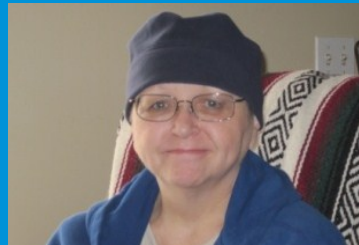




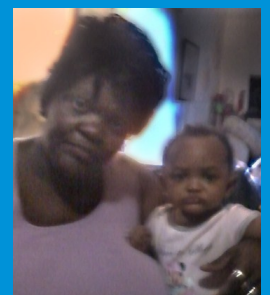
Faces



of



Medicaid



NOVEMBER 2011

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.

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Introduction

Medicaid, the public insurance program that provides health and long-term care coverage for individuals and families with low income, covers about 60 million people currently, or 1 in 5 Americans. Medicaid beneficiaries include pregnant women, children and families, individuals with a wide range of disabilities, and seniors. During down economies, Medicaid places pressure on state and federal budgets as the number of people who qualify for the program grows. Without Medicaid, most of its beneficiaries would be uninsured or lack coverage for essential care. Under the Affordable Care Act, beginning in 2014, millions of uninsured, low-income Americans will gain health coverage through a major expansion of Medicaid.

Many statistics quantify how integral Medicaid is to our health system, as a source of coverage as well as health care financing. In *Faces of Medicaid*, a new project of the Kaiser Family Foundation's Commission on Medicaid and the Uninsured, we take a qualitative look at what makes the program important. Based on interviews conducted over the course of 2011, we introduce and profile individuals and families from across the nation who rely upon Medicaid, and describe the diverse ways in which Medicaid assists them. At the interactive *Faces of Medicaid*, <http://facesofmedicaid.kff.org>, feature on our website, www.kff.org, you also can hear the voices of many of the people we profile here as they tell their own stories, and find useful information related to the economy, coverage, and health reform in the states where they live.

We extend our appreciation to the Medicaid beneficiaries who shared their experiences with us to make the *Faces of Medicaid* initiative possible.

Stories



Anthony

Oklahoma City, Oklahoma

Latrita McFadden noticed from the beginning that her son, Anthony, now age 11, always walked on his tiptoes. When he began to complain that his knees were hurting, she tried to get help. Latrita took him from doctor to doctor, but she was advised each time that Anthony would probably grow out of it and no one referred her to a specialist. Anthony fared well enough until he started school, where he was taunted about his walk and also about a speech impairment. “He used to walk around with his head low and just kind of avoid everybody,” Latrita reports. Anthony became withdrawn and would not read aloud in class. His first-grade teacher held him back, saying that he was immature and unable to speak well enough to rise to second grade.

Things changed dramatically for Anthony when, newly covered by SoonerCare (Oklahoma’s Medicaid program), he received some much-needed care. Latrita took him to a new primary care doctor, who referred him to a specialist about his walking. That led them to an orthopedist, who diagnosed Anthony’s shorter-than-normal Achilles’ tendons and operated on one of his feet (he will need the same surgery on his other foot). Anthony also began to get speech therapy, as well as some counseling. According to his mother, “Once he

“...I’m just really grateful. The Medicaid SoonerCare program has had a profound effect on my family.”

– Anthony’s mother, Latrita

got that surgery and he stopped walking on his toes like he was doing, his self-confidence kind of just skyrocketed.” Shortly after the operation on his foot, Anthony “graduated out” of speech therapy, and though he continues his exercises on his own, he no longer needs to see the physical therapist either.

Latrita has trouble containing her amazement as she describes a boy who now has the self-esteem not only to speak, but to serve as junior deacon in his church and run for student body president. And in a sharp contrast to a few years ago, his fifth-grade teacher now has him tutoring other students in his class. Anthony didn’t win the school election, but he says he’s going to run next year and keep on running until he wins. His mother enjoys the unintended pun, “It’s funny because he says, literally, I’m going to keep on running... He knows he can run and his feet are working like they’re supposed to work now.”

Medicaid’s benefits for children are comprehensive to ensure their healthy development.

Anthony was helped by Medicaid’s Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services. EPSDT, the Medicaid benefit package for children up to age 21, covers comprehensive health care, including screening, developmental assessments, vision, dental, and hearing services, as well as all medically necessary diagnostic services and treatment. Durable medical equipment and assistive devices, and services such as physical and occupational therapy that help maximize children’s function, are also covered. The goal of EPSDT’s prevention-oriented services is the early identification of conditions that can impede children’s growth and development, and early intervention and care to ensure them a healthy start and avoid the health and financial costs of long-term illness and disability.



Carmen and daughters

Hartford, Connecticut

Carmen Rosado and her two teen daughters, Crystal Marie, age 18, and Nelly Marie, age 13, are all enrolled in Medicaid. Carmen sought out the program following her divorce several years ago, when she and her girls lost the health insurance they had through her then-husband's business, where Carmen also worked. Carmen took on a night-shift job for a time, but with no health insurance. For about three years now, she has been unemployed and she continues to look for work.

Crystal and Nelly have received all their well-child care and immunizations on schedule while enrolled in HUSKY, as Connecticut's Medicaid program for children is called. HUSKY has also covered their eyeglasses and occasional doctor visits for sick care. Both girls enjoy sports – they play softball – and Carmen is grateful that they are in excellent health. But knowing that HUSKY is there if they need it gives Carmen peace of mind.

"It's helped them to be healthy, be on track with their shots and everything that's needed."

Carmen has not been as lucky with her health as her daughters have been. She has required several surgeries in the last two years to remove cysts, and she also suffered a severely sprained ankle and some infections. Medicaid covered all the hospital and physician care and prescription medicine that she needed as a result. Carmen estimates that, without Medicaid, she would be facing over \$30,000 in medical bills for her hospitalizations alone, which she could not afford to pay.

