

# Understanding Government-funded Health Insurance

A guide for patients with Duchenne muscular dystrophy and those who care for them



## We're here for you!

NS Support is a committed partner to patients and families coping with Duchenne muscular dystrophy (DMD). Our dedicated and knowledgeable team of professionals are available to help identify and tackle the access and affordability challenges to help patients receive the treatment they need.

When you enroll in NS Support, an experienced, personally assigned Case Manager will be on hand to provide ongoing, caring support and resources throughout the treatment journey by calling:

**833-NSSUPRT (833-677-8778)** Monday–Friday,  
8 AM–8 PM ET



## Know your options

When a child is diagnosed with DMD, managing the complexities and costs of their care can be overwhelming. Although you may already have health insurance, in many cases, there are government-funded health insurance plans and programs to help pay for expenses not covered by your primary health insurance. For those without health insurance, it is even more important to understand these programs so that you can decide which options best fit your needs.

*See [glossary](#) on back cover for helpful health insurance terms.*

This brochure does not include a complete list or explanation of government health plans. For other options not listed, please visit [HHS.gov](https://www.hhs.gov).

## What’s inside

This brochure is designed to help you better understand and access government-funded health insurance and financial assistance for your child with DMD.

In the pages that follow, you’ll learn about:

### Supplemental Security Income (SSI)

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Find out about the application process

### Medicaid and Medicaid waivers

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Learn when to consider applying for coverage

### Children’s Health Insurance Policy (CHIP)

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Review eligibility requirements for the program

### Medicare

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See when coverage is an option

In addition, NS Support can direct you to organizations and resources that may help you apply for these programs and answer any additional questions you may have.

Lastly, there is a “Things I Need to Do” section for each of the government-funded insurance or financial assistance options discussed in this brochure. Use these sections to help keep track of important information as you research or apply for a program that may help cover the cost of your child’s treatment.



# Understanding Supplemental Security Income (SSI)

SSI is a federal program that provides monthly payments to children younger than 18 with physical or mental disabilities. To qualify for SSI, the child’s condition must meet the Social Security Administration’s strict criteria for disability, which states that the child’s condition:

- Seriously limits activities
- Has lasted, or be expected to last, at least 1 year or result in death

DMD is a condition that fits the definition of disability for children to qualify for SSI. Eligibility for SSI also takes into account the family’s income and resources.

## Qualifying for SSI

### What SSI looks at to see if you qualify

#### Income

- Includes a family’s salary, Social Security benefits, pensions, food stamps, and nonprofit housing
- Income limits are set by each state

#### Resources

- Includes bank accounts, cash, investments such as stocks and bonds, and real estate (except your current home)
- Does not include your current home and its land, your main vehicle, household goods, personal property (such as wedding rings), and any educational funds (such as grants or scholarships)
- Resource limits are \$2,000 for an individual or child and \$3,000 for a couple

The Disability Determination Services of Social Security in each state makes the disability decision. They will also ask for information from doctors, hospitals, schools, and people who know about your child. If the state needs more information, they may arrange for a physical examination of your child (which the state will pay for) or an interview with you.

It is important to apply for SSI as soon as possible. It can take 3 to 5 months to decide a child’s SSI claim. Be sure to let the state agency know if your address or phone number changes after you have applied for SSI.

The Social Security Child Disability Starter Kit provides answers to frequently asked questions about SSI benefits for children. You can download this resource at:  
[www.ssa.gov/disability/Documents/SSA-1171-KIT.pdf](http://www.ssa.gov/disability/Documents/SSA-1171-KIT.pdf)

Signing up for SSI will help your child become enrolled in Medicaid and other programs. You'll need to complete a Child Disability Report **AND** an SSI Application.

[www.socialsecurity.gov/childdisabilityreport](http://www.socialsecurity.gov/childdisabilityreport)

- The SSI application can't be completed online
- You can apply in person at a Social Security office near you or over the phone
- Call **877-KIDS-NOW (877-543-7669)**, a free and confidential hotline, to be connected directly to your state's program

**[www.socialsecurity.gov](http://www.socialsecurity.gov)** or call **800-772-1213**



## Medicaid

Medicaid is the single largest source of health insurance for children in the United States. It is administered by state governments with both state and federal funding. Each state’s program is different, and eligibility requirements and benefits can, and often do, vary widely from state to state.

Medicaid can help you afford medical costs for DMD by covering:

- Prescription drugs
- Hospital care
- Home healthcare
- Transportation to medical care
- Doctor visits
- Medical equipment

Medicaid may even cover medical care up to 3 months before approving your application if the beneficiary would have been eligible during that time.

### Qualifying for Medicaid

Each state has different requirements on how to qualify for Medicaid. In most states, if a child with DMD is eligible for SSI benefits, he is automatically eligible for Medicaid.

