Texas
Medical Home Toolkit

Comprehensive Culturally Effective Family-Centered

Coordinated Accessible Continuous Compassionate

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Comprehensive Culturally Effective Family-Centered

"Our medical home is a place where they know my story, they listen to my son, and they respect us. They facilitate our services and recognize these service needs beyond medicine. They talk with us."

— Judie Walker, whose 18-year-old son has cerebral palsy and asthma

ACKNOWLEDGEMENTS

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This toolkit would not be complete without the HRTW Portable Medical Summary, an excellent example of a one-page health summary that can be carried by youth and families for emergencies or routine medical visits. Of course, that is only one of the many amazing tools that can be found on their website. Be sure to check out the Health & Ready to Work (http://www.hrtw.org) website!

Many thanks to the Texas Parent to Parent families who took time from their busy lives to help revise the Texas Medical Home Toolkit. We are grateful for their many contributions to strengthening the existence of medical homes in Texas.

TABLE OF CONTENTS

Texas Parent to Parent

Providing support and information for families of children
with disabilities, chronic illness and other special health care needs

Dear Friends,

When I first heard the term Medical Home, my son was around 6 or 7 years old and was no longer medically fragile. I, like most parents I know, responded I didn't have a medical home any more since my son didn't need any medical equipment at home. The response I got helped me understand the term a little but 13 years later, Medical Home is still a vague concept. It's something I wish we had in place when my son was born at 24 weeks gestation.

The first 5 years were very difficult. If I had had one physician or clinic that truly helped me with all the specialists and decisions we were faced with those 5 years, I would have been thrilled. As it was, I was the one left to coordinate all the specialists, therapists, and insurance issues as well as make the necessary decisions about surgeries or treatments. And I had no medical background! I was the kid who hid under the bed when anyone even mentioned "doctor."

I see a Medical Home as what all parents dream of – the information and support from medical professionals as partners with the parent for those difficult decisions parents must make about their child with special needs. I can also see it as an excellent tool for physicians and clinics in working with and learning from parents that may help make some of the more difficult interactions run smoother. A parent who receives information, education, and support is a much happier and easier-to-get-along-with parent than one who has to fight for information or respect.

You have received this packet of information because you have expressed an interest in learning more about the concept of Medical Home and how to get one set up for your child or clients who have special health care needs. There is a lot of information in writing and on the Internet for medical professionals about Medical Home, but not much can be found for parents. We hope this packet will start to fill that gap.

The Children with Special Health Care Needs (CSHCN) Services Program coordinates a Medical Home Workgroup that is developing materials and information to assist in making the medical home concept a reality for all children in Texas. We are in the process of establishing a listing of medical homes in Texas and need your help. If you currently have a medical home and/or if you are able to provide support to families seeking a medical home, please contact us so that we can add your information to our listing. With your help, we will create a listing of health care providers who are serving as medical homes in Texas to share with families who want to create one.

Please do us a favor by completing the enclosed survey and return it to us in the self-addressed stamped envelope. We will use your comments to improve the information provided.

Sincerely,

Laura J. Warren
Texas Parent to Parent

Texas Parent to Parent

3710 Cedar Street • Box 12 • Austin, TX 78705-1449 • 866-896-6001 • 512-458-8600
website: www.txp2p.org • Email: info@txp2p.org

What is a Medical Home?

By Tammy Mann, Texas Parent to Parent

A Medical Home (MH) is a model of care delivery that your family should already be receiving. It is the end result of parents and health care professionals acting as partners. After all, you both want the same thing, right? ...healthy children and families who are able to achieve their maximum potential. Unfortunately, most parents are not aware of what "medical home" means, most professionals think they already provide it, and the ones that don't are trying to figure out how to bill for it!

Medical Home is not the "term of the month." The definition was introduced in 1992 by the American Academy of Pediatrics. They believe **"**that all children should have a medical home where care is ***accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective."***

To be fair, health care professionals are not taught about Medical Home in school. Doctors learned to fix what was broken or bleeding, take out what didn't belong in, add in what was missing… but nowhere in the "rule book" was anything that said "play nice with the patient," never mind be ***"*accessible,"** make sure that you take all forms of payment (yes, that means insurance, Medicaid, Medicare, etc.), provide care in the family's community (not the big city 150 miles away), and make yourself available to speak directly to the families (and not after the family has left 10 messages). The MH model gives "bedside manner" a whole new meaning!

The best thing a medical professional ever said to me was that I know my child better than anyone. Well, if you think about it, that's true. Who knows our children better than we do? ***Family-centered*** care means just that - parents are the experts on their children, so why not be teammates with the health care professionals? In a true MH, recognizing that the family is the principal caregiver, the core, the one true constant in the child's life, is just an extra tool for the provider. Nowhere else can you find a more reliable source for information.

Continuous means that you have the same health care professionals available from infancy through adolescence and young adulthood. AND, they assist with transitions...including those to other pediatric providers or into adult health care systems.

Accessing health care 24 hours a day, 7 days a week, 52 weeks a year should not be difficult if your health care provider has a ***comprehensive*** office. Ideally, the preventive, primary, and tertiary care needs are addressed in the office, which should cut down on some of those "24 hour a day, 7 days a week, 52 weeks a year" emergency needs.

Providing resources falls into both ***comprehensive*** **and** ***compassionate*** services. Connecting families to support, educational, and community-based services only proves that the health care professionals understand and are working toward helping your family be the best they can be; it demonstrates concern for well-being, understanding and empathy.

The same can be said for being ***culturally effective.*** Professional translators or interpreters are great, but truly understanding that a family's culture, beliefs, rituals, and customs are a part of the "whole" family, are the "framework" of the family, is critical and should be recognized, valued, and respected as families and physicians work together to develop a care plan.

Last, the family care plan should be ***coordinated***. It should be developed by the health care provider, child/youth, and family, and shared with other providers, agencies, and organizations involved with the care of the patient. Families are linked to support, educational, and community-based services, a central record containing all pertinent medical information (including hospitalizations, and other specialty care like outside therapies, etc.) is kept and maintained in a central record by the primary provider. This can be your pediatrician, family practitioner, or as in one family I know, your dermatologist.

I hope this gives you a better understanding of what it means when someone says "Medical Home." ♥

Desirable Characteristics of a Medical Home

★ **Accessible**

- ★Care is provided in the child's or youth's community.
- ★All insurance, including Medicaid, is accepted.
- ★Changes in insurance are accommodated.
- ★Practice is accessible by public transportation, where available.
- ★Families or youth are able to speak directly to the physician when needed.
- ★The practice is physically accessible and meets Americans with Disabilities Act requirements.

★ **Family-Centered**

- ★The medical home physician is known to the child or youth and family.
- ★Mutual responsibility and trust exists between the patient and family and the medical home physician.
- ★The family is recognized as the principal caregiver and center of strength and support for the child.
- ★Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.
- ★Families and youth are supported to play a central role in care coordination.
- ★Families, youth, and physicians share responsibility in decision-making.
- ★The family is recognized as the expert in their child's care, and youth are recognized as the experts in their own care.

