Partnering with your Doctor

The Medical Home Approach

A guide for families of children and youth with special health care needs

TN Department of Health

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
Tennessee Chapter

FAMILY VOICES of Tennessee

Tennessee Department of Health, Division of Family Health & Wellness,
Children and Youth with Special Health Care Needs Section

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Table Of Contents

Introduction 4

A letter from Julie 5

A letter from Nancy 6

The medical home defined 7

Having a medical home means your child's care is 10

1. ACCESSIBLE 11

- Choosing and working with doctors 12
- Questions to ask when choosing a doctor 13

2. CONTINUOUS 16

- Medical transition 19
- Health care checklist 21

3. COMPREHENSIVE 22

- Building health partnerships 23
- Getting the most out of an appointment 24

4. COORDINATED 25

- Basic steps of coordinated care 26

5. COMPASSIONATE 28

- Key components of compassionate care 28

6. CULTURALLY EFFECTIVE 29

- Values & attitudes 30
- Interpretation & translation services 31

7. FAMILY-CENTERED 34

- Core principles of family-centered care 35

8. ADVOCATING FOR YOUR CHILD 36

- A letter from Tonya 38
- A letter from Angela 39

9. MEDICAL HOME RESOURCES 40

INTRODUCTION

Partnering with your Doctor: The Medical Home Approach is a guide to help you and your family connect with your doctor, other medical professionals, and caregivers through a medical home. Some information in the guide might be helpful now, while other sections will be useful in the future.

This guide is intended to be a user-friendly, hands-on tool to support you and your family to move forward in obtaining and providing a medical home for your child. This guide provides definitions, examples, and tools for you to use when working with your doctor to develop a medical home.

The guide is designed to:

- Provide a detailed definition and description of the medical home concept.
- Lay the foundation for understanding and advocating for a medical home.
- Provide tools and examples for parents to use and learn from while creating and maintaining a medical home with their doctor.
- Bring attention to the importance of linking families of children with special health care needs to a medical home.
- Provide advice on how to effectively partner with your child's doctor.
- Define family-centered care and demonstrate how it benefits families.
- Demonstrate how to seek culturally effective, compassionate care.
- Assist families through the transition process by providing resources and tips.
- Provide a list of resources and links to organizations that support families and the medical home concept.

Dear Families:

The birth of our first child was an emotional roller coaster. She was breech, so she arrived by C-section. Four hours later we were told our daughter had Down syndrome. As young first time parents, we were full of questions and concerns. However, we were in love with our beautiful blue eyed girl and determined to provide her anything she needed.

Within the first few months, we were overwhelmed with appointments, evaluations, and procedures. From open heart surgery to weekly TEIS (Tennessee Early Intervention Services) appointments, we learned a new alphabet. We learned about AV canal defects, O.T., P.T., S.T. and more. Trying to find more supports and ways to help our daughter, I began to cut back on my work hours more and more. Finally, my supervisor told me I had to choose between work and time off. I turned in my resignation that day.

Each new doctor, therapist, or service provider needed me to provide them with my daughter's medical history and developmental accomplishments; which became redundant and time consuming for me. I attempted to keep a good paper trail, but at times, keeping all this information organized was difficult and hard to share with other providers.

As the list of providers and specialists grew, the task of keeping information up-to-date became nearly impossible. Our daughter needed more comprehensive primary care. Her pediatrician ensured her medical needs, which included referrals, and TEIS assisted in connecting us to community services. However, there was still a sense of disconnect. She needed a medical home to coordinate her care so we could make informed decisions about her care.

I am excited about this resource to help families understand what a medical home is and how to access resources and increase their leadership skills to be full participants in their child's medical home.

Julie (Mother of Olivia and William), Tennessee parent.

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 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 we saw separately. In addition to the specialists, she was also seen by public health representatives, as we were involved in some community services, 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 was also receiving a wealth of information that needed further follow up, and additional office visits. Immediate family members also wanted updates. 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).

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 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 the medical home (below) that represents the specific needs of the pediatric population because every child deserves a medical home. Tennessee has begun many initiatives to promote the adoption and spread of the medical home.

