



Partnering with your Doctor

The Medical Home Approach

A guide for families with children who have genetic conditions



Region4
Genetics Collaborative



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ACKNOWLEDGEMENTS

Thank you to the families and Region 4 Genetics Collaborative Medical Home Education Workgroup members who contributed their time and effort to produce this helpful guide. The information and resources are intended for educational use only and are provided solely as a service. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care.

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The Region 4 Genetics Collaborative is funded by Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) Cooperative Agreement U22MC03963.

INTRODUCTION

Partnering with your Doctor: The Medical Home Approach is a guide that is intended to help you and your family connect with your doctor, other medical professionals and caregivers through a medical home.

The purpose of the Guide is to help you and your family care for your child with a genetic condition. **Some information in the guide might be helpful now, while other sections will be useful in the future.**

The Guide is intended to be a user-friendly, hands-on tool to support families of children who have genetic conditions to move forward in obtaining and providing a medical home for their children. This guide provides definitions, examples and tools for families to use when working with the doctor to develop a medical home.

The Guide is designed to:

1. Be a source of specialized information for parents to help them care for their child
2. Provide a detailed definition and description of the medical home concept
3. Lay the foundation for understanding and advocating for a medical home
4. Provide tools and examples for parents to use and learn from while creating and maintaining the medical home with their doctor
5. Bring attention to the importance of linking families of children with genetic conditions to a medical home
6. Provide advice on how to effectively partner with your child's doctor
7. Define family centered care and demonstrate how it benefits families
8. Demonstrate how to seek culturally effective, compassionate care
9. Assist families through the transition process by providing resources and tips
10. Provide a list of resources and links to organizations that support families and the medical home concept

To request additional copies of the Guide, please contact Region 4 Staff via email at info@region4genetics.org or phone 517.381.8247. The Guide also may be downloaded as a PDF file free of charge from www.region4genetics.org.

Dear Families:

The birth of my twin girls was both a joyous and overwhelming experience. Dealing with the reality of one child being healthy and the other having birth defects created challenges that we were not prepared for. My daughter was born with a grouping of anomalies: a specific group called V-A-C-T-E-R-L. We didn't know she had VACTERL until all of the anomalies were identified during her 21-day stay in neonatal intensive care. It was hard to come to terms with the fact that our 3-pound, 9 ounce baby girl could have such a hard start at life from birth. We were determined to give her a full and happy life and began the medical journey to help her.

During the first year of her life, it was a struggle to keep up with all the appointments with specialists for her heart, kidney, lungs, legs, and back. I had returned to work shortly after my maternity leave ended only to resign eight weeks later. The twins needed more one-on-one attention both maternally and medically. There were 12 or more specialists that had to be seen separately. In addition to the specialists, she also was seen by public health representatives, we were involved in some community services available, and she had to see a few therapists for speech and physical therapy.

At each visit/appointment a history form had to be completed and I had to tell them all about her condition and her current status at the time. After a while it became a very robotic process. Not only was I providing information but, I also was receiving a wealth of information that needed further follow-up and created more office visits. Immediate family members also wanted updates on all of this. It was all exhausting and the medical journey became unmanageable at times.

My daughter's primary care doctor was helpful at making sure we had the necessary referrals to the specialists, but I felt that I was left to manage the rest. So, being the organized mother I am, I created a paper file for each representative, service, therapist, specialist, and so on. I also put all appointments on our family calendar. This was my only means to keep it all organized. This worked for many years but something was still needed. My daughter needed more comprehensive primary care. I wanted to be more of a valued partner to access and coordinate specialty care and community services that were important for my daughter's overall health and well-being.

I needed to be part of a Medical Home! I still do. I am looking forward to using this guide to expand my knowledge of what a Medical Home is, have access to resources in my state and nationally, and enhance my parent leadership skills to be a participant in a Medical Home.

Nancy (Mother of Audrey, Lucy and Maureen)

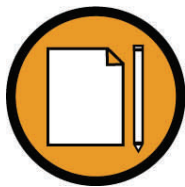
HOW TO USE THIS GUIDE

Each section of this guide describes an important component of the medical home. The sections have been assigned a color to keep the section material organized and easy to find.

-  **ACCESSIBLE CARE**
-  **CONTINUOUS CARE**
-  **COMPREHENSIVE CARE**
-  **COORDINATED CARE**
-  **COMPASSIONATE CARE**
-  **CULTURALLY EFFECTIVE CARE**
-  **FAMILY CENTERED CARE**
-  **ADVOCATING FOR YOUR CHILD**
-  **GLOSSARY**
-  **MEDICAL HOME RESOURCES**

Blue boxes titled “**Parent-to-Parent Tips**” are placed throughout the guide and showcase helpful hints and practical advice from parents who have children with genetic conditions.

Below are two icons you will find throughout the guide:



This icon designates a page that includes a tool or list of questions for you and your family to think about, fill out and possibly share with your doctor, other family members.



This icon indicates a tip or suggestion for you and your family to consider for a variety of situations, such as working with doctors, planning for life events and other potential situations.

THE MEDICAL HOME DEFINED

The [American Academy of Pediatrics](#) (AAP) describes the medical home as a model of delivering care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. The AAP has begun many initiatives to promote the adoption and spread of the medical home.

The AAP joined with the [American Academy of Family Physicians](#), [American College of Physicians](#) and the [American Osteopathic Association](#) to publish a set of principles on the medical home for doctors to focus on: personal physician, physician-directed medical practice, whole person orientation, coordinated care, quality and safety, enhanced access, and appropriate payment. The AAP developed an introduction to represent the specific needs of the pediatric population. The introduction describes the views of children and families, because every child deserves a medical home.

American Academy of Pediatrics Introduction to the Medical Home

Family-centered partnership: A medical home provides family-centered care through a trusting, collaborative, working partnership with families, respecting their diversity and recognizing that they are the constant in a child's life.

Community-based system: The medical home is an integral part of the community-based system. A family-centered, coordinated network of community services is designed to promote the healthy development and well being of children and their families. As such, the medical home works with a coordinated team, provides ongoing primary care, and facilitates access to and coordinates with, a broad range of specialty, ancillary and related community services.

Transition: The goal of transition is to optimize life-long health and well being and potential through the provision of high-quality, developmentally appropriate, health care services that continue uninterrupted as the individual moves along and within systems of services and from adolescence to adulthood.

