

## Diastrophic Dysplasia and Social Security Disability Benefits

Diastrophic Dysplasia (DD) is a cartilage and bone disorder characterized by early-onset joint pain, curvature of the spine, inward and outward turning feet, and hand deformities. Children born with DD are often very short and often have decreased mobility. In some cases, children who have DD experience respiratory disorders. Although children who have DD can adapt and learn to work around their physical differences, they will typically require an increased level of support throughout their entire lives.

As a parent raising a child with Diastrophic Dysplasia (DD), you are no stranger to adversity. You keep your child healthy by making their comfort and wellbeing your first priority. However, the cost of this increased care accumulates, and coupled with time spent away from work, can be detrimental to your family's finances.

If your child has DD, he or she may qualify for Supplemental Security Income (SSI). These benefits can be used to offset the cost of medical treatment, assistive technology, and supportive care.

### Supplemental Security Income

Supplemental Security Insurance (SSI) is a benefit program for individuals of all ages who have limited income and resources. To qualify for SSI, applicants must meet strict financial requirements. Applicants under the age of 18 will be evaluated based on the income of their parents. The financial limits will vary based on how many parents the child lives with and how many other children live within the same household.

Learn more about SSI eligibility, [here](#). Toward the bottom of the page in the link you will find a helpful chart that will allow you to look up the amount of income you can earn without disqualifying your child for SSI benefits. It is important to note that there are many types of income that won't be counted toward this amount. These include:

- Temporary Assistance for Needy Families (TANF)
- Department of Veterans' Affairs pension
- Foster care payments for children other than the child applying for SSI
- Income used to pay court-ordered support payments.

Types of resources that will not count against your child's eligibility include:

- One house
- One vehicle used for transportation
- Money in pension funds

Applicants over the age of 18 will be evaluated solely on their own income and financial resources. To get a better idea of whether or not you fall within the SSI income limits, contact the SSA. **(1-800-772-1213)**

### Disability

To clarify what is meant by the term "disability" the SSA has established an official definition of the term. For a child to be considered disabled, they must meet the following requirements.

- The child does not have a job considered to be substantial work; and
- The child has a physical or mental condition that causes severe functional limitations; and
- The child's condition has lasted, or is expected to last, at least one year or result in death.

If a child does not meet this definition, he or she will not qualify for SSI. It is important to note that children over the age of 18 will have to meet a separate definition of disability, based around his or her ability to work and earn a living.

## Medical Eligibility

The Social Security Administration uses an official guide of disabling conditions—called the blue book—to determine whether an applicant is medically eligible to receive disability benefits.

Although there is no specific listing for DD in the SSA's blue book, a child with this condition is likely to qualify under a listing associated with his or her affected body systems. Below we have listed the blue book sections that may apply to a child who has DD. Beneath each section you will find the medical requirements that must be met in order to qualify under that specific listing.

If you do not understand the following information because it is too technical, do not worry. If you work closely with your child's doctor(s) to put together his or her application, they will make sure you understand what the SSA needs from you and will make sure you have the correct medical evidence.

The blue book listings under which your child is likely to qualify include:

- **100.02—Growth Impairment related to a Medically Determinable Condition**

To qualify under this listing, your child must have medical evidence demonstrating a fall of greater than 15 percentiles in height **OR** fall to, or persistence of, height below the third percentile.

The medical evidence required to meet this listing should include a standard growth chart plotting the child's current height as well as his or her last three measurements. This chart should also include the child's corresponding weight for each height measurement. The SSA will also look for information regarding the height of the child's birthparents as well as the ages and heights of the child's siblings. You should also include records of your child's diagnosis.

- **101.02—Major Dysfunction of a Joint(s)**

To qualify under this listing, your child must have joint dysfunction characterized by an anatomical deformity, chronic pain and stiffness, and limited motion. This must involve at least one hip, knee, or ankle **OR** both shoulders, elbows, wrists, or hands.

The medical evidence required to meet this listing should include medically acceptable imaging of joint space narrowing, bony destruction, or ankylosis of the affected joints.

- **101.03—Reconstructive Surgery or Surgical Arthrodesis**

To qualify under this listing, your child must have undergone reconstructive or bone-fusion surgery of a weight bearing joint. This can include an ankle, spine, or neck surgery. This surgery must cause significant difficulty walking for at least 12 months after surgery. If your child is not of walking age, he or she will be evaluated based on his or her ability to perform age appropriate tasks. If your child is of walking age, he or she will meet this listing if extraordinary measures must be taken to travel to and from school.

- **101.04—Disorders of the Spine**

To meet this blue book listing, your child’s application must include medical evidence documenting that he or she has a spinal disorder that has compromised a nerve root or spinal cord. You must also provide evidence that your child experiences significant pain, limited spinal movement, muscle weakness, and/or sensory or reflex loss.

- **102.00—Special Senses and Speech (vision and hearing impairments)**

A child who is deaf or visually impaired may qualify under this listing. The conditions and impairments that are covered in this section include: Loss of visual acuity, contraction of the visual field in the better eye, loss of visual efficiency, hearing loss not treated with cochlear implantation, and hearing loss treated with cochlear implantation.

- **103.00—Respiratory System**

The following conditions are covered in this section: Chronic pulmonary insufficiency, asthma, cystic fibrosis, and lung transplants.

Each of these listings contains the medical requirements that a child applicant must meet in order to qualify for disability benefits. These listings will also contain the medical documentation that an applicant will need to provide with his or her application. Be sure to include the medical documentation for all listings that your son or daughter qualifies under. This is because the SSA will consider the combined effects of all symptoms and conditions.

Access all blue book listings, [here](#).

## The Application Process

Prior to beginning the application process, collect the following information:

- Medical records showing treatments and diagnosis;
- Statements from doctors, teachers, and other professionals who can confirm the limitations imposed by your child's condition; and
- Financial documents. Since you are applying for SSI benefits, your income will be assessed.

Once you are familiar with the materials needed, you should contact the SSA immediately to schedule your child’s mandatory disability interview. This can take several months to schedule. While you wait for your interview, review the [Child Disability Starter Kit](#) to learn more about the application process and the benefits themselves.

Be sure to bring all relevant documents with you at the time of your interview. This will prevent the SSA from having to find records themselves and will speed up the processing of your claim. You will also have to fill out several forms. Be sure to do so completely and accurately.

Filing a claim for SSD benefits can be a laborious process and you may at first be denied; however, it is important that you do not give up. You can appeal a denial online or through your local SSA office.

Although navigating the appeals process can be overwhelming and discouraging, it is often a necessary step toward receiving the benefits you need to care for your child. In fact, many more applicants are approved during the appeals process than during the initial application.

***For more information email Molly Clarke at [mac@ssd-help.org](mailto:mac@ssd-help.org). Molly is a writer for the Social Security Disability Help blog (<http://www.disability-benefits-help.org/blog>) and works to promote disability awareness and assist individuals throughout the Social Security Disability application process.***

***This is a free service. While this group cannot personally get involved with any individual applications because they are not legal or medical professionals, they provide helpful, up-to-date information on their site and answer questions to the best of their ability.***

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