



Complex Child E-Magazine

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Finding Primary Pediatric Care for Your Child with Complex Medical Needs or a Disability by Susan Agrawal

If your child has complex medical needs or a disability, more likely than not you have experienced problems obtaining general pediatric care or non-specialist care for your child. Finding a pediatrician who is willing and able to provide general care, care coordination, and other primary medical services is extremely difficult. Add to that the problem that many primary care pediatricians do not accept Medicaid, HMOs, or certain other insurance policies, and it can be almost impossible to find adequate care in some cases.

Why Is This Such a Problem?

First off, many general pediatricians are not trained in caring for children with special health care needs. Studies have shown that many do not feel comfortable with medical technology, such as feeding tubes, central lines, and ventilators, or medical equipment like wheelchairs, standers, and positioning chairs.¹ Others may be unfamiliar in dealing with children who have autism or significant behavioral issues. As a result, many pediatricians will simply turn down children with significant medical needs or disabilities and refer them elsewhere.

An even larger problem is the way that pediatricians are reimbursed for their services by insurance companies and Medicaid. Children with special health care needs require additional supports as compared to their typically-developing peers. They frequently need substantial quantities of paperwork for waiver programs or school, letters of medical necessity for insurance and Medicaid, and orders for nursing agencies, home health companies, and medications. Referrals to multiple specialists, including transfer of medical records, also requires additional work. And care coordination between specialists, schools, nursing agencies, and other programs demands both paperwork and time.

Currently, most insurance companies and Medicaid programs pay nothing for all of this work, which may be quite substantial for certain children. Since doctors and their staff are often already starved for time, they simply do not have the time, staff, and financial resources to handle all of these issues on their own without reimbursement. As a result, many practices limit the number of children with complex needs or disabilities they see.

To completely solve this problem, dramatic changes will need to be made in our healthcare system, on both state and federal fronts. Some of these changes are currently underway. Medical home projects, which advocate for comprehensive care, especially for people with chronic conditions or special medical needs, are beginning to grow throughout the country. These and other programs are supported by federal plans, such as the President's health reforms that form part of the Economic Stimulus package, as well as state and local grants.

How to Find a Primary Pediatrician Practice

Until these reforms become more standardized and widespread, it will continue to be a struggle for families to find adequate primary care services. The following tips are intended to help you find an appropriate practice.

- ❑ **Determine if your local hospital or area has a pre-existing practice for children with special needs, disabilities, or complex medical needs.** These programs, unfortunately, are far and few between since they cannot survive financially without support from hospitals and grants. Even if they do exist, many have experienced dramatic cuts in their funding and staffing in the past few years and are accepting very small numbers of new patients. Some have been closed entirely, shifted to inpatient-only services, or changed to consult-only services. If you are lucky enough to have one available in your area and are able to get your child into the program, definitely do so, even if it means being on a waiting list for a period of time. To find these programs, ask your specialists, case workers, or other resource providers at your local children's hospital for information and referral.
- ❑ **Try to find a Medical Home Practice in your area.** The American Academy of Pediatrics (AAP) currently has a grant to help implement Medical Home projects throughout the country. A Medical Home is not a particular place, but a concept that means that each child is entitled to comprehensive, coordinated, family-oriented, and accessible medical care in his community. For more information, see <http://www.medicalhomeinfo.org/> Each state has individual programs to support Medical Home implementation. To find your state's information, you may use this clickable map [<http://www.medicalhomeinfo.org/states/index.html>] or simply search for your state's name and the term "medical home." Many states help to sponsor Medical Home programs in specific community pediatrician practices. These practices are often the perfect place for children with special needs.
- ❑ **Ask your insurance company or Medicaid provider.** In many cases, unfortunately, you are restricted dramatically in your choice of doctors and practices by your insurance company. Many children with special needs are also part of Medicaid programs that may not be accepted by a large number of practices. Sometimes it is necessary to get a list of available doctors and practices

from your insurance company or Medicaid provider and then choose between those approved practices. These limitations sadly often force children into crowded Medicaid or public health clinics with long wait times and poor services.

- ❑ **Ask social workers, case managers, specialists, teachers, resource centers, and other parents for recommendations.** Often the best way to find practices is by word-of-mouth. Use whatever community resources are available to you to get recommendations.