Key Functions of a 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. [1]

Coordinated Care: The process of coordinating care involves the "deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services." Optimal outcomes for children and youth, especially those with special health care needs, require interfacing among multiple care systems and individuals, including the following: medical, social, and behavioral professionals; the educational system; payers; medical equipment providers; home care agencies; advocacy groups; needed supportive therapies/services; and families.[2]

Transition: Transitions are part of a normal, healthy development and occur across the life span. Transition in health care for young adults with special health care needs is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.[3]

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.[4]

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1 American Academy of Pediatrics. https://medicalhomes.aap.org/Pages/default.aspx
2 Ibid
3 "A Consensus Statement on Health Care Transitions For Young Adults with Special Health Care Needs". http://pediatrics.aappublications.org/content/110/Supplement_3/1304.full
4 "What is a Medical Home?" National Center for Medical Home Implementation. https://www.medicalhomeinfo.org

BENEFITS OF HAVING A MEDICAL HOME

- 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.
- Your family feels supported in finding resources for your child's needs and challenges.
- Your family is connected to information and family support organizations through your doctor's office.
- 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 are the "big picture" for your child and his future.

FAMILY REACTIONS TO THE CONCEPT OF THE MEDICAL HOME

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

"Everything is at your fingertips for 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."

"I can say that it seems that medical home is a concept that can benefit not only the patient but the entire environment that surrounds the patient. Every time you talk about working collaboratively and in support of the same vision, in this case, the well-being of the patient, the results are always positive." Martha, (Mother of David), Tennessee parent

"A medical home is beneficial for the consistent care it provides. They know our history and have a relationship with our family; That means a lot, when there's something going on, or we just need some level of comfort -we can always count on them."
Tonya (Mom of 3), Tennessee parent

"All referrals and care are coordinated and there is an open communication line between my family and my health provider." (Luz), Tennessee parent

"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."

"YES! When your child has multiple practitioners and providers, things can get so confusing. Many times, it makes parents simply want to give up when they get lost in the confusion. Anything that can help decrease confusion, increase inter-practitioner communication, and is client centered, is a wonderful thing!!!!!!"
Kristi (Mom of Payton), Tennessee parent

"My children are older and the concept of integrated care and care coordination services are now becoming well known. Our family could have benefitted from having behavioral health or care coordination where families are linked to community resources within the practice."
Tracy (Mom of 3), Tennessee parent

"It does sound like something from which we could benefit, especially for the purpose of being sure our daughter has an interpreter at medical facilities now that she is using sign language regularly; more so as it helps centralize medical information and provides easy access to that information among doctors. We seem to fill out tons of paperwork listing so many doctors and history of surgeries and so on - if all this could be updated in one place that provides easy access to our doctors - that would be ideal!"
Andrea (Mom of Jessica), Tennessee parent

HAVING A MEDICAL HOME MEANS YOUR CHILD'S CARE IS:[5]

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.

Continuous

- The same doctors are available from infancy through adolescence.
- Doctors and specialists work together 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.

Comprehensive

- Preventive and primary care is provided.
- Growth and developmental 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.

Coordinated

- You and your family are linked to appropriate support, educational, and community services.
- Your doctor's office staff works 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 office staff.

Compassionate

- The doctor shows concern for the well-being of your child and family as a whole.
- The doctor shows understanding for the variety of emotions you go through while caring for your child with special health care needs.
- Office staff is flexible and respond to your requests and needs.
- Office staff offers privacy when requested.
- Appointment times are scheduled with consideration of your and your family's needs.

Culturally Effective

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

Family-Centered

- Office staff members 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.

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5 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 are able to speak with your doctor when you need to. These are important components to the structure of your medical home.

A medical home is not just an accessible building or hospital, but 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 and family. By working together and identifying barriers, your medical home is creating an accessible space for the care of your child.[6]

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6 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 diagnosis similar to your child's or cared 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? Does the doctor 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 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! However, if you need more time, let your child's doctor know.

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 can appreciate and get to know your child.

Be a partner
Decide what type of partnership you want with your child's doctor.
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 is doing a good job.

SECTION 1: ACCESSIBLE CARE

QUESTIONS TO ASK WHEN CHOOSING A DOCTOR

Call the office you are interested in, explain that you are looking for a new doctor and ask to speak with someone who can answer a few questions for you. Use this sheet as a starting point to interview members of the office staff (receptionist, nurse, doctor) to get answers that will guide your decision.

Questions to ask the office receptionist

- Is this practice accepting new patients?
- Does this office regularly see children with (specify your child's condition)?
- If no, ask: Do staff members have experience with children with special health care needs?
- How long does an average appointment take? How long does an expanded appointment take?
- Does your office accept (name of your insurance, Medicaid, etc.) for payment of services?
- Does your office bill my insurance company directly?
- 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 balance?
- Does the office offer same-day sick appointments?
- What is the average waiting time to have an appointment?
- What is your telephone call policy? Does the doctor give advice or refill medications over the phone?
- Does your office charge for advice calls during the day, advice calls after hours, or medication refills?
- Does your office communicate or respond to questions through email?
- What are the office hours? Are weekend and/or evening hours available?
- Will appointments always be at this location? Are there other offices I may have to travel to for appointments?

