

Paying for Medical Care

Understanding the different methods of paying for medical services takes some time. Social workers or case workers can be helpful in explaining some of your options, especially with Medicaid and Social Security. Your first step is to understand your private insurance. Children with disabilities can also be eligible for Medicaid or Social Security on top of your private insurance. Typically, Medicaid and Social Security are based on family income. But there are government programs that do supplement private insurance that are not based on income. These programs vary state to state. Ask your social worker, or case worker, or other families with children with special needs, if they know of any programs. These programs can be very helpful, but they sometimes have a long waiting list, so it is best to start looking now. The most common waiver through Social Security, not based on income, is the Katie Beckett waiver, however not every state offers it, and the exact details vary state to state. Be patient figuring out the ropes, it will be frustrating at times, but diligence and many questions typically pays off.

Insurance companies

Insurance companies usually feel like a complex web that you are just not supposed to find your way through. Up to this point, you might not have had to rely on your insurance company for anything out of the unusual. And now you may be faced with large medical bills, or you might be anticipating what type of bills are in your future. In any case, it usually feels over-whelming. Your first step is to find out what your exact coverage is. Typically, you can contact your employer's human resource department and ask them for a copy of the policy. The next step is to attempt to read the policy, which in many cases is like reading Latin. It might help to make an outline or a grid or highlight the important parts of your policy.

After you have tried and have hopefully been somewhat successful in reading your insurance policy, you should call a representative from the insurance company to discuss any of your questions. Often if you are informed about how your insurance policy works, you will be much more successful at making decisions and avoiding some unnecessary expenses. Unfortunately, all of this can be confusing, but hang in there and ask a lot of questions. And if you find a representative that is very informed, make sure you get their name, so you call them back when you have more questions. A little tip, is when you do find a representative that is helpful; send a thank you note, along with a picture of your child to the representative and their supervisor, being on a personal level helps you in the future.

Remember that you have a contract with your insurance company. You are the beneficiary and you have to prove that the request you are making is covered in the contract. And the insurance provider has to prove that the request is not covered in order to deny a claim. Get everything in writing!

What are some of the issues to be aware of when using your insurance policy?

- Spending caps. There are different caps for different services. For example, you might have a million-dollar cap on medical procedures per individual and a \$1000 cap on medical equipment. There are also yearly and lifetime caps. Be aware of caps and spend the money wisely.
- Deductibles. Be aware of how your deductibles work. For example, one insurance policy might limit you to spending \$1000 per year on equipment, and you know that your child needs two \$1000 equipment items. If possible, it might be best to prioritize and purchase one piece of equipment this year, and purchase the other piece the following year. Or another insurance policy might have a \$500 deductible per year on equipment. In this case, you would want to purchase both pieces of equipment in the same year, so that you only pay the deductible once.
- Your physician does not know your insurance policy. This includes physicians that are part of an HMO. They do not always know your exact coverage. There are different insurance policies within HMOs. So, when your physician makes any referrals, make sure it is covered under your insurance policy.
- How is your child referred to a specialist? Some insurance companies require your child to see their primary care physician before they are allowed to see a specialist. The primary care physician then makes a referral to a specific specialist. However, you should still make sure that specialist is covered under your insurance plan.
- How does your child receive a piece of durable medical equipment? Very often, you must have a prescription from your physician for a piece of equipment and the equipment must be purchase from a specific vendor. Contact your insurance company before making the purchase.
- Therapy Limits. Most insurance policies place different limits on therapies. Be aware of your plan's limits, so that you can use the therapy benefits wisely. For example, some insurance policies allow three months of consecutive therapy per diagnosis. In this case, you would not want to start your child in therapy for a specific problem if you know you are going miss a lot of the therapy sessions due to vacation, surgery, etc. Because this stipulation will not allow your child to "make-up" missed therapy sessions. Some insurance policies allow 30 sessions per year. In this scenario, you will want to space out the therapy sessions throughout the year and ask the therapist for home programs, so that you can carry out the program at home. Some insurance plans will allow for an extension of therapy with written documentation of progress from the therapist.

