



**Medical Home
Education Workgroup**

To participate, please call:
1/866-489-0573 (toll free)
At the prompt, enter
4545164

Agenda

Friday, June 13th 2008
11:00 – 12:30pm Central
12:00 – 1:30pm Eastern

1. Role Call & Introductions - Abby
2. Parent Co-Lead position - Barbara
3. Review of Previous Meetings - Abby
 - a. WG Charge and Year One Plan
 - b. Group Focus: Parent Education Materials
 - c. Rated and Revised List of Materials
 - d. Defined Medical Home & General Educational Objectives
 - e. Revisions to Family Guide to Michigan's Children's Special Health Care Services Program
4. Region 4 Family Guide Draft #1 Overview - Jane
5. Adapting medical home materials to address the needs of children with heritable disorders in Region 4 (See **Education Plan**)
 - a. Resources currently available on the Region 4 Website
 - i. Specialist maps
 - ii. ACT sheets (NBS disorder specific information)
 - iii. Links to NBS programs in Region 4 states
 - iv. State specific parent support resources
 - b. What information specific to genetics do parents want?
 - c. What information specific to Region 4 do parents want?
6. Year 2 Conference call schedule
7. Regional meeting

Materials

Region 4 Family Guide Draft #1
Education Plan



Medical Home Education Work plan

Goal: Educate primary care providers, specialists, and families about the importance of providing a medical home for children with heritable disorders.



A. Year One Goal: Identify, review and select existing initiatives and materials to educate Region 4 families and providers			
Objective	Who	What	When
1. Identify existing training initiatives and materials	MPHI	Conduct Internet research	December 2007
	Group	Provide input re: state initiatives	
	Group	Provide existing State materials	January 2008
	MPHI	Compile and distribute list of materials/initiatives	
2. Develop criteria for assessing materials (quality, cost, feasibility, adaptability)	Group	Discuss existing materials	February 2008
	Co-chairs/MPHI	Research assessment tools	
	Group	Brainstorm assessment criteria	
	Co-chairs/MPHI	Develop/modify assessment tool	
3. Review training initiatives/materials based on established criteria	Group	Review and finalize assessment tool	March 2008
	Co-chairs/MPHI	Assess materials using assessment tool	
	Group	Compile/summarize reviews	
4. Identify the best methods to disseminate information (on-line course, face-to-face training, individual consultation, etc.)	Group	Refine list of materials and training initiatives	April 2008
	Co-chairs/MPHI	Literature review (training and dissemination)	
	Group	Review literature summary	
	Group	Determine best methods for each target group	
5. Develop Region 4 education plan	Co-chairs/MPHI	Summarize group recommendations	May 2008
	Group	Draft education plan	
	Group/co-chairs	Provide input on education plan	
B. Adapt medical home materials to address the needs of children with heritable disorders in Region 4	Group/co-chairs	Adopt finalized education plan	Year 2
	Group	Provide input on education plan	
	Group/co-chairs	Adopt finalized education plan	
C. Share adapted materials with region 4 partners, other regions, and national audiences			June 2008
D. Provide educational opportunities in Region 4			
B. Adapt medical home materials to address the needs of children with heritable disorders in Region 4			Years 2-5
C. Share adapted materials with region 4 partners, other regions, and national audiences			
D. Provide educational opportunities in Region 4			

Introduction	2
Medical Home	2
Information & Resources	3
<i>Overview of CSHCN in each Region 4 State</i>	3
<i>Michigan: CSHCS Information and Resources</i>	3
Insurance Coverage	4
Building Health Partnerships	4
Choosing a Doctor.....	4
Creating a Relationship	5
Practicing Good Communication	5
Deciding to Change Doctors	6
Getting the Most Out of an Appointment	6
Care Coordination and the Medical Home	8
Individual Care Plans	8
Parent to Parent Tip!	8
Looking Ahead	9
What is Medical Transition?	9
What families can do to prepare.....	9
Youth as managers of their own health care	9
How teens can prepare	10
Parents as managers of an adult child’s health care	10
Guardianship and Alternatives	10
Definitions	12
Reproducible forms, tools, and checklists	13