In covering childhood immunizations, Medicaid protects low-income children from deadly diseases and plays a major public health role. Carmen reports that Medicaid has enabled her daughters to get the well-child visits and immunizations they should, and on time. States are required to cover vaccinations at no cost for all children enrolled in Medicaid. According to the National Committee on Quality Assurance, about three-quarters of children with Medicaid coverage received their recommended vaccinations in 2009, similar to the share of privately insured children who did so.



Kay

Portland, Oregon

Kay Dickerson, age 57, and her husband Tom, are Hurricane Katrina survivors. After the storm, in September 2005, they relocated to Portland, Oregon. When Kay was medically evaluated at the makeshift welcome center in a Portland high school, she was diagnosed with anxiety, depression, PTSD, and high blood pressure. She also found out then that she was diabetic. Upon learning that Kay had been uninsured for many years, the medical staff directed her to a community health center run by Oregon Health & Science University, where the financial aid officer helped her apply for the Oregon Health Plan (OHP), as Medicaid is known in the state.

Having OHP has enabled Kay to get much of the care she needs and she is in good health today. Therapy helped her gain coping skills to deal with her anxiety, depression, and PTSD, and the prescription medication she needs is covered.

Her blood pressure is under control now and, with changes in her diet, she is managing her diabetes, too. At her most recent diabetic wellness check, Kay's doctor reminded her to schedule her annual diabetic eye exam. Grateful for her care and seeking to "pay it forward," Kay now sits on her health center's board as a patient advocate.

"Honestly, I don't know where I would be if I didn't have insurance."

OHP does not cover everything Kay needs. She will have to go to the Lion's Eye Foundation to get glasses, because OHP does not cover them for adults. Her dental coverage is also limited. While OHP paid for six teeth to be extracted – the casualty of years without dental care— no other dental services are covered. Kay pays a \$15 monthly premium for OHP, an amount not easy to find on the \$700 per month that she and her husband live on. Still, she is upbeat. "How we do that is a miracle...I don't know exactly how, but we manage," Kay says, adding that their neighbors help by donating their recyclables, which Kay and Tom redeem to bring in a little extra money.

Many adults covered by Medicaid use vision and dental care services that often get cut when state budgets are strained. Many adult Medicaid beneficiaries, like Kay, need but cannot get dental and vision care. While federal law requires that state Medicaid programs cover dental and vision services for children, states have the option to cover or omit these services for adults. Because of severe and ongoing strains on state budgets due to the recession, many states have reduced or eliminated optional Medicaid services for adults in recent years. For example, during 2010 and 2011, Oregon and nine other states cut back or terminated their adult dental benefits.



Caleb

Dallas, Texas

Caleb Garcia, 5 years old, was born with multiple disabilities stemming from a virus, known as cytomegalovirus or CMV, that his mother contracted during her pregnancy. Both Caleb's hearing and vision are impaired and he has a constellation of developmental delays and physical problems. The doctors prepared Caleb's family for the worst, but his father, Manuel, reports that "he has done a whole lot better than that," and he credits his son's progress to the care and services he has been receiving through Medicaid since he was born. Just like other children his age, Caleb is finishing kindergarten.

In addition to his regular pediatrician, Caleb sees several specialists. Physical, speech, and occupational therapy are all part of Caleb's care regimen, too, as are several prescription medications. A Medicaid benefit that is particularly important to Caleb's father, who is a single working parent, is the 45 hours of nursing care per week that Caleb gets. Caleb qualifies for an additional 20 nursing care hours, but Manuel enjoys caring for Caleb himself as much as he can. Durable medical equipment covered by Medicaid increases Caleb's mobility and exercises him to build his strength. A "standing frame" helps him get used to putting weight on his feet and stretching. A bath chair, a necessity for Caleb's safety since he cannot push himself out of water, is also covered by Medicaid, as is a wheelchair designed specifically for Caleb that can be modified as his needs change. Caleb cannot coordinate himself to stand up yet, but he is pushing off with his legs, a work-out that helps him grow stronger.

"Sometimes he'll vocalize but he'll definitely smile... he won't necessarily react right away but you can tell that he knows he's in a comfortable, happy place."
– Caleb's father, Manuel

Caleb's father says there is no way he would be able to afford the care Caleb needs without Medicaid. When Caleb lost Medicaid for a month because of a bureaucratic mistake, Manuel looked into private insurance for him, but the \$850 monthly premium and copays were impossible on the income he was then making as a waiter. That month, Caleb got no therapy and no nursing, and Manuel filled Caleb's prescriptions a few days at a time and postponed some of his doctor's appointments until Caleb's coverage could be reinstated. Only recently, Manuel finally got health insurance for himself for the first time, after being promoted to manager at his restaurant.

Medicaid provides nursing services that enable a father to care for his disabled son at home. Manuel Garcia is able to take care of his son, Caleb, at home while working full-time because of the home health services that Medicaid covers for Caleb. Medicaid covers many services and supports that people young and old need to live independently in the community – home health care, including nursing services, personal care, medical equipment, rehabilitative therapy, adult day care, case management, respite for caregivers, and other services. Coverage of these services is excluded or limited by both private insurance and Medicare. In addition to home- and community-based services, Medicaid covers institutional care in nursing homes and intermediate care facilities. Medicaid is, by far, the largest source of coverage for long-term care, financing 40% of total spending on these services.



Patricia

Scranton, Pennsylvania

About four years ago, Patricia Clark, now 86, went into the hospital for a hip replacement. Patricia had had various health problems over the years and she had a pacemaker, but she was doing well at the time, except that her declining mobility was making it increasingly difficult to live independently. Her doctors expected her to fare better with a new hip. Unfortunately, Patricia suffered a debilitating stroke in surgery. Once again, she was unable to get around by herself or live on her own. She was moved to a rehabilitation center but did not recover, and Patricia now lives there as a nursing home resident.

