, & Jewell, 2005; Daneshpazhooh, Nazemi, Bigdeloo, & Yoosefi, 2007 Loureiro, Costa, & da Costa, 2007; Minnwa & Steiner, 2009; Myrelid et al., 2002; National Congress on Down Syndrome, nd; Nicham et al., 2003; NIDCR, 2008; Roizen & Patterson, 2003; Snashall, 2002; Visootsak & Sherman, 2007)

Fragile X Associated Conditions

Fragile X syndrome

- Chronic otitis media
- Low muscle tone (flat feet and scoliosis)
- Cardiac problems
- Hypertension
- Early puberty
- Menopause
- UTI
- Seizures
- Behavior challenges

(Minnes & Steiner, 2009)

Coordinating Care with other Systems of Care

- School nurses (IEP, 504 Plan, IHP, EAP)
  - Health related accommodations
  - Assistive technology
  - Adaptive equipment
  - Need for health related procedures
  - Identified in the IEP/504/EAP/IHP
  - Educate other IEP/504 team members
  - Resource to Interagency representative

Coordinating Care with other Systems of Care

- Job coach in work settings (IPE)
  - Health related accommodations/modifications
  - Environmental modifications
- Human resource personnel (504 Plan)
  - Health insurance plan
  - Health related accommodations
- Occupational health nurse
  - Environmental modifications
  - Health related accommodations
  - Minor illnesses
  - Adapting health procedures
  - Well Adult Care

Coordinating Care with other Systems of Care

- Public health nurse in the community
  - Health surveillance
  - Environmental modifications
  - Equipment maintenance and usage
- Fire/Police department
  - Emergency measures
  - Environmental modifications
  - Community Safety
- Community/Direct Service Worker
  - Health surveillance
  - Environmental modifications
  - Health-related accommodations
- Vocational Rehabilitation Counselor (IPE)
  - Health-related accommodations
  - Environmental modifications

Transition Resource Referrals: Addressing Health-Related Needs

- Who is advocating for addressing the health related needs?
- Who is/are making the referrals?
- How is the information being transmitted?
- What health-related accommodations and equipment modifications are needed?
  - Health surveillance
  - Environmental modifications
  - Equipment maintenance and usage
  - Assistive technology
  - Adaptive equipment
  - Need for health related procedures
  - Resource to Interagency representatives
  - Referral to community health resources

Transition Resource Referrals: Education Services

High School Settings

- Special Education-Transition IEP
- General Education 504 Plan
- Joint Education/VR Programs
- School to Work Liaison
- Assistive Technology
- English as a Second Language
- Literacy Programs

Transition Resource Referrals: Education Services

Connecting Programs

- General/Special Education-504 Plan
- Joint Education/VR Programs
- VR Programs

Postsecondary Programs (Community Colleges, 4 year Colleges/Universities)

- Disabled Student Services
- Joint Education/VR Programs
- 504 Plans
- Vocational Education Programs

Transition Resource Referrals: Employment Services

Disability-related Employment Services

- DD Agency
- Supported Employment Agency
- Joint Education/VR Program
- Vocational Rehabilitation

Employment Services

- WIA One-Stops
  - Youth Employment Program
- Community Colleges
  - Vocational Training
  - Adult Education

SSI Work Incentives

- Impairment Related Work Expenses
- Plan for Achieving Self Support (PASS)
- 1619A
- 1619B
- Student Earned Income Exclusion

Transition Resource Referrals: Community Living Services

- DD agencies
- Child and Family Services
- Food Stamps
- Voter Registration
- Center for Independent Living
- SSI/SSDI and Work-related incentive programs

Transition Resource Referrals: Community Living Services

- RTD/Metro Access
- DMV
- Access Services
- Section 8 Housing
- Recreation
- Welfare to Work Program
- Transportation Training

Transition Tools

Washington State's Adolescent Health Transition Project

Working Together for Successful Transition Notebook

http://depts.washington.edu/healthtr/notebook/content_documents.html

Transition Timelines for Children and Adolescents with SHCN

http://depts.washington.edu/healthtr/timelines/

"What is Transition?"

health care skills checklist

http://depts.washington.edu/transmet/What%20is%20transition/checklist/html

Transition Tools

KY Commission for CSHCN

Life Maps

Listing of anticipated transition activities per age group

http://chs.state.ky.us/commissionkids/

Health Care Transition Workbooks

for youth ages 12 years to 18 years and older

http://hctransitions.ichp.edu/resources.html.