Introduction

*Letter from a parent, parent quotes, parent stories?
What will this guide do?*

Medical Home

Michigan and other states across the nation are aiming to fulfill the national Healthy People 2010 public health objectives. One is to assure access to a medical home for children with special health needs. Read details at an American Academy of Pediatrics website: www.medicalhomeinfo.org. A medical Home is not a place or location; it is a way your physician should provide care that is:

Accessible

Care is provided in the child's community

Family-centered

Recognition that the family is the principal caregiver and the center of strength and support for children

Continuous

Same primary pediatric health care professionals are available from infancy through adolescence

Comprehensive

Healthcare is available 24 hours a day, seven days a week

Coordinated

Families are linked to support, educational and community-based services

Compassionate

Concern for the well being of the child and family is expressed and demonstrated

Culturally competent

Family's cultural background is recognized, valued and respected

Source: *What Is A Medical Home? And What Does It Mean For You and Your Child?* University of Illinois at Chicago, Division of Specialized Care for Children, publication 40.16, 2003.

*What are the benefits of a medical home?
What can I expect from a medical home?*

Information & Resources

Parent support resources

Overview of CSHCN in each Region 4 State

Michigan: CSHCS Information and Resources

CSHCS information and emotional support for parents are available to all Michigan families of children with special needs. Enrollment in CSHCS is not required to access the following resources:

- Family Center
- CSHCS Family Phone Line
- Parent-to-Parent Support
- Conference Scholarships
- Children with Special Needs Fund
- Relatively Speaking Conference

The Family Center for Children & Youth with Special Needs (FC), a section of CSHCS, gives parents a voice in CSHCS programs and policy making. Most Family Center staff members are parents of children with special health needs. They and other parents of children with special health needs have formal roles in CSHCS. FC staff also runs the Family Support Network of Michigan and administers parent conference Scholarships and conference scholarships for youth and young adults with special needs.

CSHCS Family Phone Line operators help families understand and navigate the CSHCS process. By calling 1-800-359-3722, families can get answers to questions such as:

- Has my child been found eligible for CSHCS?
- Has the medical report been received?

The phone line staff also helps families find general information concerning children with special needs. Families who do not speak English may ask for an on-the-phone interpreter when they call. Families can be transferred toll-free to any CSHCS office.

Family to Family Support Network of Michigan (FSN) CSHCS's parent-to-parent support arm is the *Family Support Network of Michigan (FSN)*. It is open to all families who have children with special needs. FSN helps families come together for information and emotional support. FSN provides:

- Parent support groups

- One-to-one support by trained volunteer parents
- Information about programs for brothers, sisters, mothers, fathers, and grandparents
- Family social events
- Information about local, state, and national resources

Insurance Coverage

Medicaid

SCHIP

CSHCN

Other?

Building Health Partnerships

The parent professional partnership and the medical home
What is the parent/professional partnership?

Adapted from ***Tips from and for Parents: Building Early Intervention Partnerships With Your Child's Doctor*** Washington State Department of Social and Health Services
www1.dshs.wa.gov/iteip/Publications.html

There are many steps you can take to create the type of partnership and relationship that you want with your child's doctor*. Below are ideas for starting or improving a partnership. For ease, the word "doctor" is used. These ideas also apply for nurse practitioners, physician's assistants, and other health providers.

Choosing a Doctor

AAP Online Pediatrician Search?

Here are general qualities to seek:

Clinical skills and knowledge

Does he or she have the training and specialty interests important to your child's needs? A doctor with a special interest in child development, special needs or a specific diagnosis might be just right.

Experience

Has the doctor cared for other children who have a similar diagnosis as your child or for children with developmental delays or disabilities in general? That kind of experience can help your doctor to be more aware of resources and services that might benefit your child and family.

Mutual respect and sense of connection

Is he or she approachable? Does she or he make you feel comfortable? Do you like the interactions with your child? Do you trust the person with the health of

your child? A doctor may be better in one area than another. Choosing a doctor may mean choosing a balance between technical skills, interpersonal skills and experience. It's up to you to decide what you and your child need right now. You may find that what you need changes over time.

Creating a Relationship

Be a partner

Decide what type of partnership you want with your child's doctor. How do you want him or her to be involved in coordinating care and services for your child? What role do you want in making medical and health decisions? Whatever type of partnership you have, you should feel comfortable asking questions, sharing your insights, and feel like you and the doctor are part of a team. In turn, you should be open to the doctor's questions and insights and accept him or her as part of your child's team.