Medicare pays for most medical care that Patricia needs, but Medicaid pays for her nursing home care, and it also covers Medicare's premiums and cost-sharing, keeping her out-of-pocket costs for care very low. The nursing home costs about \$7,000 per month, a sum Patricia could not afford on her own. Her only income is her Social Security check and a very small pension from her late husband – a total of about \$1,100 a month. All of this goes to the nursing home except for a small personal allowance of \$45 a month. Likewise, when the house that Patricia still owns sells, the proceeds will go to the state toward her nursing home costs.

"She's very content here...but she would not have any of this without Medicaid, honestly. It would be a disaster for her."

– Patricia's daughter, Jill

Without Medicaid, it is unclear how Patricia would manage. Although her nursing home is in Scranton, before her hip surgery, Patricia lived in rural Pennsylvania, seven miles from the nearest town. As her walking and ability to perform everyday tasks declined, her daughter Jill found the 24-hour care her mother needed extremely hard to come by. For a short time, they hired someone for eight hours a day, but at \$1,000 per week, it was financially draining and would have left her mother destitute. Moreover, Patricia was lonesome and isolated at home, and her family worried constantly about her safety. Jill says that Medicaid changed her mother's life. At the nursing home, Patricia socializes, all her needs are met, and she is well cared for. And though Patricia now shows signs of dementia, Jill rests easier knowing that she gets her medications on time and is in good general health.

Medicaid pays for long-term care for individuals in nursing homes as well as those in the community. Medicaid is the primary payer for long-term care for over 3 million Americans. Medicaid covers care provided in institutional settings, such as nursing homes, for beneficiaries like Patricia. The program also covers a range of home- and community-based services that Medicare and private insurance exclude or tightly limit, enabling many people who would otherwise require nursing home care to live independently in the community. Paying for long-term services is expensive and can quickly exhaust lifetime savings. The cost of nursing home care averages \$72,000 per year; the average cost for assisted living facilities is \$38,000 per year; and home health services cost \$21 per hour on average.



Matthew

Garden City, Kansas

Matthew Bardgett, now 50, was in a terrible car accident at age 19 that broke his back and left him a paraplegic. At the time, he was employed in the oil fields supply industry and had health insurance that covered his health care and rehabilitation, but Matt was unable to regain the function he lost in the accident and it was a long time before he would work again.

Rather than seek disability benefits, Matt retrained himself as a certified jeweler and went back to work. However, his job offered no health insurance and, unable to get coverage on his own because of his pre-existing condition and unable to afford the premiums for the state high-risk pool, Matt remained uninsured until 2002. For more than 20 years, Matt paid for all of his health care himself but, unable to keep up with the medical bills, he often delayed needed care. In 2002, Matt was encouraged to apply for Kansas' Working Healthy program, which provides people with disabilities the opportunity to get Medicaid while they are working. Matt pays a premium to get Medicaid – about \$70 a month at his current income level.

"I've shown my employers the work I can do and what I'm capable of as my health has been able to be maintained...By putting money back into the system and being a contributor, it made me feel useful."

Having Medicaid has made a huge difference in Matt's life. Since gaining coverage, he has addressed long-neglected health problems such as frequent bladder infections. He has also gotten the preventive care and check-ups he should, as well as specialist care and improvements in his wheelchair, and he has treated a depression that he now looks back on. "I really got my health back and I have a positive outlook on my life," Matt reports. Equally important to the quality of his life, Medicaid covers help from a personal attendant with bathing, transferring, cooking, dressing, and other everyday tasks that it took Matt extraordinary time and effort to do by himself.

Today, while continuing to work as a jeweler, Matt has gone back to school, where he is earning a Bachelor's degree in organizational leadership.

Medicaid helps individuals with disabilities remain on the job by permitting them to "buy-in" to the program. Working Healthy, the Kansas program that permitted Matt to "buy in" to Medicaid by paying a premium, resolves a key dilemma for many working-age adults with disabilities who wish to work, but who need health coverage, cannot afford private insurance, and worry that their earnings will jeopardize their eligibility for Medicaid. To support employment for adults with disabilities like Matt, most states have implemented "buy-in" programs similar to Working Healthy, which allow individuals to have earnings but still keep Medicaid by paying a premium based on their income. According to a study by Mathematica Policy Research, as of December 2008, 42 states were operating a Medicaid buy-in program, providing health coverage to over 90,000 individuals nationwide.



Sarah

New Port Richie, Florida

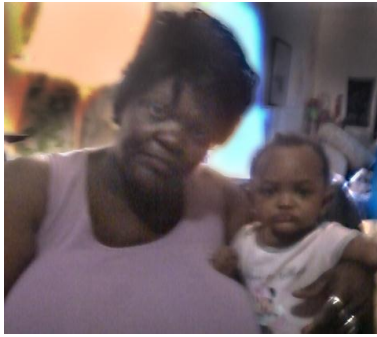
Sarah Borscha, age 6, was born with Apert syndrome, a rare genetic disorder. In individuals with Apert, the bones of the skull and face fuse too early during fetal development, disrupting normal bone growth and causing malformation of the face. Also, fusion or severe webbing of the fingers reduces flexibility and function. Sarah's mother has Apert, too, and her father, who works at the local supermarket, is legally blind.

Sarah has been enrolled in Medicaid since birth, sparing her family the enormous medical costs associated with her extensive needs for care. Medicaid has covered Sarah's many surgeries, beginning with an operation on her skull when she was ten months old to make room for her brain to grow, and followed by numerous operations to separate her fingers. Medicaid also covers special shoes for Sarah and braces for her feet, as well as her prescriptions. Speech and physical therapy several times a week, paid for by the program, are helping Sarah catch up developmentally; while she is currently in a special education class, her parents and school expect she will be mainstreamed by third grade. In the future, as she grows, Sarah will likely need facial surgery, as well as surgery to correct problems with her mouth, jaw and teeth that stem from her condition. Sarah's father expressed what Medicaid's help has meant: "Oh my God, I don't know where we would be without Medicaid."

