# Navigating the Medical System: How to build a medical home

James B. Gibson, MD, PhD.
Division of Genetics and Metabolic Disorders,
Department of Pediatrics, UTHSCSA

# Outline

- Origin of the concept
- Components of a Medical Home
- Who is involved in a medical home
- Coordination: more than a balancing act
- What is actually happening
- What should families do?
- What can families do?
- References for families

# Concept of a Medical Home

- Children are not small adults
  - Children develop skills as well as grow
- Children are a vulnerable population
  - They are dependent on adults for their needs
  - Dependence usually decreases over years
- Society values healthy children
- Some children have special health needs
- Society may cooperate with efforts to improve the health of children

# Medical Home

- Healthy People 2010
  - Federal initiative to identify and resolve certain health care problems
  - Partnership of community resources, government and health care professionals
- American Academy of Pediatrics
  - Concept in 1980s
  - 1992 - formal definition and characteristics
- Not yet achieved for many children
  - Target of 2010
  - Harder for some families than others

# What is a Medical Home

- Not (necessarily) a physical place

# What is a Medical Home

- *Is* a source of primary care
  - Accessible
  - Family-centered
  - Continuous
  - Comprehensive
  - Coordinated
  - Compassionate
  - Culturally effective
    - American Academy of Pediatrics Policy Statement, **Pediatrics** 110: 184-186, 2002
- Team approach to providing comprehensive primary health care services
  - in a high-quality and cost-effective manner

# Accessible

- Care in your community
- All insurances, including Medicaid, accepted
  - Changes in insurance are accommodated
- The practice is accessible
  - by public transportation, where available
  - The practice is physically accessible and meets Americans with Disabilities Act requirements.
- Ability to speak directly to the physician when needed

# Family-Centered

- Medical home physician is known to the child or youth and family.
- Mutual responsibility and trust exists
  - between the patient and family and the medical home physician.
- Family is the principal caregiver
  - and center of strength and support for the child.
- 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.
- Responsibility in decision making
  - shared by families, youth and physicians
- The family is the expert in their child's care,
  - youth are recognized as the experts in their own care.

# Continuous

- The same primary pediatric health care professionals are available
  - infancy through adolescence and young adulthood.
- Assistance with transitions
  - developmentally appropriate health assessments and counseling
  - available to the child or youth 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.

# Comprehensive

- Care by a well-trained physician who is able to manage / facilitate essentially all aspects of care.
  - Ambulatory & inpatient care for ongoing and acute illnesses is ensured, 24 hrs x 7 days x 52 weeks a year
  - Preventive care is provided
  - Preventive, primary, and tertiary care needs addressed
- The physician advocates for the child, youth, and family
  - obtaining comprehensive care
  - sharing responsibility for the care that is provided.
- Medical, educational, developmental, psychosocial, and other service needs are identified and addressed
- Information re private insurance and public resources
- Extra time for an office visit is scheduled for children with special health care needs, when indicated

# Coordinated 1

- A plan of care is developed by the physician, child or youth, and family
  - shared with other providers, agencies, and organizations involved with the care of the patient
- Care among multiple providers is coordinated through the medical home
- Families linked to support groups & other family resources
- A central record or database containing all pertinent medical information
  - hospitalizations and specialty care
  - maintained at the practice
  - accessible, but confidentiality is preserved

# Coordinated 2

- The medical home physician:
  - Shares information among the child or youth, family, and consultant
    - provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.
  - Upon referral, assists the child, youth and family in communicating clinical issues
  - Evaluates and interprets the consultant's recommendations for the child or youth and family
    - in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.
- Care plan is coordinated with educational and other community organizations
  - to ensure that special health needs of the individual child are addressed

# Compassionate

- Concern for the well-being of the child or youth and family
  - expressed and demonstrated in verbal and nonverbal interactions
- Efforts are made to understand and empathize
  - with the feelings and perspectives
    - of the family
    - of the child or youth

# Culturally Effective

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

Non-Ideal Medical Home

# 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 and family
- Efficient use of limited resources
- Increased professional satisfaction
- Increased wellness resulting from comprehensive care

# Who needs a Medical Home?

- Medical homes are especially important for **children with special health care needs** and their families.

