

The Medical Home

Caring for Children with Special Needs

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I would like to start by thanking the University of Oklahoma and the Heartland Genetics Conference for inviting me to talk about this topic that is very dear to me.

Every child in America deserves medical care to ensure they meet their potential. For even the healthiest child this healthcare must supervise development, wellness and nutrition, immunizations, preventive education and mental health..

The child with special needs requires all of these services as well as coordination of sub-specialist care, rehabilitative services, educational services, social and financial services and family support. Such care can only be provided in a Medical home.

The Medical Home Provides Care That Is:

- **Accessible**
- **Family Centered**
- **Comprehensive**
- **Continuous**
- **Culturally Competent**
- **Coordinated**
- **Compassionate**

The Medical home is typically an accessible primary care physician setting that coordinates the care of the medically complicated child. These include children with chronic and or debilitating medical conditions as well as children with physical and intellectual disabilities.

To be effective a Medical home must be easily accessible to the families they serve. The child and family must remain the center of the process. They must be provided with the knowledge and support to maximize their child's potential and quality of life. The care in the Medical Home must be comprehensive, continuous culturally competent, coordinated and compassionate.

Family Centered Care

- **Knowing the family**
 - **Make up**
 - **Who are the players?**
 - **What life experience do they bring?**
 - **Strengths and Weaknesses**
 - **Resources**

The core concept of the medical home is that it be family centered. The physician must know the family background,

including who is in the home,

who is involved in the child's care

who is involved in decision making

And what is the life experience these key players.

In many case parents of special needs children have had other experiences with the medical system that color their view. In the case of genetic disorders the parent may had a sibling or other relative with the same condition that their child suffers from. The care of the special child typically involves the parents but often grandparents, siblings, other relatives and friends are major providers of care

Knowing the families strengths helps the physician to build up a family's confidence by allowing them to be the main providers of care and participate in decisions. Knowing their weaknesses may be an opportunity to step in and provide more services or refer to an agency that can.

Understanding the families intellectual, emotional and financial resources helps the primary care physician in the Medical home to be compassionate and to problem solve for the child and family realistically

Collaboration

- **Referral Network**
 - **Primary care physicians must be familiar with sub-specialists, therapists, and support agencies in their area**
- **Shared management**
 - **Decisions are made with the parents, primary and subspecialty physicians, therapists and educators.**

Collaboration is the key to providing comprehensive care.

It is often assumed that physicians are aware of the services available in their community or that accessing these services is simple. It can take a physician an entire career to establish the connections necessary to care for a complicated child.

A system of information sharing that facilitates medical care, coordination of special services and access to community resources is vital. We also need to be creative in devising ways to stretch the limited manpower and resources in the subspecialties and service providers

Shared management ensures that the plan of care takes into account all aspects of the child's life and medical problems. It also allows the primary care physician the ability to manage the majority of situations. When sub-specialists involve the primary care physician in the very specialized aspects of care the primary care physician is empowered to manage the day to day issues. Taking on the day to day management by primary care allows more children access to the limited and extremely busy sub-specialist.

The Medical Home at Work

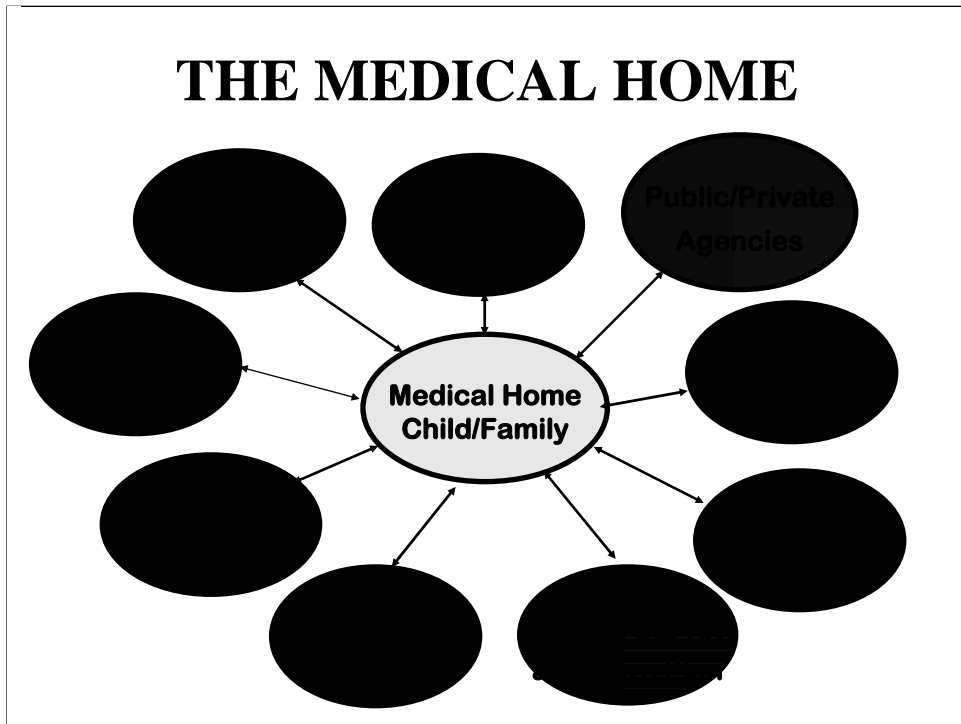
- **Medical Record**
 - accessible
 - comprehensive
 - Electronic Medical Record
- **Staff that understands and embraces the medical home concept**

