

*Opening Doors:
Adolescent Transition*

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Health Care Transitions: Definition

“The goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.”

2002 AAP Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs (AAP/AAFP/ACP)

What is Health Care Transition?

Transition is the deliberate, coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals.

Healthy and Ready to Work National Center

Components of successful transition

- Self-Determination
- Person Centered Planning
- Prep for Adult health care
- Work /Independence
- Inclusion in community life
- **Start early!**



Critical First Steps to Ensuring Successful Transitioning

- ★ Identify a medical home
- ★ Identify core knowledge and skills
- ★ Maintain an up to date medical summary that is portable and accessible
- ★ Create a written health care transition plan by age 14
- ★ Apply preventive screening guidelines
- ★ Ensure affordable, continuous health insurance coverage

HRSA/MCHB Block Grant: National Performance Measures

Transition to Adulthood

Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. (2002)

SOURCE: BLOCK GRANT GUIDANCE

New Performance Measures See p.43

<ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf>

MCHB CORE National Performance Measures

Transition &

1. Family
2. Screening
3. Medical Home
4. Health Insurance
5. Community
6. Transition

1. Youth Involvement
2. Secondary Disabilities
3. Peds to Adult
4. Extend Dependent Coverage
5. Entitlement to Eligibility
6. Inclusion in Community

Healthy and Ready to Work

How are we doing? Data

- ★ National Survey for CYSHCN
- ★ AAP Periodic Survey
- ★ Pacer Center
- ★ Healthy and Ready to Work National Center (HRTW)

NS-CSHCN 2005

Examples of Transition Questions

<p>49% NO</p>	<p>Have physicians talked with you or your child about eventually seeing doctors or other health care providers who treat adults?</p>
<p>46% YES</p>	<p>Have doctors or other health care providers talked with you or your child about his/her health care needs as he/she becomes an adult?</p>

NS-CSHCN 2005 Transition Questions

<p>79% NO</p>	<p>Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult?</p>
<p>Never 12% Some- times 16% Usually 23% Always 49%</p>	<p>How often do doctors or other health care providers encourage him/her to take responsibility for his/her health care needs, such as:</p> <p>IF 5-11 Years: learning about health or helping with treatments and medications?</p> <p>IF 12+ Years: taking medication, understanding health, or following medical advice?</p>

2008 AAP Periodic Survey of Fellows Preliminary Data

Services in place to support adolescents with special needs in transition from pediatric to adult health care?

Service	Not Provided
Establish referral to specific physician	20%
Assist with identifying options to maintain health care insurance	59%
Create individualized health care transition plan	62%

Extent of barriers to transitioning for adolescents with special needs to adult health care -- Preliminary Data

Barriers	Major barrier
Lack of available family physicians, internal medicine physicians to care for older adolescents/young adults with special needs	41 %
Lack of insurance reimbursement for transition services	38%
Lack of knowledge about or linkages to community resources that support older adolescents/young adults	39%

Youth With Disabilities Stated Needs for Success in Adulthood

PRIORITIES

- 1 Career development** (develop skills for a job and how to find out about jobs they would enjoy)
- 2 Independent living skills**
- 3 Finding quality medical care** (paying for it; USA)
- 4 Legal rights**
- 5 Protect themselves from crime** (USA)
- 6 Obtain financing for school** (USA)

SOURCE: Point of Departure, a PACER Center publication Fall, 1996

Two HRTW Surveys: 2007-08 Results

About those who responded

- ★ 52 physicians / 26 states
- ★ Most involved with Medical Home projects
- ★ 47 pediatricians, 4 Med-Peds, 1 Family

Consensus Statement- Knowledge

- ★ 50% were familiar
- ★ 6 % unsure
- ★ 42% not

HRTW:

Health Care Transition Activities

	Medical Homes N=52 26 states	State Title V Agencies N=42 of 59 States/ Territories (71%)
Create an individualized health transition plan	34%	50%
Promote health management, self care, and prevention of secondary disability	63%	72%
Recruit adult primary/ specialty providers to assume care of youth with special needs	56%	53%

HRTW Questionnaire 2006-2007

Barriers to Transition (Combination of “extremely important or very important “)	Medical Homes N=52 in 26 states
Lack of capacity of adult providers to care for youth/adults with SHCN	83%
Fragmentation of care among systems providers	87%
Lack of knowledge about or linkages to community resources that support youth in transition	85%

HRTW

Results: Core Knowledge & Skills

36% have forms to support transition

(82% want help)

39% provide educational materials regarding transition

(48% want help)

58% help youth/families plan for emergencies

(31 % want help)

68% assist with accommodations school/studying or work

(21% want help)