What to Look for in a Practice or Doctor

There are certain "clues" that can help you choose a doctor or practice that can meet your needs. Don't expect to find them all, but a good practice will incorporate as many as possible. Here are just a few:

- ❑ **24-hour access to a doctor or other advanced practice medical practitioner.** While it is reasonable to expect an answering service at night, you should be able to reach your doctor or one of her partners at any time, seven days a week. Moreover, you should not have to pay additional fees if your child has a medical emergency after hours. While it is acceptable to charge parents for dispensing routine advice after hours (that could easily wait until the next business day), doctors should not charge families of children with true medical emergencies additional out-of-pocket fees.
- ❑ **Direct phone access to the practice office during business hours.** This may seem like a no-brainer, but many practices actually do not allow you to phone the office directly. All calls are screened and then returned, often at a much later time, by office staff. For children with complex medical conditions, this practice can be extremely detrimental and even dangerous. You should be able to reach a member of the office staff in an emergency with one phone call and minimal wait time. Other members of the practice, such as the nurse and doctor, should return phone calls promptly, especially in emergency situations.
- ❑ **Same day appointments.** You would think that it would be routine to provide children with medical needs access to same day appointments. Shockingly, many practices have no plan or established system for prioritizing care for children who need to be seen more urgently. Make sure your practice is willing and able to see your child on the same day you call if it is a medical situation that requires immediate attention.
- ❑ **Separate waiting rooms or the ability to bypass the waiting room.** For children with immune system issues, behavioral problems, sensory issues, or chronic illnesses, the practice should have some sort of policy to keep them safe while visiting the office. A separate "sick" waiting room is ideal, and the ability to go directly to a treatment room should be available for certain children.

- ❑ **Accessible office, bathrooms, and location.** The practice should be fully accessible to children with mobility impairments, including at least one bathroom and treatment room. Moreover, the practice should be easily accessed by a parking facility with accessible parking spots and/or accessible public transportation options.
- ❑ **Care coordination services.** While this is one of the most difficult services to find, it is also one of the most important. The doctor or practice needs to be able to provide a comprehensive plan of care as well as coordinate with specialists, nursing agencies, schools, and therapists. Moreover, the doctor needs to be willing to keep an eye on the "big picture," assimilating all of the information from specialists and other individuals involved in your child's care. Some practices may also employ a nurse or other individual to serve as a care coordinator and liaison between the parent and doctor.
- ❑ **A program or practice to develop a written care plan.** All children with special needs or disabilities should have a written care plan in place that is available to both the doctor and the family at all times. This care plan should include both basic information (medical history, explanation of care, emergency protocols, list of medications, nutrition information, therapy information, school information, phone numbers, etc.) as well as a specific treatment, testing, and care plan.
- ❑ **A willingness to schedule longer appointment times.** A longer appointment time may be needed by your child. The practice needs to be able to schedule double-blocks of time for your child when this is necessary.
- ❑ **Familiarity with medical technologies or your child's condition.** While not entirely necessary, it is definitely helpful if your child's pediatrician has some experience with your child's specific condition, equipment, and technologies. If the doctor is not experienced in these areas, you need to choose someone who is willing to research or consult with others to provide your child with appropriate care.
- ❑ **Parents, guardians, and older children are treated as partners.** You, the parent or guardian, are the expert on your child. Your doctor should treat you as an equal, respect and listen to your opinions and suggestions, and respond appropriately to your concerns in a calm and relaxed manner. The same should be true of your child if and when he is able to participate in his healthcare decisions.
- ❑ **A parent-advisor or other resource coordinator is available.** Children with complex needs simply require resources. At least one individual in the practice should be available by phone or in person to provide resources to families.

- ❑ **Adequate staffing for filling out paperwork and coordinating orders.** We all know the mountains of paperwork required for our children. The practice or doctor must have enough competent employees to handle all of the paperwork and care coordination. In addition, you should not be charged a per-page fee for paperwork. While some practices have implemented a small yearly fee for all paperwork (usually less than \$25), others charge by the form or page. Many families find a yearly fee acceptable, but a per-page or form fee is not appropriate for children with complex medical needs.
- ❑ **Privileges at the hospital where your specialists practice.** Ideally, your primary care pediatrician should be able to admit your child to the local children's hospital where all of your child's specialty care is provided. While this is becoming less important as more hospitals employ hospitalist physicians to care for inpatient children, it usually makes the process of integrating inpatient and outpatient care much simpler. If this is not possible due to geography or the need for specialized programs at another hospital, make sure the doctor is willing to communicate and work with physicians at other institutions.
- ❑ **Shared electronic records between your doctor, specialists, and hospitals.** While still not available in most locations, the ability of your primary doctor to access all your child's inpatient records and to send reports electronically to all your child's specialists directly, can dramatically simplify care coordination for your child.
- ❑ **Speaks your language of choice, has interpreters available, and is culturally or religiously sensitive.** Since communication is so vital, the practice needs to be able to accommodate your preferred language of communication. In addition, the practice should be sensitive to your culture and background, which may include nutritional restrictions or use of alternative forms of medicine.

Keep Looking!

If you are not satisfied with your current doctor or practice, keep looking for a better option. Over time, as medical homes become more of a standard practice and care coordination is reimbursed by insurers, more appropriate practices should become available to families. We hope the aforementioned tips will help you find the perfect primary care pediatrician.

¹ Raphael C. Sneed, *et al.* "Training of Pediatricians in Care of Physical Disabilities in Children with Special Health Care Needs: Results of a Two-State Survey of Practicing Pediatricians and National Resident Training Programs." *Pediatrics* 2000;105:554-61.