



Complex Child E-Magazine

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Federal and State Assistance Programs for Children with Special Needs by Susan Agrawal

It is often overwhelming to be a parent of a child with a disability or complex medical needs. While there are federal and state programs available to help American families in this situation, most states make little effort to publicize these programs or help families in obtaining assistance. As a result, many families struggle needlessly obtaining therapy services, financial help, nursing, respite, and similar services.

Even if you know what programs are legally required in each state, it can be a struggle to find information about what is available or to find out how to apply for individual programs. Since programs tend to operate on a state-by-state basis, there is no complete chart of all available programs in all states. The intention of this article is to help you know what programs might be available and help you to search for them in your individual state.

Early Intervention (Part C of IDEA)

For parents of children birth through three years of age, Early Intervention programs provide early evaluation, therapy services, and other assistance to young children. The goal of the program, which is mandated by Part C of the Individuals with Disabilities Education Act (IDEA), is to intervene during the most critical years of development to prepare children for both school and life.

Each state is required to have an Early Intervention Program, which may go by a different name such as Early Steps, First Steps, or Early Childhood Intervention. While certain aspects of each program are mandated, such as free evaluation for any child and a requirement to find eligible children, states are given a lot of latitude in creating their programs. States may determine eligibility requirements, the amount and type of services available, and if families above a certain income level must pay a co-pay or monthly fee.

Most states provide therapy services such as physical, occupational, speech, or developmental therapies at no additional cost to children who qualify. Some states also provide supplementary services including equipment, medical services, transportation, nursing, social work, and so forth.

In these economic times, many states are unfortunately reducing services or restricting eligibility to the most vulnerable children. Even so, it is worthwhile to apply as your child may be able to receive services not typically covered by insurance. Care coordinators also may be able to provide families with information about other services available to them.

For more information about Early Intervention programs in your state, simply search for “Early Intervention” and your state name. You may also click on this link [http://www.nectac.org/contact/Ptccoord.asp] from NECTAC for a list of current program directors and websites by state. This link from the American Academy of Pediatrics also includes a clickable map:

<http://www.medicalhomeinfo.org/screening/EHDIstateinfo.html>

Women, Infants, and Children (WIC)

Another program for young children, typically children under the age of five, is the WIC program. This program is designed to provide food, nutritional counseling, and related health services (such as nutritionist services) to low-income families. Families who earn up to 185% of the poverty level, as well as families who already qualify for Medicaid, Food Stamps, or similar programs, are eligible.

While WIC is typically known as a program that provides food or vouchers for families, it is especially helpful to children with medical needs because it also supplies specialized medical formulas like Neocate or PediaSure at no cost. These formulas, which may not be covered by insurance, particularly in the first year of life, can otherwise be extraordinarily expensive for families.

Many children with feeding tubes also receive nutritional counseling through WIC, though the quality of these services is highly variable.

Information and links to state WIC programs are available here:

<http://www.fns.usda.gov/wic/Contacts/ContactsMenu.HTM>

Supplemental Security Income (SSI)

SSI is a financial program that provides cash payments to children with qualifying disabilities. Cash payment amounts are based on income, and are currently a maximum of a little over \$600.

To qualify, families must be low-income and pass an asset test, meaning they do not possess substantial non-cash holdings such as real estate or a large number of vehicles. Standard assets such as a home and a car are excluded. To find out if your family qualifies, you may use the Benefits Eligibility Screening Tool at http://connections.govbenefits.gov/ssa_en.portal

A child must have one or more disability that has lasted or is expected to last for twelve months and that severely limits his ability to function. While most children need to seek out approval before getting payments, children who have certain conditions, including blindness, cerebral palsy, Down Syndrome, extremely low birthweight, and similar conditions, are presumed eligible and may receive payments right away.

It is common for children to be denied for this program on the first attempt, so make sure to appeal if you are denied. In addition, many states have programs that will automatically qualify children who receive SSI for Medicaid. For more information on SSI and children, visit this page: <http://www.ssa.gov/pubs/10026.html>

Medicaid and the Children's Health Insurance Program (CHIP)

Children from very low-income families will qualify for Medicaid, the federal/state partnership that provides health insurance at little to no cost. Eligibility requirements vary from state to state, but generally require families to earn less than 100-150% of the poverty level (approximately \$22,000 to \$33,000 for a family of four) and have minimal non-cash assets. Children who qualify for Medicaid will typically receive standard health benefits, including outpatient care, hospital visits, dental care, and prescriptions.

In the 1990s, the federal government recognized that many children who did not qualify financially for Medicaid remained uninsured because of the high cost of healthcare and limited employer health benefits. Since the 1990s, the Children's Health Insurance Program, a federal/state partnership, began to cover children from families who earned up to 200% of the poverty line. Individual states and recent federal laws have expanded eligibility for children even further. In some states, families may earn up to 400% of the poverty line or pay a monthly stipend to "buy-in" to the program. A few states have made a commitment to cover all children, and will allow even high-income families to buy-in to their programs in certain cases.

Eligibility and benefits vary dramatically from state to state. Contact your state's health department for information about your state. A list of state agencies may be found here: <http://www.cms.hhs.gov/LowCostHealthInsFamChild/downloads/CHIPStateDirectors.pdf>

Medicaid Waivers: Katie Beckett, TEFRA, or HCBS Waivers

Children who are not financially eligible for Medicaid or who need additional services beyond those traditionally provided by Medicaid may be eligible for a Medicaid waiver in their state. Each state is required to have a program to assist children with extensive medical needs and disabilities. However, state programs vary widely in eligibility requirements, benefits, and program structure.

