



Complex Child E-Magazine

www.ComplexChild.com

Obtaining In-Home Services

by Susan Agrawal

Many children with complex needs require in-home services. These services may include nursing care, personal assistant services, behavioral services, homebound schooling, and therapies such as physical, occupational, speech, or behavioral therapies.

Having these services provided in the home is essential for many children. Some children may be too medically fragile or immune compromised to receive therapy at a therapy center or school. Others may have complex medical technologies or extensive care needs that require the skill of a nurse or home health aide. Children with autism or behavioral issues may need wrap-around services designed to help them learn and cope with daily life activities in the home. There is also a movement, which is incorporated into many Early Intervention or 0-3 programs, to provide all services in a child's natural environment, which is typically the home.

Despite the many good reasons for in-home services, obtaining services can be very difficult. Insurance and Medicaid may refuse to provide the services completely. Therapists who will agree to come to the home can be difficult to find. Some insurers may insist that a specific facility or agency must be used, or not have any in-network therapists available who can come to the home.

This article will provide information on how to obtain these in-home services. Note that procedures and programs vary widely by state, so be sure to contact your local programs for the specific information relevant to your state or region.

Nursing Care and Home Health Aides

Children who are dependent on medical technology, including a tracheostomy, ventilator, CPAP or BiPAP, central line, oxygen, or a feeding tube, may require specialized nursing services to meet their needs in the home environment, especially at night. Depending on the technology involved, a child may require an RN (central line and advanced levels of care), an LPN (most medical technology), or a home health aide. Children who are very medically unstable or fragile, such as a child with autonomic instability, may also require extra care in the home. In some cases, in-home nurses also go to school with a child.

Private duty nursing, or one-on-one nursing in the home, can be very difficult to obtain. Most private insurers have strict limits on nursing, if they cover it at all. It is common,

for example, to restrict the cost of nursing by month or by year. Usually the amounts are quite low, such as \$1500 a month, which will cover about 10-20 hours of nursing at the higher rates paid by private insurers. Other insurers limit the number of days of nursing per month or year, typically less than 60 per year. Most insurers restrict nursing to "visiting nursing," which allows a nurse to come to your home to change a dressing, provide instruction, or give a treatment, but does not allow a nurse to stay and provide ongoing care.

Even if your insurer does cover nursing, your child's care is often deemed "custodial care," or care that can typically be provided by a non-medical provider, such as dressing, bathing, and medication administration. Insurers have been known to create very wide definitions of custodial care, including everything from giving an oral feed to caring for a child on a ventilator. Designation of care as "custodial" is the most common method insurers use to deny nursing.

While it is possible to appeal these insurance decisions, it is not an easy process. Most families that have won appeals are families whose children are in the PICU on ventilators or are hospitalized with other equally demanding medical needs. These families can argue that home care is less expensive than the continuing cost of PICU treatment.

Despite the refusal of most private insurers to cover nursing, there are programs available for families of all incomes to obtain nursing services in the home. These include a not widely known Medicaid mandate and Medicaid waiver programs.

If your child receives regular Medicaid based on low-income or disability status, he is eligible for in-home nursing or personal attendant services through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program that mandates specific services, including nursing, for children enrolled in Medicaid. Typically, your child's physician must contact your state Medicaid program and obtain pre-approval for services. It is common for many states to make this little-known benefit difficult to access, so persist if you are at first met with resistance.

Children who receive Medicaid through the Children's Health Insurance Program (CHIP), which extends Medicaid to children from families who typically earn up to 200%-400% of the poverty line (depending on the state), may or may not be covered under EPSDT rules. Rules vary by state. If your child is part of CHIP, it is worth finding out whether your state extends EPSDT benefits to children who receive CHIP, as your child may then be eligible for nursing.

The primary source for nursing care for most children is through Medicaid waiver programs. These programs, most of which waive the income requirements of traditional Medicaid, vary widely by state. Most states have at least one program for children with medical technology or complexity, either a TEFRA/Katie Beckett waiver, or a Home and Community-Based Services (HCBS) waiver. The eligibility requirements are highly variable from state to state, though most states accept children with tracheostomies, ventilators, or central lines that are used on a daily basis. Some states will also accept

children with feeding tubes or children on oxygen. Additional Medicaid waiver programs for children with developmental disabilities may also provide nursing to certain children. See this previous article for more information on Medicaid waivers.