Value: Recognizing the importance of quality health care, appropriate payment for medical home activities is imperative. A high-performance health care system requires appropriate financing to support and sustain medical homes that promote system-wide quality care with optimal health outcomes, family satisfaction, and cost efficiency.²

¹ American Academy of Pediatrics. Patient-Centered Medical Home Consensus statement. www.medicalhomeinfo.org/Joint%20Statement.pdf

² What is a Medical Home? National Center for Medical Home Implementation. www.medicalhomeinfo.org/

HAVING A MEDICAL HOME MEANS YOUR CHILD’S CARE IS: ³

1. Accessible

- Care is provided in your community
- The doctor’s office accepts your insurance
- The location meets [American Disabilities Act \(ADA\)](#) requirements
- Access to health advice or care is available around the clock, 365 days per year
- If needed, the office is accessible by public transportation

2. Continuous

- The same doctors are available from infancy through adolescence
- Communication occurs between doctors and specialists to ensure your child’s needs are met at any age
- Assistance is provided to secure a medical home for adolescents transitioning to adult care

3. Comprehensive

- Preventive and primary care is provided
- Growth and development assessments are conducted when appropriate
- Care coordination is emphasized and exercised between all doctors for your child
- Referrals to specialty care services are available and offered when needed
- Child/family counseling and health education are a part of visits or available upon request
- Your doctor is knowledgeable about community resources and shares information

4. Coordinated

- You and your family are linked to appropriate support, educational, and community services
- Your doctor’s office staff communicate and work with all agencies to ensure all your child’s needs are met
- A centralized record containing important information on your child’s care will be maintained by you, your doctor and his or her office staff

5. Compassionate

- Concern for the well being of your child and family as a whole is shown by the doctor
- The doctor shows understanding for the variety of emotions your family may have around having a child with a genetic condition
- Office staff are flexible and respond to requests and needs
- Office staff offer privacy when requested
- Appointment times are scheduled with consideration of you and your family’s needs

6. Culturally Effective

- Your family’s cultural background is recognized, valued, and respected
- Office staff are sensitive to stereotypes and cultural assumptions
- Multi-language materials and translation services are made available as needed

7. Family-Centered

- Office staff recognize that you and your family are the principle caregivers and the center of strength and support for your child
- Your doctor and family share the responsibility in decision making

³ Adapted from: What is a medical home? And what does it mean for you and your child? University at Chicago, Division of Specialized Care for Children, publication 40, 16, 2003.

SECTION 1: ACCESSIBLE CARE

WHAT IS ACCESSIBLE CARE?

Accessible care means having a doctor whose office is available, not only in terms of location, but also meets or exceeds the requirements of disability access. The doctor's office also accepts your insurance, and you have the ability to speak with your doctor when you need to. These are all important components to the structure of your medical home.

A medical home is not just an accessible building or hospital, but rather it is an approach to providing quality health care services. Your primary care doctor, specialists, and other health care professionals act as partners in a medical home to identify and access all of the medical and non-medical services needed to help your child. By working together and identifying barriers, your medical home is creating an accessible space for the care of your child.⁴

BENEFITS OF HAVING A MEDICAL HOME

1. You regularly see the same doctor and office staff who know your child and family. This doctor partners with you in coordinating care for your child and exchanges information with you honestly and respectfully as you learn from one another.
2. Your family feels supported in finding resources for your child's needs and challenges.
3. Your family is connected to information and family support organizations through your doctor's office.
4. Your medical home partnership promotes health and quality of life as your child grows and develops into an adult.

THE ROLES OF FAMILY MEMBERS IN THE MEDICAL HOME

You and your family are recognized as:

- **Constants** in the life of your child
- **Experts** in the individual strengths and needs of your child
- **Supervisors** of those who coordinate your child's care
- **Visionaries** who see the "Big Picture" for your child and his or her future

FAMILY REACTIONS TO THE CONCEPT OF THE MEDICAL HOME

"Sign me up! I'll take one!"

"Everything is at your fingertips that way—easy access."

"Something like this would take the weight off...you could relax a little..."

"It sounds too good to be true!"

"Complete care. Complete care that runs smoothly."

⁴ Adapted from the brochure **Medical Home: Families and Providers Working Together** - developed by the Washington Medical Home Leadership Network. <http://www.medicalhome.org/leadership/brochures.cfm>

SECTION 1: ACCESSIBLE CARE



A TIP SHEET FOR CHOOSING & WORKING WITH DOCTORS

Clinical Skills & Knowledge

Does the doctor have training and/or specialty interests important to your child's needs?

Selecting a doctor with an interest in children's special needs is a benefit.

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?

Experience can help your doctor to be more aware of resources and services that might benefit your child and your family.

Mutual Respect and Sense of Connection

Is the doctor approachable? Do they make you feel comfortable?

Choosing a doctor may mean finding a balance between technical skills, interpersonal skills and experience. It's up to you to decide what you and your child need right now and you may find that what you need changes over time.

Don't Expect Perfection

Every relationship has rough times. Be willing to be flexible, if needed.

Recognize that doctors are human too, and give them 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.

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, be a good listener, too. 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.

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 him or her know and maybe they would be willing to work it out.

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 decisions?

Whatever type of partnership you have, you should feel comfortable asking questions, sharing your insights, and feeling like you and the doctor are part of a team. In turn, you should be open to the doctor's questions and insights as part of your child's team.

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.

SECTION 1: ACCESSIBLE CARE



QUESTIONS TO ASK WHEN CHOOSING A DOCTOR

Use this sheet to “interview” potential doctors and their offices.

1. Does this office regularly see children with *(specify your child’s condition)*?
2. If no, ask: Do staff members have experience with children with genetic conditions?
3. What types of services does your office offer? Which are provided by physician and which by a physicians assistant or nurse?
4. What approach does the office take when multiple professionals are involved in the care of my child? *Example: Is there a team approach to care when other doctors, physical therapists, teachers or home care nurses are involved?*
5. Does your office have a care coordinator available? Or, is the doctor comfortable being my child’s medical care coordinator?
6. How many patients does your office see each day? How long does an average appointment take? How long does an expanded appointment take?
7. Which hospital(s) do you have admitting privileges to?
8. What is your telephone call policy? Do you give advice or refill medications over the phone? Are there ever situations when I should call the doctor at home?
9. Does your office communicate or respond to questions through email?

(Continue to next page)

SECTION 1: ACCESSIBLE CARE



QUESTIONS TO ASK WHEN CHOOSING A DOCTOR

10. Who will my child see after hours or when the doctor is on vacation?

11. Does the office accept (name of your insurance, Medicaid, etc.) for payment of services?
Does the office bill my insurance company directly?

12. What is the average cost of an office visit? If the office charges are above what my insurance considers to be “reasonable” are you able to waive the remainder of the balance?

13. Where are tests and lab work done?

14. Is the doctor comfortable discussing alternative treatment such as the use of homeopathic treatment?

15. Does the doctor allow a parent to make an appointment specifically to ask questions and discuss a plan of care?

16. How would the doctor feel if I ever asked for a second opinion?

17. Does the office have a specialist referral list available?

18. Other Questions?

SECTION 1: ACCESSIBLE CARE



DECIDING TO CHANGE DOCTORS?

Parents are often pleased with their child's doctor, but sometimes things just don't feel right and your desire to be part of a medical home is not getting through to your doctor. Here are some questions to ask yourself if you are feeling uncertain about the quality of care your child is experiencing.

1. Does the way the office is run work for you?
2. Is the doctor available when you need him or her?
3. Are you often confused about recommendations and why certain treatments are prescribed?
4. Do you feel like your concerns are not taken seriously?

Remember: Trust your own judgment and view yourself as an expert on your child

If these questions make you 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 consider changing doctors.

Parent-to-Parent Tip

Try a positive approach through phone call or written note.

Example: "Thank you for all you have 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."

SECTION 2: CONTINUOUS CARE

Continuous care is a treatment model that informs the doctor of all the child's other medical visits, procedures and prescriptions so they can provide the best care possible. Your child may need to see a variety of doctors to ensure all of his or her special needs are being monitored, addressed and cared for. Continuous care promotes keeping your primary doctor up to date and aware of other medical consults and procedures.

As your child develops and grows, the need for him or her to see an adult-oriented doctor may become necessary. With the help of your medical home, this process will not be a surprise. Your child's doctor will be involved in the transition towards adult medical care and will work with you to ease concerns, answer questions and prepare you and your child for this next step.