★ **Continuous**

- ★The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.
- ★Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.
- ★The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

★ **Comprehensive**

- ★Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.
- ★Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.
- ★Preventive care is provided that includes immunizations, growth and development assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, safety, nutrition, parenting, and psychosocial issues.
- ★Preventive, primary, and tertiary needs are addressed.
- ★The physician advocates for the child, youth, and family in obtaining comprehensive care and shares responsibility for the care that is provided.

★The child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed.

★Information is made available about private insurance and public resources, including Supplemental Security Income, Medicaid, the State Children's Health Insurance Program, waivers, early intervention programs, and Title V State Programs for Children with Special Health Care Needs.

★Extra time for an office visit is scheduled for children with special health care needs, when indicated.

★ **Coordinated**

★A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient.

★Care among multiple providers is coordinated through the medical home.

★A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.

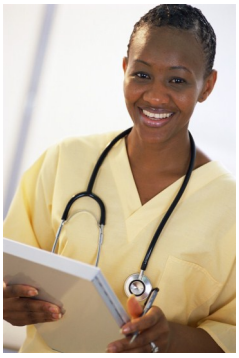
★The medical home physician shares information among the child or youth, family, and consultant and provides specific reason for referral to appropriate pediatric medical subspecialists, surgical specialists, and mental health/developmental professionals.

★Families are linked to family support groups, parent-to-parent groups, and other family resources.

★When a child or youth is referred for a consultation or additional care, the medical home physician assists the child, youth, and family in communicating clinical issues.

★The medical home physician evaluates and interprets the consultant's recommendations for the child or youth and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.

★The plan of care is coordinated with educational and other community organizations to ensure that special health care needs of the individual child are addressed.



★ **Compassionate**

★Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions.

★Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.

★ **Culturally Effective**

★The child's or youth's and family's cultural background, including beliefs, rituals, and customs are recognized, valued, respected, and incorporated into the care plan.

★All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of (para) professional translators or interpreters, as needed.

★Written materials are provided in the family's primary language.

Physicians should strive to provide these services and incorporate these values into the way they deliver care to all children. (Note: pediatricians, pediatric medical subspecialists, pediatric surgical specialists, and family practitioners are included in the definition of "physician.")

Source: http://aappolicy.aappublications.org/cgi/content-nw/full/pediatrics;110/1/184/T1

Sam & Sue

I'm the mother of and care provider for my only son, Sam, who is chronically ill with life-threatening allergies, Asthma, Herpes and Severe Chronic Atopic Eczema. Our Pediatrician said he did not have time to take on a complicated case like Sam's. He only wanted to treat Sam for simple things like immunizations, ear aches or sprains.

He said, "I don't have time to read up on your child's condition. They don't pay me enough to spend that kind of time on one patient. I'm sorry. I don't have time to coordinate a team of five physicians to give your child the care he needs. You may want to find another doctor."

When he said that, I just wanted to cry. I thought, 'how am I supposed to find a doctor who is willing to take on my child's rare and complicated case? I am providing around-the-clock-care to a very sick little boy and now I have to search for a generous doctor, too.'

However, I didn't have time to feel sorry for myself. Sam's pediatrician said I needed to find someone to coordinate Sam's health care team of specialty doctors. We were seeing the dermatologist 3 to 4 times a week for UV treatments so he seemed the logical choice.

At the next dermatology appointment, I asked Dr. Smith, Sam's dermatologist, who he would recommend to lead Sam's medical team. He said "Oh, I'll do it, no problem." It was just that easy. All I had to do was ask.

How did I find such a great dermatologist?

Very quietly, I asked receptionists and nurses at 5 other offices who they would recommend. Someone with a kid-friendly personality who would treat us with respect. The same name came up over and over. It was Dr. Smith.

Talk about **Accessibility**! His office is only 5 miles from our house. He accepts Blue Cross Blue Shield. His home phone number is in the telephone book. I only called him at home one time during an emergency. He gave me his cell phone number after Sam was diagnosed with Herpes because Sam will need immediate treatment if the herpes get in his eyes. Dr. Smith's 2 nurses are empowered to find medical care for Sam when Dr. Smith is on vacation. His nurses return phone calls the same day. One of the benefits of this Medical Home is that we regularly see the same PCP (Primary Care Physician) and the staff know us by name.

How is this practice **Family Centered**? Dr. Smith never talks down to me the way the Allergy doctor does. I am respected as an expert on Sam's skin care. He knows that we value being able to swim in the Lake 2 times per year and that means Sam will need an antibiotic because he will get infected. The doctor never forbids us from that swim because he knows it is important for Sam to feel "normal," sometimes even at the expense of a bacterial infection.

As an expert on the team, I can request trying a new moisturizer when I think it's needed. Dr. Smith even asked, "How well are all of you sleeping?" He realized that Sam's extreme itchy and raw skin was worse at night and kept my husband and me awake on alternate nights, rocking a screaming and crying child.

Every year before school starts, his office reviews the 5 medication permission forms and signs them. His office staff even remove the Glade plug-ins on the days Sam has a doctor's appointment. The air fresheners will set off a really bad itchy spell if left in place.

How is **Continuous Care** provided? Dr. Smith reviewed our insurance list of family practice providers and helped us transition from a pediatrician to a family practice doctor. We felt supported in finding a new PCP.

What about **Comprehensive Care**? Dr. Smith has briefed all the doctors on call about Sam's condition. Someone who knows all about Sam is available 24/7.

We even have a preventive game plan in place for ER visits. We know to call Dr. Smith on the way to the hospital so the ER doctors are not overwhelmed by Sam's complicated case. We had a strained ER visit once for a broken bone because the physicians were afraid of Sam's eroded skin and itchiness.

To further illustrate comprehensive care, I need to mention the special team our Dentist put together for Sam. Our Dentist held a brunch and invited the Orthodontist and Maxofacial surgeon. They discussed all of

Sam's allergies and special needs and created a long-term plan of treatment.

The orthodontist's office even has a patient liaison, Miss Jane. She reviewed Sam's orthodontic treatment plan and had him sign a patient agreement that he would do his part to make treatment successful. She told me my job as the Mom was to bring Sam to appointments and to pay the bill, period. I found it necessary to call Miss Jane when Sam and I encountered a rude and hostile dental technician in their office. The technician received more training and the orthodontist called me at home to apologize for the rude care we received from his technician. The ideal medical home model includes a patient liaison.

How is **Coordinated Care** provided? One technique we use to make sure everyone on the Team has Sam's current information is to utilize a USB Flash Drive for easy portability of Sam's entire medical record. Ask your doctor about using this method.

Our coordinated plan of care is called **The Current Treatment Plan** (see Sam's Medical Notebook [next page])). This is carried to all doctor visits and each doctor photocopies it for Sam's medical file.

Sam's dermatologist also cares about Sam's psycho-social needs. He sent Sam to Skin Camp 3 summers. It was paid for by the American Dermatological Society. For 3 glorious weeks, Sam felt like a typical kid instead of "monster boy," which is what he was called at school. Dr. Smith reads and investigates the latest pharmaceutical publications for new treatments like Elidel.

He advocates for Sam by writing letters to the school nurse to let staff know that Sam has eczema, not infectious impetigo. Dr. Smith also writes letters to the custodians asking they not use weed or bug spray near Sam's compromised skin. The coordinated care we receive helps us feel connected to new information and support organizations like skin camp.