"We would've been buried in medical bills if it wasn't for Medicaid. Medicaid is pretty much a daily part of our lives."

– Sarah's father, Robert

Medicaid's Early, Periodic, Screening, Diagnosis, and Treatment (EPSDT) benefit for children covers many services needed by children with disabilities. Because of Sarah's genetic condition, she has needed extensive health care services since she was born. She received Medicaid immediately, and she continues to get comprehensive coverage through Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit. EPSDT, the Medicaid benefit package for children up to age 21, covers many services and treatments not typically covered by private insurance. Under EPSDT requirements, states must provide children with all medically necessary services allowed under Medicaid law, even if the state does not cover some of these services for adults in Medicaid. One in seven children has special health needs that may require more intensive use of acute care services, as well as services such as physical, occupational, and speech therapy, and durable medical equipment. In addition to these services and supports, Medicaid covers non-emergency transportation, interpretation services, case management, and other assistance that helps low-income children secure access to needed care.



Michelle

Silver Spring, Maryland

Michelle Foster, age 42, gave birth to her daughter, Anthwonnia, about four months ago. Michelle was covered by Medicaid from the beginning of her pregnancy. Especially because she was caring for her ill father at the time and would have been unable to afford her prenatal care on her own, Michelle was relieved to have Medicaid. That coverage became even more important when Michelle developed gestational diabetes at 26 weeks and needed specialist care in addition to routine prenatal care. Anthwonnia was born prematurely and weighed only a little over four pounds when she arrived, but she is thriving now. “You would never think she was premature,” according to Michelle.

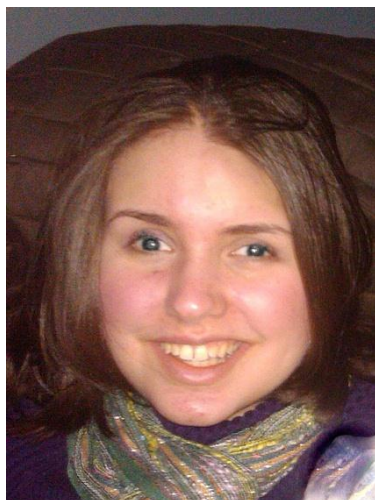
Michelle continues to benefit from Medicaid’s coverage, and because she was on Medicaid at the time she delivered, Anthwonnia is automatically covered by Medicaid, too, for her first year. (After that, she must renew her coverage.) That automatic year of coverage helps ensure that Anthwonnia can get the care that all newborns need to assure their healthy growth and development. With Medicaid, Anthwonnia is right on schedule with her well-baby visits to the pediatrician and her immunizations.

Medicaid is also there to cover Anthwonnia when she gets sick, so when she came down with a cold in her first few months, Michelle was able to take her to the pediatrician without worrying about how she would pay for the visit.

*“She came out premature but now she weighs 11 pounds at three months old!”
(On her daughter, Anthwonnia)*

Michelle is back in good health, as her gestational diabetes ended when she gave birth. However, she had a bad car accident not long ago and she needs dental care. Unfortunately, in Maryland, Medicaid’s coverage of dental services for adults is limited to tooth extractions. This means that, instead of having her top teeth repaired, she may have to have them pulled instead and wear dentures. Except for this disappointment, Michelle she considers Medicaid “very important and very beneficial.”

Medicaid covers prenatal care, which is essential to both maternal and infant health. Medicaid covered important prenatal care services for Michelle throughout her pregnancy, as well as the delivery of Anthwonnia, and Medicaid now covers Anthwonnia herself. Together, Medicaid and the Children’s Health Insurance Program (CHIP) insure one-third of children overall and more than half of low-income children, providing them access to needed care, including recommended preventive care and well-child visits, and vision, hearing, and dental care. Medicaid’s comprehensive coverage, with no deductibles and tight restrictions on cost-sharing, minimizes financial barriers to access for children and many parents in low-income families.



Tina

Rockaway, New Jersey

Tina Witowsky, age 20, suffered a ruptured arteriovenous malformation (AVM) of the brain, similar to a massive stroke, at age 16½, the result of a congenital defect. In the months immediately following, Tina was in critical care treatment. She underwent multiple surgeries, followed by intensive rehabilitation and further surgeries. Doctors had to remove the rupture, and remove and reconstruct her skull; for much of the ordeal, Tina was on a respirator and a feeding tube. Once stabilized enough to leave the hospital, Tina moved to a rehabilitation center, but still with breathing and feeding tubes. After about ten months, she was finally able to come home.

Initially, Tina was covered only by health insurance through her mother's employer, but for the last two years, Tina has also had Medicaid. Medicaid became especially important when Tina came off the feeding tube, because her private insurance would no longer cover her nursing and in-home supports. Without Medicaid, Tina's mother would have had to move Tina into a nursing home, or instead, leave her job to care for Tina full-time, sell her house, and find a job working nights. Because Medicaid covers key services Tina needs, she can remain at home and in her community and school, and her mother can continue to work.

"Without Medicaid services, Tina would not have the opportunity to live at home, choose her life, become and remain independent."
– Tina's mother, Mercedes

Through a special Medicaid option in New Jersey, Tina and her mother "self-direct" Tina's care, screening and hiring Tina's caregivers themselves, within a fixed budget. Tina receives physical therapy at both school and home to help her learn to walk again. She also receives cognitive therapy and occupational therapy to help her with daily activities, like using the bathroom, that maximize her independence. Medicaid also helps to pay for Tina's medications and her visits with the neurologist, seizure specialist, and other doctors who remain involved in her care.