Parent to Parent Tip!

When thinking about how your doctor offers continuous care, make sure you understand and are aware that offering 24/7 care does not mean it all has to be done by one doctor. Make sure you know the policies of the doctor's office, and who will be caring for your child if the primary doctor is out of the office. Make a note of this secondary doctor in your care plan.

WHAT IS MEDICAL TRANSITION?

Growing up is not always easy for children and it can be hard on parents, too. When your child has a genetic condition, growing up may be more complicated. Still, many parents of children with a genetic condition find it helpful to remember the "bottom line": you want your child to be as independent as possible. Independence in adult life (health care, employment, living, and recreation) takes preparation. The process of growing up and becoming independent is sometimes called "transition." The term refers to transition from adolescence to adulthood and is often used when your child is:

- Learning to be more independent
- Learning to manage his or her own health care
- Changing from pediatric to adult-oriented medical care
- Moving from school to work and other aspects of adult life

The medical home definition of transition is: to thoughtfully coordinate what is appropriate for the child to ensure successful transition to:

- Adult health care system
- Work
- Independence
- Inclusion in community life

Transitioning your child to the next steps of the care is the doctor's prime responsibility. Continuity of care ensures communication across the developmental continuum and among multiple doctors. It guides you through the transition from the child health care system to the adult health care system and provides you and your child with the support needed to make informed decisions about his or her health care needs. A medical home provides continuity of care and allows your child to successfully transition into the role of his or her own primary advocate.

SECTION 2: CONTINUOUS CARE



TRANSITIONING TO ADULT CARE

There may come a time to talk with your child's doctor about transitioning to adult-oriented care. The doctor may bring it up during your child's regular appointments or when they see your child becoming more independent and taking ownership in his or her care. You may feel the need to bring up transition as well. Here are some topics to think about and discuss as the time comes to transition your child to adult-oriented care:

1. Is the timing right for transition?
2. What type of doctor should my child see?
3. What can my family and/or my child expect during transition?
4. What will be the same about adult-oriented care?
5. What will be different about adult-oriented care?
6. Will my child meet the new doctor before leaving this practice?
7. What do my child and my family need to know before moving to adult-oriented health care?

SECTION 2: CONTINUOUS CARE

MEDICAL TRANSITION, CONTINUED

Youth: Managers of Their Own Health Care

For teens (who are able to be responsible for their own care) to become independent, they need family members to take less active roles in their medical care. This way they gain independence and skills to plan for and assist in medical transition.



You can assist your child early on by:

- Letting your child meet with doctors in private
- Letting your child ask questions about his or her health so he or she may gain important skills in managing his or her own care
- Encouraging your child to learn about his or her medical condition(s)
- Helping him or her understand why they are going to the doctor
- Teaching your child basic information about his or her condition(s)
- Teaching you child the names of medications, the dosage, why the medication is prescribed, and any side effects

Helping your teen prepare

Teen years are an important time in life. Planning should start by 14 years of age or younger.

Here are tips on medical transition:



1. **Help** your child create and manage a care plan to keep track of his or her health care needs
2. **Create** a calendar for your child's appointments and give your teen gentle reminders of when appointments are coming up
3. **Encourage** your child to ask questions about his or her health and any other things he or she may want to know from the doctor
4. **Ask** your doctors and other adults talk directly to your teen

See page 19 for a Checklist to help you plan your child's health care management goals

"How could I insure the best outcome for my son? An Emergency Care Plan was the perfect solution. It is in his medical record, at school and in his backpack. Now I can feel confident giving Cody some independence." Claire (Cody's mom)

Genetic Counselors and your Child

As your teen approaches adulthood and independence, often he or she becomes interested in meeting with someone to discuss his or her condition in more detail as he or she learns about managing his or her own health care. A genetic counselor can review the genetics and inheritance of the condition and answer questions and address concerns as they may be thinking about starting his or her own family someday. Ask your primary doctor to refer you and your child to a genetic counselor or center if you have not been in contact with one.

Parent to Parent Tip!

The process of parents gradually "letting go" of the care of their children is critical to the adolescent years. These teens, who will soon be young adults, will take charge of their own lives—including their health. While it can be a hard process, know that you are doing right by your child by transferring responsibilities and management of care to your child.

SECTION 2: CONTINUOUS CARE

Parents: Managers of an adult child's health care

Many children with genetic conditions may need assistance with care into adulthood.

Below are tips on what you may do to prepare for medical transition:

- Include your child in his or her care as much as possible
- Have medical information that is readily accessible to your family and to doctors when you are not available
- Be aware of support groups for parents who care for their adult children to provide peer support and resources

Guardianship and Alternatives

At age 18 your child becomes his or her own guardian; at this point some decisions will need to be made either with your child or on behalf of your child if he or she is unable to handle and manage his or her own care.

If you need to make these decisions, here are some questions to ask yourself:

- *What are my main concerns for my child's future?*
- *Are there financial, medical, or emotional concerns?*
- *What decisions will my child be able to make on his or her own?*
- *What decisions will my child need assistance in making?*

Think about what you would like to secure for your child's future. Below are some choices your family may consider.

Full Guardianship: an appointed guardian who makes all decisions for your child.

Partial Guardianship: an appointed guardian with rights in certain areas of decision making.

Durable Power of Attorney: allows health care decisions to be made by appointed guardian.

Patient Advocate: An individual, maybe family or friend, acts for the child receiving care in the event they are unable to act for themselves.

Conservatorship: an appointed individual to manage the child's finances.

Representative Payee: this person manages the finances of a person with Supplemental Security Income or Social Security Disability Insurance benefits. There may be legal fees and actions that will need to go through the court system to appoint this person.

Healthcare Representative: You may appoint a healthcare representative to make medical decisions in the event you become incapacitated. You may specify instructions to be followed by the healthcare representative, who must act in good faith and in you/your child's best interest consistent with the terms of the appointment.

You may have more options depending on the state you live in. For more resources on guardianship please see the National Guardianship Association at www.guardianship.org.

SECTION 2: CONTINUOUS CARE



HEALTH CARE SKILLS CHECKLIST ⁵

SKILL/RESPONSIBILITY	PLAN TO START	NEEDS PRACTICE	PERFORMS PARTIALLY	PERFORMS ON OWN
Understands and describes medical condition (s)				
Understands how medical condition affects life				
Accesses medical records & health information				
Prepares and asks questions to doctors				
Knows medications and what they are for, or carries information				
Is responsible for taking own medication				
Is responsible for doing own treatments				
Gets a prescription filled/refilled				
Calls to schedule medical/dental appointments				
Knows how to access transportation for appointment				
Knows height, weight and birth date				
Knows how to care for self (hygiene, feeding, changing tubes, etc)				
Cleans & maintains own living space				
Makes financial decisions (pays bills, manages checking/savings accounts)				
Knows where income will come from				
Knows where they will live				
Knows what path they are on after high school				
Knows health emergency phone numbers or carries information				
Knows about and understands medical insurance				
Obtains sex education materials/birth control/family planning information as needed				
Makes contact with community resources				
Has considered need for health advocate, if needed				
Has identified a physician for adult care (primary, specialty and gynecological, if applicable)				
Knows how to hire and manage a personal care attendant, if needed				
Has considered guardianship, if needed				
Knows how medical care will be paid for				

