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Sickle Cell Disease and the Social Security Disability Evaluation Process for Children

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What's inside

If Your Child Has Sickle Cell Disease 1

What We Mean by Disability 2

Non-Disability Requirements 5

Child Disability Evaluation Process (3 Steps) 5

Step 1: Is your child working? 6

**Step 2: Is your child's medical condition
"severe"? 7**

**Step 3: Does your child's condition satisfy the
criteria in the listing of disabling conditions or
functionally equal the severity of the listings? 8**

**Does your child's condition
satisfy the criteria in the listing of
disabling conditions? 9**

**Does your child's condition
functionally equal the severity
of the listings? 16**

Resources 19

Tips for Helping with the
Disability Evaluation 20

Contact Us 24

If Your Child Has Sickle Cell Disease

If your child has sickle cell disease, they may be eligible for disability benefits through the Supplemental Security Income (SSI) program. SSI provides monthly payments to people with limited income and resources who are 65 or older, or blind, or have a disability. Children younger than age 18 are eligible if they have a medical condition or combination of conditions that meets Social Security's definition of disability. Their income and resources must fall within the eligibility limits.

In the SSI program, a child becomes an adult at age 18, and we must redetermine whether they are eligible for disability payments. We use different medical and non-medical rules when deciding if an adult can get disability payments. See our companion guide for adults, *Sickle Cell Disease and the Social Security Disability Evaluation Process for Adults* (Publication No. 60-003), for more information about the definition and disability evaluation process for individuals who are age 18 or older.

This publication will help parents, caregivers, and representatives of children younger than age 18 who have sickle cell disease to understand the Social Security disability evaluation process and will provide tips for helping with that process.

What We Mean by Disability

The definition of disability under Social Security is different from other programs. We do not pay benefits for partial or short-term disability.

We consider a child to have a disability under our rules if *all* the following are true:

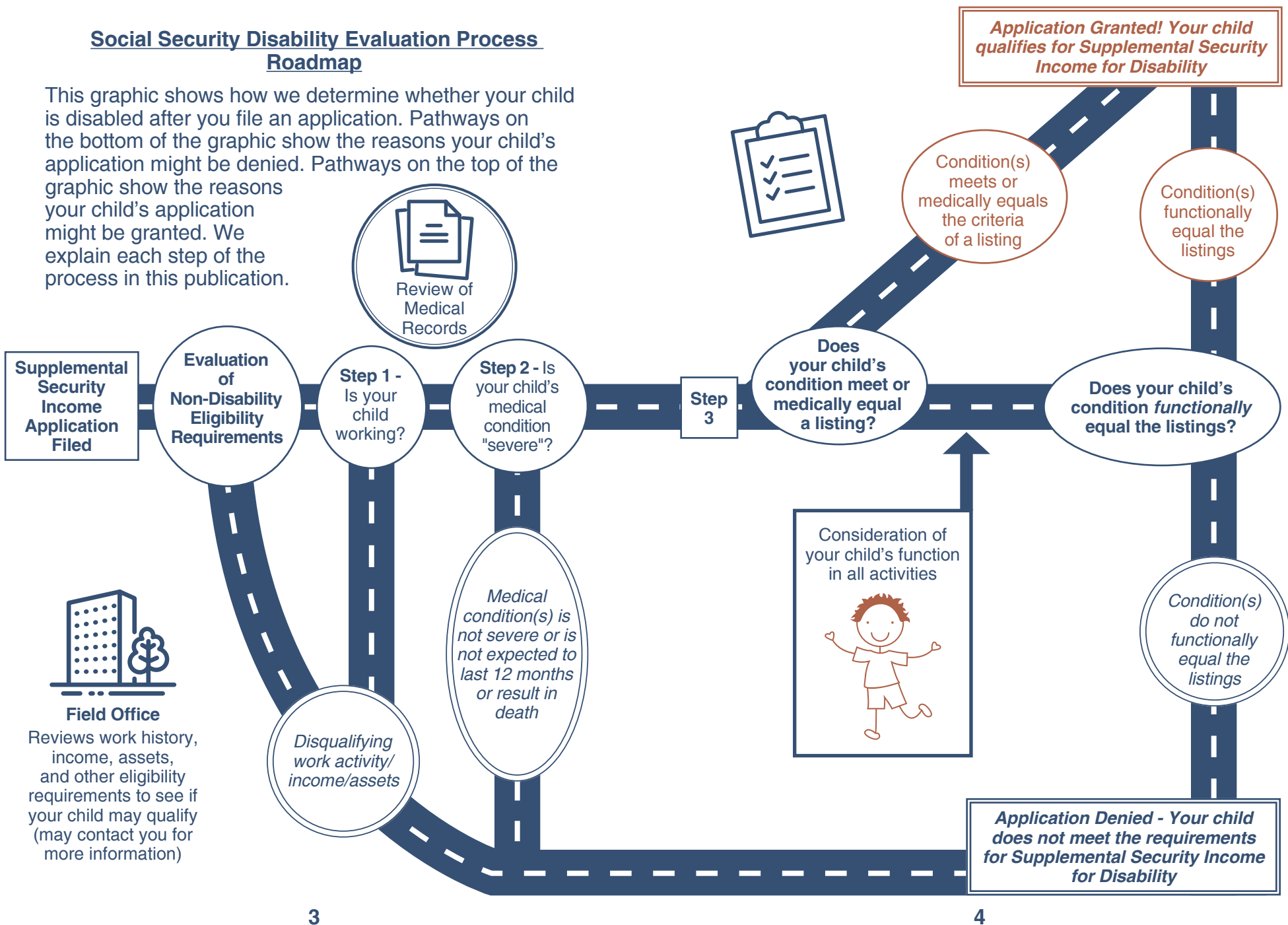
- The child, if not blind, must not be working at the substantial gainful activity (SGA) level.
- The child's condition must have lasted or must be expected to last for a continuous period of at least 1 year or to result in death.
- The child must have a medical condition, or a combination of conditions, that results in "marked and severe functional limitations." This means that the condition(s) must very seriously limit the child's activities.¹