Medicaid

Medicaid provides medical assistance for children and families with low income. It was established under Title XIX of the Social Security Act in 1965. It is jointly run by the federal and state government. Therefore, you will find differences from state to state and within the state. The states are responsible for determining the type, amount, duration, and scope of services; setting the rate of payment for services; and

administering its own program. Some Medicaid programs are now paying managed care organizations or other insurance companies to provide health services to their participants. The participants are then required to follow that benefit contract. To learn more about Medicaid within your state and eligibility visit the website <http://www.cms.hhs.gov/home/medicaid.asp>. This site is an excellent resource. Another helpful resource in determining your eligibility is your social worker. If your child does not qualify for Medicaid, some states have programs under Social Security/Medicaid that provide medical assistance to children regardless of their parent's income. This waiver is typically called the Katie Beckett Waiver.

Social Security

The information provided in this section is taken directly from the U.S Department of Health and Human Services, Social Security Administration, SSA Publication No. 05-10026, January 1993, ICN 455360.

Who is eligible for Social Security benefits (SSI)?

1. Children under 18 years old with a disability who have limited income and resources, or who come from homes with limited income and resources.
2. Children under 18 years old on the record of a parent who is collecting retirement or disability benefits from Social Security, or survivors benefits payable to children under the age of 18 on the record of a parent who has died.
3. Benefits can continue to be paid into adulthood if the child is disabled prior to age 22.

Social Security Insurance Benefits for Children with Disabilities Non-Medical Rules

SSI is a program that pays monthly benefits to people with low incomes and limited assets who are 65 or older, blind, or have a disability. Children can qualify if they meet Social Security's definition of disability and if their income and assets fall within the eligibility limits.

As its name implies, Supplemental Security Income supplements a person's income up to a certain level. The level varies from one State to another and can go up every year based on cost-of-living increases. Check with your local Social Security office to find out more about the SSI benefit levels in your State.

Rules For Children Under 18

Most children do not have their own income and do not have many assets. However, when children under age 18 live at home (or are away at school but return home occasionally and are subject to parental control), we consider the parent's income and assets when we decide if the child qualifies. We refer to this process as "deeming" of income and assets.

Check with your Social Security office for information about your child's specific situation and for a full explanation of the "deeming" process.

Rules for Children 18 and Older

When a child turns 18, we no longer consider a parent's income and assets when we decide if he or she can get SSI. A child who was not eligible for SSI before his or her 18th birthday because a parent's income or assets were too high may become eligible at 18.

On the other hand, if a child with a disability who is getting SSI turns 18, continues to live with his or her parent(s), but does not pay for food or shelter, a lower payment rate may apply.

How We Decide if a Child is Disabled for SSI

While your local Social Security office decides if your child's income and assets are within the SSI limits, all documents and evidence pertaining to the disability are sent to a State office, usually called the Disability Determination Service (DDS). There, a team comprised of a disability evaluation specialist and a doctor reviews your child's case to decide if he or she meets our definition of disability.

If the available records are not thorough enough for the DDS team to make a decision, you may be asked to take your child to a special examination that Social Security will pay for. It is very important that you do this.

Defining "Disability":

To understand how Social Security evaluates disabilities in children, you must first understand how Social Security defines disability in general.

To qualify for a Social Security or SSI disability benefit, a person must have a physical or mental impairment that is expected to keep him or her from doing an "substantial" work for at least a year. (Generally, a job that pays \$500 or more a month is considered "substantial" work.) Or a person must have a condition that is expected to result in his or her death.

Deciding SSI Disability for Children Under 18

Of course, a child's disability cannot be evaluated using these work-related adult criteria. The law states that a child will be considered disabled if he or she is not working and has an impairment that is as severe as one that would disable an adult. This means the condition must limit the child's ability to function like other children of the same age to such a degree that the impairment is comparable to one which would make an adult disabled.

To make this decision, the disability evaluation specialist first checks to see if the child's disability can be found in a specific listing of impairments that is contained in Social Security's regulations, or if the condition is equal to an impairment that is on the list. These listings are descriptions of symptoms, signs, or laboratory findings of physical and mental problems, such as cerebral palsy, mental retardation, or muscular dystrophy, that are severe enough to disable a child. If the symptoms, signs, or laboratory findings of the child's condition are the same as, or equal to, the listing, he or she is considered disabled for SSI purposes.