Dr. Smith provided **Compassionate Care** to our family when we received the Herpes Simplex diagnosis. Herpes is like having cold sores but it's all over Sam's body. I cried, and Dr. Smith put his hand on my shoulder and said "We'll get through this together. You're not alone." He encourages Sam at every visit by saying "We're gonna fix you up kiddo." Compassionate care provides hope and promotes our mental health.

No barriers to **culturally effective care** exist with Dr. Smith. There is no language barrier. We trust each other. He does not stereotype by race, sex or class. In addition, the doctor knows that at Christmas and Easter, Sam will go off his special diet and a skin infection will result. Dr. Smith never shames us or insists on Sam staying on the diet. He simply says, "Let's plan for an antibiotic and good wound care following the holiday meal." The benefit of the culturally effective care is that it promotes Sam's quality of life. He gets to have a holiday with holiday foods like typical children.

What is Sam's life like today? Today, at age 16, he is thriving! Puberty transformed his immune system by calming it down, just as the doctor predicted. His olive complexion masks much of the skin scarring. Sam not only looks normal, but also, the girls find him simply dreamy. He has long ringlets of soft brown hair down to his shoulders.

He still has food and nasal allergies and occasionally, asthma. Sam will probably have to remain on daily Valtrex for the rest of his life because of the Herpes Simplex One complication from his childhood eczema. He says, "All things considered, 'life is good." He is taking all honors classes with hopes of becoming an engineer just like his Dad.

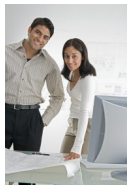
His favorite thing to do these days is to play soccer for two teams. Sam says, "Most people take for granted what it is like to be a regular, typical, normal person. I'm so glad people don't stare at me anymore just because of my skin. Now when a girl looks at me, I think, "She's checking me out…sweet!"

Sam has a lot more free time now that he does not have to see two or three doctors every week. He's down to one medication check every three months with his dermatologist and his allergy doctor.

Our Medical Home Partnership yielded a safe holding environment that brought us through the pit of despair into the light of hope for a future. Our Medical Home doctor held the hope when we could not. This emotional support was priceless. In addition, our Medical Home doctor was easily accessible for consultation when Sam had emergencies like fractures and ER visits. This avoided the frustration of educating ER doctors about Sam's complicated case. Moreover, it provided a buffer

with Child Protective Services when the ER doctors' fears caused them to think that I was either abusive or had Munchausen's-by-Proxy.

Furthermore, the MH doctor coordinated Sam's medications among his team of five specialty physicians. This provided the safe assurance that Sam would not have drug interactions since he was on numerous prescriptions and supplements.



Through our MH doctor, Sam has experienced what is like to work in partnership, and what it is like to be treated with respect by a doctor. Sam has learned through experience that doctors are not deities (gods) who control your choice of medical care. Overall Sam has learned to partner with his MH doctor and use him as a knowledgeable consultant on our team. ♥

Note: although this is a true story; the names of the individuals have been changed to maintain their anonymity.

Sue's Tips for Finding a Medical Home

- ★ Ask your current Primary Care Physician (PCP) who they refer patients to see.
- ★ [Quietly] Show a list of insurance-approved providers to receptionists, secretaries or nurses at your PCP or specialty care doctors' offices. Ask who they think is **friendly, accepting, and easy to work with**.
- ★ Ask friends who they would recommend.
- ★ Call offices that are highly recommended.
- ★ Decide whether a clinical setting or a private practice meets your family's needs best.
- ★ Schedule a get-acquainted appointment with the doctor.
- ★ Use the Medical Home checklist as a prompt for questions for the doctor and staff.
- ★ Prepare a list of questions for the appointment.
- ★ Write down the name of each staff member you meet: receptionist, nurse and secretary.
- ★ Does the doctor remind you of your least favorite relative? What is your "gut" feeling? Can you trust and work with this doctor? Does your child like the doctor and nurse? ♥

Sue's Tips for Maintaining a Medical Home

- ★ It is helpful to have respectful interactions with all members on the team. Remind yourself that you need each member on your child's team.
- ★ Ask about office procedure. "What's the best way to get ____'s school medicine papers filled out and signed?" How will you know when they are ready to pick up? Will they call you or should you check back in a few days?
- ★ Call the doctor after hours only when it is urgent; don't abuse the privilege. Some doctors have been known to provide their cell and home numbers. Ahead of time, discuss with your doctor which issues warrant an urgent call.
- ★ Send thank you notes for service beyond the call of duty.
- ★ Once a year, when possible, I give small, tasteful, inexpensive appreciation gifts to each staff person and doctor. (small potted plants, chocolate, homemade bread) I always include a heartfelt note of appreciation. ♥

Sam's Medical Notebook Table of Contents

- ★ Front cover, photo of child
- ★ Current Treatment Plan
- ★ Emergency Information form
- ★ Health history overview/diagnoses
- ★ A list of team of physicians and phone numbers
- ★ Dates and names of surgeries, fractures & treating physician
- ★ Medications, by drug, year, diagnosis and reactions, if any
- ★ Business cards of doctors, counselor, PT, and OT
- ★ Immunization Record
- ★ Prescriptions chart (when and what to refill)
- ★ School Authorization for Medication forms
- ★ Pocket for photos, if appropriate
- ★ Alternative medicine Information
- ★ Daily Medicine & Progress Charts
- ★ Pocket of blank charts ♥

Steps to Becoming a Parent Partner in Your Physician's Office

By Tammy Mann, CSHCN Medical Home Learning Collaborative

Ideally, you already have a doctor you feel provides family-centered care. But if not, your first step will be to locate a new doctor! If you need assistance with locating one in your area, The American Academy of Pediatrics Pediatrician Referral Service (herein after called AAP Pediatrician Referral Service) is intended for use by the general public to allow them quick access to information on pediatricians.

If you are looking for a pediatrician who specializes in the care of children with disabilities and/or children with developmental or behavioral issues, you can use the Pediatrician Referral Service to search for a pediatrician by specialty. You can also search on a website for a pediatrician by last name, city, state, zip code or area code at www.aap.org/referral/.

Another option, and my favorite, is to contact Texas Parent to Parent (www.txp2p.org) and see if they have any physician referrals from parents in your area of Texas. The important thing to remember is that just because a doctor is on someone's referral list does not mean that you will approve of them.

Okay, so you have a doctor; it does not have to be the pediatrician, it could be the sub-specialist (neurologist, orthopedist, cardiologist, dermatologist, etc.) that you feel is the doctor who coordinates your child's care, the one who keeps up with all the other things going on with your child in order to make sure that he/she receives ***continuous, comprehensive, and coordinated care.***

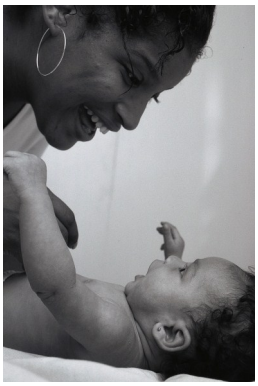
If it is a physician you have been working with for a while, you may feel comfortable giving him/her the Medical Home Brochure and asking what you can do to help his office become more involved. Of course, this is after you have expressed your appreciation for all the wonderful care your child has received over the years.