This is a strict definition of disability that Congress created.

¹ Note: Because the definition of disability for adults is different from the definition for children, we must re-evaluate disability for a child who is already receiving SSI benefits when they turn age 18. We usually do this review during the 1-year period that begins on the child's 18th birthday. We will use the adult disability rules to decide whether an 18-year-old is eligible for SSI. See *What You Need to Know About Your Supplemental Security Income (SSI) When You Turn 18* (Publication No. 05-11005).

Social Security Disability Evaluation Process Roadmap

This graphic shows how we determine whether your child is disabled after you file an application. Pathways on the bottom of the graphic show the reasons your child's application might be denied. Pathways on the top of the graphic show the reasons your child's application might be granted. We explain each step of the process in this publication.



Non-Disability Requirements

The field office first checks to see if your child meets the non-disability eligibility requirements.

To do that, we consider a child's income and resources and the income and resources of family members living in the child's household. These rules apply if your child lives at home. They also apply if your child is away at school but returns home from time to time and is subject to your control. For more information about non-disability eligibility requirements, including a tool that allows you to test whether your household income qualifies, see [Who can get SSI](http://www.ssa.gov/ssi/eligibility) at www.ssa.gov/ssi/eligibility.

If we decide your child meets the non-disability requirements, we look to see if they meet the disability requirements.

Child Disability Evaluation Process (3 Steps)

After the field office has confirmed that your child meets the non-disability requirements, it will send your child's case to a State agency for the evaluation of disability. The State agency is called the Disability Determination Services or DDS.

The DDSs are State agencies that are fully funded by the Federal Government. Trained staff at the DDS begin by developing the evidence needed to evaluate your child's claim. That evidence includes your child's medical records, and it might also include other types of records, such as school records. The DDS follows a 3-step evaluation process to determine whether your child is disabled under the law. Then, the DDS returns the case to the field office for appropriate action.

If the DDS finds that your child is disabled, the field office completes any remaining non-disability development, calculates your child's benefit amount, and begins paying

benefits. If the DDS finds that your child is not disabled, you will get a letter explaining the decision and your right to appeal it.