Be a role model

Show by example how you want to be treated and how you want your child to be treated. If you want the doctor to listen to you, then be a good listener, too. If you want your doctor to be delighted with your child, then show your delight in your child.

Be understanding

Doctors often must have appointments back-to-back, every 15 minutes or even sooner. If it seems that the doctor is in a hurry to move on to the next appointment, you are probably right! If you need more time, let her know and she should be willing to work this out. Let the doctor get to know your whole child. Talk about the good things as well as your concerns. Share pictures and stories so he or she can appreciate and get to know your child.

Express gratitude

Say thank you, in person or in writing. Let your doctor know what is helpful and when he or she is doing a good job

Don't expect perfection

Every relationship has bumpy times and so will this one. Be willing to make changes, if needed. Recognize that doctors are human, too, and give him or her the chance to make things better. If you are mostly pleased with your child's doctor, then it may be worth working through rough times.

Practicing Good Communication

A two-way conversation

Think of communicating with your doctor as having a friendly, respectful conversation. That means it is two-way and both of you should share your questions, concerns, successes, and hopes.

Get clear about how to communicate

Ask your doctor how to best communicate about your child's care. Is there a good time during the day to call? Does she or he prefer that you first talk to the office nurse if you have questions between appointments? Are there ever situations when the doctor would want you to call him or her at home? Does your doctor welcome communication via email? How about fax?

Feel okay about needing advice between appointments

If you have a concern between appointments and feel that you need or want an answer from your child's doctor, ask the nurse to have him or her call you. Explain that you are more worried than usual – for reasons you may not be able to explain just yet – and that you would really appreciate talking directly to him or her.

Reflecting

Were you able to discuss your most important questions or issues? If not, is this okay with you or is there a plan for how you will get the information you need? Did you feel like a partner in your child's health care team? Is there something you might want to do differently next time?

Deciding to Change Doctors

Parents are often pleased with their child's doctor. But sometimes things just don't feel right. Here are questions to ask yourself:

- Does the way the office is run work for you?
- Is the doctor available when you need him or her?
- Are you often confused about recommendations and why certain treatments are prescribed?
- Do you feel like your concerns are not taken seriously?
- Does this make you question and doubt your instincts or your doctor's?

Trust your gut. If the relationship doesn't feel right and you haven't been able to make it better, then know that it is time to change doctors. Try to do it in a positive way. *"Thanks for all you've done for my child. We really appreciate the time you have spent with us. But right now this is not the perfect fit for our family – I would like my child to see someone else."*

Getting the Most Out of an Appointment

Scheduling

To cut down on waiting time, schedule the doctor's visit for the first appointment of the day or right after lunch. If you have questions or concerns that may take

more time than usual, ask the office staff to schedule a longer appointment. Your doctor and staff will appreciate the advance notice and you will feel less frustrated about not having enough time.

Preparing

Think about what you would like to get out of the appointment ahead of time: Gather reports that you especially want to discuss. For children getting *Early On* services, be a link between the doctor and the program. Share questions and concerns back and forth.

Make a list of your questions, concerns and other information you would like to share. It is okay to bring up things that don't seem related to health but still matter to you and your child. Decide what on your list is the most important to you.

Ask the doctor if he or she would like a copy of your questions and concerns ahead of time. Emailing, faxing or dropping your list off before the appointment might give more time for the doctor to prepare more complete responses to your questions.

Participating

Share your list of questions and concerns at the start of the appointment. The doctor likely has his own list for what he needs to accomplish during the visit. Together you might need to decide what to discuss during this appointment and what to discuss later.

Things can move so quickly during appointments that it can be hard to remember all that is said. Here are some ideas to help with remembering:

- Take notes. Use the same notebook to write down your questions and the answers at each appointment. This will make it easier to keep track of all the information over time.
- Bring someone along who can help listen and take notes – and be there to support you, if needed.
- Sometimes you might need to get the conversation back to your concerns. Here are ways to do that:
 - Ask questions: What do you suggest about...?
 - Tell a story about something going on in your child's life that you want to discuss.
 - Simply change the topic: *"One other thing I would like to talk to you about is..."*
- If your doctor gives you information that is upsetting or hard to understand, ask if you can call later to go over your questions.