Tina was an avid singer before her stroke, and she now volunteers to sing for seniors in nursing and assisted living facilities. Tina, her mother says, "gets just as much enjoyment out of that as they get out of her performing."

Medicaid covers "self-directed care," which allows individuals who need long-term services and supports a greater measure of control over their care. Tina is able to live at home rather than in a nursing home because Medicaid also covers services and supports that individuals with long-term needs require to live independently in the community. Tina utilizes Medicaid's "self-directed care" option, also called consumer direction, which gives her a fixed budget and allows her a large degree of control over hiring, scheduling, training, and paying for her personal care. In 2009, 37 states included consumer direction in their home and community-based services programs.



Edward

Brunswick, Georgia

Edward Henry, age 64, lives independently now after spending three years in various nursing homes across his home state of Georgia. He first entered a nursing home following the amputation of both his legs due to an infection. Edward describes the care he received in the nursing homes as “alright,” but his goal was always to leave and live again on his own.

Because of his limited savings and his disability, Edward became dually eligible for both Medicare and Medicaid soon after he first entered a nursing home. Through a social worker in the nursing home, Edward found out about a Medicaid initiative known as the Money Follows the Person (MFP) demonstration, which is what made Edward’s transition to independent living possible.

“I really wanted to leave the nursing home but was told there were no funds to help me. Then a social worker came and told me about MFP.”

Edward found out about MFP through a social worker in the nursing home. MFP helped coordinate Edward’s transition, helping him find an affordable, senior-living apartment complex, setting him up with household furnishings, and connecting him to a network of providers in the community. Overall, Edward is in good health, though he takes medicine for his heart. With Medicaid’s help, he receives homemaker and meal services a few hours each day, and Medicaid also pays for Edward’s power wheelchair, which enables him to grocery-shop and get around town. He does daily exercises to keep his upper body strong, making him capable of transferring independently. Edward says the best part about being home on his own is something quite simple – the freedom to choose what and when he wants to eat. Edward is enjoying his new independence and spends his time going to church and attending bible study.

Medicaid’s “Money Follows the Person” program helps individuals transition from institutional settings to independent living at home. The Money Follows the Person (MFP) demonstration grant program was enacted into law in 2006, giving states additional options to transition Medicaid beneficiaries living in institutions, like Edward was, back to the community. Georgia, along with 28 other states and the District of Columbia, currently participates in this demonstration program. As of July 2010, nearly 9,000 Medicaid beneficiaries had been transitioned back to the community under MFP, and another 4,000 transitions are in progress. States use MFP funds for a wide range of services, including expanded case management to coordinate transitions, help with home modifications and one-time housing expenses such as security deposits or household furnishings, use of assistive technology, transportation, and expanded access to durable medical equipment, such as wheelchairs.



Claire

Washington, DC

Claire Nightingale Smith, almost 5 years old, was born with a genetic syndrome that is the only known case of its kind.

It took doctors a long time to identify her disorder, but Claire had symptoms at birth that indicated multiple, severe physical, developmental, and intellectual disabilities. Over time, the scope and seriousness of these disabilities have become more apparent. Today, Claire is only as big as an 18- to 24-month-old child and, developmentally and intellectually, she is about 9 months old. She is semi-mobile with a wheelchair, but cannot direct where she wants to go or walk independently. She does not understand language and cannot communicate, and she may be losing her hearing. Because Claire can pull herself up and also grab and bite, there are new concerns for her safety and that of her older brother and younger sister, both healthy.

Although Claire's family has private health insurance, Claire's father describes dealing with their insurer as a bureaucratic nightmare, entailing constant, exhausting fights about the medical necessity of Claire's care, which has ranged from genetic testing to a wheelchair, and from specialist visits to a personal care attendant. In Claire's father's words, these insurance struggles amounted to a "part-time job" that consumed two to four hours of her parents' time each week and placed great stress on them.

"Just to deal with a system that is not designed to make money, but a system that appears to be designed to make sure that my daughter gets the care that she needs, is fantastic."

– Claire's father, Dan

About a year ago, Claire's parents learned that Claire could qualify for D.C. Medicaid's "Katie Beckett" program. This program enables families like the Smiths, whose child with disabilities would be eligible for institutional services under Medicaid, to have their child receive the care she needs at home instead. Claire is the only member of her family covered by Medicaid. Medicaid has changed Claire's family's life immensely, her dad reports. With Medicaid, he and his wife no longer face red tape when Claire needs care. Further, because Medicaid pays the bills for her care promptly, the family no longer receives letters from providers threatening to place their account in collections. Finally, in addition to covering the out-of-pocket costs of Claire's care, which mount up quickly, Medicaid covers important services and supports that their private policy will not cover at all, like the wheelchair and a walker to help Claire walk independently, as well as occasional respite care, which gives Claire's parents a few free hours to deal with household chores or to spend needed quality time with Claire's siblings.

Medicaid enables families of children with severe disabilities to care for their children at home.

Although Claire is covered by private insurance through her father's workplace, that coverage does not meet her exceptional needs. Medicaid supplements it in crucial ways, covering care that the policy limits or excludes, as well as copayments that mount up quickly. Claire is not alone in having Medicaid as a supplement to private insurance – an Urban Institute analysis found that over 1 million privately insured children have Medicaid as wrap-around coverage. The "Katie Beckett" option in Medicaid allows Claire's family to care for her at home rather than in an institutional setting, without facing the prohibitive costs of the many services she needs. A report by the Government Accountability Office in 2003 indicated that 22 states had taken up the Katie Beckett option to support in-home services and supports for children with severe disabilities.



Brenda

Murray, Utah

Brenda Christiansen, age 52, a hospice nurse and the mother of 11-year-old Vanessa, was diagnosed with breast cancer in May 2010. At the time she first noticed a worrisome lump under her arm, Brenda had recently started a new nursing job, but she was uninsured, still in the three-month waiting period for the health insurance offered by her employer. She was within days of getting this coverage when she was laid off.

