

Common Elements

American Academy of Pediatrics

Family Voices

Maternal and Child Health Bureau

National Association of Children's Hospitals and Related
Institutions

and

Shriners Hospitals for Children



Learning Objectives

- Define the medical home concept.
- Define “*children and youth with special health care needs*” (CYSHCN).
- Understand the reality of providing care for CYSHCN from all provider perspectives: physicians, allied health care professionals, and family members.
- Define the common elements of medical home, and assess whether they have been incorporated into personal practices.
- Understand the personal importance of providing a medical home.

CYSHCN: Definition

Children and youth with special health care needs are 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.



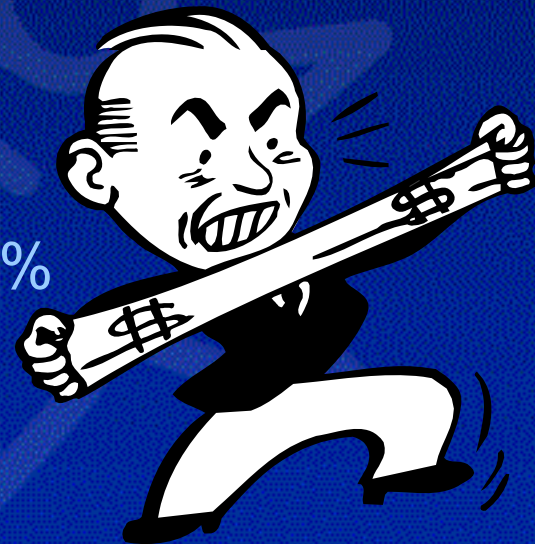
CYSHCN: Reality

- Approximately 40,000 CYSHCN in the United States, or 13% of children, have a special health care need
- Approximately 1 out of 5 homes in the United States has a child or youth with special health care needs

Note: This does not include children and youth at risk for a chronic condition.

CYSHCN: Financial Reality

- CYSHCN account for 80% of pediatric health care expenditures
- Annual cost of providing medical care to CYSHCN
 - Hospitalization: 61%
 - Specialists: 14%
 - Durable medical equipment: 5%
 - Primary care: 5%
 - Other: 15%



CYSHCN: Reality for Families

- 39.5% indicate their child's or youth's condition impacts family's financial situation
- 13.5% say they spend 11+ hours/wk coordinating care for their child or youth
- 24.9% indicate families cut back on work due to child's or youth's condition
- 28.5% indicate families stop working due to child's or youth's condition

What Is NOT a Medical Home?

- Building
- House
- Hospital



What Is a Medical Home?

- An approach to providing health care services in a high-quality, comprehensive, and cost-effective manner
- Provision of care through a primary care physician through partnership with other allied health care professionals and the family
- Acts in CYSHCN's best interest to achieve maximum family potential



Who Is Part of a Medical Home?

- Primary care physician
- Family
- Child/youth
- Allied health care professionals
- Family's community
- Pediatric office staff
- If necessary, pediatric subspecialists



Benefits of a Medical Home

- Increased patient and family satisfaction
- Establishment of a forum for problem solving
- Improved coordination of care
- Enhanced efficiency for children, youth, and families
- Efficient use of limited resources
- Increased professional satisfaction
- Increased wellness resulting from comprehensive care

Barriers to Providing Medical Homes



Pediatric primary care system is designed

- For the 80% of children who DO NOT have special health care needs
- To provide preventive care services and acute illness management
- To support single service encounter

Medical Home Initiative: Why Now?

- Healthy People 2010 objective
- Fragmented care (Institute of Medicine 2002)
- More children with chronic conditions
- Home- and community-based services preferred



Medical Home Common Elements

Care that is:

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



and for which the Primary Care Physician
shares responsibility

Accessible



- Personally

- Family/youth are able to speak directly to the physician when needed.
- The practice is physically accessible and meets American with Disabilities Act requirements.

- Geographically

- Care is provided in the CYSHCN's community.
- Practice is accessible by public transportation, where available.



- Financially

- All insurance, including Medicaid, is accepted.
- Changes in insurance are accommodated.



Family-Centered

- The medical home physician is knowledgeable about the CYSHCN and family and their needs.
- Mutual responsibility and trust exists between the patient, family, and the medical home physician.
- The family is recognized as the principal caregiver and center of strength and support for the child, as well as the expert.
- Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.
- Families and youth are supported to play a central role in care coordination and share responsibility in decision making.

