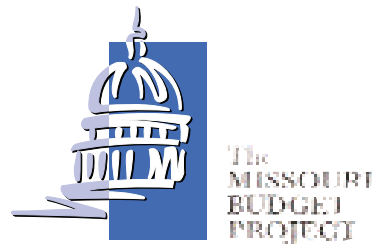




# Who is Medicaid?

Stories of Struggle...  
Faces of Hope



Missouri HealthVoice is an education and outreach program of the Missouri Budget Project

The Missouri Budget Project is a statewide nonpartisan, nonprofit organization that informs the public about Missouri's budgetary and fiscal policy options. The MBP provides timely, accurate analysis of complex policy issues and their impact on low-income Missourians.

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# Health Care: is it a right or privilege?

How can we have a discussion about the future of Missouri's Medicaid system without answering this question?

Over the past several years, Medicaid rolls have grown while benefits and eligibility levels have been cut. Some have proposed even further cuts to Medicaid, which would leave thousands more families, seniors and children without health care coverage.

Our fundamental belief is that Missourians have a right to health care. Yet, there is no plan to ensure that we all can obtain the medical care we need to be healthy and productive citizens.

Hundreds of thousands of Missouri citizens go without health care coverage. Most of them are working, but do not qualify for Medicaid. **Still, because they work at low-wage jobs, they cannot afford private insurance.**

Nearly one million— or one in six— of our children, neighbors and community members are covered by the state's largest health care program— Medicaid.

Some say Medicaid is a "handout". Missouri HealthVoice knows that Medicaid means the difference between: getting medications or skipping meals; going to the doctor for regular care or making urgent trips to the emergency room; having a healthy baby or a low birth weight infant with many health problems.

"Who is Medicaid?" introduces you to some of the families and individuals who are helped by this important program. As you will see each story is different but they have one thing in common: **All are unable to participate in the private health care market as it exists. There is no other way their health care needs can be met.**

What would these individuals and families do without Medicaid? Read their stories and you will see that they would face extreme hardship, loss of quality of life, institutionalization or worse. We must continue to work together to get the message out that Medicaid is a valued state service—and that it must be preserved.

Keeping Missouri's kids and seniors healthy is the right thing to do. Join us in protecting health care for the seniors, children, disabled and working poor families in our state.

JENNIFER HILL  
Campaign Director

Missouri HealthVoice thanks those who share their stories in the following pages. They tell of the frustrations and challenges families face on a daily basis. Their stories are powerful testimony to the critical need for access to health care for all Missourians.

Missouri HealthVoice appreciates the assistance of the following individuals and organizations:

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These are the stories of people struggling to overcome life's hardships. They range in age from infants to seniors. They come from Missouri's cities and small towns. They include all ethnic backgrounds.

With the help of Medicaid they can see a healthy future for themselves and their children.

These are the stories of the people behind the numbers. These are the faces of hope.

## Juanita's Story: In Her Own Words

BOWLING GREEN, MISSOURI

"I have great concerns about losing Medicaid. I had open-heart surgery when I was a small child, repeated at age 32. I also have pulmonary hypertension it is a problem with the pressures in the lungs, therefore I was not able to work a job. I couldn't go to school because I had learning disability and behavior problems.

I lived with my parents until I was 16 and due to sexual abuse from my father I had to get out so I run away, I lived on the streets and anywhere else I could find. I grew up a very angry young person, but my anger problems became more violent, but only towards myself. Then my parents put me in an institution where I got medication for my depression, counseling for the sexual abuse and for the first time I felt safe. I was put on other medication that I did not need as well.

Then the state started having money issues, budget cuts and I was told I had to leave the institution. When I left the institution I had a heart attack and was in the hospital due to the birth control "I did not need" while in the institution. I had no health insurance because of my age 18. I had a social worker while I was in the hospital that helped me to apply for SSI and Medicaid, I was accepted and the doctor worked very hard to get me on the right medication, so I could have a chance at life.

I have been on Medicaid most of my life. I take 15 different kinds of medications and now I have been on oxygen for seven years, I have turned my life around. I need Medicaid for my medication, doctors, to get support to live in my home, if I would lose Medicaid it would take away my life that I have worked so hard all these years to pull back together. I could not live without my medications, I could not live without my oxygen and what support I get to help me in my home is nothing to what it would cost to live in a nursing home or institution. This is not only about choice but my freedom to live."