Through Medicaid's Breast and Cervical Cancer Prevention and Treatment Program, Brenda is eligible for full Medicaid benefits, and she has needed many of them. Medicaid has covered a hospital stay and mastectomy, chemotherapy, her prescription medicines, expensive imaging and lab services, and visits to her oncologist and other cancer specialists. Brenda also needs other specialist care, which Medicaid has covered as well. The one major gap that Brenda has noticed in Medicaid is in dental care. Utah's Medicaid program does not cover dental care for adults, and although seeing a dentist is very important for chemotherapy patients, Brenda has been unable to afford this care out-of-pocket.

"It was just the thought that I did not have to worry about paying the medical bills. That would have been such a huge worry on my mind."

On her very low income – she receives unemployment benefits, and her church and family have helped with house payments, food, and utilities – Brenda says that, without Medicaid, she would probably have had to sell her house and move in with her mother, or declare bankruptcy. She estimates that her chemotherapy alone cost \$25,000 and that the total cost of her cancer care probably reached close to \$100,000. With Medicaid, she has had to pay a small amount for her prescriptions, but she was protected from devastating medical debt.

Brenda has come through her cancer ordeal well and is already actively interviewing for jobs. She is optimistic and determined that she will soon be working full-time again at a job with health insurance.

Medicaid covers costly cancer treatment for millions of women. Brenda was eligible for Medicaid because of the Breast and Cervical Cancer Prevention and Treatment Act of 2000. This law gave states the option to provide Medicaid coverage to women who were screened through the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and found to have breast or cervical cancer, including pre-cancerous conditions. All 50 states and the District of Columbia have adopted this Medicaid option. In addition, 22 states have elected the "presumptive eligibility" option, which allows states to enroll women in Medicaid for a limited time period while their full Medicaid applications are filed and processed, affording them immediate access to treatment.



Karen

Toledo, Ohio

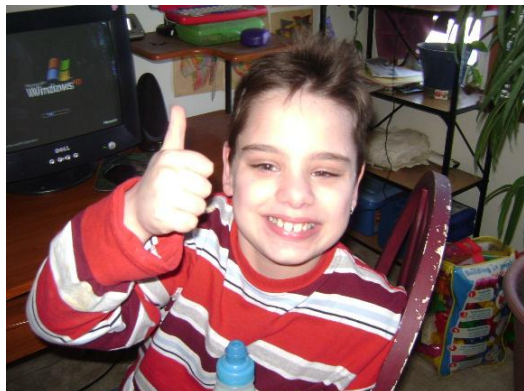
Karen Palacios, age 42, suffers from multiple chronic conditions, including diabetes, a thyroid condition, effects of a stroke, and depression. Karen has been dually eligible for Medicare and Medicaid since 1994 due to her disability and low-income. For seven years, she lived in a nursing home because she could no longer perform basic everyday activities with her hands, such as lifting pots and pans. However, after being accepted into Medicaid's "Money Follows the Person" program, Karen was able to make the transition back to living independently in the community.

Karen's transition took six months. During that time, she attended occupational therapy to help her gain the skills to live alone, but what took the longest was arranging housing. A transition coordinator helped her locate an apartment, set up bills, and furnish the apartment with the \$2,000 budgeted by Medicaid for community transition services.

"I'm highly satisfied with Medicaid and Home Choice; they are there if I need anything."

Living on her own since August 2010, Karen finds the privacy and quiet to be the best parts of being home. She hopes to get more involved in community activities, but managing her chronic conditions remains a daily struggle. Karen takes a wide range of prescription drugs and relies on a walker, a wheelchair, and the services of a personal care aide who comes for four hours a day and a nurse who comes once a week. She also receives counseling services and case management, and she uses medical transportation for doctor appointments. Karen appreciates the support of the Medicaid program, which has enabled her to live independently in her community and filled important gaps in her Medicare benefits.

Medicaid assists low-income Medicare beneficiaries with their Medicare premiums and cost-sharing and fills gaps in Medicare benefits. Nearly 9 million low-income Americans known as "dual eligibles" qualify for both Medicare and Medicaid. Medicaid plays a key role for dual eligibles, covering their Medicare premium and cost-sharing and filling major gaps in Medicare benefits, especially for long-term care, but also for items like eyeglasses and hearing aids, needed by many in the Medicare population. About six in ten dual eligibles are age 65 or older, while the others are younger persons with disabilities, like Karen. Dual eligibles account for just 15% of Medicaid enrollees but almost 40% of Medicaid spending, a reflection of their extensive needs for acute health care and long-term services and supports. Dual eligibles must navigate both Medicare and Medicaid to access the care they need. The health reform law establishes a new federal office focused on improving the coordination of care for dual eligibles.



Darius

Lincoln, Nebraska

Darius, who celebrated his 9th birthday last November, has periventricular leukomalacia or PVL, a brain injury associated with his premature birth at just 26 weeks. Darius suffers from frequent seizures because of the PLV, and he can stop breathing as many as six times a night because the part of his brain that controls breathing doesn't always work properly – a condition called central apnea. He also has mild cerebral palsy (CP) on the right side of his body, which impairs his mobility, balance, and reflexes.

