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…"

McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. "A new definition of children with special health care needs," *Pediatrics*, 102(1):137–140, 1998.

2009-10 National Survey CSHCN

- 11.2 million children ages 0-17 years in the United Statess (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

American Academy of Pediatrics Medical Home Policy Statement, *Pediatrics*, Vol. 110 No. 1 July 1, 2002 pp. 184 -186

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

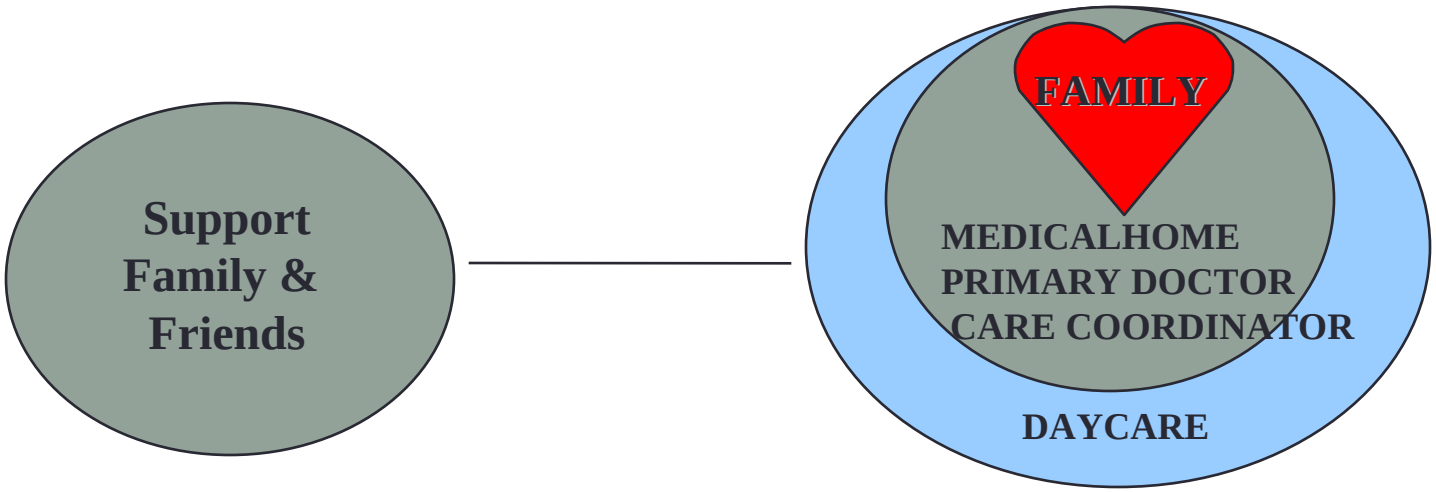
- Higher Chronic Condition Management domain scores
  - Fewer ER visits