SECTION 1: ACCESSIBLE CARE

Parent- to-Parent Tip!

Don't forget to include and prioritize your own questions. If you feel comfortable with the responses, ask to speak with one of the medical staff (nurse or doctor) to continue with your "interview". If the answers you receive are not satisfactory, thank them for their time and call another office.

Questions to ask the nurse

- What types of services does your office offer? Which are provided by a physician and which by a physician's assistant or nurse?
- Does your office have a care coordinator? Or, is the doctor comfortable being my child's medical care coordinator?
- Are tests and lab work done at the office, or do we need to go to another location?
- Does your office have a specialist referral list available?
- Does your office provide referrals for other services that might help my child and family? Example: mental health services, early intervention programs, etc.

Questions to ask the doctor

- What approach do you 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?
- Which hospital(s) do you have admitting privileges to?
- Who will my child see if you are not available?
- Are you comfortable discussing alternative treatments? (Homeopathic remedies/therapies)
- Do you allow appointments specifically to ask questions and discuss a plan of care?
- How would you feel if I ever asked for a second opinion?
- If I have an after-hours need, will I be able to reach you or another doctor in this office?

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.

- Does the way the office is run work for you?
- Is the doctor available when needed?
- Are you often confused about recommendations and why certain treatments are prescribed?
- Do you feel like your concerns are not taken seriously?

Remember :
Trust your own knowledge 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 does not feel right and you have not been able to make it better, then it is time to consider changing doctors.

Parent- to-Parent Tip!

- Try a positive approach through a 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."
- It is important to keep yourself physically and emotionally healthy so you will be able to take the best care of your child. As caregivers, we often overlook ourselves and often we do not admit we might need help. It is always okay to ask for help. There are many resources and programs that provide support for families.

SECTION 2: CONTINUOUS CARE

WHAT IS CONTINUOUS CARE?

Continuous care is a treatment model that informs your doctor of all your child's other medical visits, procedures, and prescriptions so she can provide the best care possible. Your child may need to see a variety of doctors to ensure all of his 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 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 toward 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. At your child's next appointment, ask to meet with this doctor to introduce yourself and your child, and help them become familiar with your child's condition.

TRANSITION AND CONTINUOUS CARE

Growing up is not always easy for children and it can be hard on parents, too. When your child has special health care needs, growing up may be more complicated. Still, many parents of children with special health care needs 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 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.
- Transition to work.
- Transition to independence.
- Inclusion in community life.

SECTION 2: CONTINUOUS CARE

Transitioning your child to adult-oriented medical care is a joint responsibility between you and your child's doctor. 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 heath care system and provides you and your child with the support needed to make informed decisions about his health care needs. A medical home provides continuity of care and allows your child to successfully transition into the role of his own primary advocate.

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 by:

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

Helping Your Teen Prepare

The process of parents gradually "letting go" of the care of their child is critical to the adolescent years. These teens, who will soon be young adults, will eventually take charge of their own lives, including their health. While it can be a hard process, know that you are doing the right thing for your child by transferring responsibilities and care management to your child. Transition planning is recommended to start by age 14 or younger. Here are tips on medical transition:

- Help your child create and manage a care plan to keep track of his health care needs.
- Create a calendar for your child's appointments and give your teen gentle reminders when appointments are coming up.
- Encourage your child to ask health-related questions as well as any other things he may want to know from the doctor.
- Ask your doctors and other adults to talk directly to your teen.

Parent- to-Parent Tip!

"I have encouraged Cody to understand his condition, and little by little he is taking interest in the management of his own care. He keeps his own medical record at school and in his backpack. Now, I can feel confident giving Cody some independence." Claire (Cody's mom)

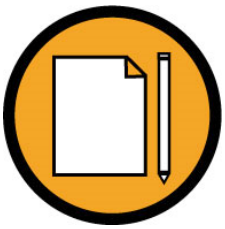
SECTION 2: CONTINUOUS CARE

Parent- to-Parent Tip!

"Many families don't think about transition until their child is pre-teen to teenage age. However, we as parents need to create opportunities to encourage independence toward transition. For example, teach your child to show his/her insurance card when checking into the appointment, even if your child is non-verbal. This allows them to initiate interaction with staff."