⁵ Adapted from Children’s Hospital in Boston, MA and the PACER Center

SECTION 3: COMPREHENSIVE CARE

Comprehensive care provides management over all aspects of your child's care. Ideally, your doctor (or their backup) would be available 24 hours a day, 7 days a week, 365 days a year to give your child the care they need. Your doctor also would be in charge of preventive care such as immunizations, growth and development assessments and other appropriate screenings as well as the monitoring of your child's complex condition. Often doctors are a secondary advocate for your child. The doctor or their office is able to provide information about private and public resources, including supplemental funding resources, education programs, waivers and other programs for children with special needs.⁶

ONE FAMILY'S EXPERIENCE

We had just been to our child's doctor the previous week but the following weekend we noticed our child was running a fever. We were worried, and were not sure anyone from the doctors office would be available during the weekend. We called our doctor's office and to our relief and surprise, we were immediately connected with an on-call doctor from the office. After accessing our child's symptoms, he suggested we come in first thing the next morning. This brief phone call put us at ease and the next morning, our child was able to get the care he needed! We are so happy that the office has an on-call doctor available after hours so that we can get the information and care we need, when we need it!



"A medical home lets you know that you're not the only one fighting to get something - that there's somebody else there doing that with you - being your advocate, it's very positive."

"Comprehensive care does not stop when you are comfortable in knowing your child's care is being managed. It is a process of providing information, referrals, treatments, emotional support and help with decision making."

Parent-to-Parent Tip

- Write down your questions ahead of time
- Record questions and answers in one place, such as in your child's care plan (see page 40 for care plan templates)
- Feel okay about needing advice in between appointments
- The best time to talk about comprehensive care is before an emergency so you are prepared with the next steps for your child's care

⁶ Massachusetts Consortium for Children with Special Health Care Needs Resources
Center: Medical Home: Compassionate Care www.neserve.org/maconsortium/rc_mh_compassion.htm

SECTION 3: COMPREHENSIVE CARE

BUILDING HEALTH PARTNERSHIPS

It's okay to ask questions

Family members often leave the doctor's office irritated for not asking what they wanted to ask. Sometimes you may forget your question (bring a list!) or on other occasions you may not feel sure if it is ok to ask. Sometimes those questions that you hesitate to ask are the ones you are most concerned about or the ones that could address a need your doctor may not have noticed before. Doctors expect questions and want to work with you to get the answers you need to care for your child.

Below are some examples of questions not always asked:

- How much will it cost?
- Is there a less expensive alternative?
- What are the likely benefits or consequences for the proposed treatment?
- Can you repeat that/write that down?

Feel okay about needing advice between appointments

If you have a concern between appointments and feel that you need an answer from your child's doctor, ask the office staff to have him or her call you.

Reflecting

It is important that you get the information you need from your child's appointment. Here are some questions to ask that could help you reflect on your child's appointment:

- Were you able to discuss your most important questions or issues?
- If not, is this okay with you?
- 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?



Parent to Parent Tip!

Remember that communication is the key to every relationship.
Take good notes, stay organized, and ask questions.

“Because we always have Amanda’s care plan and medical records with us, the specialist was able to diagnose the problem and give us a game plan right then and there, otherwise it would have taken days! This is just one example of what having a “Medical Home” has done for Amanda and us as a Family!!” Marion (Amanda’s mom)

SECTION 4: COORDINATED CARE

Coordinated care is a team process that involves family members, teachers, social service employees, and doctors. Coordinated care ensures access to appropriate community-based services and advocates for comprehensive, community-based service delivery systems. When developing a plan of care for your child, you work with the doctor and assist in providing information. You also ensure that the care plan is shared with all of your child's doctors and that it is up to date.

You can use the care plan to keep track of all of your doctors. It's a good idea to share copies with your doctors so they have a full picture of your child's treatment. Keep an UP-TO-DATE copy with you when you go to the hospital or to a new doctor to make the admission or intake interview easier.⁷

WHAT DOES CARE COORDINATION LOOK LIKE?

1. Care Coordination is a team process between your family, doctors, teachers, and other service providers
2. A plan of care is developed by you, your primary doctor and any other doctors involved in your child's care
3. A central record with pertinent medical information is kept in the primary care office
4. Your doctor's office assists when referrals need to be made to other doctors
5. Your medical home helps your family understand the referral recommendations during a follow-up visit
6. Your doctor coordinates your child's care plan with other community agencies

Some pediatric practices and other doctors employ the expertise of a care coordinator. A designated care coordinator manages your child's information and ensures complete care. If your doctor does not have a care coordinator, perhaps mention the following benefits⁸:

- Care coordinators can provide consistent staff contact for coordinating care
- They promote shared responsibility among the doctor, family and care coordinator
- They allow for direct communication between the doctor and family
- They engage the family in decision making and care planning

Parent to Parent Tip!

One thing parents recommend to other parents of children with genetic conditions is to stay organized! A really great tool for organizing care is an individual care plan. A care plan lists health problems, tests or procedures, doctors, health care services, equipment, treatment plan and expected outcomes. A flash drive is an inexpensive way to save this information and have it available at all times, without having to carry around heavy binders of paper work. Many doctor's offices have computers these days and to have information readily accessible in an easy-to-carry format is great!

⁷Adapted from the American Academy of Pediatrics, Family Voices, Maternal and Child Health Bureau, National Association of Children's Hospitals and Related Institutions for Children: Comprehensive, Coordinated, Collaborative Care PowerPoint Presentation.

⁸Adapted from: Donati, B.; Passerello, T. & Stille, C. Coordination of Care in the Medical Home. Presented at the National Association of Pediatric Home and Community Health Conference; October 2003.

SECTION 4: COORDINATED CARE

GETTING THE MOST OUT OF AN APPOINTMENT

Scheduling

To cut down on waiting time, schedule the child's visit with the doctor 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 questions, research and/or reports that you especially want to discuss. You are the coordinator between your child's care and the doctor.
- Share questions and concerns. Make a list of questions, concerns and other information you would like to share. Decide what on your list is the most important to you.
- It is okay to bring up things that don't seem related to health but still matter to you and your child because communication is an important component of care.
- 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 their own list for what they need 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. Make sure to take notes, record answers to your questions and any other important information your doctor shares with you.

Updating

Tell your doctor about your child's progress. A fun and memorable way to update your doctor is to send an occasional picture of your child with a note highlighting his or her progress. Here are some examples:

TIP!

- *"Here is my daughter having fun at dinnertime."*
- *"Through therapy, 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"*

"Having access to longer appointment times for the complex child is not only beneficial for the family but also for the physician because they can give a quality visit without having to run behind the rest of the day." Ashley (Camerynn's mom)

Parent to Parent Tip!

Encourage your doctor to install internet access in their office. The internet can serve as a tool for ease of access to your child's care plan, treatment options and other medical information.

SECTION 4: COORDINATED CARE

WHY IS CARE COORDINATION IMPORTANT?

Families of children with special health care needs on average, spend about 11 hours per week coordinating care for their child.⁹ This can create stress for the family in areas of:

- Emotional, mental, and/or behavioral health
- Finances
- Employment

By working with your doctor, office staff and others involved in the care of your child, the responsibilities of coordinating care for your child does not have to fall to you 100% of the time.



