

# Medicaid for Children who have Complex Medical Conditions

A Vital Support System for Children and Families

## What is Medicaid?

Medicaid, called Medical Assistance in Minnesota, is most commonly known for its role in providing health care coverage for those who cannot afford health care and do not have insurance. Nationwide, Medicaid covers approximately 68 million people in the U.S., of which more than 43 million are children, and accounts for 17 percent of health care spending. <sup>(1)</sup> Created in 1965 via title XIX of the Social Security Act, the program is jointly funded by the federal government and states. Because Medicaid is state-administered, specifics such as services covered, eligibility requirements, and program components can vary widely from state to state.

Medicaid also plays a critical role in covering the health care costs of children who have disabilities and medically complex conditions. The 2016 National Survey of Children's Health found that more than 14.2 million children, or 19% of all children in the U.S., have special health care needs. <sup>(2)</sup>

## Why do children who have disabilities rely on Medicaid?

When a child is born with a medically complex condition or experiences a traumatic injury, a family's world is changed forever. An example might include a baby born prematurely and diagnosed with cerebral palsy or an adolescent who experiences a traumatic brain injury. Medicaid exists to give all families support as they face medical situations—and associated costs—they never anticipated. Medicaid ensures that children and adults who have complex conditions can access and afford needed health care.

**Medicaid, as the single largest health insurer for children in the United States, is the backbone of children's health care. Children account for about half of all Medicaid beneficiaries.** <sup>(3)</sup>

## How is Medicaid eligibility determined?

As a state administered program, eligibility and the process for enrollment and coverage varies state to state. For instance, in Minnesota, families must first apply based on income, get denied, and then have their application forwarded for disability consideration with the state. Thus for children who have complex conditions, eligibility for Medicaid can occur in one of two ways:

- **Based on family income.** Through this pathway, eligibility is determined according to limits set as a percent of the Federal Poverty Level.
- **Based on the individual child's condition.** If a family does not qualify for Medicaid based on income, a child might be eligible as a result of his or her disability via a pathway authorized in the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982. In general, children who qualify for Medicaid with the TEFRA option, also known as the Katie Beckett Waiver for children, must be under 19, must be certified disabled by the Social Security Administration or a state medical review, and must have home care needs that cost less than care at a medical facility, among other criteria. Through this eligibility pathway, families pay an income-based fee to have Medicaid coverage.

**Gillette's Medicaid and Medicaid-eligible patients make up**



Source: Gillette Children's Specialty Healthcare data.

## Are Medicaid and private insurance mutually exclusive?

No. Although many children rely on Medicaid exclusively, it can also coexist with a family's private insurance. In these cases, Medicaid acts as secondary coverage—assisting when primary insurance limits are reached and helping with services not covered by primary insurance, such as hygiene equipment, personal care services, and medical transportation.

<sup>(1)</sup> Centers for Medicare and Medicaid: cms.gov

<sup>(2)</sup> Kaiser Family Foundation analysis of the 2016 National Survey of Children's Health

<sup>(3)</sup> Children's Hospital Association: childrenshospitals.org

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## The Pathway to Medicaid for Children who have Complex Medical Conditions

Because the Medicaid enrollment process is not specifically designed for children who have disabilities, the process can be confusing and tedious. This puts additional stress on families facing already-overwhelming circumstances surrounding a child's health care needs. *The below pathway is an example of the process for Minnesota families.*

### Route 1

**Step 1:** Child is born with or develops extensive medical needs and becomes a Gillette patient.

**Step 2:** Gillette social worker meets with family if they are listed as self-pay or if they request assistance with insurance coverage.

**Step 3:** Social worker shows family how to use MNsure.org\* (for income-based eligibility). Family completes their application online and finds out whether or not they qualify.

**Step 4:** **If accepted**, family begins receiving assistance from Medicaid via a Prepaid Medical Assistance Plan (PMAP).  
**If denied**, see route 2.

\* MNsure is Minnesota's state health insurance marketplace, created following the 2010 passage of the Affordable Care Act, for consumers to compare and select health insurance coverage.



**Maddy Lavalier, age 10, has spina bifida and is a lifelong Gillette patient.**

### Route 2

**Step 5:** If family does not qualify for Medicaid based on income, social worker talks with them about monthly fees through TEFRA<sup>†</sup> to see if they are interested. If family expresses interest, social worker assists them in contacting their county's financial assistance department to request a TEFRA application.

**Step 6:** TEFRA application is sent to their county worker who forwards it to the State Medical Review Team (SMRT) unless client is already approved as disabled by the Social Security Administration. Application must be mailed or faxed, which can present difficulties. The SMRT team then reviews and client is approved or denied based on disability.

**Step 7:** It takes approximately 60 days from when family submits packet to when SMRT makes their decision.

**Step 8:** Family is notified by the state whether or not their child has been deemed certified disabled. If certified, the state determines family's monthly TEFRA premium based on detailed financial information submitted, including income, tax, and other financial worksheets. Payments are backdated to time of application, meaning family often faces several months' worth of payments.

**Step 9:** Family must resubmit financial information every six months.

**Step 10:** Depending on the condition, family must resubmit paperwork to confirm the child's disability and condition for eligibility every 3-5 years.

<sup>†</sup> The Tax Equity and Fiscal Responsibility Act, or TEFRA, allows Medicaid eligibility for medically complex children whose parents have too much income to qualify for Medicaid by paying a sliding (monthly) fee. See the opposite side of this handout for more on TEFRA.