However, just like everything else in our lives, it is easier if you have ideas of ways you can "help" the office become more family-friendly, provide families with much needed information, help the office run smoother, and even SAVE the office $$$$. The latter is a very important point because cost is usually one of the first responses from the office manager or physician as to why things cannot be changed.

The American Academy of Pediatrics believes in the philosophy of Medical Homes for all children because not only does it enhance the quality of care a family receives, it also enhances the overall effectiveness of the practice. The AAP has developed a link on their website that covers the reimbursement arena for practices.

The following is a list of a few ideas to help you get started.

1. Ask your child's doctor if some of the family-centered things he/she does could become more general practice. Suggest that the office organize a meeting of parents, staff, and providers to talk about how to improve services for families like yours.
2. One thing that has been discussed in meetings is accessibility: How easy is it for you to get to your appointment?
    a. What could make it easier?
    b. When you get to the office, is parking available?
    c. Can you put a wheel chair lift down and get a person in a wheelchair out of the vehicle in the space provided?



d. Are the doors electric?
e. Does a staff member help you get in?
f. Is there ample space in the office for a person in a wheelchair?
g. How long is the wait time?
h. How difficult is the wait time for you and your child?
i. Is there enough time during the actual visit?
j. Is there some sort of code to alert the appointment desk to schedule extra time during the visits of patients with special needs?

3. Offer to set up a Parent Resource and Networking Bulletin Board in the office. This may sound like a lot of (free) work and it can be but it does not have to be! TxP2P's website has a Resource Directory that is regularly updated and printable. Are there meetings in your area? If so, put it on the board too! Remember to keep the board current.

4. If there are parent meetings in your area, maybe some of the information would be helpful to the office staff - invite them to attend the meetings.

5. Invite the physician to speak at one of the meetings or maybe the office would like to host a "Parents Night." There are numerous topics that could be a possibility (disability specific topics, potty training, behavior, transitions, resources, etc.).

6. Does your child have a Care Plan? How about an Emergency Room Information Sheet? A positive point to stress is that if the patient goes into the ER with an Emergency Care Plan, they will not have to contact the physician in the middle of the night when their patient shows up!

If you have a care plan, discuss it with your doctor and let them help you make sure the information on it is really what a stranger would need to know about your child to provide the proper care. Offer to share your plan with other patients in the office; this could also be another topic for a parent meeting.

You may even be able to get your local emergency department to host or sponsor such a meeting because of the valuable information the plan would provide them. If you do not have a care plan, you can search the internet or go to the AAP website at www.medicalhomeinfo.org/tools/care_notebook.html, contact Texas Parent to Parent, or contact the CSHCN Services Program office at the Department of State Health Services, 1100 West 49th St, Room 442, Austin, TX 78756, www.dshs.state.tx.us/cshcn/default.shtm or call the CSHCN Services Program Inquiry Line at 1-800-252-8023. ♥

Providers Partner with Families in Medical Homes

Parent-professional teamwork is a key part of developing medical homes for all children.

What are families looking for in a health care provider?

- ♥ A respectful listener
- ♥ Someone who sees their child as a "whole" person
- ♥ A caring attitude
- ♥ Understanding, support, and someone to be there for them
- ♥ Clinical know-how
- ♥ Someone who can add to their power and knowledge
- ♥ Someone who allows for and supports hope

Questions to Ask When Choosing a Doctor

(excerpt from http://www.patientsafetypartnership.org/Choosing_Doctor.html)

QUESTIONS TO ASK YOURSELF

Is your doctor's age a factor? The years of patient experience accumulated by older physicians can be a significant advantage. Some research suggests that patients tend to prefer the bedside manner of older doctors. A physician with many years of experience may also have better clinical judgment, which could translate into improved ability to diagnose and manage complex health problems. But a study published in a February 2005 issue of the Annals of Internal Medicine reported the seemingly counterintuitive finding that, overall, the more experience a physician has, the worse his or her care becomes. In general, if your priority is someone familiar with current evidenced-based standards of care, you may want to opt for a younger physician. And if you have multiple, complex health problems, or put a premium on bedside manner, you may lean toward an older one.

Male or female? Some research suggests that women prefer getting care from female doctors; that's particularly true for screening tests for breast, cervical, and colon cancer. Other research hints that female physicians may do a better job than male ones in providing basic preventive services to both women and men. So if you're particularly concerned about preventive health care, consider seeing a female doctor-especially if you're a woman yourself.

Are you looking for a collaborative partner or a trusted leader? The caricature of the average primary-care doctor has gradually shifted from the father figure who makes medical decisions for you to a technician who lays out an array of treatment options for you to choose from with hardly a word of guidance. The reality, of course, is that a good doctor has always been someone whose judgment you trust but who is also willing to take your preferences into account and to admit when the medical evidence is uncertain. And most physicians combine both characteristics, at least to some extent. Still, doctors do tend to lean toward either relying mainly on their professional judgment or using a shared decision-making model that involves actively educating patients and seeking their input.

QUESTIONS TO ASK A POTENTIAL DOCTOR

How long will I have to wait for an appointment? Look for practices that offer "open-access" scheduling, in which doctors typically leave part of each day's schedule unbooked so they can offer some same-day appointments.

Do they keep paper or electronic medical records? Computer-based record-keeping is considered a major step toward improving the quality and efficiency of medical care. But only about one-quarter of Canadian and U.S. doctors surveyed recently said they currently use electronic records, compared with 8 out of 10 or more in Australia, the Netherlands, New Zealand, and the United Kingdom.

Do they take questions by e-mail? Though searching for health information is one of the most popular uses of the Internet, less than 10 percent of patients communicate with their doctors by e-mail. That relatively small number may be due, in part, to many doctors' reluctance to hand out their e-mail addresses, for fear both of liability implications and of being overwhelmed by "cyberchondriacs." E-mail "conversation" is great for non-emergency matters: problems or advice about a chronic disease, an appointment, test results, clarification of some item that came up during an office encounter, an overlooked question, a medication side effect, or any question requiring only a yes or no answer. And it's a direct link to your doctor, without a telephone intermediary such as a nurse or assistant and can supplement your time with you.

ASKING AROUND—PEOPLE AND PLACES TO HELP WITH YOUR SEARCH

Once you have a sense of what kind of doctor is best for you, ask people you trust, for example, friends, family, and coworkers, about doctors they use and like. You might ask questions such as:

- ★Do you know a good doctor?
- ★Would you recommend your doctor?
- ★What do you like about your doctor?
- ★How long does it take to get an appointment?
- ★Can you usually see your doctor right away if you need to, like on the same day if you get sick?

In addition to talking to friends, family, and coworkers, you can talk with other health professionals you see, for example, your heart doctor or the doctor you see for your lung problems, and ask for recommendations...

Medical Home Checklist

Your child's pediatrician or family physician may not have all of the following pieces of Medical Home in their practice, but it will help to know what to ask for and what you can work on together. You can use this list when choosing a new physician for your child, or as a way to start a conversation with your child's doctor about Medical home.

Your child's primary care doctor and their office is accessible.

- ☐ Available after hours, on weekends and holidays
- ☐ Accepts your child's health insurance
- ☐ Office and equipment physically accessible to your child

Staff within your child's primary care office know you and help you.