Below, we describe the 3-step evaluation process that we use to decide if your child is disabled.

Step 1: Is your child working?

We generally use earnings guidelines to decide whether your child's work activity is substantial gainful activity (SGA). If your child is working in 2024 and their monthly earnings average more than \$1,550 (\$2,590 if they're blind), their work is generally considered SGA. See the annual *Update* (Publication No. 05-10003) for more information.

○ **If your child's work activity is SGA, they are not disabled, and their application will be denied.**

▶ **If your child is not working or is working below the SGA level, we will continue to step 2.**

It is important to note that our definition of disability is significantly different from some other definitions of disability you might be familiar with.

Example: Susie, who is not blind, is working in 2024 and earns \$2,500 per month. Susie does not have any exceptions or deductions from earnings that can be taken under our SGA rules. Since Susie is working and earning SGA, Susie does not qualify for SSI disability benefits. Susie's application would be denied at "step 1."

Example: Sally is working in 2024 and earns \$1,200 per month. Because these earnings are below the SGA level, Sally is not earning SGA. We would continue to step 2.

Step 2: Is your child’s medical condition “severe”?

At this step, the DDS will begin reviewing the evidence, including the medical records, in your child’s case. If the DDS cannot get enough medical evidence from your child’s medical sources, the DDS will arrange for your child to attend a consultative examination at no cost to you. For more information about consultative examinations, see “*A Special Examination Is Needed for your Disability Claim*” (Publication No. 05-10087).

We will look at your child’s medical record to determine what medical conditions your child has and whether or not they are severe. We need medically acceptable clinical and laboratory findings to show that your child has a particular medical condition.

Under the law, we cannot find a child disabled based on symptoms alone, but the effects of symptoms may be important in determining whether a child is disabled. If clinical signs or laboratory findings show that a child has a medical condition, we refer to it as a “medically determinable impairment” or MDI.

- ⊙ **If your child *does not* have any medically determinable impairments, we will find that they are not disabled, and their application will be denied.**

Once we determine that your child has an MDI(s), we look at your child’s ability to function compared to children of the same age who do not have impairments. We consider all available evidence from your child’s medical sources and nonmedical sources about how your child functions. Nonmedical sources may include you (the applicant), your child, teachers, social workers, family members, caregivers, friends, neighbors, employers, and clergy.

To be severe, your child’s MDI must be more than a slight abnormality and must cause more than minimal functional limitations, and it must last, or must be expected to last, for a continuous period of at least 1 year (12 months)

or must be expected to result in death. If it meets those requirements, we will find that your child’s medical condition is *severe*. If your child has multiple medical conditions, we consider the combined effect of their conditions at this step and throughout the disability evaluation process. In this document, we use the term “condition(s)” to show that we consider the combined effect of all your child’s MDIs.

⊗ **If your child’s medical condition(s) is *not severe*, we will find that they are not disabled, and your application will be denied.**

▶ **If your child’s medical condition(s) is *severe*, we will continue to step 3.**

Example: John has significant limitations in the ability to stand and walk because of chronic pain and fatigue from sickle cell disease. Because John has significant limitations in his ability to function, John’s condition is severe. The evaluation of disability will continue to step 3.

Example: Jessica broke their wrist. Jessica had to wear a cast and was unable to do many activities for about 4 months. However, the wrist healed, and Jessica was able to return to all activities without limitation after 5 months. Because this condition did not significantly limit her ability to function for a continuous period of at least 1 year, it is not severe. Jessica’s application would be denied at step 2.

Step 3: Does your child’s condition satisfy the criteria in the listing of disabling conditions or functionally equal the severity of the listings?

Our “Listing of Impairments” (“listings”) describes medical conditions, including sickle cell disease, that cause marked and severe functional limitations. Each listing explains the medical findings and other requirements needed to satisfy the listing. If your child’s condition satisfies the listing criteria, we will find that they **meet** or **medically equal** the criteria in the listing and find them disabled at step 3.

If your child has a severe condition(s) that does not meet or medically equal any listing, we will then decide whether your child's condition(s) results in limitations that **functionally equal** the severity of the listings. We look at six different domains (areas) of functioning to determine whether a child's condition(s) functionally equal the listings.