If the disability cannot be established using the "listing" criteria, then the disability evaluation team will assess the child's ability to function in everyday life. Children are considered "disabled" for SSI purposes if their impairment substantially reduces their ability to do the things and behave in the ways that children of similar age normally do.

A Special Message to Parents of Children with Severe Disabilities

The disability evaluation process generally takes several months. But the law includes special provisions for people (including children) signing up for SSI disability whose condition is so severe that they are presumed to be disabled. In these cases, SSI benefits are paid for up to 6 months while the formal disability decision is being made. (Of course, these payments can only be made if the child meets the other eligibility factors.)

Following are some of the disability categories in which we can presume the child is disabled and make immediate SSI payments:

- HIV
- Blindness
- Deafness (in some cases)
- Cerebral Palsy (in some cases)
- Down Syndrome
- Muscular Dystrophy (in some cases)
- Significant mental deficiency
- Diabetes (with amputation of one foot)
- Amputation of two limbs
- Amputation of leg at the hip

If we make these special payments and we later decide that the child's disability is not severe enough to qualify for SSI, the benefits do **not** have to be paid back.

Social Security Benefits for Older Children with Disabilities and for Adults Disabled Since Childhood **Non-Medical Rules**

As indicated earlier, a child under the age of 18, including a child with disability, qualifies for Social Security benefits simply because he or she is a minor child of a retired, disabled, or deceased worker. In other words, we don't consider a child's disability when deciding if he or she can get Social Security dependent's or survivor's benefits.

However, when a child who is getting a dependent's or survivor's benefit from Social Security reaches 18, those benefits generally stop unless one of the following conditions is met:

- The child is a full-time student in an elementary or high school. In this case, benefits continue until age 19; or
- The child is disabled. In this case benefits can continue as long as the child remains disabled, even into his or her adult years.

Many times, an individual doesn't become eligible for Social Security until later in life. Here's an example: John Jones starts collecting Social Security retirement benefits at the age of 62. He has a 38 year old son, Ben who has had cerebral palsy since birth. Ben will start collecting a disabled "child's" benefit on his father's Social Security record.

How We Decide if an "Adult Child" is Disabled

We will evaluate the disability of an adult child (age 18 or older) who is applying for Social Security for the first time, or who is being converted from a Social Security dependent child's benefit, by using adult disability criteria. Briefly, to qualify for disability, an adult must have a physical or mental impairment or combination of impairment, that is expected to keep him or her from doing "substantial" work for at least a year or is expected to result in death. (Generally, a job that pays \$500 or more per month is considered substantial.)

The individual's condition is compared to a listing of impairments that are considered to be severe enough to prevent an individual from working for a year or more. If the individual is not working and has an impairment that meets or is equal to a condition on the list, then he or she is considered disabled for Social Security purposes.

If we cannot match the person's impairment with one of the listings, then we assess his or her ability to perform the same type of work he or she did in the past (if any). If the person cannot do that work or does not have any past work history, then we consider his or her ability to do any kind of work he or she is suited for (based on age, education, and experience). If, considering all these factors, a person is found to be unable to do any substantial work, then he or she would qualify for disability benefits from Social Security.

Applying for Social Security or SSI Benefits...And How To Expedite the Process

You can apply for Social Security or SSI benefits for your child by calling or visiting your local Social Security office. You can help expedite the claims process if you have the child's Social Security number and birth certificate viable when you apply. If you're signing up your child for SSI, you also will need to provide records that show your income and your assets, as well as those of the child.

The medical evaluation specialists at the DDS needs thorough and detailed medical records to help them decide if your child is disabled. When you file, you will be asked to provide names, addresses, and telephone numbers of all doctors, hospitals, clinics, and other specialists your child has visited.

In addition, if your child is under age 18 and applying for SSI, you will be asked to describe how your child's disability affects his or her ability to function as a child of similar age normally would. Therefore, we will ask you to provide the names of teachers, day care providers, and family members who can give us information about how our child functions in his or her day-to-day activities.