Medicaid waivers typically provide up to 20 hours per day of nursing for children with the greatest medical complexity, as long as the cost of home care is less than the cost of the same care provided in a hospital or residential facility.

Behavioral Modification and Personal Attendant Programs

Children with autism, behavioral problems, emotional issues, or mental health disorders may need in-home care to function in a home environment and learn how to manage their behaviors appropriately. In most cases, these children are at high risk for needing institutionalization due to their extreme needs.

In general, these children are not typically eligible for nursing services since their care is not medical in nature. While insurers may cover some limited in-home behavioral therapies when provided by a licensed therapist (such as an occupational therapist or clinical psychologist), the vast majority of these types of services are not covered by insurance or standard Medicaid.

In some states, children are eligible for Medicaid HCBS waivers that may include in-home services, including behavioral modification services, in-home aides, wrap-around services, ABA therapy, and similar services. Some states have designated waivers for children with autism, while others cover all children with developmental disabilities. Children with mental health conditions are often not eligible for these programs, unfortunately, though a few states have waiver programs for children with mental health diagnoses who require in-home care.

In most states, parental income is waived in determining eligibility for Medicaid waivers, but some states restrict their waivers to low and moderate income families or ask families to pay a monthly copay. Some waivers cap the total amount that can be spent per child each month or year. It is important to check with your state's Medicaid office to determine what programs are available.

In many states, behavioral programs and wrap-around services are administered locally by city, county, or region. Many states have extensive programs available on the local level. Programs vary widely in what services are provided and to whom. Some focus more on children in the criminal justice system, while others are dedicated to children with diagnoses of autism, Fragile X, or other disorders that create behavioral challenges.

While personal attendant and homemaker services are available for adults to help with feeding, housework, and other daily tasks, these programs typically do not serve children. In some locations, families may receive some personal attendant hours as a part of Medicaid waiver services.

Homebound Schooling

Some children are not able to attend school, usually due to significant medical needs, such as extreme medical fragility or immune compromise. For these children, homebound schooling is an option that they are legally entitled to, whether they receive special education services or not. Homebound services may be temporary (such as after a surgery), long term, or intermittent.

Children who already receive special education services may simply be placed on homebound through their Individualized Education Plan (IEP). Children with frequent absences or who will be out of school for an extended period of time may be permitted to receive homebound services on a short term or intermittent basis. Many children with complex needs are allowed to receive services either at school or at home, with the family notifying the school each day or week which environment the child requires. This allows children to attend school when they are able to, and receive homebound services on the other days. It is not uncommon for children with the most complex needs to attend school a few hours or days a week. and then receive homebound services on the other days.

Children who are not in special education but have significant health issues should have a 504 plan developed. These plans provide accommodations, such as those required by a child with diabetes or juvenile arthritis, to help a child access the regular school curriculum. Having a 504 plan in place will make it much easier to receive homebound services for these children on a short term or intermittent basis.

Specific homebound services, such as the number of hours of instruction, are not guided by any federal laws and vary widely by state and school district. Most schools only provide one to two hours per day of instruction. Special education students must be taught by a special education teacher. While children are supposed to receive all of their related services (such as occupational or speech therapy) while on homebound, whether this actually happens or not is usually dependent on the school district and its willingness to customize instruction.

In-Home Therapy Services

Children with significant medical technology, immune compromise, fatigue issues, or severe behavioral problems may benefit from receiving their therapy services, such as physical therapy, occupational therapy, and speech therapy, in the home environment. While home-based therapies are the standard of care for children from birth to age three in Early Intervention programs, it can be much more difficult to receive services for older children.

In some cases, a school district may provide in-home therapy services for a child receiving homebound instruction on a permanent basis. Note that these services must be

intended to meet IEP goals, and are therefore geared toward accessing the educational curriculum, and not medical or physical goals.

If the school district does not provide services, it may be possible to find a provider who will work in the home. This will most likely require many, many phone calls on your part, as home-based providers are often difficult to find. Therapists who provide services in the home do not receive any compensation for travel and have little incentive to provide home-based therapy. In some cases, home health agencies may provide therapists for home-based care.

Insurance and Medicaid do not differentiate between care provided at home and care provided at a therapy facility. As long as you are able to find a home-based provider who is in-network for your insurance, your insurance should cover the charges in the same manner as services provided at a therapy center.

Legwork

Finding in-home services can be quite difficult, but it is possible. Do not be surprised if you receive denials at first. It is always worthwhile to appeal. Persist in obtaining these types of services if they would benefit your child.