Achieving a System of Care for Children and Youth with Special Health Care Needs and Their Families

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Learning Objectives

- Outline the mandates on the system for the development of comprehensive, coordinated, community-based services for CYSHCN and their families
- Define children and youth with special healthcare needs (CYSHCN)
- Describe current efforts in the DSCSHN to develop the system of care
- Outline the 6 core outcomes of a comprehensive system of care
- Describe the medical home and healthy ready to work initiatives
Crossing the Quality Chasm: How Do We Fix the System?

“Current care systems cannot do the job. Trying harder will not work. Changing systems of care will.”
The Context: Past and Present

- Building on a 20-year history
  - development
  - demonstration
  - partial implementation

- Legislation and Policy
  - National Agenda for CSHCN-1987/88
  - Legislative Changes in Title V- OBRA 89
  - Healthy People 2000 and 2010
  - President’s New Freedom Initiative 2001
Mandates for the System

- Amended Legislation for Title V of the Social Security Act (1989):
  - “Provide and promote family-centered, community-based, coordinated care
  - Facilitate the development of community-based systems of services”
- Healthy People 2010 Objective 16-23
  - “Increase the proportion of States and territories that have service systems for children with special health care needs.”
- The President’s New Freedom Initiative (2001)
  - Responsibility given to HRSA for developing and implementing a community-based service system
Who are CYSHCN?

Children and Youth with Special Health Care Needs are those who have or 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. (Maternal and Child Health, 95')
Principles Underlying the System of Services

- Family and Youth-Centered
- Culturally-Competent
- Coordinated
- Comprehensive
- Community Inclusion
6 Components of Service System of Care

- Family participation and satisfaction
- Access to a Medical home
- Access to Affordable Insurance
- Early and Continuous Screening
- Easy-to Access Community-based Service Systems
- Services Necessary to Transition to Adulthood
The Medical Home Initiative
What is a Medical Home?

- An approach and process to providing care
- Partnership with the child, family, and practice staff
- Involves a provider that is familiar with the family
- Emphasizes the primary care practice as the “home” where family and child
  - Feel recognized and supported
  - Find a centralized base for medical care
  - Find a connection to other medical and non-medical community resources

(American Academy of Pediatrics, 2002)
Components of Care in a Medical Home

- Family-Centered
- Accessible
- Comprehensive
- Continuous
- Coordinated
- Compassionate
- Culturally-effective

Provided in an environment of trust and mutual responsibility
Medical Home Initiative

- Statewide Implementation and Spread
  - Medical Home Grants
    - National Center for Medical Home Initiatives-AAP
    - Community-based Primary Care Practices
      - PA, MA, NY, IL, OH, NH
    - Autism Spectrum Disorder and Medical Home-Waisman Center, Univ. of Wisconsin
    - Medical Home and Specialty Care – Univ. of Florida
Goals and Objectives

1. National leadership
2. Technical Assistance
3. Training and education
4. Resource development and distribution
5. National, state and local mentorship
Healthy and Ready to Work: Successful Transition to Adulthood
Here’s Some of What We Know?

YSHCN

- 45% Lack access to physicians familiar with their health condition
- 40% Lack a payment source for needed health care

SOURCE: 1997 survey of young adults served by the CHOICES Project of Shriners’ Hospital

- 6% of Youth between 13-18yrs meet all of the criteria for successful transition to adult providers
  (CSHCN National Survey 2000)
Transition & Health: 1980s, 1990s & Now

- Surgeon General Koop 1989 Conference was dedicated to the transition of health care for YSHCN.
- MCHB - demonstration grants 1989-92
- MCHB launched Transition initiative 1996
  Healthy & Ready to Work
  “Because Everyone Deserves a Future”
    1996-2001> Phase 1: 9 Demonstration Sites
    2001-2005> Phase 2: 6 State Implementation
    2002-2006 > HRTW National Center
Lessons Learned
HRTW Phase I

- **Early** - Transition planning is a life-long experience that must start early.

- **Inter-professional** - It takes an interprofessional approach that must be youth- and family-centered.

- **Health Impacts Performance** - The role of health is not well understood; training can help incite change with participation from all parties. Wellness and prevention needs to be promoted.
Lessons Learned
HRTW Phase I

- **Expectations & Aspirations** - Youth routinely encounter low performance expectations from health care providers and other professionals.

- **Youth-centered**
  Too many health care professionals direct communications to parents rather than youth. [assent to consent]

- **Self-determination**
  Teaching self-determination skills is valuable; allow youth to speak for themselves.
Consensus Statement on Health Care Transitions

- American Academy of Pediatrics
- American Academy of Family Physicians
- American College of Physicians-American Society of Internal Medicine

**Consensus Statement calls on physicians to:**

1. Understand the rationale for transition from child-oriented health care

2. Have the knowledge and skills to facilitate that process

3. Know if, how, and when transfer of care is indicated

(Pediatrics 2002:110 (suppl) 1304-1306)
Consensus Statement
Key Points

- **Create** a written health care transition plan by **age 14**: what services, who provides, how financed

- **Apply** primary and preventive care guidelines

- **Ensure** affordable, continuous health insurance that includes transition planning/care coordination.
Outcomes for Successful Transition

1. HRTW Systems Development
2. Youth Participation in Decision Making
3. Accessible & Affordable Health Insurance
4. Medical Home / Adult Health Care
5. Education, Employment, Independent Living and Recreation
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