Updating

Tell your doctor about your child's progress. Ask questions and share any concerns. A fun and memorable way to update a doctor is to send an occasional picture of your child with a note highlighting his or her progress.

"Here is my daughter having fun at dinnertime. Through Early On, I learned how to encourage her to eat more table foods. She doesn't gag and cry at the sight of food anymore and I'm not so worried about her growth. Early intervention helped me have a better relationship with my daughter and helped my family, too – mealtimes are no longer a battle. Thanks for the referral"

Care Coordination and the Medical Home

What is care coordination?

What is a care plan?

Individual Care Plans

Types of Care Plans

Care Plan Options (Web-based, Emergency, Paper, etc.)

Parent to Parent Tip!

One thing parents always recommend to other parents of children with special needs is to stay organized. A really great tool for organizing care is an individual care plan. Your care coordinator may refer to this as a "Plan of Care." Your care coordinator can help you develop a written care plan. Typically, it lists the member's:

- health problems
- upcoming tests or procedures,
- providers,
- health care services and equipment, and
- treatment plan with expected outcomes.

You also may want your care plan to note what is covered by Medicaid or by your private health insurer.

You can use the care plan to keep track of all of your providers. It's a good idea to share copies with your doctors so they each have a full picture of your child's treatment. Keep a copy with you when you go to the hospital or to a new provider to make the admission or intake interview easier.

To get started, think about the questions below:

- Do you need more information about your or your child's medical condition or treatment?
- Which specialists will you or your child see?
- Are the specialists already CSHCS-approved providers? If not, what are your options?

- What therapies are needed?
- What prescription medications do you or your child use?
- Is equipment needed, such as a wheelchair, braces, oxygen, etc?
- Do you need help with transportation to medical appointments?
- Is surgery a possibility?
- Do you have a plan for emergency care?
- Are medical or health services needed at school?
- Do you need medical documentation for an Individualized Education Plan (IEP) meeting?
- Does a caregiver need training for any medical treatment to be given?
- Do you need CPR training?
- Would you like to speak to another parent of a child or youth with special health care needs?

Looking Ahead

What is Medical Transition?

Medical Transition is the time when teens move from pediatric services to adult services. This may mean seeing new health care providers. It also may mean using adult health care coverage.

Often, transition into adult services is stressful for families. Your son or daughter may fear making health decisions. You may fear losing input into complex medical care. Or, you may need to take legal steps to make decisions for your adult child. In either case, medical transition can be challenging.

What families can do to prepare

- Plan early. The move to adult care may not happen until age 18, 21 or even older. It is still important to plan ahead. Planning for educational transition begins around age 14. That is also a good time to start planning medical transition.
- Find out about adult providers in your area. Research adult services. Research your child's options for health care plans. Find out when it is time to make the transition into adult care. Pediatric providers and CSHCS representatives can help.
- Talk to your child's pediatric providers. Get referrals for adult providers. Find out what adult services they may be eligible for at age 18. Your local health department can help with referrals and information on services.
- Choose whether you or your child will manage his or her care or if you will share responsibility

Youth as managers of their own health care

For teens to become independent adults they need family members to take less active roles in their medical care. In this way they gain independence and skills.

To plan for and assist in medical transition, families can:

- Provide your child the opportunity to meet with health care providers in private.
- Let them ask questions about their health. This will allow your son/daughter to gain important skills in managing their own care.
- Encourage your child to learn about their medical condition(s). They should know what they are going to the physicians for. They should know basic information about their condition. If taking medications, they should know the names of medications. Also, why they take them.

How teens can prepare

This is an important time in your life. Here are tips on medical transition:

- Learn about your health care needs.
- During appointments with your physicians, spend some time alone with them. Ask questions about your health. Or, ask anything else you want to know.
- Be involved. Try to plan your next doctor's visit. Make sure that physicians and other adults talk directly to you. Don't be afraid to ask questions about your care!

Parents as managers of an adult child's health care

Many youth with special health care needs may need assistance with care into adulthood. Below are tips on what parents and family members may do to prepare for medical transition.

- Include your son or daughter in their care as much as possible.
- Have medical information readily accessible to your family and to providers. That guarantees information is on hand even when you are not near

Guardianship and Alternatives

At age 18, a teen becomes his or her own guardian. Some youth are unable to handle that. If so, you may face tough legal choices. Questions to ask yourself are:

“What are my main concerns for my child's future? Are they financial, medical, or emotional concerns?”