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

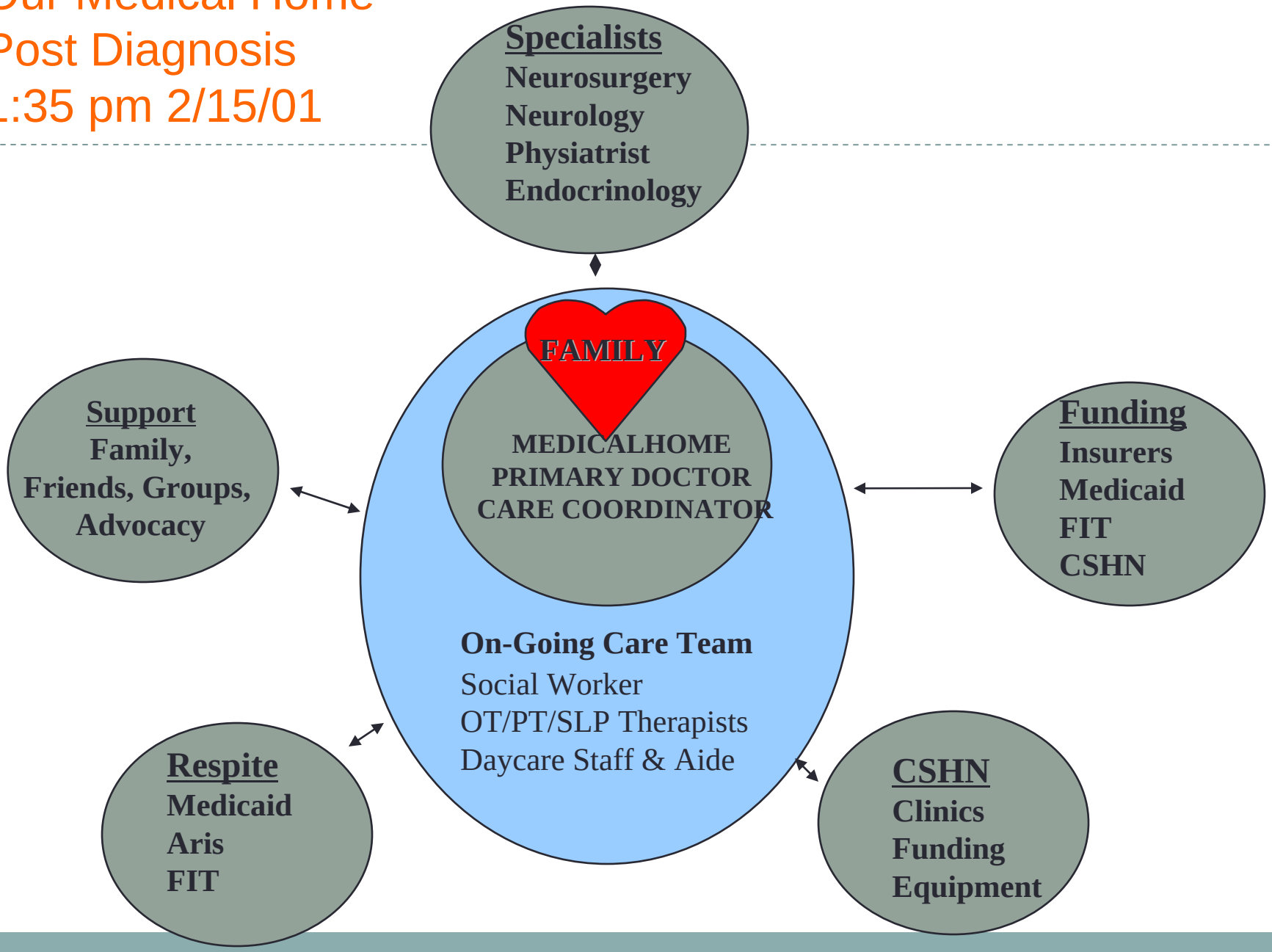
Our Medical Home Until 1:30pm 2/15/01



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



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%)