35% Make transportable medical record for some patients

(43% want help)

AAP Identification of Need

Issues surrounding **transition** needs
identified as one of the
Top 10 Resolutions at the
2007 AAP Annual Leadership Forum

AAP Response to Needs

- ★ Development of “State of Transitions”:
review of literature and activities at
national, state and medical home levels
- ★ Needs assessment across AAP
Committees, Sections and Councils
- ★ Establishment of Transition Task Force

Collaborative Partnerships

Maternal and Child Health National Centers

National Center for Medical Home Implementation

HRTW

Family Voices

National Center for Cultural Competence

Catalyst Center

Champions for Inclusive Communities

Centers for Disease Control and Prevention

American Academy of Family Physicians

American College of Physicians

AAP Response to Needs

Task Force Participants

Families and youth

Generalists

Specialists (Adolescent and otherwise)

Med-Peds

American Academy of Family Physicians

American College of Physicians

Healthy and Ready to Work

Centers for Disease Control

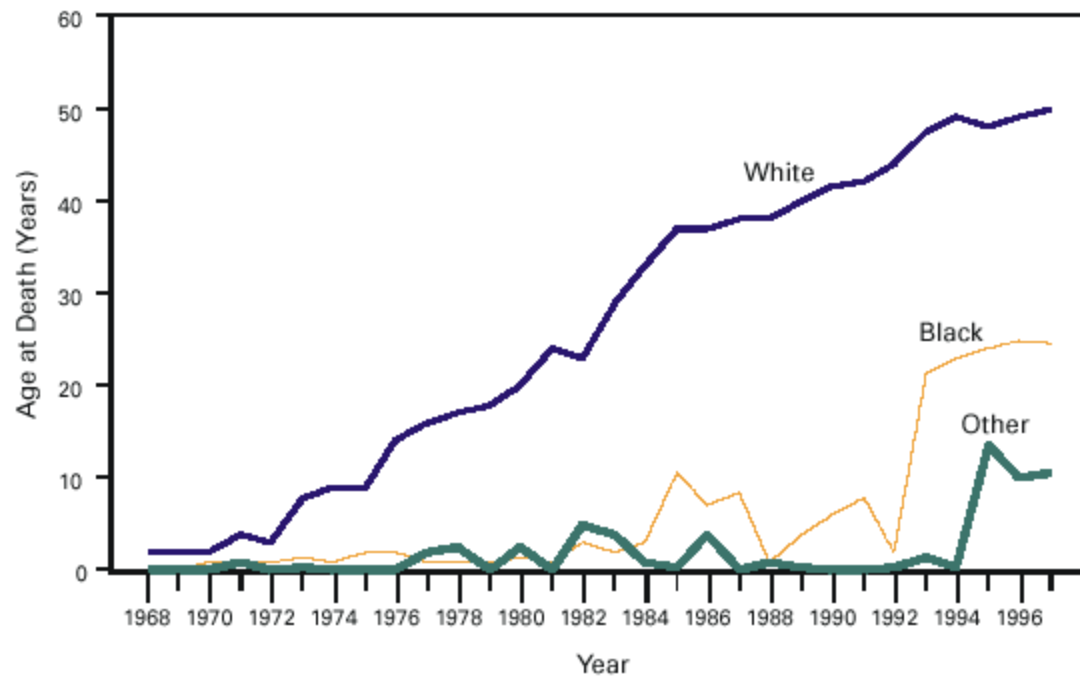
Maternal and Child Health Bureau

Task Force Work Plan

- ★ Clinical Report--with implementation algorithms
- ★ Electronic Medical Record Initiatives
- ★ Residency Education
- ★ Advocacy for Appropriate Payment of Transition Activities

Racial/Ethnic Disparities

FIGURE 1. Median age at death of persons with Down Syndrome, by race — United States, 1968–1997



Racial/Ethnic Disparities

- ★ Hispanic (55%) adults with disabilities are more likely to rank their health status as fair or poor compared to Whites (37%) or Asians (25%)
- ★ Special needs African-American children and Hispanic children whose parents completed surveys in Spanish were more likely than white to report unmet mental health needs.

Health Equity

Delivering health care through a **system** that **reduces or removes barriers** to any remediable differences in health care access and quality based on social status, gender, geography, or any factor that connotes less social disadvantage.

The elimination of health disparities.

Not an official AAP definition

Summary

- ★ The needs are great...but there has been improvement
- ★ There is desire for additional education and improvement
- ★ Collaboration and partnerships are critical as we move forward

For More Information

★ Website

– www.medicalhomeinfo.org/training

★ E-mail requests or questions

– mhtraining@aap.org



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THANK YOU