Julie (Mother of Olivia and William), Tennessee Parent.

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 he sees your child becoming more independent and taking ownership in his 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:

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

SECTION 2: CONTINUOUS CARE

Parents: Managers of an Adult Child's Health Care

Many children with special health care needs may need assistance with care into adulthood.
Below are tips on what you may do to prepare for medical transition:

- Include your child in 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 her own guardian. At this point some decisions will need to be made, either with your child or on behalf of your child, if she is unable to handle and manage 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 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 provides full decision-making rights to an appointed guardian.
- Partial guardianship provides rights to an appointed guardian in certain areas of decision making.
- Durable power of attorney allows health care decisions to be made by the 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 the child's finances.
- A representative payee 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.
- Health care representative: You may appoint a health care representative to make medical decisions in the event you become incapacitated. You may specify instructions to be followed by the health care representative, who must act in good faith and in you and your child's best interest, consistent with the terms of the appointment.

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

See the next page for a checklist to help you plan your child's health care management goals.

SECTION 2: CONTINUOUS CARE

HEALTH CARE SKILLS CHECKLIST[7]

SKILL/RESPONSIBILITY	PLAN TO START	NEEDS PRACTICE	PERFORMS PARTIALLY	PERFORMS ON OWN
Understands and describes medical condition(s)				
Understands how medical condition(s) affects life				
Accesses medical records & health information				
Prepares and asks questions of 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 (basic needs: feeding; hygiene; etc.)				
Cleans & maintains own living space				
Makes financial decisions (pays bills, manages checking/ savings accounts)				
Knows where income will come from				
Knows where he/she will live				
Knows what path he/she will be 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				
Considered need for health advocate, if necessary				
Has identified physicians 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				
Can explain to others how his\her customs, beliefs and values might affect his\her health care decision				

7 Adapted from Children's Hospital in Boston, MA and the PACER Center

SECTION 3: COMPREHENSIVE CARE

Comprehensive care provides management of all aspects of your child's care. Ideally, your doctor (or his backup) would be available 24 hours a day, seven days a week, 365 days a year to give your child the care she needs. Your doctor also would be in charge of preventive care, such as immunizations, growth and developmental 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. Your doctor and office staff are able to arrange care with other qualified specialists and professionals when necessary. They are also able to provide information about available state, local and community resources, including health services, education programs, and other supports for children and youth with special needs. Comprehensive care allows for the doctor to manage your child's care and incorporates you and your family into the decision-making process.

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 doctor's 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 assessing 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!"

"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.
- 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.

SECTION 3: COMPREHENSIVE CARE

BUILDING HEALTH PARTNERSHIPS

It's okay to ask questions:

Family members often leave the doctor's office irritated with themselves for not asking what they wanted to ask. Sometimes you may forget your question (bring a list!) or on other occasions you may not be sure if it is okay 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 that are not usually 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/write that down?

Get clear details about communication:

Ask your doctor how to best communicate about your child's care. Is there a good time during the day to call? Does she 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 her at home? Does your doctor welcome communication via email?

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 the doctor 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 the doctor.

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.

SECTION 3: COMPREHENSIVE CARE

GETTING THE MOST OUT OF AN APPOINTMENT

Your partnership with your child's doctor is primarily based on visits to the doctor's office. This page will give you and your family some things to think about when working to get the most out your child's doctor appointments.

Scheduling:

To cut down on waiting time, schedule your 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 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. 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 progress. Here are some examples:

- "Here is my daughter having fun at dinnertime."
- "Through therapy, I learned how to encourage him 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."

Parent- to-Parent Tip!

"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).

SECTION 4: COORDINATED CARE

WHAT IS COORDINATED CARE?

Medical care often is fragmented and doctors do not always have the time or ability to communicate with each other about your child's care. When you have a child with a complex medical condition, you will see any number of health and other service providers for different reasons. Coordinating your child's multiple doctor visits, tests, procedures, and medical information is a daunting task and one of the most important in keeping your child healthy.[8]

Coordinated care is a process that links children and their families with the right services and resources in a coordinated effort to achieve good health. Care coordination for children with special health care needs is often complicated because of the child's complex condition. Your child's doctor and office team play a vital role in the process of care coordination; there are many effective models for providing it. Some offices have a nurse or other health professional whose job is to coordinate the care of patients. In other offices, the doctor steps in to provide care coordination. While there are few doctors' offices that are set up to perform care coordination services that link all of the other activities that impact your child's health, there are ways that you and your doctor can partner to coordinate the care of your child. With well-coordinated information, everyone involved in your child's care will be better adapted and more in control of helping you and your child meet the challenges associated with your child's condition.