Financial eligibility is based on household size, income, and assets. Families and individuals whose income is below the state’s standard may be eligible for Medicaid. Social security benefits, individual retirement contributions, and tax-exempt interest do not count toward the income requirement.

Even if your income exceeds your state’s eligibility income levels, you may be able to qualify for Medicaid through “spend-down” rules. Under these rules, you may subtract the amount of uncovered medical expenses from your regular income to qualify for Medicaid. You can find out if your child qualifies for Medicaid under spend-down rules by visiting:

[www.oms.nysed.gov/medicaid/resources/medicaid\\_spend\\_down.pdf](http://www.oms.nysed.gov/medicaid/resources/medicaid_spend_down.pdf)

### Supplementing a commercial health plan with Medicaid

Parents of a child with DMD may have a commercial health plan at the time of diagnosis. Many may also enroll in Medicaid to help pay for costs that their commercial health plan does not cover.

For example, you may consider applying for Medicaid if your commercial health plan provides limited coverage for your child’s:

- Visits to specialists
- Home healthcare
- Medical equipment

In many states, a child with DMD who qualifies for SSI is automatically enrolled in Medicaid. Once approved, Medicaid can help pay for some of the cost that may not be covered by commercial insurance.



## Medicaid waiver programs

People living with DMD who do not qualify for Medicaid assistance, based on their income alone, may be able to get benefits through the use of Medicaid waivers. A Medicaid waiver allows the state Medicaid service to waive the rules that usually apply to the Medicaid program. Medicaid waivers may also help provide additional services so that a child with DMD can receive long-term care in their own community.

How Medicaid waivers are applied varies considerably by state, including the number of people covered, services provided, and whether there is a waiting period for application and coverage.

### Types of Medicaid waivers

- **1915(c) waivers, more commonly known as Home and Community-Based Services (HCBS) waivers**
  - Allow Medicaid to be used as a primary or secondary insurance option to help certain children, such as those with DMD, to be treated in home- or community-based settings, rather than in long-term care facilities, such as nursing homes
  - All states have some type of HCBS waiver program and most states have more than one HCBS program
- **Tax Equity and Fiscal Responsibility Act (TEFRA)/Katie Beckett waivers**
  - Provide full or additional coverage, including the cost of medications, for children younger than 19 who live at home with long-term disabilities, mental illness, or complex medical needs
  - Financial eligibility for children with DMD is based only on the child's income and assets, without regard for the family's financial status
  - States cannot limit the number of Katie Beckett participants, so there are no waiting lists
- **Section 1115 waivers**
  - Present an opportunity for states to institute reforms that go beyond routine medical care to:
    - Expand eligibility to individuals who are not otherwise Medicaid or CHIP eligible
    - Provide services not typically covered by Medicaid
    - Use innovative service delivery systems that improve care, increase efficiency, and reduce costs as long as these systems do not increase federal Medicaid expenditures



## Applying for Medicaid waivers

Your NS Support Case Manager may be able to help.

When applying for a Medicaid waiver, you will need to provide information that proves the person with DMD is in need of the services that the program provides. Typically, this includes a detailed report from a physician describing the applicant’s condition, how well they are able to walk, and any other supporting documents to be submitted with the application.

### To begin the application process:

#### Contact your state Medicaid office

To find an office near you, visit: [www.medicaid.gov/about-us/contact-us/contact-your-state-questions/index.html](https://www.medicaid.gov/about-us/contact-us/contact-your-state-questions/index.html)

- You will then be given information on how to submit an official application
- Because each state sets a maximum number of people that can be served under any given HCBS waiver program, it may take some time before an application is approved and benefits are awarded for this type of waiver
- To help individuals in extreme situations receive the funds they need in a timely manner, ask the agent about priority designations

To learn more about waivers available in your state, visit: [medicaidwaiver.org](https://medicaidwaiver.org) and click on “Disability Benefits.”

[Kidswaivers.org](https://kidswaivers.org) is another helpful resource for learning more about Medicaid waivers for children.

*Medicaid waivers: things I need to do*

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## Children’s Health Insurance Program (CHIP)

CHIP provides free or low-cost health insurance for a child with DMD whose family’s income is too high to qualify for Medicaid. The qualification rules and what the plans cover vary from state to state. Like Medicaid, CHIP can help you pay for equipment, treatment, and services needed to care for a child with DMD.

CHIP provides insurance for prescription drugs and for vision, hearing, and mental health services in all 50 states and the District of Columbia. Your state Medicaid agency can provide more information about CHIP.