- However, all children benefit from coordinated, family-centered care.

# Children with Special Health Care Needs

- Children 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.
- From DHHS, Maternal Child Health Bureau,1997
  - Adopted by the AAP six years after the medical home concept
    - McPherson M, Arango P, Fox HB, A new definition of children with special health care needs. Pediatrics 1998; 102:137-140
- Broad Definition
  - covers asthma, diabetes as well as genetic disease

Medical Home Construction?

# A Home Under Construction

- Assuring that all children with chronic health care conditions or disabilities have a medical home by 2010 is a goal for:
  - the US Maternal and Child Health Bureau
  - the American Academy of Pediatrics
  - each state's Department of Health or Maternal-Child Services
- Families can accelerate the building schedule
  - Individually
  - As community members

# A Trusting Partnership

- Involves the child or youth, his or her family, primary care physician, and other health professionals
  - based on mutual responsibility and respect for each other's expertise
- Partners share complete information with each other
- Together, families, health care professionals and community service providers identify and access all medical and non-medical services needed to help the child and family

# Different Expertise

- Family - valued & supported in their roles
  - as primary care giver
  - expert on their individual child.
- PCPs bring experience with larger numbers of children
  - with similar conditions
  - medical expertise
  - help families understand and integrate recommendations from a variety of health care providers

# PCP Roles

- The primary care practice (PCP's office) serves as the "home" where the family and child or youth:
  - Feel recognized and supported
  - Find a centralized base for their medical care
  - Find connections to other medical and non-medical community resources

# Recommendations for PCP

- Use evidence-based practice guidelines
- Should co-manage care with specialists
  - All children need a PCP!
- Have an information exchange method
  - MD to MD
  - MD with family
    - fax-back, email, web-based systems
- Have a Clinical Information System
  - Identify C/YSHCN (key indicators/problems)
  - Use a registry to enroll identified CSHCN, use visit reminders, to support care planning process and monitor care needs

# Medical Record

- Problem List - conditions or diagnoses
  - How diagnosed (key tests)
  - Active or Resolved Problem?
    - When (Start and end)
  - Allergies
  - Medications
- Providers
  - Therapists, Dietitians, Physicians
- DIET
- Social Risks
- Growth Chart(s)

Modified from AAFP guidelines

# Care Model for Child Health in a Medical Home

- Not all PCP's practices are excellent medical home builders
- Target areas have been identified for PCPs
  - Community
    - Meet with community partners (e.g. "lunch & learn" time)
    - Catalog community resources and contact persons
      - update this list
  - Health System and $
    - Get health care leadership to commit to have quality standards in place
      - to meet the needs of CYSHCN & families
    - Establish plan to maximize reimbursement for medical home visits/services

# Improvement by Partnership

- Parents as partners at the practice level
  - Develop a care planning process
  - Families are expected to plan with your PCP
- Delivery
  - PCP's office need to develop a strategy and identify specific roles for care coordination and communication
    - Whose job is it?
  - Use planned visit encounters
    - May mean more visits
    - May mean longer visits
    - Separate MD and family agenda at a given visit

# Limited Time and Resources

- Families
- PCPs
- Specialists
- Public Organizations
- Community Resources

- Need strategies to maximize the benefit to the children for the time and financial investment

# Delegated Team Coordinator

- Know the family
- Know the available resources
- Anticipate usual and unusual issues
  - Non-standard ‘well care’
    - Scheduling of  subspecialist appointments
    - Coordination of testing or painful procedures
    - Office accommodations and waiting times
    - Inpatient and outpatient care
- Currently not well reimbursed by third party payers

Burg-Eltz, Germany

# Family Roles

- Be pro-active!
- Get organized
  - You should receive lots of information
    - You know lots of important information
    - Can you quickly find that information?
- Ask questions
- Anticipate situations
  - Going to a school 6 months in advance
  - Look for new PCP before moving (if possible)

