

Building Medical Homes for Children with Special Health Care Needs



James C. Ledbetter, M.D., F.A.A.P.

Every Child Deserves a Medical Home

Objectives

- Define Children and Youth with Special Health Care Needs (CYSHCN)
- Understand the evolution of caring for CYSHCN
- Identify major barriers in our current health care system to providing quality care for children with chronic conditions
- Know the 7 main characteristics of a Medical Home
- Appreciate the role of state title V programs in promoting Medical Home
- Know the 6 outcome indicators in HP2010 related to improving health care for CYSHCN

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Who are Children with Special Health Care Needs?

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Conceptualizing the Population: A Long and Winding Road (Newacheck, 2003)

<u>Era</u>	<u>Terminology</u>	<u>Scope</u>
1930s-60s	Crippled Children	Orthopedic impairments
1970s-80s	Handicapped Children	Above plus developmental disabilities, other physical conditions
1990s-	Children with Special Care Needs	Above plus emotional and behavioral conditions

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Definition of Children With Special Health Care Needs

Children who have or are at risk for a chronic physical, developmental, behavioral or emotional condition and who also require health related services of a type or amount beyond that required by children generally.

(MCHB July 1998 - adopted by AAP October 1998)



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What Is Current Status of CSHCN in Colorado?

- Out of all children in Colorado, ages 0- 18, 11.7% have special health care needs.*
- That means about 170,000 children in Colorado have a health need requiring care beyond what you would expect for a normal child.
- This is consistent with the national average of 12.8% of children, between ages 0-18, who have special health care needs.*

*National Survey of CSHCN 2001

Care Giving for CSHCN: Another Long and Winding Road

(Newacheck, 2003)

Paradigm Shifts in Care Giving Approach

Care of Defects



Care of Children



Care of Children
and their Families

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Family-Centered Care

- Families are usually constant in the life of CSHCN, while service systems and their personnel change frequently.
- Physicians, who have been accustomed to the role of authority and control, should accept the change in the family role from grateful recipient to partner in the health care process.
- The family is now considered the center of the health care universe, not the physician and or hospital (McPherson, 1989).

Family Expectations of Pediatricians in Primary Care

- Most parents would advocate that it is the physician's role to help fit the medical care plan into the overall management of their child with a disability.
- They look for guidance and support in the form of creative problem solving rather than ultimate decision conferring.

Healthy People 2010 Goals As They Relate to CSHCN

- **Family Participation and Satisfaction in Decisions Around Care**
- **Access to Affordable Insurance**
- **Early and Continuous Screening**
- **Easy-to-Access Community-based Service Systems**
- **Services Necessary to Transition to Adulthood**
- **Access to a Medical Home**

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Why Do Children With Special Health Care Needs (CSHCN) Need A Medical Home?

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Pediatric Primary Care is

- Designed for 80% of children who **do not** have special health care needs.
- Designed to provide well child preventative care services and acute illness management.
- Designed to support a single service unit: the provider – patient encounter.

Obstacles to Improving Primary Care for CSHCN

- Offices lack systematic approaches to CSHCN
- Practices lack intrinsic processes for change or improvement
- Care roles are not explicitly defined among parents, specialists, PCP and others

Obstacles to Improving Primary Care for CSHCN

- Reimbursement is inadequate and linked to acute care of healthy children
- Consumer involvement is limited or non-existent



What Is A Medical Home?

- A medical home is not a building, house or hospital but it is an **APPROACH** to providing health care. The parents and the primary care physician (PCP) or supervised designee **are PARTNERS** in the health care of children with special health care needs (CSHCN).

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Colorado's "Vision" for Medical Home

A Medical Home is not a building, house or hospital, but a team approach to providing health care. A Medical Home originates in a primary health care setting that is family-centered and compassionate.

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Colorado's "Vision" for Medical Home

A partnership develops between the family and the primary health care practitioner. Together they access all medical and non-medical services needed by the child and family to achieve maximum potential.

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Colorado's "Vision" for Medical Home

The Medical Home maintains a centralized, comprehensive record of all health related services to promote continuity of care.

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Colorado's "Vision" for Medical Home

Children with special health care needs (CSHCN) may have many professionals invested in their physical and emotional well-being.

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Colorado's "Vision" for Medical Home

Coordination of care is an essential activity to assure communication and planning amongst team members, including family, primary health care practitioners, specialists, community programs and insurance plans.

