

Quick Guide to Accessible Healthcare for Children and Adults with Disabilities

What is accessible healthcare?

Accessible healthcare is defined by:

1. Healthcare providers who are educated about the unique issues facing people with disabilities,
2. Healthcare facilities that are designed to accommodate people with disabilities, and
3. Insurance coverage which adequately addresses the special health issues of people with disabilities.

How do I find accessible healthcare?

Identify your needs. Asking the following questions of yourself and your family will help you identify your healthcare needs as a person with a disability:

1. What is important to your family in dealing with medical needs?
2. What do you expect?
3. What do you think you need?
4. In what ways are your child's needs different from other children's needs, that is, specifically how is your child unique?
5. Do you need several doctors and therefore need each to be open to discussions with the others?
6. Do you need a doctor more frequently than other families and therefore want someone close to home?
7. Do you need a wheelchair accessible office?
8. Does your child have more complex medical needs than other children or is the major difficulty in the area of development and behavior?

People with disabilities often have health care needs that vary in type and intensity over time. One challenge for you, as a consumer, is to find a health care plan that best meets your needs. This requires understanding how different health insurance plans work. Medicare, Medicaid, Workers' Compensation, an HMO, PPO, or traditional health plans all come with a policy. Some plans are traditional fee-for-service programs with few restrictions on choice of doctors, while some are preferred provider organizations (PPOs) that require the equipment or treatment to come from specified providers. Others are health maintenance organizations (HMOs) that restrict your choice of providers.

With the various insurance plans, some rules you're likely to encounter may include:

- Required letters of medical necessity
- Required pre-approval, exclusion of certain equipment
- Yearly deductibles (the amount of money you have to pay before insurance will cover costs)
- Limits on care provided out-of-state

It's important to know the rules ahead of time in order to choose the best plan for you. **When choosing a health insurance plan, consider the following questions:**

1. Are pre-existing conditions covered?
2. Do I need to choose a primary provider to coordinate my care, or can I obtain care from any provider?
3. How will the health plan treat my health condition? What are the plan's clinical protocols regarding treatment of my particular condition?
4. Can I go outside of the health plan network to seek care from a non-network provider?
5. Will I have to pay a co-payment or deductible for visits to my provider? For tests? How much?
6. Will the plan pay for the prescription drugs I need?
7. If I need care in a hospital, which one does the plan use? How much of the cost is covered?
8. Can I see a specialist when needed? How do I do that?
9. Does the plan cover allied services like therapies?
10. Does the plan cover medical equipment, medical supplies, orthotics, prosthetics, and assistive technology?
11. If I have a problem with the plan, what is the process for handling my complaint?

Seek a personal recommendation.

Remember, however, that if your or your child's needs are significantly different from your neighbor or your neighbor's children, the neighbor's pediatrician may not be the best choice for you or your child. You may be more successful talking to individuals or families with needs more like your own. Such families can be found through organizations such as United Cerebral Palsy, the Epilepsy Foundation, the Spina Bifida Association, Parer Parent, EPICS, or the Learning Disabilities Association of America (formerly ACLD). Perhaps your child is very young and you don't know other families in your area with children like yours. Families can find a lot of information in the phone book by contacting doctors listed as Developmental Pediatricians. If there are no listings, contact a Pediatric Neurologist or child psychiatrist or call the Department of Pediatrics at the closest hospital and ask for the name(s) of Developmental Pediatricians. Another resource may be the state university medical school's Department of Pediatrics. If you usually get medical care from a clinic, group, Public Health Department or Indian Health Services, you may want to ask the head nurse there for suggestions. It is important to remember that if your medical expenses are covered by a particular service provider, referral to a specialist may need to come through formal channels unless you will be covering all costs yourself.

When asking for a referral to a local pediatrician, there are several important steps. Be sure to request a referral rather than ask for a recommendation; it is difficult if not impossible for someone on the phone to recommend a doctor to someone he/she has never met. In this instance your choice of words is important. A referral is less formal and will net better results. Ask for several referrals if possible to allow you some choices and to place responsibility on the person making the suggestions. You can say, "I have a child (age) who does not seem to be developing like other children his age. Do you see such children in your practice? Is this an area of interest for you? If not, can you refer me to a pediatrician whose special interest is children with possible developmental difficulties?" Be specific about your child's needs; if this is a child whose behavior is very difficult, be honest about this. After all, you are looking for a doctor who is accepting and comfortable with such conditions.

Interview potential healthcare providers.