WHAT DOES CARE COORDINATION LOOK LIKE?

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

Some doctors employ the expertise of a care coordinator or appoint a current employee to provide care coordination. 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 benefits[9]:

- 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.

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8 Adapted from the AAP, Family Voices, MCHB, National Association of Children's Hospitals and Related Institution: "Comprehensive, coordinated, collaborative care" presentation.

9 Adapted from Donati, B; Passerello, T. & Stille, C. "Coordination of care in the medical home." October 2003.

SECTION 4: COORDINATED CARE

ONE FAMILY'S EXPERIENCE

"Our daughter requires blood work every six months. It is extremely hard for her and requires several staff members to assist. Her pediatrician's office decided the best way to provide her the level of care she needed was to have us come in before they typically opened. This allowed the nurses to focus on our daughter and it decreased her anxiety since she doesn't have to wait to be seen. The nurses learned that distraction was a great tool and so several staff members were employed to pass through and speak to our daughter in a way to draw her attention away from the procedure. Over the years, it has become much easier to complete her blood work."
Julie (Mother of Olivia and William), Tennessee

Parent- to-Parent Tip!

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.

BASIC STEPS OF COORDINATED CARE

Assessing and identifying needs:

Activities performed by your doctor/care coordinator are based upon a complete assessment that includes a discussion with your family about the needs of your child. In your child's doctor's office, your care coordinator may use an assessment checklist to gather information to develop a plan of care for your child.

Developing a plan of care:

After identifying your family's needs, a plan of care is developed based on your family's goals for your child. The care coordinator may clarify the action steps that will be addressed by your family and those that will be addressed by the care coordinator.

Implementation:

The plan is implemented and actions are taken to work toward the goals you and your doctor discussed. The care coordinator organizes and assists the family with resources, referrals, coordination of care with specialty physicians, schools, and other agencies.

Evaluation:

Your care coordinator will take time to look over the plan of care with you and your family, and makes changes as new needs are identified.

SECTION 4: COORDINATED CARE

WHAT IS A CARE PLAN?

A care plan is written information about how to best care for your child's needs. It is something you and your child's doctor can develop together. A care plan may include:

- What medicines your child takes and when.
- What foods your child should avoid.
- What to do for your child in an emergency.
- Goals for your child's health and steps to achieve them.

Your child, family, doctor and other care providers will benefit from having a clear, written care plan. The care plan can be written on paper, saved to a data flash drive, or if possible, be web-based. There are multiple purposes of the care plans. Care plans are an available source of information for parents to provide to the medical, educational, and other care teams, and a quick reference with child-specific information for a medical emergency. Care plans are an action plan that the entire care team, including the family, develops to use in prioritizing, assigning tasks, and implementing and assessing care. Having a written care plan helps you share important information with others who care for your child. This group may include doctors, nurses, therapists, emergency medics, teachers, child-care providers, friends, and neighbors.

Parent to Parent Tip!

Encourage your doctor to have internet access in the office, and to use it for care coordination. The internet can serve as a tool for ease of access to your child's care plan, treatment options, and other medical information. Many doctors' offices have computers, and having readily accessible information is great.

SECTION 5: COMPASSIONATE CARE

WHAT IS COMPASSIONATE CARE?

Compassionate care is concern for the well-being of the child and family 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:

- 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.
- Your child's doctor takes time to listen to you and your family's concerns.
- 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.
- The doctor's office staff works with community groups to help meet your child's specific needs.
- Your child's doctor takes the time to get to know your child's special health care needs.
- Your child's doctor recognizes the impact your child's chronic health needs have on you and your family.
- Changes in ways the office staff cares for your child are made in response to your and your family's unique needs and challenges.

An example of compassionate care:

When you come in with your child for an appointment, the doctor is interested in your child, your child's progress, and any updates. The doctor is attentive to your questions and expresses 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).

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 needs to hear the information from the doctor.
- Who in your family provides you with the most support.

SECTION 6: CULTURALLY EFFECTIVE CARE

WHAT IS CULTURALLY EFFECTIVE CARE?

"Culturally effective care" starts with letting your doctor know that you have certain cultural beliefs or requests you would like him to observe or consider when treating your child. When the doctor is aware of your requests, he works 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 differences among people with respect to age, class, ethnicity, gender, physical and mental ability, race, sexual orientation, spiritual practice, and public assistance status. Your doctor demonstrates culturally effective care when he acknowledges, understands, and accepts these differences.

