We All Have a Story:
Medicaid in Missouri

Missouri Health Care for All
Summer 2020
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Dear Reader,

My name is Britt and I am Missouri Health Care for All’s Story Bank Organizer. Missouri Health Care for All is the only permanent, statewide organization in Missouri focused solely on grassroots mobilization on health care issues. We provide individual and organizational supporters with meaningful, effective ways to take action. As part of this work, we speak with Missourians across the state and help them tell their health care stories. We believe stories are essential for health care advocacy as the lived experiences of Missourians guide our grassroots organizing and shapes the policy work we do. As the organization’s statewide Story Bank Organizer, it brings me great joy to speak with people across our state and to now share these stories with you.

This collection of stories highlights the critical need for Medicaid in Missouri. Here you will find stories of people benefiting from the existing program and those that are in need of expanded care in our state. All stories are true in the time that they were written and each story teller has agreed to share their story with us and you as part of our mission to expand health care to all Missourians.

In solidarity,

Britt Zuniga

Do you have a story to tell? Click here to tell us!
Sandy has been a personal dog trainer for over 20 years and recently decided to go into business for herself after being let go from a company in February 2019. While she was excited for her new business venture, working for herself meant she no longer had health insurance. Sandy did what she could to find an affordable plan but was quoted $900/month for private insurance, far more than she could afford while building her business. She applied for Medicaid, but as a single adult whose children are grown, she was denied. This left Sandy in the Coverage Gap as she pursued her business venture as a dog trainer.

Recently, Sandy broke her arm at a client’s home while dog-sitting. She is currently unable to work and relies on her daughter to help her bathe and get dressed. She wakes up every night in excruciating pain and reaches out to friends in the medical field for advice on how best to care for herself.

Sandy states that if she had Medicaid she would have much better treatment plans from doctors and would receive the medication she needs more easily. As it stands, she is worried that her bone will not heal properly and even if it does heal, she knows she will need physical therapy which she currently cannot afford. Sandy wants people to know that she wants to work. As she states, “I love my job. I love to work. I love training dogs but without health insurance, I have no idea how I will be able to get back to work. Without a healed arm, I can’t do anything.”

Missouri has one of the lowest Medicaid eligibility levels in the country for adults – just $3,612 a year for a family of three. Adults without custodial children or a total and permanent disability cannot qualify at all.
Van is a 56 year old resident of Sparta, Missouri. He and his wife Renda have a variety of illnesses that they try to manage despite their limited access to care. The couple applied for Medicaid a few years ago but their application was denied because they owned a home. Van qualified for SSI disability seven years ago and relies on this for the oxygen he uses full time, as well as their bills and groceries. Van states, “we are so lucky to have this disability check, our illnesses keep us from working and it’s the only way we survive but we are barely getting by.”

Renda suffers from restless leg syndrome, thyroid problems, high blood pressure, and neuropathy in her feet. She has also had two essential surgeries. While Van navigates his health concerns in a well-respected hospital, Renda is less fortunate. She is currently uninsured and struggles to find affordable care for her health conditions.

The couple wants people to know how hard it is for older adults to access care in Missouri. As Van states, “there really aren’t healthcare options for people without disabilities and before the age of 65. Older adults have a lot more possibility for health problems and that begins much earlier than 65. If you develop an illness around the age of 45 and you can’t get on Medicare until 65, you’ve been sick for twenty years by that point. That’s not right, it really feels like older people have been forgotten.”

Van and Renda have since moved from their home into an apartment. They have reapplied for Medicaid and are hopeful that their new financial situation will increase the chances of them getting approved this time around. As Van states, “getting Medicaid would change everything for us. My wife could get the care she needs to keep herself healthy instead of waiting til she was sick. We could have more money to live off of, it really would change our lives.”

37 states and the District of Columbia have expanded Medicaid to provide health insurance to people like Van and Renda.
Benefits of Medicaid Expansion

The Medicaid program, called MO HealthNet in Missouri, is a jointly funded health insurance program for low-income people, funded by both federal and state money. This partnership controls costs for Missouri’s budget as well as for Missourians.