When you have your list of referrals, begin the process of "interviewing" the prospective doctors. Talking to doctors about their areas of interest is not uncommon; there is no reason to feel uncomfortable about such a process. Begin by phoning the physician's office. Ask to speak to the receptionist or nurse first and ask again if this doctor sees people with disabilities in his/her practice. If the answer is yes, or if the nurse seems positive about the doctor's interest in cases such as yours, ask for the doctor to give you a call. Doctors usually set aside some time each day to return calls; be sure to make it clear that this call will take a bit longer than most and that you would like him/her to phone when there is time to talk for about 5 or 10 minutes. Do this for each of the doctors on your referral list.

If your family receives medical care through a public health clinic, talk to the person in charge to learn how the public health department works with adults or children who need in-depth medical attention. Find out what services are available, how to access them, who is the case manager or keeper of all the records, and the eligibility requirements for all of this. Ask what interagency relationships this clinic has with other health providers in your state and with the education department, when applicable. Services are available through Medicaid, WICC (Women, Infants, and Children's Care), local health departments, and state Department of Health. Public Law 102-119, Part H, the Early Intervention Program for Infants and Toddlers with Disabilities may also cover some services, especially in the areas of developmental screenings, hearing and vision testing, therapy, and family information services. (For more information on PL 102-119, contact National Information Center for Children and Youth with Disabilities). If the person you are asking does not know the answers to your questions, ask who on staff is familiar with your needs. If the person you are asking is too busy to talk to you, ask when you could come back or when he/she could phone you so you will have time to discuss your concerns. There are policies for public health clinics to work with other medical facilities to meet the needs of children with unique or chronic health care difficulties. You will need to keep asking questions until you find the person who can make these connections for you. By asking lots of questions, you can learn how to work effectively with your state's and county's public health service to provide all the specialized medical services your child may need.

Families using a public health facility also can arrange to see specialists. Speak either to the doctor who is your child or to the nurse on duty. Discuss your child's needs and ask about the procedure for being referred to children's specialty services. You may be concerned that your child is not developing normally without knowing the specific needs. This too can be discussed with the doctor or nurse. The names of specialty children's services and the process of assessing them may vary state to state, but basically, a public health clinic can refer a child to one or more specialty clinics. Generally these clinics cover orthopedic needs, seizure disorders, neurological conditions, hearing loss and other special needs. The doctors at these clinics are usually specialists working on an honorary basis and payment is generally on a sliding scale from no payment up to whatever the family can afford to pay. A child who is referred to a specialty clinic would still be followed by the original well-baby clinic for routine needs, shots, well baby visits, and common childhood illnesses.

In cases where a child may be referred for surgery or treatment at a hospital, the public health clinic should be able to help make arrangements. If the hospital to which the child is referred is not local, plans for transportation, lodging for the parent, and payment can be made.

The following questions are useful when interviewing potential doctors or clinic staff:

1. How many disability space are available in your parking lot?
2. Is the clinic entrance disability accessible?
3. Is the inside of the clinic disability accessible, with elevators and accessible restrooms?
4. Is there a pharmacy in your building, or nearby?
5. Do referral providers have offices in your building, or nearby?
6. Does your staff make house calls or referrals for house calls?
7. Are providers and staff in your office trained to use alternate forms of communication such as sign language or hearing amplification?
8. Is printed information and health promotion material from your office available in alternate forms, as Braille or large print?
9. Is there a TTY phone line available in your office for both incoming and outgoing calls?
10. Is the following equipment available in your office to help patients with special needs?: wheelchair walker or crutches; adjustable examining table, or a stool or steps to climb up to the examining table; bedpans or portable urinals.
11. Does your clinic have an emergency evacuation plan? If so, are there specific procedures to help patients who have difficulty seeing, hearing, or who have mobility limitations?
12. Do you see children or adults with disabilities in your practice?
13. Do you have experience with children or adults who have (describe your/your child's disability)?
14. Would you be comfortable working in a medical team situation with other doctors who will be seeing me/my child?
15. Can you schedule extra long appointments?
16. Who sees your patients when you are not available?
17. Which hospital do you use for patients who require hospitalization or hospital tests?
18. What are the facilities of this hospital for children and families like mine? If my child were hospitalized would I be allowed to stay with him/her?
19. After you've examined my child, can you arrange for one of your staff to watch him/her for a few minutes so we can talk alone?
20. Would there be any additional charges for any of these arrangements?

Sources for more information

(Please note: these links will leave Community Access Washington site.)

National Information Center for Children and Youth with Disabilities

<http://www.nichcy.org/>

Orchid: Health and Wellness for Women with Disabilities

<http://www.fpg.unc.edu/~ncodh/orchid/pages/index.cfm>

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