Please be as specific and thorough as possible when you answer these questions. This means that you should give us the dates of visits to doctors or hospitals, the account numbers and any other information that will help us to get your child's medical records

as soon as possible. If you do not have this information, tell the interviewer as much as you know. If you have any school records, bring them with you to the interview.

In many communities, special arrangements have been made with medical providers, social service agencies, and schools to help us get the evidence we need to process your child's claim. Most DDS's have Professional Relations Officers who work directly with these organizations to facilitate this process. However, your additional cooperation in obtaining records and evidence would be helpful.

Other Health Care Services

If we decide a child is disabled and eligible for SSI, we refer him or her for health care services under the Children with Special Health Care Needs (CSHCN) provisions of the Social Security Act. These programs are generally administered through State health agencies.

Although there are differences, most CSHCN programs help provide specialized services through arrangements with clinics, private offices, hospital-based out-and in-patient treatment centers, or community agencies.

CSHCN programs are known in the States by a variety of names, including Children's Special Health Services, Children's Medical Services, and Handicapped Children's Program. Even if your child is not eligible for SSI, a CSHCN program may be able to help you. Local health departments, social services offices, or hospitals should be able to help you contact your CSHCN program.

Checklist for application

As an aside note from Michelle, applying for SSI is a tedious process and often your child is denied the first time around because all the information is not given. So, I have provided you with a checklist below to help you at the application process. Good luck and keep trying.

Checklist

- Child's Social Security Card
- Child's Birth Certificate
- Records that show your income and assets, as well as those of the child.

Income Tax Statements, Mortgage or Rent cancelled checks, Utilities cancelled checks

- **Detailed** Medical Records

Name, address, and telephone numbers of **all** doctors, hospitals, clinics and other specialists your child has visited. It is also helpful if you have your child's medical numbers. Give the dates as to when your child visited these medical professionals or facilities.

- Letter of how your child's disability affects his or her ability to function as a child of similar age normally would.

Name of teachers, day care providers and family members who can give information about how your child functions in his or her day-to-day activities.

- School records

IFSP, IEP, Any record that indicates a disability

How to contact the Social Security Office

Website: <http://www.ssa.gov>

Telephone number: 1-800-772-1213

Visit your local office

Katie Beckett Waiver a.k.a Deeming Waiver a.k.a. Children's Medical Waiver a.k.a. Model 200 Medicaid Waiver

The Katie Beckett Waiver is a federal waiver that is intended for children from birth to eighteen years of age with a chronic disability. It entitles children to Medicaid that would not otherwise qualify due to their parent's financial status. It originally was intended for children at risk of institutionalization. But do not be scared off by the word, institutionalization, it does not mean you are thinking about placing your child in an institution, it just means your child has lifelong medical needs.

Each state can determine whether or not they want to administer this waiver, and how they want to administer it. Therefore, it varies greatly among the states and a few states do not choose to offer it. You will have to contact your state agency to determine if it is available in your state. T

The Katie Beckett Waiver can be extremely helpful to many families. Most families struggle to pay their child's medical bills and this waiver will cover these expenses. The medical bills can be physician, hospital, therapy, prescriptions, respite care, diapers, vision and dental care, whatever Medicaid covers in that state. In some states this Waiver entitles children to a life-time of unlimited therapy. So, it is worth the hassle of finding out if your state offers this program and how to apply for it.

The general procedure to apply for the Katie Beckett Waiver (again, this varies from state to state) is as follows:

1. Apply for SSI and be denied. Ask them to send you a letter stating that you have been denied.
2. Ask for an application for a Katie Beckett Waiver by contacting your Social Service office, (a.k.a Department of Family and Children Services a.k.a. Department of

Developmental Disabilities). You can also find the telephone number for your state's Medicaid office, on the web site: <http://www.cms.hhs.gov/home/medicaid.asp>, and ask them where to call about the Katie Beckett Waiver.

3. Complete the application. Typically, you should provide only information about your child and not about your financial status. Typically, your child's physician will need to complete paperwork called the DMA-6 or some type of form that states your child's disability.

4. If you are denied, ask for an appeal. Often they change their decision, and grant the waiver. Sometimes, they put your child on a waiting list and years later they are approved.

It is always helpful if you have a caseworker or social worker helping you through this process.