- ☐ Knows you and your child when you call
- ☐ Recognizes and accommodates your child's special needs
- ☐ Responds to requests for prior approvals, letters of medical necessity for your child's insurance or documentation for other programs and services
- ☐ Provides written materials in a language you understand

Your child's primary care doctor and office staff help you to coordinate your child's care.

- ☐ Follows up with difficult referrals
- ☐ Helps you to find needed services such as transportation, durable medical equipment, home care and ways to pay for them
- ☐ Explains your child's needs to other health professionals
- ☐ Reaches out to your child's school or day care providers to help them understand your child's medical condition
- ☐ Encourages and supports frequent communication between all persons involved in your child's care (with your consent)
- ☐ Organizes and attends team meetings about your child's plan of care that includes you and other providers

Your child's primary care doctor respects you and listens to your observations about your child.

- ☐ Asks you to share your knowledge about your child
- ☐ Seeks your opinion when decisions are needed
- ☐ Talks to you about how your child's condition affects your family (other children in the family, child care expenses, work, sleep)
- ☐ Acknowledges and respects your family's cultural values and religious beliefs
- ☐ Provides interpreter services if needed

Your child's primary care doctor and office staff work with you to plan your child's care.

- ☐ Helps you set short-term (3-6 months) and long-term (the next year) goals for your child
- ☐ Gives you important information, such as recommendations or new treatments, in writing
- ☐ Works with you to create and update a written plan of care for your child's medical and non-medical needs
- ☐ Reviews your child's medical records with you when needed
- ☐ Helps you consider new and emerging treatment choices for your child's condition

Your child's primary care doctor and office staff support you as a caregiver.

- ☐ Helps you connect with family support organizations and other parents in your community
- ☐ Provides information on community resources
- ☐ Finds and shares new information, research or materials that are helpful in caring for your child
- ☐ Helps you to advocate on behalf of your child
- ☐ Plans for adult health care services (if appropriate for your child's age)

Adapted from **A NEW WAY…A BETTER WAY**. The Medical Home Partnership: Building a Home Base for Your Child with Special Health Care Needs: New England SERVE http://www.neserve.org/neserve/med_hm.html

PORTABLE MEDICAL SUMMARY*

NAME	John Smith

Mailing Address	Email Address	Home Phone	Cell Phone
4567 Main Street, Anytown, Texas 71111	john@whatever.com	123-456-7891	234-567-8912

Insurance		Subscriber Name and #
Blue Cross Blue Shield of Texas	Primary	987-66-5432 BC/BS PPO Plan Code 200, Cust Svc #: 800-789-4561
	Secondary	987-66-5432 BC/BS Blue Choice Plan 2, POS Code 200, Cust svc: 800-789-4561

Legal Health POA	Name	Relationship	Cell	Work	Home	other
	Jane Smith	sister	234-567-8913	234-678-1111	123-456-7891	
	Name	Relationship	Cell	Work	Home	other
	Sam Smith	son	234-567-8914	234-678-1112	123-456-7892	

DOB	Social Sec #	Height	Weight	Blood Type	DNR Signed	Advanced Directives	Organ Donor
1-01-51	999-88-7777	6' 3"	198	O+	yes	no	yes

NOTES:	
	High intelligence (130 IQ), compliant patient, high tolerance to pain
	Incomplete Quad (has sensation), only movement left index finger 10 cm
	Need to explain EVERY procedure, when possible, ask for consent prior to doing

Health Issues			
	Neuro Muscular	ICD-9 359 MD 335.1 SMA	Spinal Muscular Atrophy Type 2, dx age 9mos, 3/74 (Severe Anterior Horn Cell disease/Werdnig-Hoffman) Incomplete quad (has full sensation), no functional movement
	Pulmonary	ICD-9 V44 Trach 518.81 Resp Failure 486 Pneumo Org NOS	Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis Recurrent pneumonia, Respiratory insufficiency, poor residual functions/reserved capacities, Elective Trach 3/82 for Ortho Surgery

Medications

Rx DAILY

Alprazolam (xanax)	0.5 mg QID	anxiety
Aspirin-Child	81 mg 1 x	prevent clots
Temazepam	15 mg H S	sleeping pill
DuoNeb	1 vial QID	nebulizer*
	*(Ipratropium, Bromide & Albunterol)	

Rx MONTHLY

Thiamine	100 mg monthly	
Cyanocobalamin	1000 mcg/ml mon	(B12)

Rx PRN

Darvocet-N		
Zithromax SUS PFIZ	200/5ml 45ml	antibiotic
Diphnoxylate/atropine	1-2 tablets	diarrhea

Herbs/Drops

Lymphatic	5 x2
Flu Balancing	10 x2
Respiratory	7 x2
Allertox –airborne	x2
" " Aleer-Tota	x3
" " A	x4
	6 x2
	5 x2
	8 x2
Digestive	3 x2
Mucous	5 x2
Cell	7 x2
Muscular	4 x2
Integumentary	8 x2
Er Cheng Tang	1 tsp x2

VENT—Pulmonetic LTV 900

Tidal Volume 310
Ins[illegible]on 1.1
P[illegible] Support 13
[illegible]sitivity 02
[illegible]0
Low 02

TRACH: Shiley 6 cuffed (deflated)

SPEAKING VALVE: Passy-Muir PMV007

OXYGEN 1.5 liters

Medical History

Specialty	Procedure	Description
GI		
Ortho		
Urological		

Immunizations (what, when)

Physicians

Specialty	Name	Phone Number	Address/Website

Other

PORTABLE MEDICAL SUMMARY

NAME							
Mailing Address				Email Address		Home Phone	Cell Phone
Insurance		Primary	Subscriber Name and #				
		Secondary	Subscriber Name and #				
Legal Health POA	Name		Relationship	Cell	Work	Home	
	Name		Relationship	Cell	Work	Home	
DOB	Social Sec #	Height	Weight	Blood Type	DNR Signed	Advanced Directives	Organ Donor
NOTES:							
Health Issues							

Medications	Herbs/Drops	Other Equipment

Medical History

Specialty	Procedure	Description

Immunizations (what, when)

Physicians

Specialty	Name	Phone Number	Address/Website

Other

Department of State Health Services
Children with Special Health Care Needs (CSHCN) Services Program
NATIONAL, STATE, AND LOCAL INITIATIVES TO PROMOTE MEDICAL HOMES

The federal **Maternal and Child Health Bureau (MCHB)** has established a national performance measure that all children with special health care needs will receive regular, ongoing, and comprehensive care within a medical home.

The **Texas CSHCN Services Program** receives funding from the federal Title V Maternal and Child Health Block Grant and is responsible for helping to achieve this national performance measure in Texas. The CSHCN Services Program rules state that each program client should receive care in the context of a medical home. The CSHCN Services Program coordinates a Medical Home Workgroup that is developing materials and information to assist in making the medical home concept a reality for all children in Texas. For additional information on the Medical Home Workgroup, call 512-458-7111, x3026 or 800-252-8023 (toll-free) or email cshcn@dshs.state.tx.us.