Does your child's condition satisfy the criteria in the listing of disabling conditions?

Part B of the Listing of Impairments lists the criteria that apply to children under age 18. There are 15 major body systems in Part B, and each body system has a name and number. For example, the "Hematological Disorders" body system covers diseases related to blood and is numbered "107.00." One of the listings in that body system is "listing 107.05." Listing 107.05 covers "hemolytic anemias," including sickle cell disease. Visit www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm for more information.

If the criteria in part B do not apply, we might use the criteria in part A of the Listing of Impairments (which generally apply to adults) when appropriate.

Examples of Listing Criteria That Could Apply to Sickle Cell Disease

Note: For **SOME** listings, your child's condition only needs to meet or medically equal **ONE** of the criteria for them to be found disabled at step 3, even though several criteria are listed. For example, listing 107.05 requires *either* 107.05A *or* 107.05B *or* 107.05C. When we use the word "or," that means that only one of those criteria needs to be present. Even if your child's condition only meets the criteria in listing 107.05A, their medical condition would meet the listing. The examples below explain the most relevant parts of the criteria and how they relate to sickle

cell disease. We also explain what we mean by “medically equals” the listing criteria later in this document. The detailed criteria for each listing below are available at www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm.

Listing Criteria in the Hematological Disorders Body System

- Listing 107.05A – sickle cell disease with 6 documented painful crises in 1 year, each requiring intravenous (IV) or intra-muscular (IM) narcotic medication, and each crisis at least 30 days apart.
- Listing 107.05B – sickle cell disease with complications requiring 3 hospitalizations in 1 year, each 30 days apart and each lasting at least 48 hours.
- Listing 107.05C – sickle cell disease with blood tests showing hemoglobin values at or below 7.0 grams per deciliter (g/dL), measured at least 3 times in 1 year and at least 30 days apart.
- Listing 107.17 – sickle cell disease treated with bone marrow or stem cell transplantation.

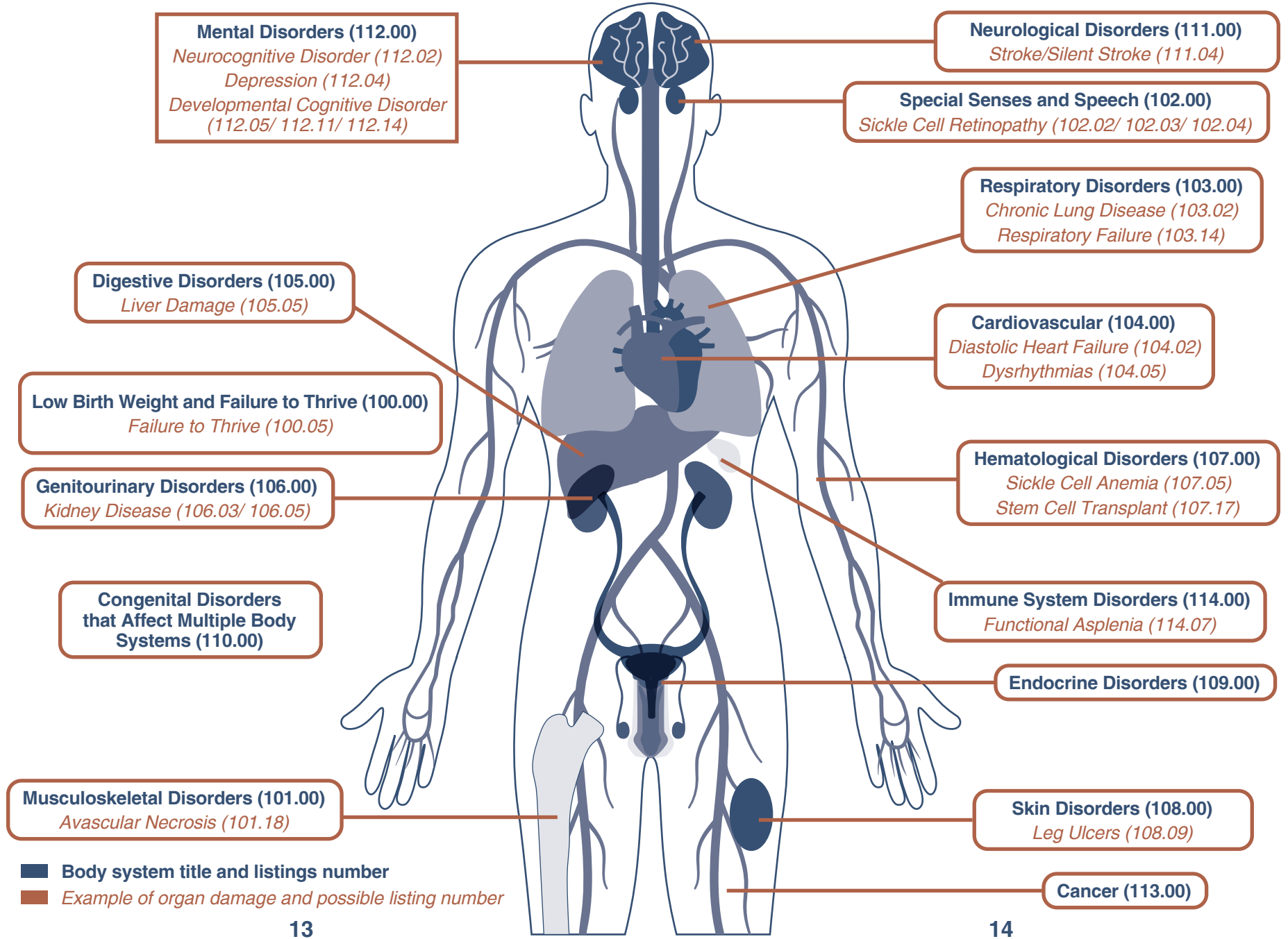
These are only common examples of listings in the hematological body system. If your condition(s) does not meet any of the listings in this body system, we will also consider whether you have a condition(s) that satisfies the criteria of a listing in another body system.

