Down Syndrome Coverage
That’s Medicaid

ThatsMedicaid.org
Since 1965, Medicaid has been a backbone of the U.S. health care system. The joint state-federal insurance program covers one in five Americans—including many elderly and disabled individuals and 40 percent of all U.S. children.

That’s Medicaid is a Robert Wood Johnson Foundation-led effort to share diverse stories of people who have been covered by Medicaid at critical points in their lives, underscoring the importance of stable health insurance coverage to a nationwide Culture of Health.

This booklet focuses on the role of Medicaid coverage in supporting individuals with Down syndrome. We look at the story of Valerie, whose youngest son has Down syndrome and has had a tracheostomy and other significant surgeries covered by Medicaid. We look at the story of Alecia, who is able to work and live independently thanks to her Medicaid coverage. And we look at the story of Matthew, whose Medicaid coverage has given him the freedom to work and live as a member of his community.

Each of these stories represents a unique example of how Medicaid coverage has been valuable in many people’s lives. We encourage you to use these stories as resources, and to check out the full collection of stories and videos on www.ThatsMedicaid.org.
Valerie and her husband Christopher wanted to adopt two boys from foster care, both with significant health complications.

As a pediatric nurse, Valerie knew she could handle the children medically but was not sure if her family could afford the expenses of their care. However, during the adoption process, she found out both children were automatically covered by South Dakota Medicaid because of their time in foster care. The children, now 5 and 2, will stay on Medicaid until they are 18 or graduate high school, whichever comes first.

The oldest has a heart defect that requires him to be taken to specialist appointments several times a week. The youngest has Down syndrome and has needed a tracheostomy and other significant surgeries, as well as follow-up care, over the years.

The parents now plan their work schedules to make sure at least one of them is home with the boys at all times and trade off attending doctors’ visits.

Though Valerie and Christopher are both privately insured through work, they say adoption was only possible because of Medicaid.

“Without Medicaid there would have been absolutely no way for us to adopt our boys,” Valerie says. “Medicaid lets us focus on the most important thing—taking care of them.”

Watch: Valerie’s story in her own words
Alecia was born with Down syndrome, a lifelong condition that comes with physical and developmental challenges. She needs extra help in her everyday life, but her goal is to live as independently as possible. Alecia enrolled in Medicaid through Iowa's Consumer Choices Option, which provides extra support and training for people with disabilities.

The program empowers Alecia to live by herself and pursue the life she wants. She works with a Medicaid-funded coach who helps her develop skills such as cooking, exercising, and other daily tasks. Alecia also has her learning permit and is practicing driving so she can obtain her full driver's license.

Alecia supports herself by working part-time at a local grocery store, and also serves as a member of Iowa's Developmental Disabilities Council.

“I need extra help because of my disability,” Alecia says. “Medicaid gives me the freedom to live independently.”
Matthew was born with Down syndrome, a condition that could have hindered him from being able to live independently. He did not, however, let his disability dictate his life.

Alabama’s Medicaid program provides him home- and community-based assistance and the freedom to hire his own care team. It has also given him the opportunity to enjoy his favorite activities, like attending art and dance classes, and maintain his job at a family restaurant, where he has worked for more than two decades. With his own independence in place, Matthew spends his free time with others who have disabilities.

“I try and help people in the community, to teach them how I’ve been able to live, how to get a job, and how I spend my days successfully,” he says.

With the support of Medicaid, his personal coach, and his family, Matthew lives a full life, and he wants to be able to share that with others.

“I want to help other people who have disabilities,” he says. “I want people to be positive with the things they can do in life.”