Medicaid provides access to critical health care services, and does it less expensively than private insurers do, spending less per enrollee than private insurers for both children and adults. Furthermore, more than 3/4 of Missouri’s Medicaid program is financed through federal funds or provider taxes.

Medicaid Expansion would provide health care to more than 230,000 Missourians who are currently uninsured, ensuring that hardworking families do not have to choose between paying for life-saving health care and putting food on the table. Missouri families have needed this relief for years. The COVID-19 pandemic has made two things even more clear: It is crucial that everyone have health care, and Missouri must have a safety net for people who lose their jobs in an economic downturn.

Medicaid Expansion is a good deal for the State of Missouri: The federal government will cover 90% of the costs. In fact, Missouri will actually save money in its budget, because that 10% will be more than offset by savings in other current programs. For example, Missouri currently pays 100% of the cost of Medicaid for people who are blind or have low vision; under Expansion, the state’s share would shrink from 100% to 10%. Because of savings like this, Washington University researchers found that Medicaid Expansion could save the state as much as $1 billion per year.
Nichelle
Kansas City, MO

Nichelle lives with her husband and three children in the Kansas City area, where she works for a heating and cooling service provider. Although she and her husband have health care coverage through her job, she cannot afford to add her three children to their plan, so their children have been covered through Medicaid for several years. When Nichelle went to make a doctor’s appointment for one of her kids, she was told her kids were kicked off of Medicaid in November 2018.

Nichelle couldn’t get a direct answer as to why, but after contacting the Department of Social Services (DSS), she was told she failed to send back a form they had mailed her. Nichelle knew she had filled out and returned every form DSS sent her regarding her children’s Medicaid coverage. As it turns out, DSS sent their forms to an address they haven’t lived at for five years – a home she moved away from long before she had ever applied for Medicaid.

“They gave excuse after excuse as for why they dropped my kids, but they couldn’t give me a legitimate reason,” she said. “How is it that when I applied for Medicaid, I applied with my current address, but they were sending all of these forms to an old address?” Despite re-applying for Medicaid online every single month since discovering they lost coverage, Nichelle and her husband are consistently told there are no records of their applications and are told that they need to re-apply.

Nichelle’s family lives paycheck to paycheck and losing health care coverage for her kids has caused a lot of undue stress. Her kids are 2, 3 and 5, and because of their loss of coverage, they are all three behind on their vaccinations. Her oldest starts kindergarten in the fall, and she doesn’t know what will happen if he’s unable to get his vaccinations updated by then. Nichelle’s 3-year-old suffers from mild hemophilia, and she is constantly concerned that if she gets hurt, a hospital visit will put them in a financial crisis. As she states, “I’m just trying to survive right now. I wish that I didn’t need Medicaid, but I can’t afford health care for my kids without it.”
Autumn
Springfield, MO

Autumn is a Springfield resident with a seven year old daughter who was dropped from Medicaid unexpectedly. Her daughter suffers from severe migraines which require frequent visits to doctors' offices. Autumn has taken her daughter to an allergist, a cardiologist, and a neurologist and they have still not discovered the root of her migraines. The stress of her daughter’s ailment was significantly alleviated by Medicaid until her daughter was suddenly dropped from the program. When Autumn inquired, she was told that she had not turned in her Medicaid renewal paperwork in time, which she knew to be false information. After two weeks of fighting, Autumn was able to re-enroll her daughter on Medicaid.

While relieved that her daughter is now covered again, she herself remains uninsured. Autumn was previously on Medicaid but was kicked off for making too much money from her part time job - $8,000 a year. She applied for Marketplace insurance but her income is too low to qualify for discounts, and the full cost would have been $600 per month - nearly her entire income. Autumn has been uninsured for about three years now and has a list of treatments and care she would love to receive if only she had access. If she had care, Autumn would seek out birth control options for herself, maintain regular visits for her dental and vision care, and check on her heart health as her family has a genetic condition she is worried about.