In general, states may choose one of two methods for creating a program. The first, often called a "Katie Beckett Waiver"¹ or TEFRA waiver, simply extends regular Medicaid services to children with extensive needs by counting only the child's income and not the income of the parents. These programs are typically only for children who are medically fragile and dependent on technology and would otherwise need institutionalization. States must provide benefits to ALL children who qualify under TEFRA guidelines if they offer a TEFRA waiver, meaning there are no waiting lists.

You can find out if your state has a TEFRA programs by contacting the state agency that administers Medicaid. Alaska, Arkansas, Delaware, Georgia, Idaho, Maine, Massachusetts, Michigan, Minnesota, Mississippi, Nebraska, Nevada, New Hampshire, Rhode Island, South Carolina, South Dakota, Vermont, West Virginia, and Wisconsin all had TEFRA programs as of 2004.

The second and more common method is for a state to apply to the federal government for an HCBS (Home and Community-Based Services) waiver, often called an HCBS Section 1915(c) waiver. Some states may have both HCBS and TEFRA waivers. HCBS waivers provide traditional Medicaid and additional services, such as nursing, home modification, respite, and behavioral therapy. Most states have multiple programs, including one for children who are medically fragile or physically disabled (if they do not have a TEFRA waiver), another for children with developmental disabilities, and additional specialized programs for children with autism, HIV, or brain injuries. To find the available programs in your state, you may use this clickable map: http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/08_WavMap.asp

States have a lot of latitude in creating their HCBS programs. In some states, only the most vulnerable children, such as those who have tracheostomies, are eligible. Other states allow a wider range of disabilities or medical needs. Some programs require a parental co-pay or restrict the total amount that can be spent per month. Since states may cap the number of available spots in HCBS waiver programs, many states have long waiting lists, sometimes as long as five or ten years, to get into their programs. It is important to apply as soon as possible, as your child may remain on a waiting list for quite a long time. Most states prioritize spots based on the level of need.

Title V Programs for Children with Special Health Care Needs

Each state is also required to have a program for children with special health care needs, funded by Title V of the Maternal and Child Health Block Grant and state funds. Typically, children must have a qualifying chronic medical condition to receive services. All children with qualifying conditions are eligible for certain services, usually including evaluation and care coordination.

Children who come from low-income families, typically 200-300% of the Federal Poverty Level, may receive additional services such as therapies, medical equipment, and medical services not covered by insurance. These vary considerably from state to state.

For more information on these types of programs, see https://perfddata.hrsa.gov/mchb/mchreports/LEARN_More/Block_Grant_Program/block_grant_program.asp

You may use this link to search for your state's program director, phone number, and website: https://perfddata.hrsa.gov/mchb/mchreports/link/state_links.asp Often these programs are listed on state websites as services for children with special health care needs, CSHCN or CYSHCN.

EPSDT Nursing Care and Other Programs for Children Enrolled in Medicaid/CHIP

Children who are enrolled in regular Medicaid or CHIP programs (in most cases), including Medicaid waivers, may receive nursing care through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program of Medicaid. This federal program requires states to provide certain health benefits to children under age 21, starting from screening at birth and continuing through appropriate treatment. These include nursing care for children with medical needs, personal attendants, therapy services, equipment, and even diapers. Basically, EPSDT extends normal Medicaid coverage to provide for the more comprehensive needs of children. For more information on EPSDT, see <http://www.hrsa.gov/epsdt/>

Children already enrolled in Medicaid or CHIP programs will need to apply and be preapproved for nursing services. In general, the level of medical acuity is lower in this program, and children who receive enteral feeds or have other less-involved medical technologies may qualify for nursing.

Each state has a different preapproval process. Typically, your child's doctor needs to write a letter of medical necessity and request a certain number of hours of care if nursing care or personal attendant hours are requested. Other services, such as equipment and diapers, also have varying preapproval processes.

State, County, and Local Programs for Children with Developmental or Other Disabilities

Each state has divisions to help people with developmental disabilities, rehabilitation needs, and other conditions. In addition, city and county programs may be available in certain areas. These programs vary widely, but may include a wide-range of services otherwise not available. It is important to review your state and local programs to see if there are any that may help your child.

Often, the easiest way to locate these programs is to search for your state, county, and city along with terms like "developmental disability" or "physical disability." Also check the government websites for your area. Hospitals, case managers, social workers, other

parents, and disability resource centers may also be able to refer you to appropriate services.

Never Give Up!

It can be very difficult to find available programs, and even more difficult to qualify for them. Don't be surprised if you get turned down one or more times when applying. It is always worthwhile to appeal. Also, don't be put off by program coordinators or social workers who may tell you your child does not qualify for a given program. Insist on applying anyway, because they might just be wrong!

It is also always essential to get your child's name on a waiting list as soon as possible, even if you don't think you need services right now. This ensures a spot for your child if he does need one in the future.

It will take a bit of research to find your local programs, but don't give up! The services are well worth all the research, piles of paperwork, and other "hoops" you must jump through in order to receive them.

¹ Please note that some states have retained the terminology "Katie Beckett Waiver" but converted these waivers from TEFRA to HCBS waivers.