Continuous

- The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.
- Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the CYSHCN and family.
- The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

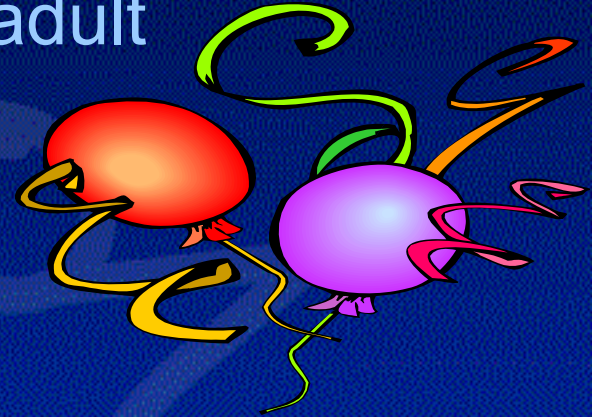
Be Aware of the Impact of Transitional Change

Developmentally

Birth → infant → toddler → preschool → school-
aged → adolescent → young adult

In Critical Life Events

- Anniversaries
- Family changes (eg, birth of a new child without special needs, step-parents or siblings, moves, finances)
- Serious diagnoses or changes in the health status of the child
- Deaths



Be Aware of the Impact of Transitional Change (cont'd)

Across Levels of Care



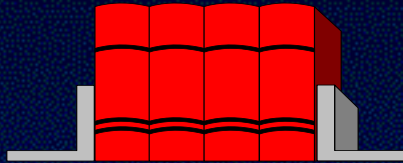
- Primary care physician → primary/frequent subspecialist → secondary subspecialist
- Intensive care → inpatient unit hospital → extended care facility
- Hospital → home and community → hospital

Be Aware of the Impact of Transitional Change (cont'd)

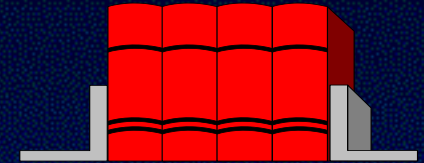
Among Supports and Services

- Early intervention → preschool
- Grade school → high school
- Vocational school or college → work





Comprehensive



- Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.
- Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.
- Extra time for an office visit is scheduled for CYSHCN, when indicated.

Comprehensive (cont'd)

- Preventive, primary, and tertiary care needs are addressed.
- The CYSHCN's and family's medical, educational, developmental, psychosocial, & other service needs are identified and addressed.
- The physician advocates for the child or youth and family in obtaining comprehensive care.
- Information is made available about private insurance and public resources.

Coordinated

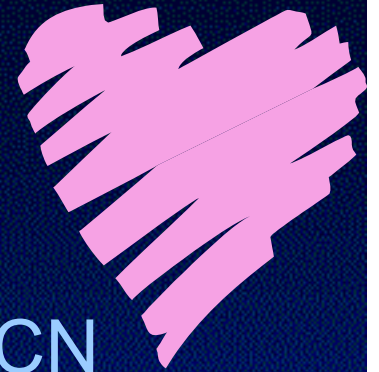


- A plan of care is developed by the physician, CYSHCN, and family and is shared with other providers involved with the care of the patient.
- Care among multiple providers is coordinated through the medical home.
- A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.

Coordinated (cont'd)

- The medical home physician shares information among the CYSHCN, family, and consultant; provides specific reason for referral; and assists the family and CYSHCN in communicating clinical issues.
- Families are linked to support and advocacy groups, parent-to-parent groups, and other family resources.
- The medical home physician evaluates and interprets the consultant's recommendations for the CYSHCN and family and, in consultation with them and sub-specialists, implements recommendations that are indicated and appropriate.

Compassionate



- Concern for the well-being of the CYSHCN and family is expressed and demonstrated in verbal and nonverbal interactions.
- Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the CYSHCN.



Culturally Effective

- The CYSHCN's and family's cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan.
- All efforts are made to ensure that the CYSHCN and family understand the results of the medical encounter and the care plan, including the provision of professional translators or interpreters, as needed.
- Written materials are provided in the family's primary language.

Learning Objectives

- Define the medical home concept.
- Define *children and youth with special health care needs (CYSHCN)*.
- Understand the reality of providing care for CYSHCN from all provider perspectives: physicians, allied health care professionals, and family members.
- Define the common elements of medical home, and assess whether they have been incorporated into their personal practices.
- Understand the personal importance of providing a medical home.