Autumn is frustrated that legislators expect people in her situation to afford healthcare coverage costs on their own. As she states, “I’d love to see legislators live off what we make. If they had to live off of my income, I guarantee the laws would look different”. She continues, “There are all these random qualifications to get help. We just can’t do it. They’re punishing us even though we are trying. Rent alone takes all my money and I still have to eat and feed my kid. These policies restricting Medicaid and kicking people off are pushing us deeper into poverty.”
Medicaid Purge

In a 24 month period from 1/31/18 – 1/31/20, Missouri dropped 131,468 people – including 102,378 children – from its Medicaid program. Most people were never notified that their coverage had been terminated, and instead found out when they tried to go to the doctor or fill a prescription.

All evidence indicates that the vast majority of these people did not actually become ineligible, but were dropped in error through no fault of their own.

There are real, known, fixable causes for this "Medicaid Purge." For example, Missouri is violating Federal regulations, which requires the state’s Medicaid program to count data already submitted for SNAP (“food stamps”) for purposes of certifying Medicaid eligibility. Unfortunately, the Missouri officials with the power to address these problems have refused to do so, instead spinning a series of talking points justifying the coverage losses.

While the COVID-19 pandemic and associated economic downturn have caused Medicaid enrollment to grow, the underlying problems that led to the 2 year Medicaid purge have not been fixed. Missouri must fix its Medicaid reauthorization systems and processes to ensure that people who qualify don’t lose their coverage.

Job growth was not the reason for children losing their health coverage. "The states with especially sharp enrollment declines did not have especially sharp unemployment declines." (Center on Budget and Policy Priorities) Missouri followed this trend with a 13.1% decline in coverage and only a 0.3% decline in unemployment during the 24 month period before the pandemic began.
Since 2017, Brittany has relied on Medicaid to provide health care for her three children. She found out they were dropped from coverage when she attempted to enroll them in child care. Brittney was confused, as she knew she had submitted all the paperwork required.

Her youngest child, Karis, has disabilities and requires an oxygen tank to breathe. Sorting out what happened with her children’s Medicaid coverage was an urgent need. As she says, “I would never forget to do paperwork. These are my babies. I would never forget.” Brittney shares that she could not get through to anyone with the state on the phone and ended up having to take all three of her young children to the state office to find out the status of her Medicaid coverage. She was told she made too much money and her Medicaid and Food Stamps were taken from her. Brittney works part time as a home health nurse, and her income had not changed since she originally applied and received Medicaid. This response left her confused and frustrated.

Brittney had to make several trips to the state office in the winter months with her children, which led to Karis developing pneumonia. Karis continues to struggle to recover. A surgery was scheduled to test Karis’ lungs and make a plan for her improved breathing, but the hospital canceled it when she lost her Medicaid. Doctors have given Brittney no other suggestions for how to care for her daughter’s critical breathing problems.

As it stands, Brittney struggles to pay her bills and fears her utilities will be shut off soon. If this happens, her daughter’s oxygen tank will not be functional and Brittney does not know what she will do. Securing Medicaid for her three children would eliminate one heavy financial burden for Brittney’s family. For Brittney, securing Medicaid for her children, especially for her youngest, is a matter of life and death.
Rai
St. Louis, MO

When Rai became pregnant at age 19, she was on her mother’s insurance. Unfortunately, her mother did not have pregnancy coverage on her plan. Luckily, Rai had a connection with a nursing organization that helped Rai navigate the Medicaid system for herself and her child. Rai qualified for Medicaid and was impressed by the care she received throughout her pregnancy.

Rai states, “it was such a relief, I felt like I could be a happy pregnant person.” The trouble is that mothers are cut off from Medicaid shortly after giving birth. While they can apply for Medicaid as a parent, the eligibility levels are so low that many people who qualified for Medicaid for pregnancy do not qualify once the baby is born.

"Getting on Medicaid for pregnancy was fairly easy, but there was no coverage for me after I gave birth, which just doesn’t make sense. If I am not well, there is a good chance my child will not be well.” After giving birth, Rai endured months of postpartum depression, and received no medical care for this. Breast pumps and education on how to breastfeed were also not covered. While she is grateful for her relatively smooth experience with childbirth on Medicaid, Rai feels that this medical care should do more to support people that have just given birth.