“What decisions will my child be able to make on his/her own?”

“What decisions will my child need assistance making?”

Think about what you would like to secure for your child's future. Below is a list of choices a family may consider. The list does not include all options. Other choices may be best for your family.

Full Guardianship provides full decision making rights to an appointed guardian.

Partial Guardianship provides rights in certain areas of decision making to an appointed guardian.

Durable Power of Attorney allows health care decisions by an appointed guardian. Power of Attorney can cover other decisions.

A Patient Advocate acts for the individual receiving care. Most hospitals and providers have information on this choice. The appointed individual might be a family member or friend.

In a **Conservatorship** an appointed individual manages a person's finances.

A **Representative Payee** manages the finances of a person with SSI or SSDI benefits. Applications and help are available at local Social Security Administration offices.

Many of these actions must be done through the court system. Start exploring them at least by the time your child turns 17. There may be legal and court fees for each. Seek qualified legal counsel. For more resources, contact local human service agencies or the local health department.

Definitions

What needs to be added?

Acute : A condition that happens suddenly and lasts a short time. It is the opposite of “chronic.”

Children’s Special Health Care Services (CSHCS): A program within the Michigan Department of Community Health which helps children and some adults with special health care needs, and their families. One way that it helps is by covering costs of specialty care associated with their CSHCS covered condition.

Chronic: An illness or condition that slowly persists or progresses over a long time. It is the opposite of “acute.”

Diagnosis: The name of a condition or illness. To qualify for CSHCS, an individual must have a diagnosis where activity is or may become so restricted by disease or deformity as to reduce normal capacity for education and self-support. CSHCS can cover more than one diagnosis per person.

Diagnostic Evaluation: The process of identifying a disease or condition from its signs and symptoms; a careful examination of facts to try to understand or explain the cause of an illness.

Disability: The result of any physical or mental condition that affects a person’s ability to develop, achieve or function.

Early On (Part C of IDEA): A program for Michigan infants and toddlers through age 36 months who have special needs and their families. The Michigan Department of Education coordinates it. However, early intervention services it provides come from many different agencies, programs and professionals in each community. For details call 1-800-Early On (1-800-327-5966).

Health Care Professionals: Workers who have special health care skills. They include nurses, doctors, social workers, physical therapists, pharmacists and so on.

Health Maintenance Organization (HMO): A medical insurance program which gives care through specified doctors and hospital

IDEA: Individuals with Disabilities Education Act. A federal law authorizing special education for children.

Local Health Department: The local county office where one or more CSHCS representatives are located. This office can provide free or low-cost basic medical care and other health-related services.

Medicaid: Federal and state health care coverage for low-income or medically needy individuals and working families that qualify.

Occupational Therapy: Treatment to help a person develop mental or physical skills to aid in daily living. It focuses on hand and finger movement and self-help skills, such as dressing or using a fork and spoon.

Pediatric: The branch of medicine dealing with the care of children.

Pediatric Specialist: A physician specialist who has a specialty area of knowledge, skills and training, to treat children.

Pediatrician: A doctor who specializes in caring for children.

Physical Therapy: The treatment of disease by physical and mechanical means, such as massage, regulated exercise, water, light, heat, and electricity.

Primary Care: General or basic health care. Traditionally provided by a pediatrician, internist or family practitioner.

Primary Payer: The company or organization that must be billed first for CSHCS-covered services before CSHCS will consider payment. By law, CSHCS is always the last to pay.

Prior Approval: The CSHCS process which gives a provider approval to provide certain services or equipment, as needed

Provider: A person, organization or company that provides medical care, medications, medical supplies or equipment.

Respite: A temporary period of rest or relief for caregivers that provide daily care to an individual enrolled in CSHCS.

Severity of condition: The rating by a MDCH medical consultant of the need for specialty medical care. The decision is whether care would prevent, delay or significantly reduce the risk of activity becoming so restricted by disease or deformity as to reduce the individual's normal capacity for education and self-support.

Specialist: A medical practitioner whose practice is limited to a particular class of patients (such as children) or of diseases (such as skin diseases) or of technique (such as surgery). Typically, a specialist is qualified by advanced training and certification.