For the medical home model to function well in the office two major criteria are required. Complete and accessible Health records must provide a summary at a glance of diagnoses, treatment plans, and services being provided. There must also be a medication list which is reconciled at every visit to minimize medical errors. Ideally the family should have a portable medical record that contains the problem list, plan of care, medications. This ensures that all care providers that come in contact with the child have enough information to provide safe and sound care.

Availability of an Electronic Medical Record would streamline this process. There are not only programs that will generate problem lists and medication lists, but even programs that allow families to complete developmental screening online prior to the visit. A good EMR can also flag the patient with special needs so that staff can easily identify them when the family calls.

The office staff is paramount to the success of any medical home. The understanding and endorsement of the medical home concept by administrative and nursing staff is critical. In a small office like my own the receptionist recognizes individual patients and know to schedule extra time at visits. Good office management software can help by identifying special needs patients allowing extra time to be scheduled for visits and can notify families when healthcare maintenance is due.

THE MEDICAL HOME



The Medical Home Model is a wagon wheel in which the child and his family are axle, The sub-specialists, public and private agencies, educators, social workers, medical records, financial resources, family support services, and religious and cultural support are the spokes. As the primary care physician I see myself as the grease. As flattering as this sounds, I like to think it is my job to make sure things run smoothly.

As situations arise I am able to use my knowledge of a child to help coordinate services. The primary care physician act as an interface between the groups and provides support for families. This support comes in the form of helping families access services, explaining options and aiding in decision making. Sometimes the primary care physician's role is to provide hope

One Child's Medical Home

- **GL is a four and a half month old girl with Trisomy 13.**
 - **Her prenatal period was marred by bad advice**
 - **Her delivery was dreaded and feared by her parents**
 - **Her siblings were told she would not live and no nursery was prepared**

I would like to present the case of a patient that I have had the pleasure of caring for over the last 4 and a half month.

GL is a now 4 1/2 month old with Trisomy 13. By some measure she has already beat the odds and brought her family much joy.

In December of 2006 CL had a 20 week ultrasound that demonstrated a Dandy-Walker malformation. Referral to perinatology led to an amniocentesis and the diagnosis of Trisomy 13 was made. The perinatologist did not refer the family to a geneticist or a neurologist but rather suggested that the family find a pediatrician. The pediatrician that they interviewed crushed all their hope when he told them they did not need a pediatrician their baby was not likely to survive the delivery.

Fully expecting their daughter to die the family told their other children that their baby sister was not going to live. GL's parents purchased no clothes or diapers and did not set up a nursery for her. When the time came for the induction they assembled their family, their minister and their closest friends to be present for the delivery hoping each would have a brief time with GL.

One Child's Medical Home

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When GL was 3 hours old the neonatal nurse practitioner who attended the delivery asked me to come see her. She weighed 6 lbs 11 oz and was pink and vigorous, only becoming dusk during breath holding spells related to crying. She had obvious microphthalmia and a loud cardiac click but was otherwise vigorous.

I asked the mother if she had breast fed her other children. When she said yes, I asked her if she would like to nurse GL. She looked surprised but pleased and GL nursed vigorously. She continued to breast feed with good weight gain for 6 weeks until her first cold.

When told the story of this pregnancy, I was in disbelief when I heard what the pediatrician had told this family. This misinformation had created a situation in which the parents were completely unprepared both physically and emotionally to take their daughter home.