After your appointments with a variety of doctors or specialists, you may have some new questions. Follow-up may take more time and energy but is worth it and will make you better informed.

TIP! **Tip 1: When you have questions during appointments or at home:**

- Write them down and take notes
- Do some research before you call (if you can)
- Check online resources related to your question

If you still need more information contact the office staff during regular business hours. If it is an emergency, call 911 or go to the nearest emergency room

Tip 2: When you schedule follow-up appointments with a doctor:

- Bring questions with you and any information you feel would help the situation
- Bring up your situations, for example, “What do you suggest about...?” or tell a story about something going on in your child’s life that you want to discuss
- Bring your care plan or a note book with your questions so that you can record answers and write down other notes and questions

Tip 3: Record dates on a calendar for upcoming appointments:

- Stay organized with a calendar that is accessible to all family members in the household

Tip 4: Update the care coordination plan:

- Make sure to update you child’s information, as well as any new contact information or new doctors
- Also make sure your family knows how to access your child’s care coordination plan

Tip 5: If you receive information from the doctor that is upsetting or hard to understand:

- Ask if you can call later to go over your questions so you can give yourself some time to understand the changes and collect your thoughts

⁹MCHB/NCHS. National Survey of Children with Special Health Care Needs. 2002

SECTION 5: COMPASSIONATE CARE

WHAT IS COMPASSIONATE CARE?

Compassionate Care is concern for the well-being of the child and family and is expressed in verbal and nonverbal interactions. Efforts are made to understand the feelings and perspectives of the child as well as the family.

Key Components of Compassionate Care:

1. Your child's doctor treats you, your family and child with respect and care. You notice other families are treated with the same respect and care.
2. Your child's doctor takes time to listen to you and your family's concerns.
3. The doctor's office staff takes the time to ask you and your family about any special needs or concerns and helps your family meet those needs.
4. The doctor's office staff work with community groups to help meet the specific needs of your child.
5. Your child's doctor takes the time to get to know your child's special health care needs.
6. Your child's doctor recognizes the impact your child's chronic health needs have on you and your family.
7. Changes in how the office staff cares for your child are made in response to you and your family's unique needs and challenges.
8. Office staff help groups in your community learn about the needs and concerns of children with genetic conditions and their families.¹⁰

Examples of Compassionate Care: When you come in with your child for his or her appointment, you notice the doctor is interested in your child, his or her progress and any new updates. They are attentive to your questions and express concern for your child in an understanding manner.



“We have a care plan that is always with us, and the hospital and clinic are aware of the special needs and openly give Miriam that much needed “extra” time and gentleness. All these little changes are making a significant difference not only for Miriam, but for our family.”

Jennifer (Miriam’s mom)

¹⁰ From the American Academy of Pediatrics, Family Voices, Maternal and Child Health, Bureau National Association of Children’s Hospitals and Related Institutions, and Shriners’ Hospitals for Children: Common Elements Medical Home: www.occrra.org/inf-todd/module/physical_health/Medical_Home_Common_Elements_AdaptedFinal.ppt

SECTION 6: CULTURALLY EFFECTIVE CARE

WHAT IS CULTURALLY EFFECTIVE CARE?

Culturally effective care starts with communicating to your doctor that you have certain cultural beliefs or requests you would like your doctor to observe or consider when treating your child. When the doctor is aware of your requests, he or she will be able to make you and your family more comfortable with the care of your child.

What is Culture?

Culture is a way of life, values, beliefs, behaviors, experiences, tastes, preferences, languages, and customs.

What is Diversity?

Diversity is generally defined as acknowledging, understanding, accepting, valuing, and celebrating differences among people with respect to age, class, ethnicity, gender, physical and mental ability, race, sexual orientation, spiritual practice, and public assistance status.

Communication

“English as a primary language” does not always mean that a person is able to understand every word spoken to him or her. “English as a second language” could mean full understanding or that a person speaks or writes little English. It may be necessary to get the help of a trained/certified bilingual person to help you better understand information.

Listed below are some points for your family and doctors to keep in mind when seeking to increase cultural awareness in the health care setting.

TIP!

Key points to keep in mind...

- Ask questions when you do not understand a word or phrase
- Ask a person to slow down when giving you treatment options
- Bring another person who can help explain things to you
- Ask for visual aids or physical gestures to help you
- Ask the person to rephrase the question or instructions if you do not understand the words he or she is using



Parent-to-Parent Tip

It is important for your child’s health care team to be aware of values, beliefs, and practices that are common in your community and important to your family. Although your health care team may be familiar with some of the general health care practices or norms for your culture, it is still very important for you to communicate your own personal feelings about how you would like to participate in the health care process.

SECTION 6: CULTURALLY EFFECTIVE CARE

VALUES AND ATTITUDES

“Family” can be defined in many ways. Share how you define your family so your child’s doctors will understand the role each member may have in your child’s care plan. Let the staff know:

- How important medical decisions are made in your family
- Who the people are that need to hear the information from the doctor
- Who in your family provides you with the most support

“Health and well-being” mean different things to different people. Understanding and sharing what this means for you and your family can help a doctor in developing a care plan.

Let them know things such as:

- How you handle your emotions in public and in private
- What you consider ‘healthy’ for your child with a genetic condition
- What you consider a ‘good’ place to be in their health care
- What foods you and your child eat to promote good health

Religion and other beliefs influence how families respond to illness, disease, disability and death. Awareness of your belief system will give your child’s doctors a better understanding of what is important to your family. The doctor and office staff may wish to know:

- How your family typically celebrates the birth of a child
- What activities your community offers for families of children
- What type of response you would get from the community about your child with a genetic condition
- What the cultural expectations are for self-help skills such as dressing and feeding ¹¹



Children with genetic conditions and their families bring unique cultural perspectives to service delivery systems. Each child and family has strength and resilience as well as needs and challenges. It is essential that integrated systems of care within states and communities understand and respond effectively to the extent to which children and families are satisfied with the services and supports they receive. The National Center for Cultural Competence (NCCC) presents a series of articles to increase awareness, knowledge and skills in this important aspect of care.¹²

¹¹ A Guide for Michigan Families: Special Care for Special Kids (2006 edition)

www.michigan.gov/documents/mdch/1-21_SpecialCareGuide_203487_7.pdf

¹² National Center for Cultural Competence (NCCC) www11.georgetown.edu/research/gucchd/nccc/

SECTION 6: CULTURALLY EFFECTIVE CARE

TRANSLATION SERVICES

Most large hospitals and outpatient clinics are able to provide an interpreter for common languages, if you request one. Be sure to let the office know an interpreter is needed when scheduling your child's appointment. There are many organizations that provide language translation services. The services may include translating written documents, interpreting speech, or both. Some translation agencies may charge a fee for their services.

To find a translator, check the yellow pages of your local telephone book or internet search under "Translations" or "Translators." Interpreters may be found through community or government agencies, colleges or universities, or translation-related businesses. Families also may find health care and other kinds of assistance offered in their native language through community organizations.

TIP!

To help you choose your translator, keep these four tips in mind:

TIP 1: Find a translator who understands the primary language spoken at home
Medical words and phrases can be confusing. If your translator is new to the language or has just learned how to speak English, he or she might miss important details. A confused translator can give incorrect information and this can be dangerous.