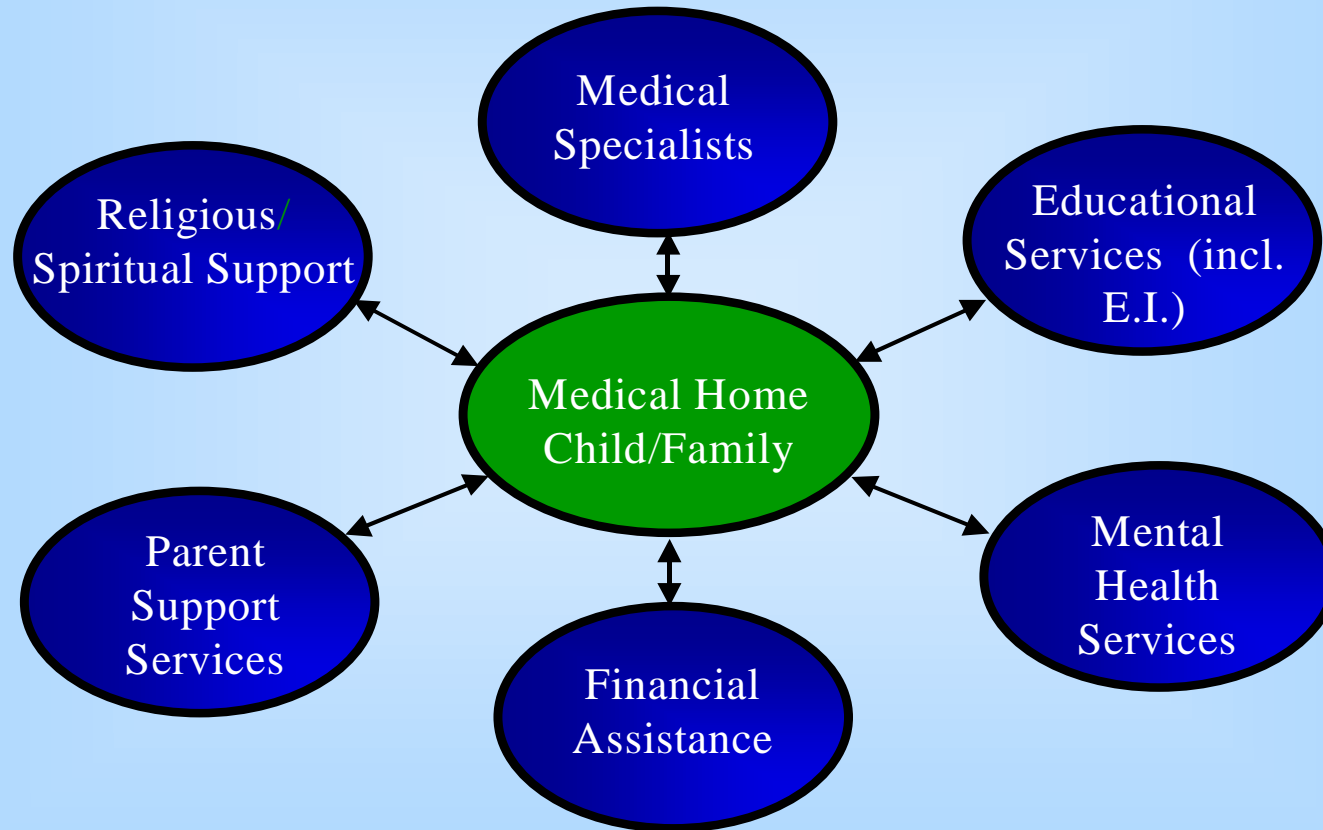
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Pediatric Medical Homes

Provide a primary care process of chronic condition management which...

- Serves children and families **who use** the health care system **most** often (CSHCN)
- Expands services to include
 - Care coordination
 - Advocacy
 - Information exchange & family education
- Responds to family and community needs

THE MEDICAL HOME CONCEPT



AAP Department of Community Pediatrics

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Pediatric Medical Homes

Should be able to...

- Form active partnerships with families
- Identify and monitor CSHCN
- Coordinate care in a systematic manner
- Communicate with other community resources and pediatric specialty services

What Does a Medical Home Look Like?

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



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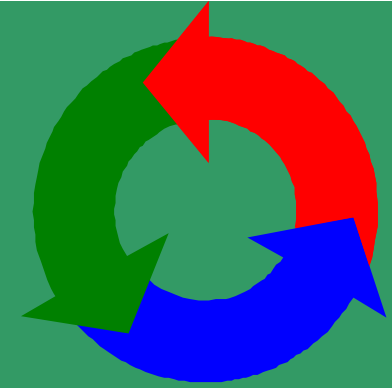
Accessible

- Care is provided in the child's community
- All insurance, including Medicaid and CHP+, is accepted & changes are accommodated
- The location meets ADA requirements
- Access to health advice or care 24 hours a day, 7 days a week

Family-centered

- Recognition that the family is the center of strength and support for the child
- Recognition that the family is the principal caregiver
- Recognition that the family knows the child best
- Family input is sought and valued
- Family-to-family support is made available

Continuous



- Consistent primary health care providers are available from infancy through adolescence
- Communication occurs across agencies: schools, Early Intervention Service (Part C), Developmental Disability Services through community centered boards (CCB), mental health services (including MHASA and county mental health clinics)
- Assistance is provided in securing a medical home for the adolescent transitioning to adult care