# Care Organizing Tools

  - To keep track of important information
  - Easier to find and share key information with their child's care team.
- Care Notebook - a 3-ring binder
  - With supplies that make it easier to find information quickly.
  - Plastic pages that hold business cards
  - Several pocket dividers that hold papers
  - Also contains forms that families may fill in
- Care Organizer
  - plastic expanding file folder with individual pockets labeled to help organize paperwork

# Parts of A Care Notebook

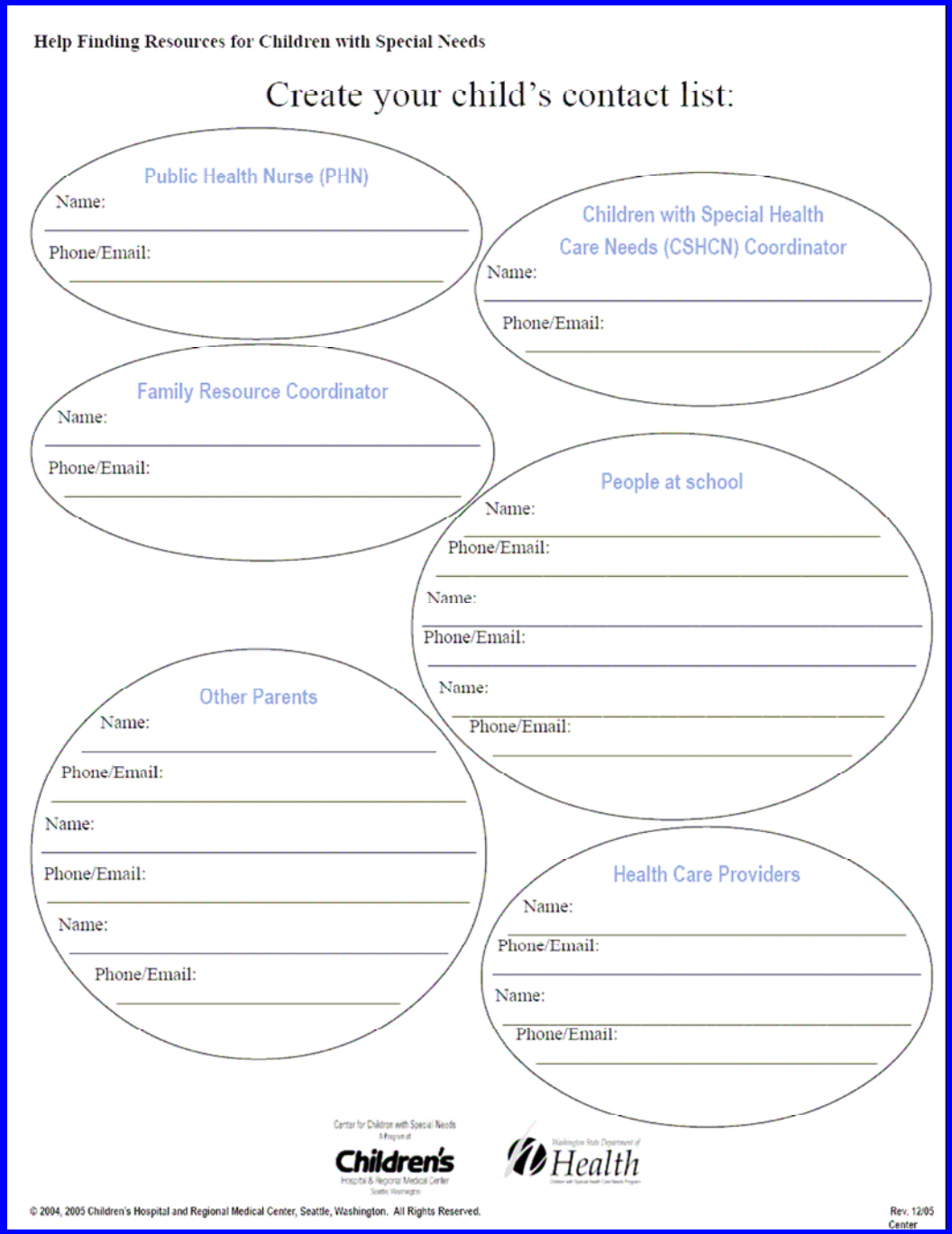
- Index
- Acronym List or Glossary
- Calendar Pages
  - Appointments
- Diet Tracking Form
- Equipment/Supplies
- Growth Tracking Form
- Hospital Stay Tracking Form
- ***Emergency Information Form***
- Tests/Procedures
  - What and results
- Medical Bill Tracking Form
- Medications
- Notes
- Care Summary:
  - Abilities & Special Care Needs
    Activities of Daily Living
    Care Schedule
    Child's Page - Now & Later
    Communication
    Coping/Stress Tolerance
    Mobility
    Nutrition
    Respiratory
    Rest/Sleep
    Social/Play
    Transitions - Looking Ahead