TIP 2: Pick a translator who is at least 18 years old

Some things you will talk about with your doctor can be serious or complicated. Your translator must be mature enough to handle any topics that come up. Your translator also must understand everything and be able to translate the doctor's advice correctly so you can understand it.

TIP 3: Choose someone you trust

Office visits are often routine. However, sometimes you may have to answer tough questions or talk about personal topics. Make sure you are comfortable including your translator in these private conversations.

TIP 4: Think carefully before bringing a family member

Many people bring their family members as translators. If your family member is an adult, this may be an easy decision. But if you have a younger family member, remember that some topics you talk about with your doctor may be sensitive. You may not want to make your family member uncomfortable.

Keep in mind: If the translator you bring doesn't fully understand the topic or information given, ask your doctor to write down the important information and have it translated later. Use these tips to make a list of the people you know who may be right for the job. If you don't have a friend or family member who meets your needs, check with your doctor's office, they may be able to further assist you.

Parent-to-Parent Tip

Good communication is an important key to better health outcomes. Sometimes your child's doctor may come from a different ethnic or cultural background than your family. A language difference may make it difficult for you to understand one another, but remember that what you have in common is a desire to help your child.

SECTION 7: FAMILY-CENTERED CARE

WHAT IS FAMILY-CENTERED CARE?

Family-centered care is team work between patients, families, doctors, nurses, and other health care professionals for the planning, delivery, and evaluation of health. It assures the health and well-being of children and their families through a respectful partnership between the family and doctor. It honors the strengths, cultures, traditions and expertise that everyone brings to the relationship. Family-Centered Care is the standard of practice that results in high quality services.¹²

Key Components of Family-Centered Care

- The family is essential to the child's care and is constant in the child's life
- The doctor acknowledges who the key family members are
- The doctor asks families what they value
- Decision-making is shared

Example of Family-Centered Care: Upon bringing your child in to the doctor's office for a concern about your child's health, the doctor asks you what you have observed, what you think could be the cause of your concern and what you think could be a possible course of action to take. By communicating with you, the doctor is utilizing your knowledge and is able to provide quality treatment and care for your child.

How to make Family-Centered Care work:

Keep the lines of communication open and honest

- *Share your thoughts and ideas about decision making for your child*

Be aware of office patient procedures

- *Request to schedule a longer appointment to go over your list of concerns, updates and questions*

Be involved in discussions or focus groups

- *Request to schedule a longer appointment if needed*

Participate on the clinic's advisory board

- *This is a great chance to get to know other families with similar situations and learn from them!*

Complete patient and family satisfaction surveys

- *Giving and receiving feedback is important to your doctor and their office staff so that they may continue to provide you and your child with quality, family-centered care!*

A Definition of Family

"Families are big, small, extended, nuclear, and multi-generational with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks or as permanent as forever. We become part of a family by birth, adoption, marriage or from a desire of mutual support. A family is culture unto itself, with different values and unique ways of realizing its dreams together, our families become the sources of our rich cultural heritage and spiritual diversity... Our families create neighborhoods, communities, states, and a nation".

*Polly Arango,
Family Voices*

¹³ Adapted from American Academy of Pediatrics, Medical Home Initiatives Every Child Deserves a Medical Home Training Manual, Appendix D: Family Centered Care Fact Sheet

SECTION 7: FAMILY-CENTERED CARE

CORE PRINCIPLES OF FAMILY-CENTERED CARE

1. **Respecting** each child and his or her family.
2. **Honoring** racial, ethnic, cultural diversity and its affect on the family's experience and views on care.
3. **Recognizing** and building on the strengths of each child and family member, even in difficult and challenging situations.
4. **Supporting** the choices of the family about approaches to care and decision making.
5. **Ensuring** flexibility in office policies, procedures, doctor practices, and services tailored to the needs, beliefs, and cultural values of each child and family.
6. **Sharing** honest and unbiased information with families on an ongoing basis and in ways they find useful and assuring.
7. **Providing** and/or ensuring formal (example: doctor to patient relationship and referrals to other services) and informal support (example: family-to-family support) for the child and family during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood.
8. **Collaborating** with families at all levels of the medical care of the individual child and in professional education, policy making, and program development.
9. **Empowering** each child and family to discover their own strengths, build confidence, and make choices and decisions about their health.¹³



Parent-to-Parent Tip

Children identified with genetic conditions often have multiple needs—both physical and emotional—that benefit from health care and other services provided by a number of different health professionals, educators, and community agencies. A well developed and coordinated care team is important to assure the best possible outcome for your child's health. Ideally, parents work together with a child's doctor to identify needs and coordinate services available through the health care system and community settings.

¹⁴ Core Principles of Family-Centered Care. American Academy of Pediatrics
<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;112/3/691>

SECTION 8: ADVOCATING FOR YOUR CHILD

Advocacy means educating others about a need, small or large, in an effort to help meet that need. It can refer to community issues, like making a plea for a stop sign at a dangerous intersection or improving the accessibility of a playground so that all children can enjoy the space. For families of children with genetic conditions, advocacy becomes an everyday effort to improve the quality of life for their child and others like them.

Advocacy happens at many levels, from a conversation in the doctor's office, up to a visit with your legislators, but any effort you make is a step in the right direction. You can write letters, send emails, make phone calls, or attend support group meetings. The more you do to voice your needs, the more attention your issue will receive.

LEVELS OF ADVOCACY

The most basic level of advocacy affects your own child. You may need to advocate when:

- Your child needs to see a doctor after hours, or when there are no appointments available
- You would like your health insurance provider to make an exception on a denied payment
- You wish to see your doctor's office take on the concept of the medical home



When you are advocating for your child's medical home, take Angela's letter (Page 33) with you to break the ice. It will give your doctor a full picture of what you would like to see happen for your child's care.

The next level of advocacy could also affect other children and their families. You are advocating at this level when:

- You request your doctor's office to hire a care coordinator or specify a current employee to promote care coordination. Share how this person's time will assist your family in managing the complex care of your child and what he or she can do for other families in the doctor's office.
- You ask your insurance company to cover the purchase of sterile water for use in a ventilator, which is critical for a child needing humidification. Again, the policy change you are asking for will help others in a similar situation.

The next level of advocacy involves asking for a system change. A change in a system might be involved when:

- You bring attention to the financial burden of medical care for families who have children with genetic conditions. You explain how care coordination in your doctor's office and others could save costs for families and the health care system as a whole.
- You explain your needs (which also represent the needs of many others) to a state agency that influences how funding is dispersed. Reimbursement from insurance providers on medical foods and formulas to care coordination are issues that families face every time they visit the doctor's office.

SECTION 8: ADVOCATING FOR YOUR CHILD

BASIC GUIDELINES FOR ADVOCACY

1. **Choose and learn about your issue(s)**

Identify the issue you most need to focus on and learn as much as you can about it. Talk to other parents, find information through your local or hospital library, the internet, health newsletters and local parent support groups. Locate existing advocacy groups and find out what has already been done on your issue.

2. **Identify decision-makers**

Find out who has authority to make decisions, whether it's a supervisor, a program director, a chief administrator or your local legislator. These are the people to whom you must appeal for changes in the system. Your local parent support groups can help you identify the appropriate decision-makers.

3. **Learn how to navigate the system**

Navigating the system can mean anything from learning the right vocabulary to use when calling about an insurance statement to asking for the same office administrator when you need help at your doctor's office. It can also mean learning how the legislative process works so you can influence potential legislation.