Examples of Other Listings That May Apply to Complications from Sickle Cell Disease

Complication	Possible Listing	Brief Description
Failure to Thrive	100.05	Growth measurements less than the third percentile and significant developmental delay in children from birth to attainment of age 3
Avascular necrosis	101.18	Abnormality of a major joint documented by certain symptoms and medical findings, resulting in certain functional limitations
Sickle cell retinopathy	102.02	Loss of central visual acuity (generally 20/200 vision or less in the better eye)
	102.03	Contraction of visual fields in the better eye with certain documented measurements
	102.04	Loss of visual efficiency in the better eye with certain documented measurements
Chronic lung disease	103.02	Chronic respiratory disorder with certain findings on pulmonary function tests or, for children from birth to age 2, a required number and severity of exacerbations (attacks)
Respiratory (lung) failure	103.14	Respiratory failure from a chronic respiratory disorder (other than cystic fibrosis) needing certain treatments twice in 1 year
Diastolic heart failure	104.02	Chronic heart failure while on prescribed treatment with certain measurements of heart rate or respiratory rate, markedly decreased exercise tolerance, or growth failure
Dysrhythmias	104.05	Certain recurrent arrhythmias resulting in episodes of cardiac syncope (fainting) or near syncope documented by laboratory testing
Liver damage	105.05	Chronic liver disease with certain complications or lab test values

Complication	Possible Listing	Brief Description
Kidney disease	106.03	Chronic kidney disease with chronic hemodialysis or peritoneal dialysis
	106.05	Chronic kidney disease with certain lab test values
Leg ulcers	108.09	Chronic skin lesions or contractures causing chronic pain or other physical limitations and certain functional limitations
Stroke, Silent stroke	111.04	Vascular insult to the brain, with certain effects on motor function or certain functional limitations
Neurocognitive disorder	112.02	Documented decline in cognitive function, resulting in marked and extreme functional limitations or marginal adjustment
Mood disorder (depression)	112.04	Depressive, bipolar, and related disorders, documented by symptoms and medical signs, and resulting in marked and extreme functional limitations or marginal adjustment
Developmental cognitive disorder	112.05	Intellectual disorder beginning before age 22 with significantly subaverage general intelligence (generally based on IQ scores) and significant functional deficits
	112.11	Neurodevelopmental disorder resulting in marked and extreme functional limitations and either: attention deficit, hyperactivity, significant learning difficulties, or recurrent movements or vocalizations
	112.14	Developmental disorders for children from birth to age 3 with developmental delay and marked and extreme functional limitations
Functional asplenia	114.07A	Immune deficiency disorders with certain infections that are either resistant to treatment or require hospitalization or intravenous (IV) treatment 3 or more times in 1 year