One Child's Medical Home

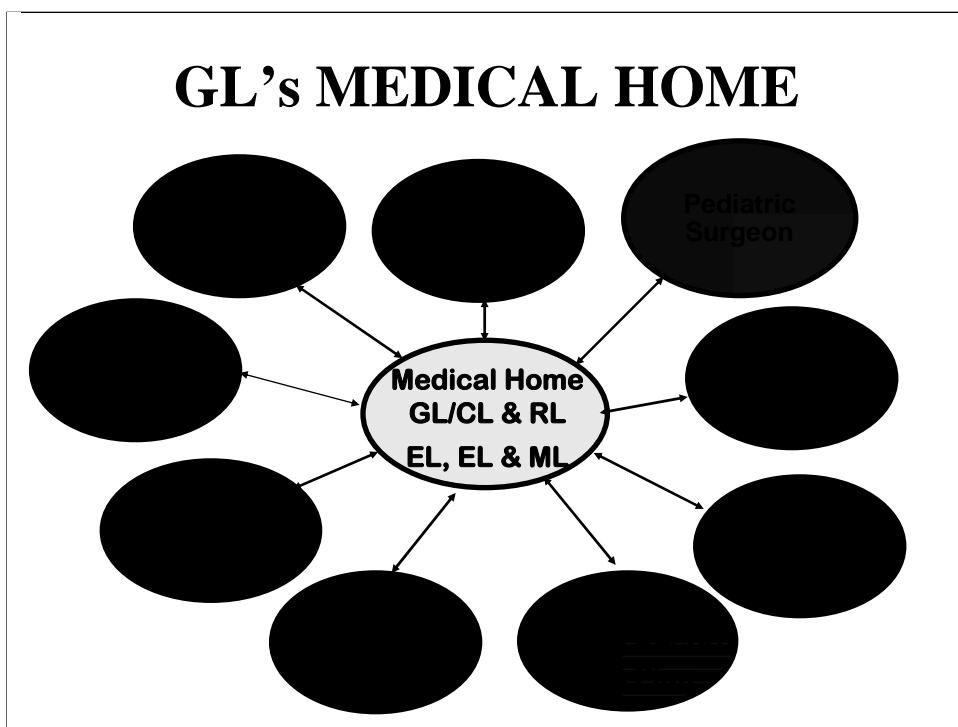
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While preparing for this talk I visited the website “Living with Trisomy 13” I knew it had brought CL and RL hope. More important that experiencing hope I learned what GL’s life meant to her family. I want to read what CL wrote before her daughter’s birth.

“ We have known the diagnosis since right before Christmas 2006. God has been very faithful to carry us through these last few months. I am married with 3 children ages 10,8, and 5. G is a very special part of our family. Please pray for some time with her alive.

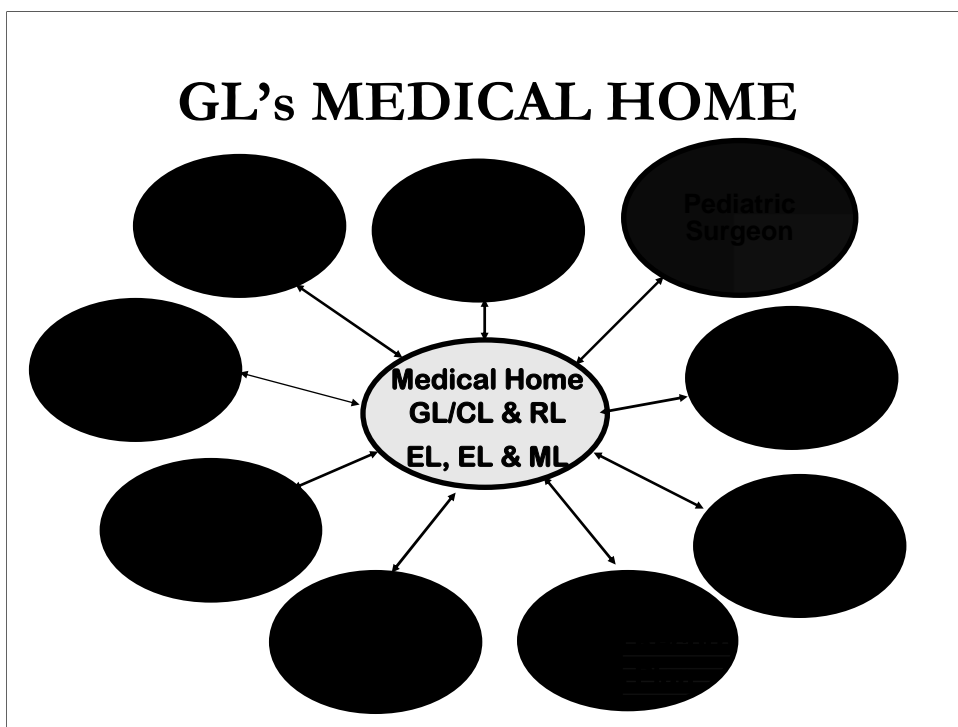
Due to my high blood pressure, we have to induce on Wed. April 11. I was hoping for more time with G, so we're having a hard time realizing that the day is coming so soon. I just keep reminding myself that this is not a surprise to God. It is all part of His perfect plan.”