4. **Communicate your views**

When making your request, be brief, to the point and polite. Identify yourself, your issue, and give one or more reasons for your position. Sometimes it helps to write this down first, to make sure you can summarize what you want and why. And remember, change takes time so you may need to be patiently persistent.

5. **Thank those who have helped**

Always remember to thank those who have taken the time to listen to your needs. A simple written note of thanks can make a difference when the next person comes to ask for help.

Dear Parents,

I was sent into a tail spin when my third child was diagnosed with Congenital Adrenal Hyperplasia. My other two children were born healthy and I had no experience with any medical disorder. I didn't even know which pediatrician to contact as a primary care doctor as my other children were under the care of a family doctor.

Luckily, I found a fantastic pediatrician who practiced using the medical home model. When my daughter was first born, I was less focused on the medical home model and more focused on her medical condition. It didn't take long before I realized what a wonderful concept the medical home model is.

Through our medical home, my daughter was provided with a care coordinator. This RN is our lifeline to medical care. She met with us during the first appointment to explain how the office did things differently. First, she showed us the private waiting room that we could utilize so that our daughter didn't have to be exposed to germs. Next, she told us how to make direct contact with her and what to do in her absence. She went on to discuss what appointments would entail and how to manage the paper work involved. Prior to each visit she contacts me to find out if my daughter has seen a specialist, had an emergency room visit, or if I have any special concerns for the doctor. This is all coordinated prior to the appointment so that we can have all the facts in front of us when we see the doctor. This pre-visit coordination helps tremendously with information flow. The patient care coordinator also contacts specialists to follow up on their reports regarding my daughter's care. We don't have a medical folder; instead, we have a medical binder and any medical paperwork regarding my daughter's care from inside or outside of the pediatrician's office is in that binder. Paperwork from hospital visits and other specialist visits are all included so that the pediatrician has a total picture of my daughter's care.

Our primary doctor is fantastic. Upon the first visit he introduced us to a secondary doctor that he wanted us to see in his absence. Although the office has seven doctors, he wanted to have her care managed by only two doctors who would understand everything about her condition. Together, both doctors spent ample time with my daughter on her initial visit. They also worked with me to discuss a medical plan for her. We discussed when to call them, what to do after hours, medicine dosages, and how to handle emergency room visits. I left the office feeling as if both doctors truly had a vested interest in seeing my daughter thrive.

Under the Medical Home model the office also holds quarterly Parent Advisory Group meetings. This is a time for staff and families of special needs children to come together to educate and share information with each other. The staff contacts outside organizations to come speak to parents on a variety of topics. We have had many guest speakers, ranging from camps that provide for children with special needs to government agencies. Occasionally, parents will request certain topics to be addressed and the staff will coordinate a workshop. Recently, I asked for refresher training for an injection class. The staff not only provided this to my entire extended family, but they also invited other families who could benefit from this training. These meetings also give parents the time to collaborate, share, and support each other on their journey to providing the best possible care for their child.

While my daughter's pediatrician may be the exception, I would encourage you to find an office that is practicing the medical home concept. This office should be the central hub of your child's care. They should collaborate with both your family and your specialists. They should support you in finding resources, second opinions, and advanced specialists in your area. And most importantly, your pediatrician's office should be connected with and supportive of your medical treatment endeavors.

Best wishes,
Angela (Mother of a daughter with Congenital Adrenal Hyperplasia)

GLOSSARY

Term	Definition
AAP	The American Academy of Pediatrics: a professional organization for pediatricians where members dedicate their efforts and resources to the health, safety and well-being of infants, children, adolescents and young adults. The AAP has approximately 60,000 members in the United States, Canada, Mexico, and many other countries. Members include pediatricians, pediatric sub-specialists and pediatric surgical specialists.
Accessible Care	One of the components of the medical home concept that encourages your doctor and their office to be available in terms of transportation, insurance acceptance and disability access.
Acute	A condition that happens suddenly and lasts a short time. It is the opposite of “chronic.”
Audiologist	A health care professional who is trained to evaluate hearing loss and related disorders, including balance (vestibular) disorders and tinnitus (ringing in the ears) and to rehabilitate individuals with hearing loss and related disorders. An audiologist uses a variety of tests and procedures to assess hearing and balance function and to fit and dispense hearing aids and other assistive devices for hearing.
Care Coordinator	A person who assists in the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health.
Caregiver	A person who provides direct care (as for children, elderly people, or the chronically ill).
Chronic	An illness or condition that slowly persists or progresses over a long time. It is the opposite of “acute.”
Comprehensive Care	One of the components of the medical home concept that ensures you doctor will manage all aspects of your child’s care and be available when needed.
Consumable Medical Supplies	Non-durable medical supplies that: are usually disposable in nature; cannot withstand repeated use by more than one individual; are primarily and customarily used to serve a medical purpose; generally are not useful to a person in the absence of illness or injury; may be ordered and/or prescribed by a physician.
Coordinated Care	One of the components of the medical home concept that involves the family, doctors, teachers, social service professionals and other caregivers to ensure access to appropriate services and planning.
Continuous Care	One of the components of the medical home concept that encourages doctors to know about their patient’s other medical visits, procedures and medications so they can provide the best care possible.

GLOSSARY

Term	Definition
Culturally Effective Care	One of the components of the medical home concept that encourages communication between the doctor and patient to share certain cultural beliefs be observed or considered during treatment.
Diagnosis	The name of a condition or illness. To qualify for various programs, 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.
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.
Durable Medical Supplies	Medical supplies that: can withstand repeated use; is primarily and customarily used to serve a comfort; generally is not useful to a person in the absence, is appropriate for use in the home; and/or prescribed by a physician.
Eligible	Meets specific requirements to qualify for a program or services.
Empathetic Manner	The action of understanding, being aware of, being sensitive to the feelings, thoughts, and experiences of another person without having the same feelings, thoughts, and experiences.
Endocrinologist	A medical endocrinologist is a physician who specializes in the diagnosis and management of hormonal conditions. They usually have background training in one of a number of different medical fields such as pediatrics, oncology and obstetrics/gynecology.
Evaluation	A way of collecting information about an individual's needs, strengths and interest.
Family Physician	Family physicians have skills, and knowledge which qualify them to provide continuing and comprehensive medical care, health maintenance and preventive services to each member of the family.
Genetic Condition	An illness caused by abnormalities in genes or chromosomes. Most disorders are quite rare and affect one person in every several thousands or millions.
Geneticist	A scientist who studies genetics, the science of heredity and variation of organisms.
Genetic Counselor	They work as members of a health care team and act as a patient advocate as well as a genetic resource to physicians. Genetic counselors provide information and support to families who have members with genetic conditions, and to families who may be at risk for a variety of genetic conditions.