The **American Academy of Pediatrics (AAP)** promotes the "medical home" as best practice. The AAP's "Medical Home Policy Statement" notes that the provision of a medical home is cost effective, ensures quality of care, and can lead to improved health outcomes through an identified primary source of care. The AAP's medical home website (http://www.medicalhomeinfo.org/tools/index.html) is a valuable resource for additional information on the AAP medical home initiative.

Texas Early Childhood Comprehensive Systems (TECCS) – Raising Texas — "Raising Texas" is an effort to strengthen Texas' system of services so that all children enter school healthy and ready to learn. There are four workgroups that collaborate on this effort: (1)Access to Insurance and Medical Home, (2)Social Emotional Development and Mental Health, (3)Early Care and Education, and (4)Parent Education/Family Support.

Several sites in Texas are implementing a family centered, community based training program that focuses on educating physicians-in-training about CSHCN and their families. The innovative curriculum brings doctors out of the hospital and into the home to learn first-hand from the family's perspective and offers a curriculum for teaching physicians and other professionals the key health care services and resources necessary for children and adults with special health care needs to live in the community. ***The following is a list of contacts for information on the Texas area physician training programs:***

Texas Parent-to-Parent Medical Education Program (MEd)— In response to a growing population of children with chronic illness and developmental disabilities who are living at home and actively participating in our communities, Texas Parent to Parent (TxP2P) created the MEd program to give medical residents a more complete understanding of what life with a child with special health care needs is like. The goal of MEd is to give Pediatric and Family Practice Residents and other medical professionals a comprehensive understanding of life for a family of a child with chronic illness or disability, and to teach them the skills they need to work in partnership with the family to provide high quality care. For more information, go to www.txp2p.org.

Project DOCC (Delivery of Chronic Care) is a training program that draws on the experiences of families of children with chronic illness/disabilities, involving them as faculty to transfer their knowledge to first year pediatric resident physicians. Since the pediatric resident physicians receive an extensive education, this is one component that focuses specifically on how families successfully manage their children's complex needs at home and in the community. Project DOCC's parent teachers provide physicians with a unique perspective on culturally effective, family-centered care. Project DOCC Houston is a family faculty program at Baylor College of Medicine in partnership with Texas Children's Hospital that educates 52 first-year pediatric residents a year.

Amarillo, Austin or Temple	**Houston**
Debbie Wiederhold	**Elaine Hime**
Texas Parent to Parent Medical Education Program	Project DOCC
866-896-6001 (toll-free)	713-926-2580
debbie@txp2p.org	projectDOCCHouston@yahoo.com

Medical Home, Health Care Transition & Other Helpful Resources

A Young Person's Guide to Health Care Transition: *Envisioning My Future*	http://hctransitions.ichp.ufl.edu/hct-promo/ This guide will help you and your family start thinking about health care transition and making a health care transition plan so that it will be a successful process. Health care transitions work best when they are planned. In order to plan, you and your family need to learn about new choices and new ways of getting health care services. We hope that you and your family will begin to talk about this important part of your future. (English & Spanish) 
Academy for American Pediatrics	http://aap.org/ American Academy of Pediatrics Preamble to Patient-Centered Medical Home Joint Principles: "Every child deserves a medical home. The American Academy of Pediatrics describes the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care."
American College of Physicians	http://www.acponline.org/running_practice/pcmh/help.htm?gclid=CJqFku-NuqYCFSVa7AodCyatGw Provides a wealth of information about the patient-centered medical home, including "Introduction to the Patient Centered Medical Home Video."
Balanced Mind Foundation, The	http://www.bpkids.org/ Family resources for kids with mood disorders.
Community Access to Child Health (CATCH)	http://www.aap.org/catch/index.html The Community Access To Child Health (CATCH) Program is a national program of the American Academy of Pediatrics (AAP) designed to improve access to health care by supporting pediatricians and communities that are involved in community-based efforts for children.
Center for Medical Home Improvement	www.medicalhomeimprovement.org The mission of the Center for Medical Home Improvement is to establish and support networks of parent/professional teams to improve the quality of primary care medical homes for children and youth with special health care needs and their families. Useful tools, assessments, and resources are available on this site.
Children with Special Health Care Needs (CSHCN) Services Program	http://www.dshs.state.tx.us/cshcn/default.shtm The CSHCN Services Program website provides information on programs, rules, laws, legislative issues, family supports, transitions, medical homes and much more. 800-252-8023 http://www.dshs.state.tx.us/cshcn/benefits.shtm
Department of State Health Services (DSHS) - CSHCN Services Program / Medical Home	http://www.dshs.state.tx.us/cshcn/medicalhome/mhresources.shtm Includes: Medical Home Fact Sheet, Medical Home Brochure (Spanish and English), Medical Home Workgroup, Emergency Preparedness for Children with Special Health Care Needs and more.
Disability Resources on the internet	http://www.disabilityresources.org/index.html Disability Resources Monthly's guide for cutting through the morass of disability-related material on the Web.
Early Intervention (Part C of the Individuals with Disabilities Act-IDEA)	http://www.dars.state.tx.us/ecis/index.shtml Early Childhood Intervention (ECI) is a statewide program for families with children, birth to three, with disabilities and developmental delays. ECI supports families to help their children reach their potential through developmental services. Services are provided by a variety of local agencies and organizations across Texas.

Medical Home, Health Care Transition & Other Helpful Resources, cont'd

Exceptional Parent	http://www.eparent.com/ EP's on-line resource site containing information, support, ideas, encouragement & outreach for parents and families of children with disabilities, and the professionals who work with them.
Family Village	http://www.familyvillage.wisc.edu/index.htmlx A global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide services and support.
Family to Family Health Information Centers (F2F HICs)	http://www.familyvoices.org/states?id=0017 F2F HICs provide family friendly and culturally sensitive health care information to families in order to help them make good health care decisions. F2F HICs are run by experienced parents, and supported by private and public funds. Texas Parent to Parent received one of the Family to Family Health Information Center grants awarded through the Centers for Medicare and Medicaid Services. The Family-to-Family Health Care Information and Education Centers are part of the Real Choice Systems Change grants. The grants were created to establish family-run centers that provide information, education, and training opportunities for families with children with special health care needs.
Grant and Funding Opportunities	♦ MCHB Medical Home and Integrated Service Grantees (http://mchb.hrsa.gov/programs/medicalhome/) ♦ CATCH Medical Home Planning Grants (http://www.aap.org/catch/residentgrants.htm)
Health Care Transition (University of Florida)	http://hctransitions.ichp.ufl.edu/ The mission of the Health Care Transition Initiative at the University of Florida is to increase awareness of, gain knowledge about, and promote cooperative efforts to improve the process transitioning from child-centered (pediatric) to adult oriented health care. Our vision is to improve the transition process for all adolescents and young adults, although our current efforts focus on those with disabilities and special health care needs. Tools include transition guides for teens in high school, middle school, and workbooks for various age groups. Available in English and Spanish.
Internet Resources for Special Children	http://www.irsc.org/ This site covers a wide variety of topics from I & R, clothes, recreational sports, home schooling, to guide dogs, and employment.
Institute for Child Health Policy	http://www.ichp.ufl.edu/ichp The Institute for Child Health Policy brings together a multidisciplinary faculty from the University of Florida to conduct innovative and rigorous science to promote the health of children, adolescents, and young adults. We particularly focus on examining factors that contribute to and developing strategies to address disparities in health and health care outcomes for minority and underserved children and youth.
MedHome Portal	www.medhomeportal.org The MedHome Portal is a web-based resource aimed at providing primary care physicians with ready access to information, tools, and services to improve their care and coordination of care for their patients with special needs . Reliable information and resources to help physicians and parents care for children and youth with special health care needs (CYSHCN).

