CARING FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Providing Family Centered Care in the Pediatric Medical Home

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Caring for CSHCN

Objectives

• Define CSHCN and Medical Home
• Review data from 2009-10 National Survey of CSHCN
• Examples of how pediatric practice supports the Core quality outcomes of MCHB measured by National Survey
• How medical home benefits the typical child
Our Medical Home Program

- Three pediatricians, Dr. Joseph Hagan, Dr. Jill Rinehart, Dr. Gregory Connolly
- Two Pediatric Nurse Practitioners, Maryann Lisak & Tonya Wilkinson
- One main RN Care Coordinator Kristy
- Office manager, Accounts manager, one office assistant, four additional part-time nurses, three medical assistants
- ~4000 Active Patient List
- Dr. H 1991, Dr. R 1999, Dr. C 2010
- Insurance mix: 35% Mcaid, 60% Private,<5% uninsured
Who are Children with Special Health Care Needs (CSHCN)?

“…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…”

2009-10 National Survey CSHCN

- 11.2 million children ages 0-17 years in the United States (15.1%) have special health care needs
- Prevalence of CSHCN ranges from 10.6% to 19.8% across the 50 states
- Over 1 in 5 households with children in the United States have at least one child with special health care needs (9 million households nationally)
- About 60% of CSHCN experience more complex service needs that go beyond a primary need for prescription medication to manage their health condition
- Compared to non-CSHCN children, CSHCN are more likely to be male (58.9% vs 49.7%) and older 12-17 years (40.9% vs. 32.2%)

Source: 2009-2010 NS-CSHCN; www.childhelathdata.org
Children with Special Health Care Needs

• The prevalence of chronic conditions in childhood ranges from 1/11 children (ADHD) and 1/20 (asthma) to 1/733 (Down syndrome, the most common chromosomal disorder), 1/4,500 (fragile X syndrome), 1/16,000 (MCADD), and 1/1,000,000 (Hurler syndrome).

• While the majority of CSHCN in a practice will have a relatively common condition, the majority of the conditions the patients have will be uncommon or rare.

http://www.medicalhomeportal.org/diagnoses-and-conditions/diagnosis-prevalence-list
Medical Home Definition

• Accessible
• Culturally Effective
• Continuous
• Comprehensive
• Coordinated
• Compassionate
• Family Centered

Medical Home Definition

The Medical Home is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care and chronic condition management in a planned, coordinated and family-centered manner...

~National Center for Medical Home Improvement
CMHI National Outcomes Study
Cost/Utilization

Medical Home Index; 43 Practices, 7 Plans/5 States

- Higher overall MHI scores or higher domain scores for care coordination, chronic condition management, office organizational capacity
  - Lower hospitalization rates

- Higher Chronic Condition Management domain scores
  - Fewer ER visits

Cooley, McAllister, Sherrieb, Kuhlthau, Pediatrics, July 2009
What the Julius Medical Home Was at HRC

- Incredible reputation
- Amazing Physicians
- 24/7 Coverage
- Nurses that were lactation specialists
- Integrated approach and interest in Matt’s whole life
Our Medical Home Until 1:30pm 2/15/01

- Support Family & Friends
- FAMILY
- MEDICAL HOME
- PRIMARY DOCTOR
- CARE COORDINATOR
- DAYCARE
And Then…Along Came the Amazing Miss Kate

- Congenital Hydrocephalus
- Multiple revisions, infections, complications
- Cerebral Palsy, Epilepsy
- Downright remarkable
Our Medical Home
Post Diagnosis
1:35 pm 2/15/01

Specialists
- Neurosurgery
- Neurology
- Physiatrist
- Endocrinology

MEDICAL HOME
PRIMARY DOCTOR
CARE COORDINATOR

On-Going Care Team
- Social Worker
- OT/PT/SLP Therapists
- Daycare Staff & Aide

FAMILY

Support
- Family
- Friends
- Groups
- Advocacy

Funding
- Insurers
- Medicaid
- FIT
- CSHN

Respite
- Medicaid
- Aris
- FIT

CSHN
- Clinics
- Funding
- Equipment

Support
- Family
- Friends
- Groups
- Advocacy
2009-10 National Survey of CSHN
MCHB 6 Core Quality Indicators