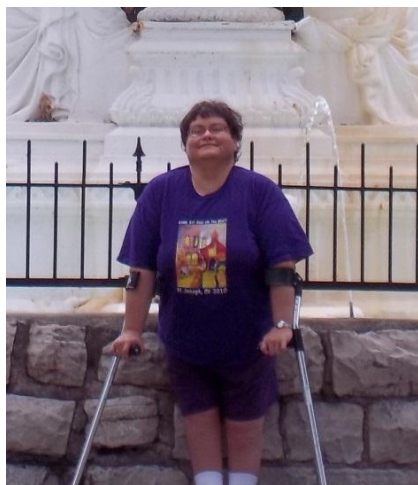
Since the moment Darius was born, Medicaid has covered an extensive array of care for him, including specialist care from neurologists, a gastroenterologist, and an endocrinologist; seizure medication; medical equipment, including an apnea monitor, oxygen regulator, tank, oximeter, and wheelchair; specialized dental care; nursing care; regular physical and speech therapy; and visits to the emergency room necessitated by his seizures and apnea episodes. These services have saved Darius' life and significantly mitigated the neurological and developmental problems that often come with PVL. Today, Darius is excelling in school, an achievement his mother, Stephanie, credits to Medicaid's coverage of crucial early intervention services, including speech, occupational, and physical therapy, that he received "from day one." While social interaction with other children remains difficult, with the services and supports Darius receives, he is able to participate in many normal childhood activities, including basketball.

"He is on that machine every time he has a seizure...Without [Medicaid] paying for the medication and the machines, my son would not make it 12 hours."

– Darius' mother, Stephanie

Stephanie and her husband sometimes have to fight hard for all the Medicaid services Darius needs, but Stephanie describes the program as a life-saver for her son and family.

Medicaid covers school-based services for children with special needs. Darius is able to receive health services at school because of a provision in the Medicare Catastrophic Coverage Act of 1988. Before that law was enacted, Medicaid funding for school-based services was limited to routine screenings and treatment of acute, uncomplicated problems. Since 1988, Medicaid pays for school-based medical services provided to Medicaid-eligible children with special health care needs. In order for Medicaid to pay for a child's school-based care, the child must have an Individualized Education Plan (IEP) in accordance with the Individuals with Disabilities Education Act. These services provided at school enable Darius and other children with special needs to go to school with their peers, while ensuring that they get the care they need.



Heather

St. Joseph, Michigan

Heather Holloway, age 39, was born with a rare congenital disorder that left her with permanently dislocated hips and knees. Heather is eligible for Medicaid because of this disability, and she relies on the program to cover her health care needs, which are modest but critical. She needs regular check-ups and preventive care, new crutches every three or four years, and dental care. When she needed glasses last year, Heather had to purchase them on her own, as Michigan cut adult vision benefits from Medicaid recently. They cost over \$200, and she was only able to afford them because she had received money from a relative for Christmas. Home health services covered by Medicaid help Heather with everyday activities like grocery-shopping that she has trouble doing on her own, enabling her to live independently.

"I need to be able to walk. I need to be able to live. I need Medicaid so I can at least have a reasonably decent livable life."

Over a period of several years, Heather suffered severe and debilitating depressions and mood swings. Finally, on the urging of a friend, she sought help from her primary care provider, who diagnosed her condition. With anti-depressant medication and other mental health services, also covered by Medicaid, Heather reports that she feels back in control of her life. Although she is unemployed currently, Heather is active in her community, volunteering at the Volunteer Center once a week and chairing an interagency council for services. She is hoping for an opportunity soon to provide peer support in a mental health facility nearby.

Medicaid provides access to mental health treatments and medications. One of the important kinds of help that Heather gets from Medicaid is coverage of the prescription drugs she takes to treat her depression. Staying in good mental health enables Heather to be productive and stay engaged with her friends and community. Medicaid is the largest single source of financing for mental health care in the nation, covering over a quarter of all spending. Medicaid plays such a large role because it covers many people with significant needs and it pays for a broad range of services. About one in 20 Medicaid beneficiaries have a mental illness severe enough for them to receive Supplemental Security Income (SSI), a federal cash assistance program for low-income aged, blind, and disabled individuals that triggers automatic eligibility for Medicaid in most states. However, about two-thirds of Medicaid beneficiaries who use mental health services qualify for Medicaid on some other basis.



Sheila

Waterville, Maine

Sheila Malone, a 66-year-old former surgical nurse, suffers from a multitude of health problems stemming from her exposure to DES, a drug her mother took while pregnant with Sheila to reduce her risk of miscarriage. DES has been linked with certain cancers and other anomalies in girls and young women who were exposed to the drug *in utero*.

Sheila's health issues began early. At age 8, she had colon cancer and her first of many cancer surgeries. During puberty, she developed bone deformities, including leg bones that were abnormally short and heavy, and she had polio as well. She says that, still today, "nothing matches." Sheila has also had multiple skin cancers, breast, cervical and ovarian cancer, and a second bout with colon cancer, and she is diabetic. After her last cancer surgery eight years ago, her doctors did not think she would be able to eat solid food again or live long. She surprised them.

"I need to be independent...I couldn't even afford the wheelchair, my copay, if I didn't have the Medicaid. These things actually keep me independent, these programs."

Sheila has Medicare but she also qualifies for assistance from Medicaid due to her low income of about \$1,200 a month. Although she is not eligible for the extra services that Medicaid covers, like eyeglasses and the surgical support stockings she needs, Medicaid's "Medicare Savings Program" covers her monthly Medicare Part B premium of \$115.40 per month, her Medicare deductibles, and the 20% coinsurance charged for most services she receives. Sheila receives other assistance, too. The federal Low-Income Subsidy program pays her premium and deductible for the Medicare Part D prescription drug program and protects her from the Part D "donut-hole." Maine's Drugs for the Elderly or Disabled program reduces the copays for her ten or so prescriptions to a few dollars each.

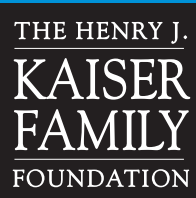
Sheila estimates that without the assistance she receives for her medical costs, her drugs alone would cost her \$300 per month. Plus, she would face 20% cost-sharing for her doctor visits and scans, which she must have regularly. The cost-sharing on her wheelchair, which is replaced every five years, would cost her more than she makes in a month. Sheila says she does not know what she would do without Medicaid and the other help she receives.