# Other Pages: Create a Care Team and Resources List

- Children's Hospital or Regional Medical Center Information Form
- Local Hospital Information Form
- Travel Location Resources
- Other Special Resources for Children with Special Health Care Needs
- Community Health Care/Service Providers:
  - Medical/Dental
  - Public Health
  - Home Care
  - Therapists
  - Early Intervention Services
  - School
  - Child Care
  - Respite Care
  - Pharmacy
  - Special Transportation
  - Family Information
  - Family Support Resources
  - Insurance/Funding Sources

# Example of one possible page for a Care Notebook

Washington State Department of Health Children with Special Health Care Needs Program



Help Finding Resources for Children with Special Needs

Create your child's contact list:

Public Health Nurse (PHN)
Name:
Phone/Email:

Children with Special Health Care Needs (CSHCN) Coordinator
Name:
Phone/Email:

Family Resource Coordinator
Name:
Phone/Email:

People at school
Name:
Phone/Email:
Name:
Phone/Email:
Name:
Phone/Email:

Other Parents
Name:
Phone/Email:
Name:
Phone/Email:
Name:
Phone/Email:

Health Care Providers
Name:
Phone/Email:
Name:
Phone/Email:

Center for Children with Special Needs
A Program of
Children's Hospital & Regional Medical Center
Seattle, Washington

Washington State Department of Health
Children with Special Health Care Needs Program



Rev. 12/05
Center

# Planning Ahead

- Prevents some of the unexpected
- Care plans for well child

- Children get sick
- CSHCN may get sicker more quickly
- ‘Sick day’ action plans for families
- Emergency care plans (ECPs)
  - Action plans for families
  - Emergency letters for other providers
  - Emergency Information Sets or Forms

# CSHCN and Emergent Care

- When a crisis occurs, CSCHN access the emergency system
- Vulnerable because of a lack of access to information about their medical problems
  - Unfamiliar health care providers
  - Risk for suboptimal treatment
  - Delays in treatment and/or unnecessary tests
  - Sometimes serious errors
- Errors in medical management may stem from
  - failure to recognize hidden conditions
  - lack of familiarity with rare or complex medical problem
  - lack of prior knowledge of baseline physical findings
- Problem that can be solved

# Emergency Care Plan

- Formulation of ECPs advocated
  - by the Emergency Medical Services for Children (EMSC) program
    - through its Children With Special Health Care Needs Task Force.
- Many Federal programs adopted some form of medical passport or plan of care
  - Was specific to the goals of the program
  - Not universally accepted
- This effort is a more standardized but customizable approach
  - Endorsed by the AAP and American College of Emergency Physicians

# Emergent Care Solutions?

- Emergency information form (EIF)
  - Contains patient-specific information
    - Special physical findings or history
    - May be a clue for specific interventions
  - Essential diagnostic and therapeutic interventions
    - What labs to draw
    - What IV fluid to use
  - A ready personal reference for a CSHCN.
- Medical identification jewelry
- Electronic transmission system
- Potential to eliminate management errors in the care of CSHCN

# Emergency Information Form for Children With Special Needs

American College of Emergency Physicians*

American Academy of Pediatrics

| Date form completed | Revised | Initials |
|---|---|---|
| By Whom | Revised | Initials |