Medical Home, Health Care Transition & Other Helpful Resources, cont'd

Medical Home Mentorship Program	http://www.medicalhomeinfo.org/how/clinical_care/developmental_screening/implementing/mentorship.aspx The Medical Home Mentorship Program offers guidance, resources, and networking opportunities for individuals, communities and states to assist them in achieving increased access to medical homes. The success of the program relies heavily on the continued efforts of state, community, and practice-based medical home teams to share their strategies, lessons learned, tools, and resources designed to improve the delivery of care to CYSHCN.
Medical Home Policy Statement	http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;110/1/184 The American Academy of Pediatrics proposed a definition of the medical home in a 1992 policy statement. Efforts to establish medical homes for all children have encountered many challenges, including the existence of multiple interpretations of the "medical home" concept and the lack of adequate reimbursement for services provided by physicians caring for children in a medical home. This new policy statement contains an expanded and more comprehensive interpretation of the concept and an operational definition of the medical home.
Medical Home Resources in Spanish	http://medicalhomeinfo.org/how/resources/spanish.aspx The National Center has worked to compile a list of resources both at the AAP and externally that are available in Spanish.
National 211	http://www.211.org/ 2-1-1 is an easy to remember telephone number that connects people with important community services and volunteer opportunities. While services that are offered through 2-1-1 vary from community to community, 2-1-1 provides callers with information about and referrals to human services for every day needs and in times of crisis. Call 2-1-1 for help with food, housing, employment, health care, counseling and more.
National Center for Medical Home Implementation	http://www.medicalhomeinfo.org The National Center for Medical Home Implementation is a cooperative agreement between the Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP). The National Center is housed in the AAP Division of Children with Special Needs. The mission of the National Center is to work in cooperation with federal agencies, particularly the MCHB, and other partners and stakeholders to ensure that all children and youth, including children with special needs, have access to a medical home.
Oregon Medical Home website	http://www.ohsu.edu/cdrc/medicalhome/index.html This site contains general information about the medical home and educational materials and resources to support families of CSHCN, health care providers and other community professionals such as teachers and early intervention professionals. Their primary purpose is to make these supports available to the pediatric practices and medical home resource teams who are partners in the Oregon Medical Home Project.
Parent to Parent USA	http://www.p2pusa.org Parent to Parent USA (P2PUSA) is a national non-profit organization committed to promoting access, quality and leadership in parent to parent support across the country. This site highlights statewide organizations that have parent to parent support as a core program and demonstrate a commitment to implementing evidence-based P2P USA endorsed practices.

Medical Home, Health Care Transition & Other Helpful Resources, cont'd

Patient-Centered Primary Care Collaborative	http://www.pcpcc.net/ The purpose of the Patient Centered Primary Care Collaborative (PCPCC) is to develop and advance the patient centered medical home (PCMH). Through our center, the Center for Multi-Stakeholder Demonstrations (CMD), we play an active role as convener and supporter of demonstration projects and pilot programs designed to field the PCMH in communities, regions and states.
Primer on the Illinois Medical Home Model for Families	http://internet.dscc.uic.edu/medhome/familyprimer/FamilyMHPrimer.asp "What Families Need to Know about a Medical Home" has been developed to explain the Medical Home Model for families and children with special health care needs. It explains the family-professional partnership and how it relates to accessing quality health care.
Primer on the Illinois Medical Home Model for Physicians	http://internet.dscc.uic.edu/forms/medicalhome/MedHomeMonograph.pdf The primer includes references, video clips, PowerPoint presentations and many handouts that are downloadable. Also included is the 2nd edition of the UIC-DSCC Medical Home CME Monograph for community pediatricians and family physicians. The document is downloadable as a PDF file.
Project DOCC	http://www.projectdocc.org/ http://www.projectdocchouston.org/ Project DOCC is a training program that draws on the experiences of families of children with chronic illness/disabilities, involving them as faculty to transfer their knowledge to first year pediatric resident physicians. Since the pediatric resident physicians receive an extensive education, this is one component that focuses specifically on how families successfully manage their children's complex needs at home and in the community. Project DOCC's parent teachers provide physicians with a unique perspective on culturally effective, family-centered care.
Questions to Ask When Choosing a Doctor	http://www.patientsafetypartnership.org/Choosing_Doctor.html http://www.consumerreports.org/cro/2012/12/how-to-choose-a-doctor/index.htm
Raising Texas	http://www.raisingtexas.com/ Texas Early Childhood Comprehensive Systems (TECCS) – Raising Texas — "Raising Texas" is an effort to strengthen Texas' system of services so that all children enter school healthy and ready to learn. For more information, go to the Texas Health and Human Services Commission Office of Early Childhood Coordination or the Raising Texas Website.
Screening Initiatives	*National Center Surveillance and Screening Activities - The National Center of Medical Home Initiatives for Children with Special Needs engages in many types of surveillance and screening activities including hearing, vision, developmental and newborn metabolic/genetic screening. *Partnerships with the Maternal Child Health Bureau, Centers for Disease Control and Prevention's National Center for Birth Defects and Developmental Disabilities and the Federal Department of Education, allow the National Center to promote the natural role of surveillance and screening within quality primary care.

Medical Home, Health Care Transition & Other Helpful Resources, cont'd

Special Needs Resource Directory of Southwest Ohio	www.cincinnatichildrens.org/svc/alpha/c/special-needs/resources/default.htm The Center for Infants and Children with Special Needs at Cincinnati Children's Hospital Medical Center has created an extensive, one-stop resource directory to assist caregivers of children with specialized health care needs. The goal of the Special Needs Resource Directory is to provide comprehensive web-based information -- assembled in one convenient location -- to both parents and professionals.
TelAbility	*www.telability.org/index.pl* An innovative, community oriented, interdisciplinary program that uses telecommunications to improve the lives of children with disabilities. Using real time video-conferencing and internet technologies, TelAbility provides comprehensive, coordinated, family centered care to children with disabilities across North Carolina and offers education, training, and peer support for people who care for them.
Texas Medical Home Workgroup	http://www.dshs.state.tx.us/cshcn/medicalhome/mhgroup.shtm The mission of the Medical Home Workgroup is to enhance the development of Medical Homes within the primary care setting. The workgroup includes family members of children with special health care needs, representatives from community organizations, state agencies and family advocacy organizations, community physicians and other health care providers, and other partners. The workgroup develops and implements a strategic plan to achieve the goal that all children in Texas, including children and youth with special health care needs, will receive their health care in a medical home. A key part of the strategic plan is to increase the number of health care practitioners who provide a medical home.
Texas Parent to Parent	www.txp2p.org Statewide nonprofit (§501(c)(3) organization that provides support, information, resources, one on one matching, quarterly newsletter, resource database, trainings, technical support and more to families who have children with disabilities, chronic illness or other special health care needs and the professionals that work with them.
Training Programs and Materials	http://www.medicalhomeinfo.org/training/ Includes: *Building Your Medical Home* toolkit, Education Medical Students & Residents on Medical Home, LEND Medical Home Competencies, Continuing Medical Education (CME) Opportunities, Medical Home Information Sharing Webinars for AAP Leadership and Upcoming Conferences.
Washington State Medical Home	www.medicalhome.org/ Use this website to find successful strategies and practical medical home tools developed for busy families and professionals.