1. Families of CSHN are partners in decision making
2. CSHN receive coordinated comprehensive care within a medical home
3. CSHN have adequate public and/or private insurance to pay for the services they need
4. Children are screened early and continuously for special health care needs
5. Community-based services for CSHN are organized so families can use them easily
6. Youth with special needs will receive services necessary to transition to adulthood

Bonnie Strickland,
http://mchb.hrsa.gov/mchirc/dataspeak/events/2012/0119/archive.htm
MCHB Core Quality Indicator #1

Families of CSHCN are partners in decision making

• Doctors discuss range of treatment options
• Doctors encourage questions
• Doctors make it easy to ask questions
• Doctors consider and respect family choices

• Estimated proportion of CSHN Meeting this Goal: 70.3%

Bonnie Stickland, http://www.childhealthdata.org
Family Centered Care

Rare and Remarkable

- McKayla is a 12 year old with Nonketotic Hyperglycinemia
- Developmental Delay
- Choreoathetosis
- Seizures
- Dysphagia (G-Tube)
- Friend, classmate, daughter, niece
Compassionate

Admitted for aspiration pneumonia
Comprehensive, Coordinated

- Physician facilitates essentially all aspects of care

- Medical Home communicates with neurometabolism program to adjust feedings/meds

- Family as experts: provides medication lists, dietary history, clinical expertise: “She’s herself again!”
MCHB Core Quality Indicator #2

- CSHN receive coordinated, comprehensive care within a medical home
- Child has a usual source of sick care and preventive care
- Child has a personal doctor or nurse
- Family experiences no problems in obtaining needed referrals for specialists
- Child receives needed care coordination
- Care provided is family centered
- Estimated Proportion of CSHN Meeting the Goal 2009-2010: 43% (Compared to 2005-06: 47%)

Bonnie Strickland, http://www.childhealthdata.org
Teagan is a 2 year old with Kabuki (Make-up) Syndrome.

- Had a Nissen and G-Tube placed in infancy for severe aspiration, oral aversion.
- Late last fall, she presented with seizures associated with hypoglycemia.
- Difficult IV access.
- Sister, clown, cousin.
Coordinated Care

• PICC placed by anesthesia
• Pediatric Urologist attempted renal calculi surgery
• Labs coordinated by genetics, endocrine, GI, me (some first a.m., some fasting, etc.)
Comprehensive & Coordinated

Coordinating Superspecialty Care

- Pediatric Medical Home
- Pediatric Resident Team
- Pediatric Nephrology
- Pediatric Gastroenterology
- Pediatric Endocrinology
- Genetics
- Anesthesia
- Pediatric ENT
- Pediatric Surgery
- Pediatric Ophthalmology
- Pediatric Neurology
MCHB Core Quality Indicator #3

- CSHN have adequate public and/or private insurance to pay for the services they need
- Child has private or public health insurance at the time of interview
- Child had no gaps in coverage during past 12 months
- Health insurance covers services that meet the child’s needs
- Costs not covered by insurance are reasonable
- Health insurance permits the child to see the provider he or she needs
- Estimated proportion of CSHN to reach the goal 2009-2010: 60.6%
  (Compared to 2005-06 62.0%)

Bonnie Strickland, http://www.childhealthdata.org
MCHB Core Quality Indicator #4

Children are screened early and continuously for special health care needs

• Child had a routine preventive visit in past year

• Child had a routine dental visit in past year

• Estimate Proportion of CSHN Meeting Goal (2009-10) 78.6%

http://www.childhealthdata.org
Medical Home for Non-CSSHN


- 58% of 70,007 children without special health care needs had a medical home

- Having a Medical Home is significantly associated with increased preventive care visits

- Bright Futures is an evidenced based approach to preventive health care, that is **best delivered in the medical home**
Medical Home for Non-CSHN


- Decreased outpatient sick visits
- Decreased emergency department sick visits
- Increased odds of “excellent/very good” child health
- Increased health promoting activities such as being read to daily, reported helmet use, and decreased screen time

Medical Home: Health Supervision

At any given time we have 2 distinct populations in Pediatrics:

1) Relatively healthy: need preventive health care, education and community support
Medical Home: Health Supervision