Last name:

**Name:** Birth date: Nickname:

Home Address: Home/Work Phone:

Parent/Guardian: Emergency Contact Names & Relationship:

Signature/Consent*:

Primary Language: Phone Number(s):

**Physicians:**

Primary care physician: Emergency Phone:

Fax:

Current Specialty physician: Specialty: Emergency Phone:

Fax:

Current Specialty physician: Specialty: Emergency Phone:

Fax:

Anticipated Primary ED: Pharmacy:

Anticipated Tertiary Care Center:

**Diagnoses/Past Procedures/Physical Exam:**

1. Baseline physical findings:

2.

3. Baseline vital signs:

4.

Synopsis:

Baseline neurological status:

*Consent for release of this form to health care providers

**Diagnoses/Past Procedures/Physical Exam continued:**

Medications: Significant baseline ancillary findings (lab, x-ray, ECG):

1.

2.

3.

4. Prostheses/Appliances/Advanced Technology Devices:

5.

6.

Last name:

**Management Data:**

**Allergies: Medications/Foods to be avoided** **and why:**

1.

2.

3.

**Procedures to be avoided** **and why:**

1.

2.

3.

**Immunizations**

| Dates | | | | | | Dates | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| DPT | | | | | | Hep B | | | | | |
| OPV | | | | | | Varicella | | | | | |
| MMR | | | | | | TB status | | | | | |
| HIB | | | | | | Other | | | | | |

Antibiotic prophylaxis: Indication: Medication and dose:

**Common Presenting Problems/Findings With Specific Suggested Managements**

| Problem | Suggested Diagnostic Studies | Treatment Considerations |
|---|---|---|
| | | |
| | | |
| | | |

**Comments on child, family, or other specific medical issues:**

**Physician/Provider Signature:** **Print Name:**



http://www.aap.org/advocacy/blankform.pdf

# Emergency Information Set

- Should be considered a part of the overall plan of service (component of medical home)
  - AAP Committee on Children With Disabilities
- Completed summary as a medical history
  - Child care, school, day camp, or resident camp
- Implementation of an EIS or ECP
  - By a pediatrician or other provider
  - Can be from specialist
  - part of a comprehensive Emergency Medical Services for Children program
  - will improve the ability to care for CSHCN

# Essential components of care plans

- Use of a standardized form
- A method of identifying at-risk children
- Completion of a data set by the child's physicians and other health care professionals
- Education of families, other caregivers, and health care professionals in use of the emergency plan
- Regular updates of the information
- 24-hour access to the information by authorized emergency health care professionals
- Maintenance of patient confidentiality

# What a Medical Home is Not:

# Are we making progress?

- 2010 is only a few years away
- Multiple agencies are heavily invested in making medical homes work
- Progress is being made
  - A series of targets with identified resources to help reach that goal
  - Assessment tools for the PCP
    - Medical Home Index
    - Medical Home Family Index

# Critical Indicators of Progress

- Early and continuously screening for SHCNs
- CSHCN will receive regular ongoing comprehensive care within a medical home
- Families of CSHCN
  - will participate in decision making at all levels and will be satisfied with the services they receive.
  - will have adequate public and/or private insurance to pay for the services they need.
- Community-based service systems will be organized so families can use them easily.
- Youth with SHCN will receive the services necessary to make transitions to all aspects of adult life

# Issues for the Future

- Electronic Medical Records
  - May help serve as ECPs
    - Not a national record
  - Possible better communication within a health care delivery organization
  - Flash drive personal medical records
- Maldistribution of Health Care Resources
  - Urban vs. Rural America
- Re-imbursement for time
  - Preventative medicine vs. crisis care
- Complete coverage for all children

California’s Governor’s Mansion

# Resources

- http://www.medicalhomeinfo.org/about/hp_2010.html
  - The concept and goal
- http://www.medicalhomeinfo.org/
  - American Academy of Pediatrics site
  - Links to the state programs for CSHCNs
- Support groups
- Your PCPs