Language and communication:

Spoken and written language is our primary form of communication. If you find it difficult to communicate with your doctor, it may be necessary to get the assistance of a trained or certified bilingual translator to help you understand what information your doctor is telling you and your family.

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

TIP!

- Ask questions when you do not understand a word or a 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 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 personal feelings about how you would like to participate in the health care process.

SECTION 6: CULTURALLY EFFECTIVE CARE

"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 the doctor know things such as:

- How you handle your emotions in public and in private.
- What you consider 'healthy' for your child with special health care needs.
- 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 with special health care needs.
- What type of response you would get from the community about your child with special health care needs.
- What the cultural expectations are for self-help skills such as dressing and feeding.[10]

10 A Guide for Michigan Families: Special Care for Special Kids (2006 edition.) http://www.michigan.gov/documents/mdch/1-21_SpecialCareGuide_203487_7.pdf

SECTION 6: CULTURALLY EFFECTIVE CARE

EFFECTIVE COMMUNICATION: INTERPRETATION AND TRANSLATION SERVICES

Health care providers have a duty to provide appropriate auxiliary aids and services when necessary to ensure that communication with people with disabilities is as effective as communication with others that do not have disabilities. The Americans with Disabilities Act (ADA) requires that healthcare providers ensure effective communication with patients and companions with disabilities. This requirement includes providing auxiliary aids and services free of charge to the patient or companion. For individuals who are deaf or hard of hearing, qualified sign language interpreters and transcribers are examples of auxiliary aids or services. The health care provider should ascertain the particular language needs of the deaf or hard of hearing patient before hiring an interpreter.

Many organizations provide interpretation, translation and sign language interpreting services which may include interpreting spoken and signed communication, translating written documents, or both. Healthcare providers can find interpreters through various avenues including community agencies and interpreting businesses.

Title VI

Title VI of the Civil Rights Act of 1964 requires health care providers to overcome language barriers to care. This law applies to any provider or hospital receiving federal funds, including providers who treat Medicaid or Medicare patients. The Americans with Disabilities Act (ADA) requires that service providers contract and pay for interpreters to provide medical interpretation for the deaf and hearing impaired. Asking someone to interpret medical information after the patient's appointment is not acceptable under the ADA. Title V1 regulations state that "No person in the United States shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." These regulations were put in place to ensure that people receive equal treatment, equal access, equal rights, and equal opportunities, without regard to their race, color, national origin or limited English proficiency.

Your Rights as a Patient

As a patient, you have the right to ask your doctor's office if they receive federal financial assistance, and if they do, they are required to provide you with free interpretation or translation services for your provider visit. If they do not, then ask them if their office has provision for translation or interpreter services. Sometimes it is tempting for a doctor's office to require the person who needs an interpreter to bring along a friend or family member to interpret. However, section 35.160 (c) (1) and 36.303 (c) (2) specifically states that:

"A covered entity shall not require an individual with a disability to bring another individual to interpret for him or her." The only exception being an emergency involving an imminent threat to the safety or welfare of an individual or the public where there is no interpreter available, or if the person with a disability specifically requests that the accompanying adult interpret, the adult agrees, and reliance on that

adult is appropriate under the circumstances. A professional office cannot lawfully rely on a minor child to interpret except in an emergency involving an imminent threat to the safety of welfare of an individual or the public where there is no interpreter available.

Who qualifies for translation and interpretation services?

- Patients, customers, clients and other individuals with disabilities seeking or receiving the services.
- Family members, spouses, partners, etc. with disabilities.

Provision of translation and interpretation services:

- Is determined on a case by case basis.
- Is based on the person's needs and situation.
- Involves consulting with the individual to determine what communication method or technology will be effective for him or her.

Here are some tips to help you advocate for qualified interpreter services:

Give your doctor ample time to secure an interpreter for your visit:
In many cases healthcare providers need time to schedule a qualified interpreter or transcriber to meet your unique communication needs. It is best to try to make your appointment as far in advance as possible in order to allow for scheduling.

Be prepared:
Think about what communication help you might need and resources your healthcare provider might be able to use. When you contact the healthcare provider's office to make your appointment, let them know that you will need assistance with communication access. Request the specific type of interpretation or technology you will need. Be prepared to explain how your disability impacts communication.