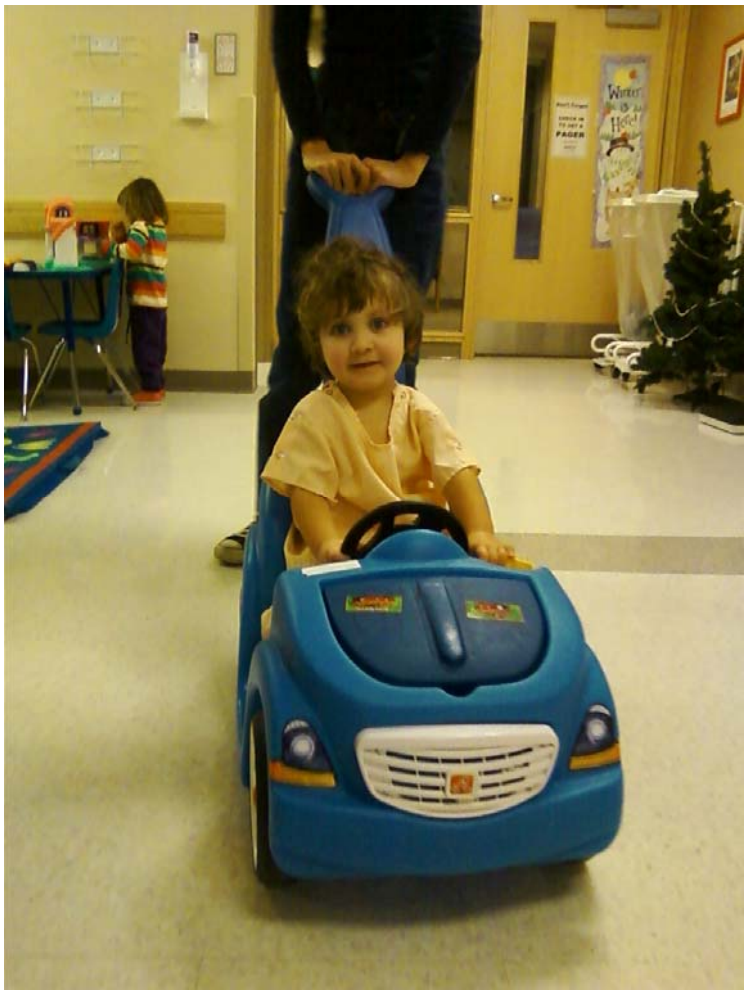
Bonnie Strickland, http://www.childhealthdata.org

Coordinated Care

- 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 Supspecialty Care

- Pediatric Medical Home
- Pediatric Resident Team
- Pediatric Nephrology
- Pediatric Gastroenterology
- Pediatric Endocrinology
- Genetics
- Anesthesia
- Pediatric ENT
- Pediatric Surgery
- Pediatric Opthalmology
- 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

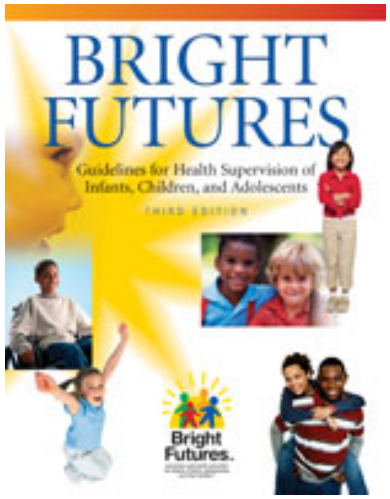
Medical Home for Non-CSHN

"The Value of the Medical Home for Children Without Special Health Care Needs,"*Pediatrics*, December 2011

- 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

"The Value of the Medical Home for Children Without Special Health Care Needs,"*Pediatrics*, December 2011

- 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

Webb E. Long, Howard Bauchner, Robert D. Sege, Howard J. Cabral and Arvin Garg "The Value of the Medical Home for Children Without Special Health Care Needs**,"***Pediatrics*; originally published online December 19, 2011; DOI: 10.1542/peds.2011-1739