Comprehensive

- Preventative and primary care is provided
- Growth and development assessments
- Care coordination
- Referrals to specialty care services
- Patient/family counseling & health education
- Provider is knowledgeable about community resources

Coordinated

- Families are linked to appropriate support, educational, and community-based services
- Provider communicates and collaborates with all service agencies
- A centralized record, with relevant information from all service providers, is maintained

Compassionate



- Concern for well-being of the child and family is expressed and demonstrated
- There is empathy for the variety of emotions a family may have around a child with special health care needs
- Staff are flexible
- Staff offer privacy when requested.
- Appointment times are scheduled in consideration of the family's special needs

Culturally-competent



- Family's cultural background is recognized, valued and respected
- Staff are sensitive about stereotypes and cultural assumptions
- Multi-language materials and translation services are made available as needed

What Is Current Status of Medical Home in Colorado?

- Only 70% of families with CSHCN feel that they have a primary care physician that identify, discuss, and address the needs of their child. *
- Only 51.6% of families with CSHCN in Colorado felt that they received coordinated comprehensive care in a medical home (consistent with national average of 52.5 %).*

*National Survey of CSHCN 2001,

Colorado's Health Care Program for Children with Special Needs



HCP

Colorado's Title
V program for
CYSHCN

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HCP and the Provision of Pediatric Specialty Care

Since 1935, the federal Title V program has supported states in the initiation of programs for pediatric special needs populations. State Title V programs have fostered the development of specialty clinics and multidisciplinary services for children with a variety of specific chronic illnesses.

The Evolving Role of Title V Programs Such As HCP

Few state Title V programs have developed substantial relationships with their state's primary care community, provided direct support or liaison to primary care systems, or actively engaged in the systematic improvement of primary care services.

Colorado's Health Care Program for Children with Special Needs (HCP)



HCP is the public health agency in Colorado responsible for building family driven, sustainable systems of health services and support.

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Colorado's Health Care Program for Children with Special Needs (HCP)



**Through
interagency
collaboration, HCP
connects culturally
respectful
community based
resources.**

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Colorado's Health Care Program for Children with Special Needs (HCP)



HCP monitors surveillance of chronic health conditions impacting children with special health care needs and seek to provide outcome data that assures meaningful lifestyles for those children.

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The Colorado Medical Home Initiative



Medical Home Advisory Board

Kathy Watters- Director of HCP

Don Cook- Past President, American Academy of Pediatrics

Colorado Medical Home Initiative

James Ledbetter, MD- Medical Consultant and AAP Liaison

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The Colorado Medical Home Initiative

AIM: Colorado's Health Care Program for Children with Special Needs (Title V) will support the development of Medical Homes in Colorado

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Colorado Medical Home Initiative

Goal #1: All children with special health care needs in Colorado will have a medical home.

Goal #2: Families of CSHCN will be able to recognize and advocate for a medical home for their child.

Goal # 3: Primary and Sub-Specialty health care providers will recognize the components of a medical home and will implement medical home practices.

Goals #4: Reimbursement for health care for children with special needs will reflect the level of funding necessary to provide medical homes.

Developing Medical Homes through the Colorado Learning Collaborative

The Learning Collaborative provides an opportunity for health care providers of children, interested in implementing Medical Home qualities within their practices, to collaborate with other practices and their state's CSHCN program.

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Medical Home Learning Collaborative State CSHCN Team

- **Kathy Watters, Director Health Care Program for Children with Special Needs**
- **Dr. Jim Ledbetter (HCP), Project Director**
- **Christy Blakely (Family Voices), Parent Consultant**
- **Gina Robinson (EPSDT Outreach), Community Resource Consultant**

Medical Home Learning Collaborative State CSHCN Team

- **Work with Primary Care Practices for children to make incremental changes toward implementing a medical home.**

Medical Home Learning Collaborative State CSHCN Team

- **Encourage Parent Partnerships with Primary Care Practices for children.**

Medical Home Learning Collaborative State CSHCN Team

- **Increase awareness of community resources to Primary Care Practices for children.**

Medical Home Learning Collaborative State CSHCN Team

- **Work with Primary Care Practices for children to implement a systematic approach to the identification of CSHCN within their practice.**

Medical Home Learning Collaborative State CSHCN Team

- **Develop and assimilate outcome data to support implementation of medical homes for CSHCN within their practice.**

Role of French Physician (15th Century)

Gurer parfois...

Soulager souvent...

Consoler toujours...

(To cure sometimes...

To relieve often...

To comfort always...)

For Further Information

Contact:

- James C. Ledbetter, M.D., F.A.A.P.
Medical Consultant, Health Care Program
for Children with Special Needs,
Colorado Dept. of Public Health and
Environment
- Ph. 303 692-2431
- Fx. 303 782-5576
- Email: james.ledbetter@state.co.us