Rai is in school and works part time. She is grateful for the coverage Medicaid offers for her child. Rai states, “I have considered dropping out of school to make more money for my daughter, but knowing that her medical needs are taken care of allows me to stay in school so I can pursue a career for myself. Of all the things I have to worry about, my daughter’s medical care is not one of them. I am grateful for that.”

Medicaid Eligibility is Much More Restrictive for Parents than Pregnant Women, Particularly in States that Have Not Expanded Medicaid
Louis
St. Louis, MO

Louis, a 47 year old St. Louis resident, knows first-hand the difficulty in navigating the health care system without insurance. While Louis usually works, sometimes multiple jobs at a time, his work does not provide insurance, leaving Louis unable to properly treat his type 1 diabetes and heart problems.

Rather than using both the short- and long-acting insulin that he needs, Louis is limited to an off-brand, short-acting insulin, and has even had to reuse needles. He is supposed to see a doctor every 3 months but is unable to afford these appointments.

The inability to do maintenance and preventative care has had major consequences. Louis has wound up in the emergency room several times, leaving him with hundreds of thousands of dollars in medical debt. He says, "It makes you feel bad, you know? I feel like I am sponging off the system but I have no choice. I’m just trying to survive." In addition to the overwhelming medical bills, Louis has lost at least three jobs due to his inability to maintain consistent health and is now unemployed.

Recently, Louis had to get an emergency aortic valve replacement in his heart, which cost him $25,000. He is applying for financial assistance but does not know what he will do if he is not approved. Louis states, “If I had been able to see the doctor regularly, I would be so much healthier. I almost died and ended up having open heart surgery that could have been avoided.” Now Louis is expected to see a doctor weekly for check-ups and is being prescribed medications, neither of which he can afford.

About Medicaid Expansion, Louis says, “It is a political thing. They didn’t do the right thing by not expanding. It makes me feel like Missouri doesn’t care about the people. Either they don’t see it or they don’t care, I don’t know which, but we need Medicaid expansion... My health is suffering because of politics. If it wasn’t for the charity of the hospital I got my emergency surgery from, I would be dead. Medicaid Expansion would improve the lives of so many people. I could be working right now."
Bridget
Springfield, MO

Bridget is a 39-year-old Springfield resident who is legally blind. She began receiving health care through Medicaid when she was 18, as well as receiving SSI (supplemental security income). Medicaid is critical to her health and well-being.

When Bridget married her husband Rob in 2007, their combined income put her on a spend-down (which required her to spend them into poverty in order to keep her coverage.) Bridget applied for a blind pension. She was initially denied due to her sight not meeting eligibility criteria. She appealed this decision in 2008 and won. In addition to the eye care she needs, Bridget also receives mental health care for depression and anxiety through Medicaid.

Although Medicaid provides critical health care for Bridget, she has experienced gaps in coverage due to problems with the state’s reauthorization systems. A few years after receiving her blind pension, her vision was reviewed again; once again she was denied, appealed, and won. “I’m afraid one of these years I’m going to get a state ophthalmologist who won’t even accept my appeal.”

Moving to her husband’s insurance through his employer is unaffordable for Bridget and Ron, making Medicaid Bridget’s only real option. Bridget worries about what would happen if she lost her coverage. “I see my eye doctor twice a year and a psychiatrist 4 times a year. We could end up in debt.” With Bridget’s next visual review in 2022, her coverage remains in the hands of a doctor who could deny her, as others have in the past.
References

Sandy
Missouri Budget Project (2016). The Health of Missouri is at Stake. https://www.mobudget.org/the-health-of-missouri-is-at-stake/

Van and Renda

Benefits of Medicaid Expansion


Nichelle; Medicaid Purge

Medicaid Purge


Rai

Healthy Mothers, Healthy Babies


Louis

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And finally, a thank you to each of our story tellers for their vulnerability and courage to share their experience. Thank you for sharing your expertise, and for dreaming of a better Missouri with us at Missouri Health Care for All.

Do you have a story to tell? Click here to tell us!

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