### Qualifying for CHIP

To be eligible for CHIP, a child must be:

- Younger than 19
- Uninsured (determined ineligible for Medicaid, and not covered through a group health plan or creditable health insurance)
- A US citizen or meet immigration requirements
- A resident of the state
- Eligible within the state’s CHIP income range, based on family income, and any other state specified rules in the CHIP state plan

### Annual Household Limits Income (before taxes)<sup>a</sup>

| Household Size <sup>a</sup> | Maximum Income Level per Year |
|-----------------------------|-------------------------------|
| 1                           | \$49,960                      |
| 2                           | \$67,640                      |
| 3                           | \$85,320                      |
| 4                           | \$103,000                     |
| 5                           | \$120,680                     |
| 6                           | \$138,360                     |
| 7                           | \$156,040                     |
| 8                           | \$173,720                     |

<sup>a</sup> For households with more than 8 people, add \$17,680 per additional person. Always check with the appropriate managing agency to ensure the most accurate guidelines.

Always check with the appropriate managing agency in your state to ensure the most accurate income limits.

Depending on your income, you may need to pay low premiums and cost-sharing for some CHIP services. The remaining costs are paid by the federal government and your state.

Eligibility for CHIP varies from state to state.

**800-318-2596 (TTY: 855-889-4325) and speak to an agent who will help you with the application process**

- Call your NS Support Case Manager if you still have questions

To find out more about CHIP in your state visit:

Not all doctors accept patients who have Medicaid or CHIP. You may want to ask the office staff if they accept Medicaid or CHIP when you make an appointment.

If you have trouble finding a doctor, your CHIP plan can help you.

## Medicare

### When is Medicare an option for individuals with DMD?

Until relatively recently, boys with DMD usually did not survive beyond their teen years. Thanks to advances in cardiac and respiratory care, survival into the early 30s is becoming more common, and there are cases of men with DMD living into their 40s and 50s.

Medicare benefits are only available for those younger than 65 under exceptional circumstances. “Children” over the age of 20 with DMD are automatically enrolled in Medicare after receiving Social Security Disability Insurance (SSDI) benefits for at least 2 years. Your adult child may be able to receive SSDI, even with no work history if they:

1. Developed a disability before age 22
2. Have at least one parent who receives Social Security retirement benefits
3. Are unmarried

However, patients with DMD are much more likely to receive healthcare insurance from Medicaid and CHIP than Medicare.





# Glossary

**Child Disability Report:** A form that must be completed on behalf of a child applying for Supplemental Security Income (SSI) disability benefits.

**Children's Health Insurance Program (CHIP):** A program created in 1997 to provide insurance coverage to children whose families earn too much to qualify for Medicaid, but who cannot afford to purchase private insurance. CHIP is the single largest taxpayer-funded expansion of health care insurance coverage for children since President Lyndon Johnson established Medicaid in 1965.

**Co-insurance:** A percentage of the cost of your medications and healthcare services that you are responsible for paying, commonly 20%.

**Co-pay:** A set amount, determined by your health plan, that you pay for medications and healthcare services at the time of service.

**Deductible:** The out-of-pocket amount you must pay before your health plan begins to pay.

**Home- and Community-Based (HCBS) Waivers (also called 1915[c] waivers):** Waivers that allow state Medicaid programs to provide coverage for children and adults with significant disabilities who prefer to receive long-term care services and supports in their home or community, rather than in an institutional setting.

**Medicaid:** A joint federal and state program that helps with medical costs for some people with physical or mental disabilities and/or limited income and resources.

**Premium:** The periodic payment to Medicare or a health insurance company for healthcare or prescription drug coverage.

**Section 1115 Waivers:** Waivers established under Section 1115 of the Social Security Act that allow states to waive certain provisions of the Medicaid program so that states have additional flexibility in designing and improving their programs. In addition to reducing costs, these waivers have been used to increase eligibility, expand services covered, and implement innovative service delivery systems to improve efficiency, quality of care, and health outcomes.

**Social Security Disability Insurance (SSDI):** A Social Security Administration program that can pay monthly benefits if you become disabled with a long-term medical condition before you reach retirement age and aren't able to work.

**Spend-down rules:** Under these rules, a person whose income exceeds their state's eligibility income levels to qualify for Medicaid may subtract the amount of uncovered medical expenses from his or her regular income to qualify for Medicaid.

**Supplemental Security Income (SSI):** A Social Security Administration program that pays benefits to disabled children and adults who have limited income and resources.

**TEFRA/Katie Beckett Waivers:** Waivers that allow states to provide Medicaid services to individuals 21 years of age and younger who have a physical and/or developmental disability, who would normally not qualify for Medicaid due to family income. These waivers are named after Katie Beckett, a child who was ventilator-dependent for over 3 years after contracting encephalitis. Although home nursing care would have been one-sixth of the cost of her care in the hospital, if she left the hospital, she would no longer be eligible for Medicaid. President Ronald Reagan granted an exception that allowed Katie to move home and still receive Medicaid coverage that included private duty nursing. This exception was passed into law as the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, which gives any state the option to provide Medicaid to a child with a significant disability in their home or community-based setting.



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