Medicaid's "Medicare Savings Program" helps low-income individuals with their Medicare premiums and out-of-pocket costs. Sheila is one of more than 2.1 million Medicare beneficiaries who receive assistance with their Medicare premiums and cost-sharing through Medicaid's "Medicare Savings Program." Medicare premiums and out-of-pocket costs can be difficult to afford for beneficiaries with low income. The monthly Part B premium alone is \$115.40, and beneficiaries must pay 20% coinsurance when they receive services, and a \$1,132 deductible for each hospitalization. In 2006, one in four Medicare beneficiaries spent 30% or more of their income on health care, and one in ten spent more than half their income on health care. Through the Medicare Savings Program, Medicaid helps Medicare beneficiaries like Sheila who have annual income below the poverty line (\$10,890 for an individual) and limited assets.

Medicaid and the Uninsured: Key State Data

State	Total Population	Medicaid enrollees		Uninsured		Adults gaining Medicaid by 2019
		Number	Percent	Number	Percent	
United States	303,343,300	59,468,700	20%	50,674,300	17%	15,904,200
Alabama	4,686,900	908,100	19%	674,900	14%	351,600
Alaska	666,900	117,800	17%	128,000	19%	42,800
Arizona	6,511,200	1,538,900	24%	1,273,300	20%	105,400
Arkansas	2,831,900	701,700	24%	526,400	19%	200,700
California	36,641,700	10,659,800	29%	7,083,700	19%	2,008,800
Colorado	4,917,600	558,900	11%	771,200	16%	245,700
Connecticut	3,453,300	552,100	16%	380,400	11%	114,100
Delaware	868,600	192,400	22%	105,900	12%	12,100
District of Columbia	593,000	165,500	28%	66,500	11%	28,900
Florida	18,170,900	3,021,300	16%	3,868,400	21%	951,600
Georgia	9,549,500	1,677,200	17%	1,843,900	19%	646,600
Hawaii	1,225,900	216,600	17%	100,300	8%	84,100
Idaho	1,518,700	210,300	14%	234,100	15%	85,900
Illinois	12,708,600	2,428,900	19%	1,764,600	14%	631,000
Indiana	6,321,100	1,081,900	17%	837,200	13%	297,700
Iowa	2,990,300	482,600	16%	312,600	10%	114,700
Kansas	2,717,500	354,400	13%	347,400	13%	143,400
Kentucky	4,262,400	849,500	20%	688,000	16%	329,000
Louisiana	4,384,400	1,097,700	25%	790,000	18%	366,300
Maine	1,305,300	350,100	27%	134,700	10%	43,500
Maryland	5,586,800	777,800	14%	730,700	13%	246,000
Massachusetts	6,514,900	1,521,800	23%	323,500	5%	29,900
Michigan	9,809,700	1,966,600	20%	1,250,600	13%	590,000
Minnesota	5,157,000	807,100	15%	450,000	9%	251,800
Mississippi	2,867,200	736,600	25%	510,300	18%	320,700
Missouri	5,909,200	1,022,900	17%	826,600	14%	307,900
Montana	970,900	109,500	11%	153,500	16%	57,400
Nebraska	1,772,400	242,100	14%	208,300	12%	83,900
Nevada	2,601,000	259,500	10%	516,600	20%	136,600
New Hampshire	1,305,000	147,500	11%	135,400	10%	55,900
New Jersey	8,591,200	975,700	11%	1,286,300	15%	390,500
New Mexico	1,967,900	511,600	26%	449,000	23%	145,000
New York	19,247,700	4,936,400	25%	2,778,900	14%	305,900
North Carolina	9,230,400	1,705,000	18%	1,553,000	17%	344,100
North Dakota	626,200	71,200	11%	70,800	11%	28,900
Ohio	11,413,200	2,076,400	18%	1,475,900	13%	667,400
Oklahoma	3,576,200	745,700	20%	578,500	16%	357,200
Oregon	3,821,800	519,800	14%	649,400	17%	294,600
Pennsylvania	12,286,700	2,197,600	17%	1,310,000	11%	482,400
Rhode Island	1,036,400	194,600	18%	124,900	12%	41,200
South Carolina	4,482,700	858,600	19%	736,800	16%	344,100
South Dakota	795,300	123,700	15%	103,800	13%	31,300
Tennessee	6,171,200	1,485,300	24%	947,200	15%	330,900
Texas	24,366,200	4,276,600	18%	6,258,700	26%	1,798,300
Utah	2,770,700	294,600	11%	389,400	14%	138,900
Vermont	613,900	167,500	27%	59,000	10%	4,500
Virginia	7,669,700	885,100	11%	987,900	13%	372,500
Washington	6,574,400	1,179,600	18%	838,600	13%	295,700
West Virginia	1,798,000	401,300	22%	261,800	15%	121,600
Wisconsin	5,551,800	1,027,600	18%	531,100	10%	206,000
Wyoming	532,300	77,400	15%	78,700	15%	29,900

Sources: Population data (total and uninsured): KCMU/Urban estimates based on March CPS, 2009 and 2010. Medicaid enrollment: KCMU/Urban estimates based on FY2008 MSIS and population data estimates for July 1, 2008. Adults gaining Medicaid: "Medicaid Coverage and Spending in Health Reform: National and State-by-State Results for Adults at or Below 133% FPL," KFF, May 2010.



THE HENRY J. KAISER FAMILY FOUNDATION

Headquarters

2400 Sand Hill Road

Menlo Park, CA 94025

Phone 650-854-9400 Fax 650-854-4800

Washington Offices and

Barbara Jordan Conference Center

1330 G Street, NW

Washington, DC 20005

Phone 202-347-5270 Fax 202-347-5274

www.kff.org

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