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

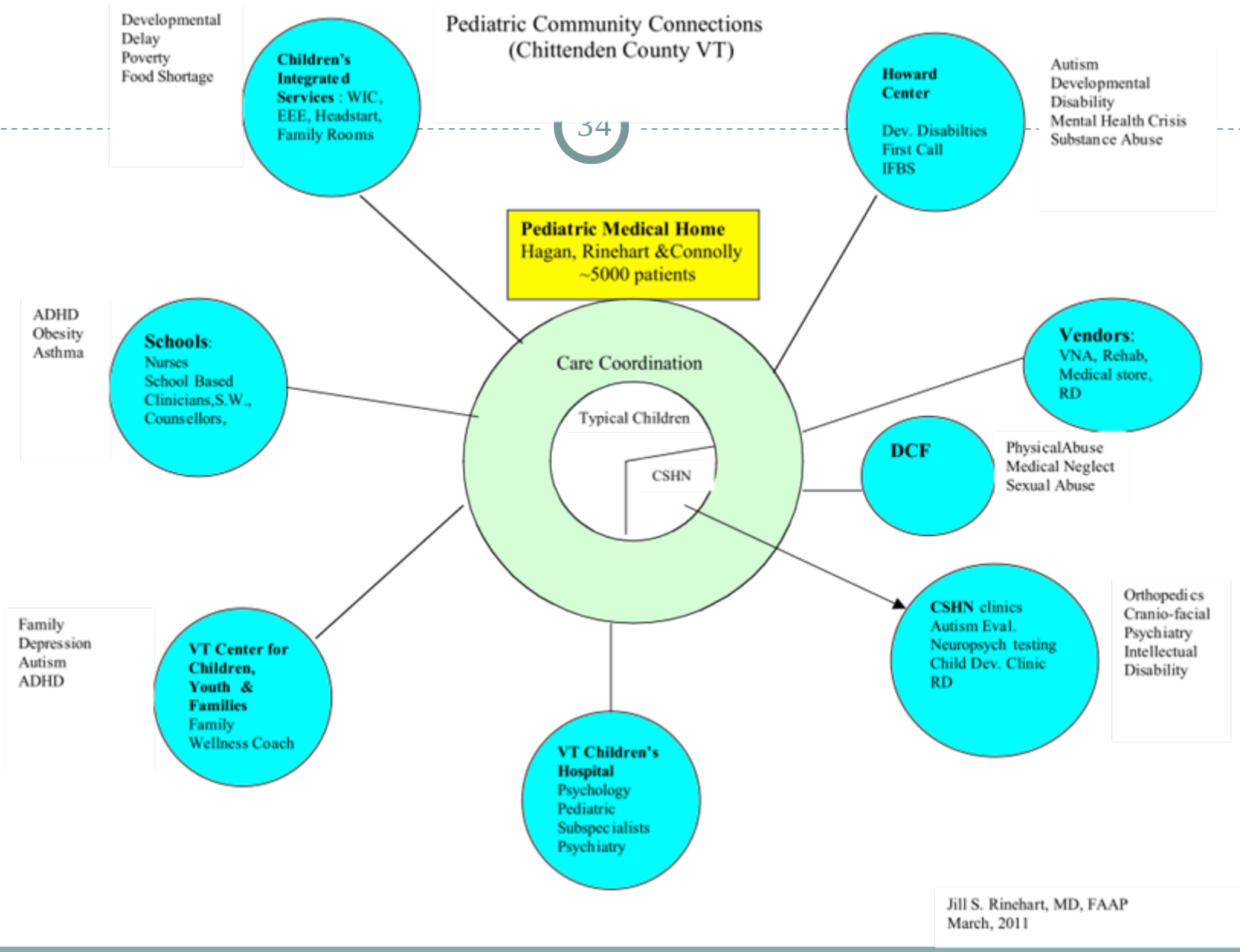
- Conclude with readiness to change steps--switch from chocolate milk to skim at school, review healthy choices for food in all settings, identify opportunity for role as a babysitter/mother's helper in the neighborhood
- Support psychotherapy around divorce issues
- Immunizations: HPV, Tdap, Menactra

MCHB Core Quality Indicator #5

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


Pediatric Community Connections
(Chittenden County VT)
Developmental
Delay
Poverty
Food Shortage
Children's Integrated Services : WIC, EEE, Headstart, Family Rooms
Howard Center
Dev. Disabilties
First Call
IFBS
Autism
Developmental
Disability
Mental Health Crisis
Substance Abuse
Pediatric Medical Home
Hagan, Rinehart &Connolly
~5000 patients
ADHD
Obesity
Asthma
Schools:
Nurses
School Based
Clinicians,S.W.,
Counsellors,
Care Coordination
Typical Children
CSHN
Vendors:
VNA, Rehab,
Medical store,
RD
DCF
PhysicalAbuse
Medical Neglect
Sexual Abuse
Family
Depression
Autism
ADHD
VT Center for Children, Youth & Families
Family
Wellness Coach
VT Children's Hospital
Psychology
Pediatric
Subspecialists
Psychiatry
CSHN clinics
Autism Eval.
Neuropsych testing
Child Dev. Clinic
RD
Orthopedics
Cranio-facial
Psychiatry
Intellectual
Disability
Jill S. Rinehart, MD, FAAP
March, 2011