Terms & Abbreviations

for medical home and health related terms

term	definition
AAP	American Academy of Pediatrics
CYSHCN	Children and Youth with Special Health Care Needs
CSHCN	Children with Special Health Care Needs
EHR	An Electronic Health Record (EHR) is an electronic version of a patient's medical history that is maintained by the provider over time, and may include all of the key administrative clinical data relevant to that person's care under a particular provider, including demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports The EHR automates access to information and has the potential to streamline the clinician's workflow. The EHR also has the ability to support other care-related activities directly or indirectly through various interfaces, including evidence-based decision support, quality management, and outcomes reporting. EHRs are the next step in the continued progress of healthcare that can strengthen the relationship between patients and clinicians. The data, and the timeliness and availability of it, will enable providers to make better decisions and provide better care. For example, the EHR can improve patient care by: •Reducing the incidence of medical error by improving the accuracy and clarity of medical records. •Making the health information available, reducing duplication of tests, reducing delays in treatment, and patients well informed to take better decisions. •Reducing medical error by improving the accuracy and clarity of medical records. (source: https://www.cms.gov/EHealthRecords/)
medical home	The medical home is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care and chronic condition management in a planned, coordinated, and family-centered manner.
NCMHI	National Center for Medical Home Implementation
NCQA	National Committee for Quality Assurance
PCMH	Patient-Centered Medical Home
patient liaison	The Family/Patient Liaison is a member of the team who helps coordinate care for Medical Home patients and facilitates communication with the medical team.
PCMH	Patient-Centered Medical Home
tertiary	of third rank, importance, or value
transition	Transition, as defined by the Society for Adolescent Medicine, is the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centered to the adult-oriented health care system. It is one of the many transitions or changes that all young people face as they grow up and become adults.

Frequently Asked Questions

What is the patient-centered medical home? A Patient-Centered Medical Home is a team-based model of care led by a personal physician who provides continuous and coordinated care throughout a patient's lifetime to maximize health outcomes. The PCMH practice is responsible for providing for all of a patient's health care needs or appropriately arranging care with other qualified professionals. This includes the provision of preventive services, treatment of acute and chronic illness, and assistance with end-of-life issues. It is a model of practice in which a team of health professionals, coordinated by a personal physician, works collaboratively to provide high levels of care, access and communication, care coordination and integration, and care quality and safety. *(source: American College of Physicians)*

What is the family-centered medical home? A family-centered medical home is not a building, house, hospital, or home healthcare service, but rather an approach to providing comprehensive primary care. In a family-centered medical home, the pediatric care team works in partnership with a child and a child's family to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric care team can help the family/patient access, coordinate, and understand specialty care, educational services, out-of-home care, family support, and other public and private community services that are important for the overall health of the child and family. The American Academy of Pediatrics (AAP) developed the medical home model for delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to all children and youth, including those with special health care needs. *(source: National Center for Medical Home Implementation)*

Where can I find a medical home for my child? The AAP and the NCMHI do not make referrals to families for a medical home, nor does the AAP recognize, certify, or accredit practices as medical homes. The NCMHI does, however, track information on projects and initiatives related to medical home that occur in states. This information can be found on the State Pages section of the NCMHI Web site. For information on practices that have successfully completed a recognition or accreditation program, visit the program that offers recognition/accreditation programs Web site. The NCQA hosts a Web page that allows visitors to search for practices by state that have completed their Patient Centered Medical Home recognition program. Remember that these practices have been recognized by the NCQA program, which the NCMHI is not affiliated with and does not formally endorse. The NCMHI Web site provides information about the various programs that are currently available or are under development on the Medical Home Recognition and Accreditation Programs page. (*source: National Center for Medical Home Implementation*)

I wouldn't say that my child's doctor qualifies as a medical home, but we really like him and his staff and don't want to change doctors. How can we get more of the "medical home" type of services and support through my child's doctor? You can start by sharing this toolkit with your physician and beginning a discussion about the reasons you believe your child would benefit from having a medical home. You can also share some of the research that shows how to create a medical home, financial considerations for medical homes, etc. Here's what the National Conference of State Legislatures has to say: Research shows that in countries where patients are connected to a medical home — and primary care physicians are the foundation of that home — people live longer, populations are healthier, patients are more satisfied with their care and health care costs are lower. When PCPs are able to provide care beyond brief face-to-face encounters, they are able to perform more screenings and immunizations, provide better preventive care for chronic conditions, and their patients experience fewer complications and fewer hospitalizations for preventable conditions. (source: http://www.ncsl.org/IssuesResearch/Health/TheMedicalHomeGetsUpdatedImprovingOutcome/tabid/14154/Default.aspx)

Are there any Medical Homes in Texas? Here is some information from a Texas Medical Home pilot you can share with your/your child's physician: Medical Clinic of North Texas (MCNT) & CIGNA North Texas Collaborative, Accountable, Coordinated Patient Centered Medical Home Pilot reports [that] "*...although very preliminary, after 6 months of data measurement (started 1-1-10), the results are encouraging and directionally positive including: improved medical trend relative to the market, decreased ER utilization, decreased admissions, decreased use of ancillary outpatient services, improved use of generic pharmaceuticals, improved physician and patient satisfaction.*" Additionally, your/your child's doctor will find a wealth of extremely valuable information on the following websites: (1)Patient-Centered Primary Care Collaborative (http://www.pcpcc.net/), (2)National Center for Medical Home Implementation (http://medicalhomeinfo.org), (3)American Academy of Pediatrics (http://aap.org/), and (4)American College of Physicians (http://www.acponline.org/).

Medical Home Toolkit
Evaluation

Please give us your opinion of the Medical Home Toolkit you just reviewed. By sharing your opinions, you can help us make this a more effective document. Your input will be used to improve the toolkit, so please be candid. *Please return the completed evaluation at the end of the training you attended or mail it to: Texas Parent to Parent, 3710 Cedar Street, Box 12, Austin, Texas 78705.*

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
1. The Medical Home Toolkit was well organized.	○	○	○	○	○	○
2. The Medical Home Toolkit was useful to me.	○	○	○	○	○	○
3. The Medical Home Toolkit provided information that was new to me.	○	○	○	○	○	○
4. I feel I have more information to take to my child's doctor about the help I need from him/her.	○	○	○	○	○	○
5. I have a better understanding of the concept of Medical Home.	○	○	○	○	○	○
6. I currently have a medical home for my child/family.*	○	○	○	○	○	○
7. I can provide support to families who would like to have a medical home.	○	○	○	○	○	○

Please use the space below to share any thoughts or suggestions you have to improve this document.

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*We would like to have information from you to create a listing of health care providers who are serving as medical homes in Texas to share with families wishing to create one. Please contact us at 866-896-6001 (toll-free) or email: jeanine@txp2p.org or debbie@txp2p.org. Thanks!