Think carefully before using a family member or friend as an interpreter or transcriber:
Healthcare providers cannot require you to use a family member or friend as an interpreter or transcriber. It is generally not appropriate to use a family member or friend as an interpreter or transcriber for medical appointments. In the limited instances when it is appropriate, you may choose to use a family member or friend as an interpreter or transcriber if you want. Before deciding to use a family member or friend as an interpreter or transcriber, you will want to consider:

- Your family member or friend may not be qualified to provide interpretation or transcription services for you, especially in a medical setting.
- Some things you discuss with your provider may be private or serious in nature.
- Information provided may be complicated and require specialized vocabulary.
- Due to the relationship you have with your family and friends, it may be difficult for them to remain impartial about treatment options and diagnoses.
- It is never permissible for a child under the age of 18 to act as an interpreter or transcriber.

SECTION 6: CULTURALLY EFFECTIVE CARE

Schedule enough time with your provider to discuss your medical needs:
Interpreting and transcribing takes time. This process should not be rushed and you should understand everything prior to the end of your doctor visit. If necessary ask your provider to extend the time of your appointment in case any issues arise that may need to be addressed in further detail

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.

- Research the Americans with Disabilities Act. Learn more about effective communication and how to advocate for your child. Make a list of important resources within your community that will help you facilitate your child's unique communication needs.

For more information and further reading, please visit www.ada.gov

SECTION 7: FAMILY-CENTERED CARE

WHAT IS FAMILY-CENTERED CARE?

Family-centered care 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.

Key Components of Family-Centered Care:

- Your family is essential to your child's care and is a constant in your child's life.
- Your doctor acknowledges key family members.
- Your doctor asks your family about values.
- Decision making is shared.

Example of Family-Centered Care:
Upon bringing your child into 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. 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.

- Participate on the clinic's advisory board.
  This is a great chance to be involved in discussions, 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 office staff so 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

SECTION 7: FAMILY-CENTERED CARE

CORE PRINCIPLES OF FAMILY-CENTERED CARE

These set of values describe the family-centered care that a medical home practice provides.[11] Use this list as a conversation starter with your doctor.

- Respecting each child and his family.

- Honoring racial, ethnic, and cultural diversity and its effect on family experiences and views on care.
- Recognizing and building on the strengths of each child and family member, even in difficult and challenging situations.
- Supporting the choices of the family about approaches to care and decision making.
- Ensuring flexibility in office policies, procedures, doctor practices, and services tailored to the needs, beliefs, and cultural values of each child and family.
- Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and assuring.
- 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.
- Collaborating with families at all levels of the medical care of the individual child and in professional education, policy making, and program development.
- Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health.
- Participating in decision making and celebrating achievements.

Parent-to-Parent Tip!

Family-centered care starts with the family and doctor communicating and building a successful partnership. As a parent, you will prepare, organize, schedule, and advocate for your child. Never forget that you are an expert on your child and your opinion is important to the health and happiness of your child and family.

11 Core principles of family-centered care. American Academy of Pediatrics. http://aappolicy.aappublications.org/cgi/content/full/pediatrics;112/3/691#SEC3

SECTION 8: ADVOCATING FOR YOUR CHILD

WHAT IS ADVOCACY?

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. Advocacy also can be as simple as asking for written instructions to compliment what you are being told, whether you are at a pharmacy or at the car repair shop. For families of children with special health care needs, advocacy becomes an everyday effort to improve the quality of life for their children 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 no appointments are available.
- You would like your insurance 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 39) 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 the policy 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 families in managing the complex care of their children.
- You ask your insurance company to update their policy 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 go to state agencies and government entities to bring attention to the financial burden of medical care for families who have children with special health care needs. You explain how care coordination in your doctor's office 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 or care coordination are issues that families face every time they visit the doctor's office.

BASIC GUIDELINES FOR ADVOCACY

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.

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.

Learn how to navigate the system:

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

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.

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 Families,

My daughter, Jasmyn, was born at 24 weeks. She was in the Neonatal Intensive Care Unit (NICU) for 4 months. Before leaving the NICU, we had to find a pediatrician. I did some research and went to visit a recommended pediatrician. She answered my questions and I felt comfortable with her. After discharge from the hospital, Jasmyn had many short-term hospital stays over the next year. In addition to that, we had a variety of specialty appointments that included pulmonology, physical therapy, feeding therapy, and occupational therapy. Jasmyn's doctor and her staff helped coordinate all of these appointments and made referrals to specialists, as necessary.

That was almost 15 years ago. Jasmyn has since been diagnosed with multiple challenges. Our pediatrician has been with us through every step. I've had 2 other children since then. The primary nurse at the pediatric practice has been a valuable asset as well.