GLOSSARY

Term	Definition
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 hospitals.
IDEA	Individuals with Disabilities Education Act. A federal law authorizing special education for children.
Legislator	A legislator (or lawmaker) is a person who writes and passes laws, especially someone who is a member of a legislature. Legislators are usually politicians and are often elected by the people.
Lobbyist	A person who attempts to persuade (to lobby) politicians to vote in a certain way.
Local Health Department:	This office can provide free or low-cost basic medical care and other health-related services.
Long-term Treatment	The act or manner or an instance of treating someone or something for an unspecified amount of time.
Medicaid	Federal & state health care coverage for low-income individuals or families, medically needy individuals and working families.
Occupational Therapist	Occupational therapy is a health profession whose goal is to help people achieve independence, meaning and satisfaction in all aspects of their lives. The occupational therapist's goal is to provide the patient with skills for the job of living - those necessary to function in the community or in the client's environment.
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.
Pharmacist	A professional who fills prescriptions, and in the case of a compounding pharmacist, makes them. Pharmacists are familiar with medication ingredients, interactions, cautions, and hints. Pharmacists are thus trained to prepare and distribute medicines and to give information about them.
Physical Therapist	Helps patients suffering from disease or injury improve mobility, relieve pain, increase strength, and decrease or prevent deformity. They assess, plan, organize, and participate in rehabilitative programs.
Primary Care	General or basic health care. Traditionally provided by a pediatrician, internist or family practitioner.
Primary Care Provider	General or basic health care professional who is involved with overall care as well as the coordination of care when specialists are involved.

GLOSSARY

Term	Definition
Primary Payer	The company or organization that must be billed first for agency-covered services before the agency will consider payment.
Provider	A person, organization or company that provides medical care, medications, medical supplies or equipment.
Psychologist/ Psychiatrists	The difference between a psychologist and a psychiatrist is a psychologist primarily aids the depressed patient by counseling and psychotherapy. A psychiatrist may also perform psychotherapy; but, in addition, can prescribe medications and perform ECT (electroconvulsive therapy). A psychiatrist is a medical doctor. A psychologist may hold a doctoral degree (Ph.D.) and be called "doctor"; but, is not a medical doctor.
Public Health	The art and science dealing with the protection and improvement of community health by organized community effort and including preventive medicine and sanitary and social science.
Respite	A temporary period of rest or relief for caregivers that provide daily care to an individual.
Social Worker	A social worker is a professional who is distinguished from other human service professionals by a focus on both the individual and his or her environment. Generally, social workers have at least a bachelor's degree in most states they must be licensed, certified, or registered.
Specialty Care	A medical practitioner whose practice is limited to a particular class of patients or of diseases or of technique.
Speech Therapists	A specialist who evaluates and treats communication disorders and swallowing problems. A speech-language pathologist is sometimes called a speech therapist or speech pathologist.
Sub-specialist	A physician who has a <i>subspecialty</i> , meaning a narrower field of specialization.
WIC (Women, Infants and Children)	A program that provides supplemental nutrition, breastfeeding information, and other resources to foster healthy mothers and babies.

MEDICAL HOME RESOURCES

NATIONAL RESOURCES

American Academy of Pediatrics (AAP) National Center of Medical Home Initiatives for Child with Special Needs www.medicalhomeinfo.org/

The National Center works to ensure that children and youth with special health care needs have access to a medical home. Through the National Center, physicians, parents, administrators, and other health care professionals have access to educational, resource, and advocacy materials, guidelines for care, evaluation tools, and technical assistance.

Center for Medical Home Improvement (CMHI) www.medicalhomeimprovement.org/

CMHI is committed to supporting practices, patients, and families to develop strong and sustainable medical homes. CMHI aims to link you to the most helpful resources for medical home development. CMHI has developed a Parent Partners Guide to help parents (and physicians) better understand their critical role as parent partners.

Institute for Family-Centered Care www.familycenteredcare.org/

The Institute for Family-Centered Care provides leadership to advance the understanding and practice of patient- and family-centered care in hospitals and other health settings.

Medical Home Portal www.medicalhomeportal.org/

The Medical Home Portal aims to provide ready access to reliable and useful information for professionals and families to help them care and advocate for children and youth with special health care needs, as partners in the Medical Home model.

National Initiative for Children's Healthcare Quality (NICHQ) www.nichq.org/

NICHQ provides information about the Medical Home as it pertains to children and youth with special healthcare needs.

STATE RESOURCES

Building a Medical Home Partnership - A Wisconsin Toolkit

www.wimedicalhometoolkit/aap.org/toolkit.index.cfm

In this Toolkit, Wisconsin physicians and families share their stories and insights on creating a Medical Home Partnership. They will guide you through the key steps of quality improvement – they small steps that can make big differences for Children and Youth with Special Health Care Needs.

Illinois Chapter of the American Academy of Pediatrics (AAP) www.illinoisAAP.org/

The Illinois Chapter of the AAP provides information about the Illinois Medical Home Project as well as general information and resources about the medical home.

Minnesota Medical Home www.health.state.mn.us/divs/fh/mcshn/medhm/

This website provides information and resources about the medical home, including information about the medical home initiative for children with special health care needs.

What Families need to know about a Medical Home

<http://internet.dscc.uic.edu/medhome/familyprimer/FamilyMHPrimer.asp>

This Illinois Medical Home Project website provides resources for families on the concept of the medical home.

MEDICAL HOME RESOURCES

BROCHURE RESOURCES

A new way... A better way: The Medical Home Partnership

www.medicalhomeinfo.org/states/Downloads/MA%20Info/Family%20Brochure.pdf

This brochure describes what a medical home is and provides information about what you should expect from a medical home.

Building Early Intervention Partnerships with your child's Doctor: Tips from and for Parents

<http://www1.dshs.wa.gov/pdf/Publications/22-557.pdf>

This booklet gives suggestions and ideas for getting started with a new doctor and also for improving a partnership that you already have.

Does your child have a medical home? www.medicalhome.org/4Download/medicalhomebro.pdf

Provides information about what a medical home is, benefits from having a medical home, and a checklist to determine whether or not your child has a medical home.

Extraordinary care: Improving your Medical Home

www.medicalhomeimprovement.org/pdf/Complete-FE-LearningGuide_4-29-09.pdf

The learning guide is designed to assist families and others in their education about the basics of "medical home". It also suggest specific activities one can use to strengthen their medical home or advocate for stronger primary care services.

Families partnering with providers www.familyvoices.org/pub/general/PartneringWithProviders.pdf

This brochure provides tips to help families build effective partnerships with their child's doctors.

Family-Centered Care Self-Assessment Tool - Family Tool

www.familyvoices.org/pub/projects/fcca_FamilyTool.pdf

Families, both individually and within family support and advocacy organizations, can use this tool to increase awareness and knowledge of the specifics of family-centered care.

Family-Centered Care Self-Assessment Tool - User's Guide

www.familyvoices.org/pub/projects/fcca_UsersGuide.pdf

The User's Guide provides a detailed set of steps to use the Family and Provider Tools for a full assessment of a practice setting or family. In addition, the tool may be used as an educational tool to build awareness and knowledge of family-centered care for families, youth, doctors, health plans and policy-makers.

Making health care work for you: Medical Home 101

www.medicalhomeinfo.org/tools/Presentations/MedicalHomeforFamilies.ppt

This presentation defines the medical home concept, defines the common elements of a medical home and helps you assess whether they have been incorporated into your child's care, and helps you understand the personal importance of having a medical home.

Medical Home for Coordinated Pediatrics www.chfs.ky.gov/ccshcn/foster.htm

The Commission for Children with Special Health Care Needs, in collaboration with the University of Kentucky, has created a clinic to provide a medical home to children in foster care in central Kentucky.

What is a medical home? And what does it mean for you and your child?

<http://internet.dsc.uic.edu/forms/medicalhome/4016.pdf>

This brochure provides information about the components of a medical home.



Region4
Genetics Collaborative

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