It was while reading to this that I full grasped how devastating the pediatricians comment was to these parents. They believed that the end of the pregnancy as the end of their daughters life.



GL did not go to the NICU. She roomed in and continued to nurse. She had an Echocardiogram which showed only a bicuspid aortic valve. She passed her newborn hearing screen and a carseat study. She received vitamin K, Hepatitis B and newborn screening labs. She was seen by a geneticist who gave the parents a realistic but not devastating prognosis. She went home on hospice which was discontinued after her two month check up.

I truly believe that had the family been referred to a geneticist after perinatology made the diagnosis they would have been given more thorough description of the child with Trisomy 13 and hopefully referred to a pediatrician who was better able to support them. I think that one of the most important roles the geneticist can play is to help a family with a prenatal or perinatal diagnosis make sure they are in the appropriate medical home. Even if the family has already selected a physician the geneticist can provide that physician with as much information as they can to allow the physician to coordinate the infant's medical care and support the family. A phone call to the physician to discuss the findings, prognosis, expected complications and parent's wishes helps the PCP to be prepared for the first meeting. Being prepared to meet a family with a special needs child or as I call it "Looking Good" is vital to establishing parent-physician trust and bond. That trust allows the PCP to respond to the child's and family's needs and defines the medical home.



At her two month check up hospice was discontinued GL received her 2 month shots and early intervention consulted.

At three months GL developed feeding difficulties and aspirated. At that time GL's parents rescinded her DNR status. She was intubated and following a brief stay in the PICU a decision was made to proceed with a g-tube and fundoplication to prevent another such event. We also started the process of applying for a Medicaid waiver.

At four months GL's home health nurse was concerned about her slow weight gain despite tube feedings. I tried to reassure her by reminding her of her multiple chins and chubby arms and legs, but she wasn't buying it. It then occurred to me that while I had requested one month's earlier I still did not have a growth chart for Trisomy 13. A call to a genetic counselor at university and a fax later we were all relieved to know that GL is at the top of the chart for height and weight.

At four and a half months I am more concerned about GL's mother. GL is blind and despite very loud active siblings has not straightened out her days and nights. GL sleeps all day and is awake all night, and fatigue is really starting to affect her mother. We have arranged a combination of respite care and volunteers from the families church. Any day now I expect CL to trust one and actually sleep.

Supporting the Medical Home

- Enable Physicians to provide care by educating and supporting them in the care of their more complicated patients.
- Encourage Pediatricians and Pediatric residents to be the specialists they were trained to be.
- Include the Medical Home concept in resident education.

As physicians in academia geneticists and other sub-specialists can support the Medical home in many ways.

As I have discussed at length sub-specialists must provide primary care physicians with the information they need to care for the day to day needs of their patient, coordinate services and support the family.

The sub-specialist's role in physician training is vital to the Medical Home concept. There has been a phenomenon that for lack of a better word I refer to as the dumbing down of Pediatrics. As practicing medicine has become more difficult and lives busier many pediatricians have opted to do well child checks, ear infections and sore throats and have punted the responsibility of caring for complicated children to the already overwhelmed subspecialists. Typical waits in Omaha for a sub-specialist are 3-6 month. I remind pediatricians that we are specialists and we are trained in residency to care for complicated sick and special needs children.

Finally I encourage you to include the medical home concept in resident education. A young idealistic physician in training might assume that the core traits of the Medical home are norm not the exception. Unfortunately as the pressures of practice and life grow the idealism can be extinguished. In many academic settings the term chronic care is often used to describe clinics and multidisciplinary groups that care for special needs children. This is such a negative term as it focuses on the hopelessness of all things chronic, and discourages residents from taking an active interest in caring for kids with special needs. We as educators must show residents that caring for these children keeps medicine interesting, encourages physician learning and provides a great sense of satisfaction and hope.