Comprehensive

- 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

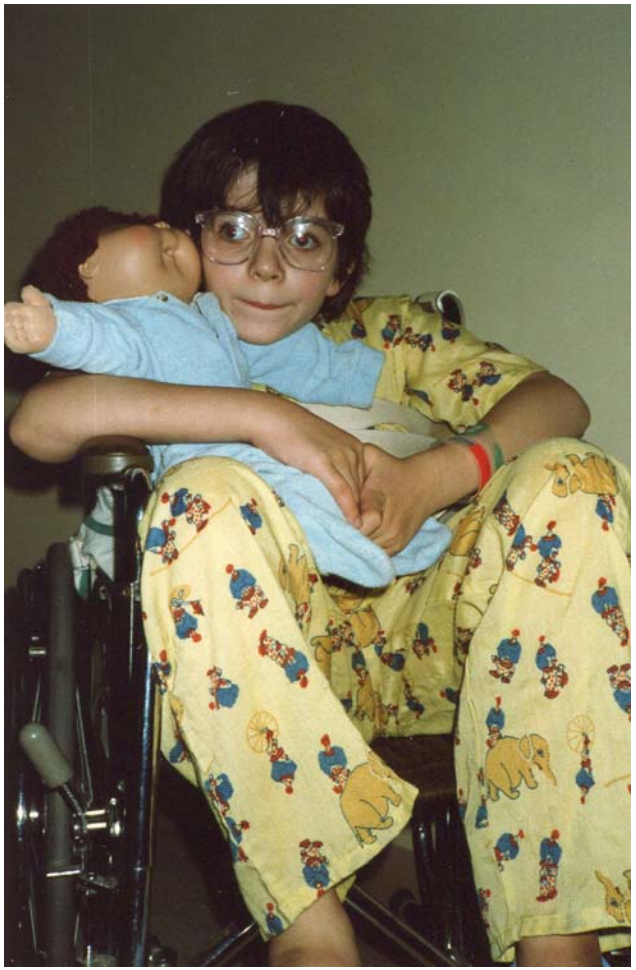
Meeting All Core Quality Indicators

- 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

AAP Medical Home Policy Statement, *Pediatrics*, Vol. 110 No. 1 July 1, 2002 pp. 184 -186

Antonelli RC, Stille CJ,Care , Antonelli DM, "Coordination for CYSHCN: A descriptive Multisite Study of Activities, Personnel Costs, and Outcomes," *Pediatrics*, July 2008

Baruffi G, Miyashiro L, Prince CB, Heu P. "Factors associated with ease of using community-based systems of care for CSHCN in Hawaii," *Maternal Child Health J*, 2005

Broyles RS, Tyson JEH, Heyne ET, et al. "Comprehensive follow-up care and life-threatening illnesses among high-risk infants: a randomized controlled trial," *JAMA*. 2000

Childrenhealth.org

Christakis D, Mell L, Koepsell TD, Zimmerman FJ, Connell RA. "Association of lower continuity of care with greater risk of emergency department use and hospitalization in children,"*Pediatrics*. 2001

Resources

Cooley C, McAllister J, "CMHI National Outcomes Study Cost/Utilization," *Pediatrics*, July 2009

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

Homer CJ, Klatka K, Romm D, et al. "A review of the evidence for the medical home for children with special health care needs." *Pediatrics*. 2008

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

Resources

Murphy, Nancy, et. al, “Parent–Provider-Community Partnerships: Optimizing Outcomes for Children with Disabilities,”*Pediatrics*, Vol. 128 No. 4 October 1, 2011 pp. 795 -802

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

Strickland, et.al.,“New Findings from the 2005-2006 NS-CSHN,” *Pediatrics*, June 26, 2009

Questions?