Major Body Systems and Examples of Listings Applying to Common Complications of Sickle Cell Disease



■ **Body system title and listings number**
 ■ *Example of organ damage and possible listing number*

What if your child's condition is severe but it does not meet the requirements of a listing?

If your child's condition(s) does not meet a listing, we will consider whether it **medically equals** a listing. A child's condition(s) medically equals a listing if it is at least equal in *severity* and *duration* to the criteria of any listing.

We can find **medical equivalence** in any of three ways:

1. If there is a listing that applies to a child's condition, but one or more of the required findings is missing or is not as severe as the criteria requires, and other findings related to their condition are at least of "equal medical significance" to the missing criteria.
 2. If a child has a condition(s) that is not described in any listing, and the findings related to their condition(s) are at least of "equal medical significance" to the required findings of a similar listing.
 3. If a child has a combination of conditions, but none of their conditions meet a listing by themselves, and the findings related to their combined conditions are at least of "equal medical significance" to the criteria of a similar listing.
- ✓ **If your child's condition *meets* or *medically equals* a listing, we will find them disabled at step 3.**
- **NOTE: If your child's condition does *not* meet or medically equal a listing at step 3, this does NOT necessarily mean that they are not disabled. We will evaluate whether their condition(s) *functionally equals* the listings.**

Does your child’s condition functionally equal the severity of the listings?

If your child has a severe condition(s) that does not meet or medically equal any listing, we will decide whether the condition(s) results in limitations that *functionally equal* the listings. When we determine whether a child’s condition(s) functionally equals the listings, we look at six domains of functioning. The child’s condition(s) must result in “marked” limitations in at least two domains of functioning or an “extreme” limitation in one domain to functionally equal the listings.

- **Marked limitation** means that the child’s condition interferes *seriously* with their ability to independently start, carry through, or complete activities. “Marked” limitation also means a limitation that is “more than moderate” but “less than extreme.”
- **Extreme limitation** means that the child’s condition interferes *very seriously* with their ability to independently start, carry through, or complete activities. “Extreme” limitation also means a limitation that is “more than marked” and is the rating we give to the worst limitations.

When we evaluate your child’s functioning in the six domains, we consider how your child functions compared to children the same age who do not have impairments. We look at whether they do the things that other children their age typically do or whether they have limitations and restrictions because of their condition(s). We consider how your child’s condition(s) affects all their activities. Their activities are everything they do at home, at school, and in their community.

We evaluate the “whole child” when we make a finding about functional equivalence. We consider how the child functions every day and in all settings compared to other children the same age who do not have impairments. We

consider the extent to which their condition(s) affects their ability to independently start, carry through, and complete activities. We will also look at how well they do the activities and how much help they need from their family, teachers, or others, and we consider the effects of their medications or other treatment. We consider each activity under each domain of functioning involved in doing it. The six domains are as follows:

Six Childhood Domains of Functioning

1. **Acquiring and using information:** how well your child learns information, and how well they use the information they have learned.

Example: Some children with sickle cell disease might have limitations in acquiring and using information due to stroke, including silent stroke. A stroke can cause brain injury that impairs a child's ability to learn, concentrate, speak, and remember.

2. **Attending and completing tasks:** how well your child is able to focus and maintain their attention, and how well they begin, carry through, and finish their activities, including the pace at which they perform activities and the ease with which they change them.

Example: Frequent pain crises can result in limitations in attending and completing tasks at school and at home. If a child does not feel well due to pain, it may be difficult for them to stay focused on activities long enough to complete them in an age-appropriate manner. A child with sickle cell disease who is experiencing pain may also have difficulty paying attention to details and may make mistakes on schoolwork due to an inability to concentrate.