And 2) The pretty sick: who need preventive health care, education, community support AND chronic care management.
Medical Home and Health Supervision
Comprehensive

- 11 year old boy, Bright Futures Visit
- BMI: 87%, SMA II
- Strengths based assessment
  H-ome
  E-ducation
  A-ctivities
  D-rugs
  S-ex
  S-uicide
  S-afety
Medical Home and Health Supervision
Comprehensive

• **Parent Concerns:**
  Mom concerned about anxiety around swim meets and whether divorce adjustment ok

• **Youth Concerns:**
  Warts-hands and fingers, biggest kid in 5th grade

• **Physician Concerns:**
  Elevated BMI, needs Immunizations, puberty
Medical Home and Health Supervision

• Strengths Based Assessment, developmental milestones of pre-adolescent

• Generosity: likes younger kids, book buddy has special needs
• Independence: self-reliance, supervises younger brother at Dad’s
• Mastery: qualified New England’s 9 swim events
• Belonging: loves school, has friends, loves Vermont
Health Supervision in the Medical Home

• Conclude with readiness to change steps--switch from chocolate milk to skim at school, review healthy choices for food in all settings, identify opportunity for role as a babysitter/mother’s helper in the neighborhood

• Support psychotherapy around divorce issues

• Immunizations: HPV, Tdap, Menactra
Community-based services for CSHN are organized so families can use them easily

- Child’s family experienced no difficulties or delays getting services
- Estimated Proportion of CSHCN Meeting Goal (2009-2010) 65.1%

Bonnie Stickland, http://www.childhealthdata.org
• 2 brothers live with their dad and paternal Grandma in Burlington, VT
• Scotty is 6, has CP
• Sam is 7 has Autism
• Chief Complaint: Truancy
• Scotty unable to get a power chair because home is not accessible
• Accessible “units” not possible due to Sam’s sleep dysfunction
Coordinated

- Care Conferences: Kidsafe Collaborative, Burlington Housing Authority, Howard Center, Bridge Program, Burlington School district, Shelburne School District, psychologist, CSHN social worker, school nurses, PT, OT, SLP
Compassionate

- BHA found a house in Shelburne, Vermont, needed indoor modifications and a ramp
- Generous donor--donated supplies, labor
- Family moved in last August, the boys started school last September!
MCHB Core Quality Indicator #6

Youth with special needs will receive services necessary to transition to adulthood

- Child receive anticipatory guidance in transition to adulthood
- Doctors discuss shift to adult provider
- Doctors discuss future health care needs
- Doctors discuss future insurance needs
- Youth has been encouraged to take responsibility for his/her health care needs
- Estimated Proportions of Teen CSHCN Meeting Goal 2009-10 40% (2005-06: 41.2%)

Bonnie Stickland, http://www.childhealthdata.org
Got Transition?

National Health Care Transition Center
http://www.gottransition.org
Meeting All Core Quality Indicators

• Only a small percentage of CSHCN receive services in a system that meets the criteria for a well-functioning Medical Home

• 20.2% of CSHN ages 0-11 met all five indicators (transition not applicable)

• 13.6% of CSHN ages 12-17 met all six indicators
Take Home Points

From National Survey CSHCN 2009-10

- Children with significant special needs continue to fare less well than those with less significant needs
- Disparities continue to exist based on poverty, race and ethnicity
Take Home Points

• Medical Homes improve care for all children, both those with and without special health care needs
• Caring for CSHCN requires proactive planning, especially in transition to adult care services
• Knowing your community helps connect families with CSHCN to needed resources
Thank You to Our Parent Partners

- Carolyn Brennan
- Kimberly Cookson
- Sandy Julius
- Scott Metevier
- Peggy Mann Rinehart
- Kate & Michael Stein
Resources


Childrenhealth.org

Resources


Hagan, J.F, Duncan, P., Shaw, J., *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents*, p.4


MCHB/NCHS. National Survey of Children with Special Health Care Needs, 2002

MCHB/NCHS. National Survey of Children with Special Health Care Needs, 2005-6

MCHB/NCHS. National Survey of Children with Special Health Care Needs, 2009-10

National Center for Medical Home Implementation “Building Your Medical Home Toolkit,” www.pediatricmedhome.org/

Questions?