Sub-specialist: A physician who has a *subspecialty*, meaning a narrower field of specialization. For example, pediatric cardiology is a *subspecialty* of general cardiology.

Support Parent: A parent of a child with special needs who gives one-to-one support to other parents.

WIC (Women, Infants and Children): A program that provides supplemental nutrition, breastfeeding information, and other resources to foster healthy mothers and babies.

Sources: MEDLINEplus, a service of the U.S. National Library of Medicine and the National Institutes of Health, and CSHCS

Reproducible forms, tools, and checklists

What else should we include in this section?

All About My Child

Child's Information

Name: First _____ Middle _____ Last _____

AKA _____
(Also Known As) (If child uses two different last names, please include)

Nickname: _____

Address _____ City _____ State _____ Zip Code _____

Phone: (_____) _____

Date of Birth: Month _____ Date _____ Year _____ Blood type: _____
.....

Diagnosis: _____

Special Care Instructions: _____

Current Medication(s)	Dosage and Administration
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Allergies: _____
.....

Child's Preferred Language: _____

Child's Ethnicity: _____ Religion : _____
(race)

Parent(s)/Primary Caregiver(s) _____

Address _____ City _____ State _____ Zip Code _____

Family's Preferred Language: _____

Phone: **Mother** Home (____) _____ Work (____) _____ Cell (____) _____

Father Home (____) _____ Work (____) _____ Cell (____) _____

Primary Caregiver Home (____) _____ Work (____) _____ Cell (____) _____

Family's religion and/or customs that may affect the medical treatment or health care of _____
(child's name)

Special Dietary Needs (Kosher, Vegetarian, etc.):

What to AVOID!
(food, dust, animals, etc.)



Goal: Educate families about the importance of medical homes for children with heritable disorders

- Revise medical home materials to address heritable disorders
- Distribute materials and/or provide training opportunities in each state

	Example(s):
<p>1. Educational Objectives</p> <p>Medical Home What do parents want to know about medical home? What content will we cover? What resources or tools are important?</p>	<p>1. Medical Home</p> <p>a. <i>What is a medical home?</i></p> <p>b. <i>What are the benefits of a medical home?</i></p> <p>c. <i>What can I expect from a medical home?</i></p> <p>2. Working with physicians</p> <p>a. <i>What is a parent/professional partnership?</i></p> <p>b. <i>What is my role as a parent?</i></p> <p>c. <i>How do I communicate effectively with my physician?</i></p> <p>3. Care coordination</p> <p>a. <i>What is care coordination?</i></p> <p>b. <i>What is a care coordination plan?</i></p> <p>4. Parent support resources</p> <p>5. Reproducible forms, tools, checklists (record keeping, etc.)</p>
<p>Region 4 & Heritable Disorders What do parents want to know about genetics/genetic conditions? What state specific information will we cover?</p>	<p><i>Region 4 Website</i> <i>FAQ's about Genetics</i> <i>Newborn Screening Fact Sheets</i> <i>Region 4 Specialist Map</i></p>
<p>2. Target Group</p> <p>Who is the intended audience?</p>	<p><i>Families of children with genetic conditions in Region 4 States</i></p>
<p>3. Educational Materials</p> <p>What written materials will be used to educate parents?</p>	<p><i>Brochures (Title)</i> <i>Website (Title)</i> <i>Poster (Title)</i> <i>PowerPoint Presentations (Title)</i></p>
<p>4. Point in Time</p> <p>At what time will parents benefit most?</p>	<p><i>Parents need to have everything at time of diagnosis</i> <i>Information should be made available on an ongoing basis so that parents can access it as they need it</i></p>
<p>5. Method of Dissemination</p> <p>How will the materials get to our target group?</p>	<p><i>Web-based</i> <i>Email list</i> <i>Conferences</i></p>
<p>6. Training Methods</p> <p>What training methods will be employed?</p>	<p><i>One-on-one (parent mentoring, nurse coaching)</i> <i>Group presentation</i> <i>Online Training Module</i></p>
<p>7. Partnerships</p> <p>What other groups will we need work with in order to accomplish our goals?</p>	<p><i>Parent advocacy groups</i> <i>Genetics organizations</i> <i>Physician groups</i></p>
<p>8. Evaluation Strategies</p>	