3. **Interacting and relating with others:** how well your child starts and carries on emotional connections with others, learns and uses the language of your community, cooperates with others, follows rules,

responds to criticism, and respects and takes care of the possessions of others.

Example: Sickle cell disease can cause limitations interacting and relating with others. The unpredictable nature of pain in sickle cell disease may cause anxiety and difficulty maintaining relationships. Children suffering from complications of sickle cell disease may also become withdrawn, uncooperative, or unresponsive.

4. **Moving about and manipulating objects:** how your child moves their body from one place to another and how they move and manipulate things. These are called gross and fine motor skills.

Example: Sickling in the hip bones, knees, and ankles due to sickle cell disease may cause joint pain and problems with walking, running, and climbing up and down stairs.

5. **Caring for yourself:** how well your child keeps a healthy emotional and physical state, including how well they get their physical and emotional wants and needs met in appropriate ways; how they cope with stress and changes in their environment; and whether they take care of their own health, possessions, and living area.

Example: A child with sickle cell disease may avoid taking medication or ignore complications of the disease out of frustration with the limitations of sickle cell disease.

6. **Health and physical well-being:** the total physical effects of physical or mental conditions and their treatments or therapies on your child's functioning that we did not consider in the other domains.

Example: A child with sickle cell disease may have periodic pain crises that affect their ability to function physically. We consider the frequency and duration of the crises as well as the extent to which they

affect a child's ability to function physically. We also consider the effect of treatment, such as blood transfusion.

- ✓ **If your child's condition(s) *functionally equals the listings*, we will find them disabled at step 3.**
- ⊗ **If your child's condition(s) *do not meet or medically equal a listing or functionally equal the listings*, we will find that they are not disabled, and your claim will be denied at step 3.**

Resources

- *Sickle Cell Disease and the Social Security Disability Evaluation Process for Adults* (Publication No. 60-003)
- *Benefits for Children with Disabilities* (Publication No. 05-10026)
- *Child Disability Starter Kit* (Publication No. 64-112)
- *Your Right to Representation* (Publication No. 05-10075)
- *If You Are Blind or Have Low Vision—How We Can Help* (Publication No. 05-10052)
- *Apply Online for Disability Benefits* (Publication No. 05-10550)
- *What You Need to Know About Your Supplemental Security Income (SSI) When You Turn 18* (Publication No. 05-11005)
- Blue Book (Listings) (Disability Evaluation Under Social Security). This is also known as the Blue Book. It was made for doctors and other medical providers. It has the listing of impairments for adults and children. See <https://www.ssa.gov/disability/professionals/bluebook/> for more information.
- Other SSA Disability Publications can be found at <https://www.ssa.gov/pubs/>

Tips for Helping with the Disability Evaluation

- Use the checklists, worksheets, and other information in the *Child Disability Starter Kit* (Publication No. 64-112) to help get ready for your disability interview or online application. To apply online, go to <https://www.ssa.gov/apply>.
 - Note: Plan to spend at least an hour, in total, completing your application.
 - Tip: If you cannot apply online, or do not want to apply online, you can apply by phone or in person at any Social Security office. You can also call or go to any Social Security office if you have questions that you would like to discuss with us. You can find your nearest Social Security office through our Social Security Office Locator at <https://secure.ssa.gov/ICON/main.jsp>. Call **1-800-772-1213** to make an appointment. Community organizations, like your local sickle cell disease advocacy organization, may also be able to help.
- Submit a *Child Disability Report* (Form SSA-3820-BK) when you apply and include details about your child's condition(s), symptoms, treatment, and functional limitations.
- Complete and submit any forms we send you as soon as possible.
- Tell us as much as you can about your child's medical condition(s) and how it affects them:
 - Explain how your child's treatment affects their functioning.
 - Tell us about medications they take, procedures they get (such as blood transfusions), and other therapies, like massage or physical therapy.