I feel like the pediatric team takes my concerns to heart. They make timely referrals. They listen. They also talk to my kids directly and engage them as patients. I know I can count on them and I feel they respect my role as a parent.

It means a lot to have a good relationship with our pediatric practice. I think you will find that valuable as well. Good collaboration and partnership go a long way in helping our children in their healthcare journey.

My best to you and your family,
Tonya (mother of Jasmyn, Jeffrey and Jacob), Tennessee Parent.

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 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 assigned a care coordinator. This nurse 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 directly contact her and what to do in her absence. She went on to discuss what appointments would entail and how to manage the paperwork 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 a refresher training on performing injections. 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 your family and your child's 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).

RESOURCES

TENNESSEE RESOURCES

Tennessee Department of Health: http://tn.gov/health/topic/MCH-cyshcn

Tennessee Medical Home: http://www.tennesseemedicalhome.com/tnaap/

Tennessee Parent to Parent Program: http://www.tndisability.org/tennessee-parent-parent

Tennessee Parent to Parent brochure: http://tn.gov/assets/entities/health/attachments/P2P_Brochure_final_07172014.pdf

Transition: http://www.tndisability.org/transition-planning

Family Voices of Tennessee: http://www.tndisability.org/familyvoices

Family Voices-Transition Planning: http://tndisability.org/transition-planning

Support and Training for Exceptional Parents (STEP) Transition Services:
http://tnstep.org/resources/transitionServices.aspx

Kidcentral tn: http://www.kidcentraltn.com

Disability Pathfinder: http://vkc.mc.vanderbilt.edu/vkc/pathfinder/

Disability Rights Tennessee: http://www.disabilityrightstn.org/

Disability Law and Advocacy Center of Tennessee: http://www.dlactn.ivdc.com/

NATIONAL RESOURCES

National Center for Medical Home Initiatives for Children 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 healthcare 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.

Family Voices
www.familyvoices.org

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

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 Center for Family/ Professional Partnerships
www.fv-ncfpp.org

The National Center for Family/Professional Partnerships (NCFPP) promotes families as partners in the decision-making of healthcare for children and youth with special health care needs (CYSHCN) at all levels of care.

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

The National Initiative for Children's Healthcare Quality provides information about the medical home as it pertains to children and youth with special health care needs.

Got Transition
www.gottransition.org/

Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

Opportunities and Resources for Youth
Youth Transition: www.youth.gov.

Youth.gov is the U.S. government website that helps you create, maintain, and strengthen effective youth programs. Included are youth facts, funding information, and tools to help you assess community assets, generate maps of local and federal resources, search for evidence-based youth programs, and keep up-to-date on the latest, youth-related news.

OTHER RESOURCES & TOOLKITS

A new way… A better way: The Medical Home Partnership
http://fha.dhmh.maryland.gov/genetics/docs/NESERVE_Maryland_Families.pdf?Mobile=1

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://del.wa.gov/publications/esit/docs/ParentTips_English.pdf

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

Extraordinary care: Improving your Medical Home
http://www.medicalhomeimprovement.org/pdf/Complete-FE-Learning%20Guide_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 suggests specific activities that help to strengthen their medical home or advocate for stronger primary care services.

Families Partnering with Providers
http://medicalhome.org/families/partnering-with-providers/

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

Family-Centered Care Self-Assessment Tool - Family Tool and User Guide
http://www.fv-ncfpp.org/activities/fcca

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.

Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home
http://pediatrics.aappublications.org/content/128/1/182.full

This is article published by the American Academy of Pediatrics. The publication provides guidance to families and providers on how to achieve a successful transition.

HEATH Resource Center at the National Youth Transition Center
Graduate School of Education and Human Development
The George Washington University
http://heath.gwu.edu

The HEATH Resource Center is an online clearinghouse on postsecondary education for individuals with disabilities. Since 2000, the HEATH Resource Center has served as a national clearinghouse on postsecondary education for individuals with disabilities, managed by The George Washington University Graduate School of Education and Human Development.

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

For More Information, contact the Tennessee Department of Health CYSHCN Program:

Web: http://www.tn.gov/health/health-program-areas/mch-cyshcn.html
Phone: 615-741-7353
Email: mch.health@tn.gov

Your Child's Doctors' Visits:

Notes: _____

For More Information, contact the Tennessee Department of Health CYSHCN Program:

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For more information, contact the Tennessee Department of Health
Children and Youth with Special Health Care Needs (CYSHCN) Program:

Web: http://www.tn.gov/health/health-program-areas/mch-cyshcn.html
Phone: 615-741-7353
Email: mch.health@tn.gov

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