- Tell us about *long-term treatments* to manage your child's condition and any *short-term treatments* they need for acute complications.
- Tell us how treatment improves your child's function and any *burdens or side effects* that come with it.
- Tip: If you have a "pain plan" from your child's doctor that explains how to treat your child's pain at home or in the hospital, share it with us.
- Describe your child's symptoms of sickle cell disease and its complications.
 - Tell us about any pain, fatigue, shortness of breath, mental symptoms (for example, memory loss, difficulty concentrating, anxiety, or depression), or other symptoms.
 - Tell us how often your child experiences them, and how intense they are.
- Describe any sickle cell crises or pain crises your child had for at least the past year.
 - Explain how long they last(ed), how often they happened, and the intensity of your child's pain, fatigue, shortness of breath, or other symptoms.
 - Tell us about any complications or organ damage that happened.
 - Tell us the dates and providers for any medical treatment your child got.
 - Tip: If you have a "pain diary," or other record of your child's symptoms and daily activities during their pain crises, send a copy to us.

—Explain how your child’s symptoms, including the side effects of their treatment, impact their physical and mental ability to function, including their ability to:

- attend school or work,
- perform their daily activities,
- move around,
- use their hands and arms,
- learn and use information,
- pay attention and concentrate,
- interact with others,
- handle stress, and
- tolerate environmental conditions like heat or humidity.

- Give us the dates of visits to doctors or hospitals and the name of the office or hospital.

—If you have them, give us the patient account numbers for any doctors or hospitals and any other information that will help us get your child’s medical records.

- Send us copies of any medical or school records or information you already have.

NOTE: You do not need to request information from your child’s doctors. We will contact them directly for reports or information that we need.

- Let us know if something changes after you submit your application – for example, if your child is hospitalized or has new complications or new organ damage.
- You can give us the information listed above in many ways. For example, you can include it in (or attach it to) your Child Disability Report or other forms, share it when you talk to us on the phone or at the

field office, or mail or fax it to us. You can find the local office fax number and address from the Social Security Office Locator page, which can be found at <https://secure.ssa.gov/ICON/main.jsp>.

Disability Application Myths and Facts

Myth: If I don't understand something or if my application was denied initially, there is nothing I can do.

Fact: If you need help, visit our website at www.ssa.gov/ssi or call 1-800-772-1213 to make an appointment at the field office. Write down your questions beforehand and bring a friend or family member if helpful. Local community organizations may also be able to help. For more information on appealing a denial, visit our website at <https://www.ssa.gov/ssi/text-appeals-ussi.htm>.

Myth: The Social Security Administration only needs my child's medical information.

Fact: Provide us with all the information about your child's condition(s) and how it affects their ability to perform their daily activities. We will consider your descriptions, explanations, pain diaries, home pain plans, reports from those who observe your child, and other information you can provide, because these are all important.

Myth: I do not need to complete forms or respond to every request for information.

Fact: Complete the Child Disability Report (Form SSA-3820-BK) when you file your application and return any forms we send as soon as possible. Let us know right away if your contact information changes.

Contact Us

There are several ways to contact us, such as online, by phone, and in person. We're here to answer your questions and to serve you. For nearly 90 years, we have helped secure today and tomorrow by providing benefits and financial protection for millions of people throughout their life's journey.

Visit our website

The most convenient way to conduct business with us is online at **www.ssa.gov**. There are several things you can do online:

- Apply for most types of benefits.
- Start or complete your request for an original or replacement Social Security card.
- Find copies of our publications.
- Get answers to frequently asked questions.

When you create a personal *my* Social Security account, you can do even more.

If you live outside the United States, visit **www.ssa.gov/foreign** to access our online services.

Call us

If you cannot use, or do not want to use, our online services, we can help you by phone when you call our National toll-free 800 Number. We provide free interpreter services upon request.

You can call us at **1-800-772-1213** — or at our TTY number, **1-800-325-0778**, if you're deaf or hard of hearing — between 8:00 a.m. – 7:00 p.m., Monday through Friday. For quicker access to a representative, try calling early in the day (between 8 a.m. and 10 a.m. local time) or later in the day. **We are less busy later in the week (Wednesday to Friday) and later in the month.** We also offer many automated telephone services, available 24 hours a day, so you may not need to speak with a representative.



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