## Quincy: A Cancer Survivor

### Looks Ahead

ST. LOUIS, MISSOURI

Quincy is a 62 year-old Vietnam Veteran who works full time for the state of Missouri at Bellfountain Habilitation Center where he has been a food service helper for four years.

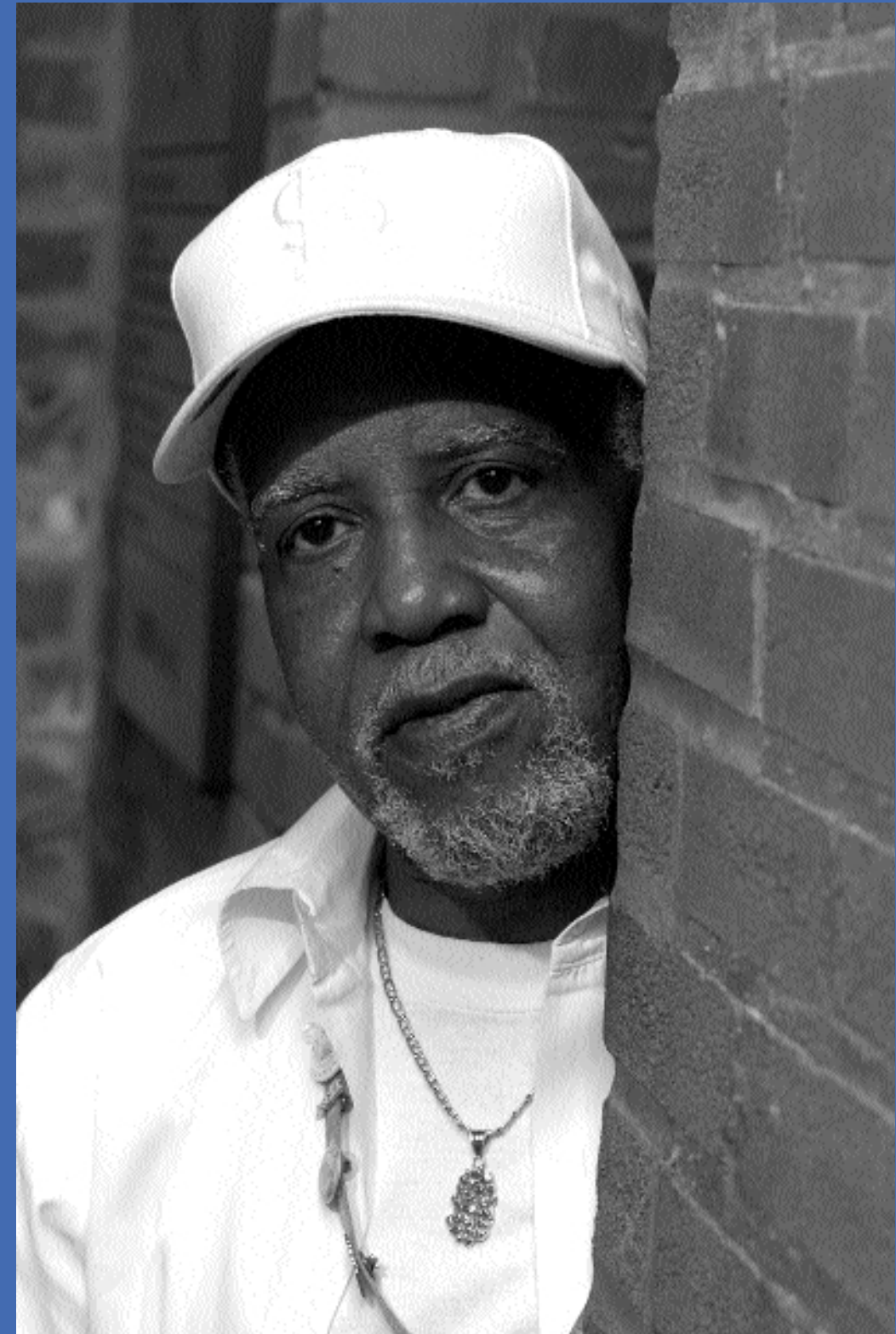
Quincy is insured through MCHCP, the state employees' insurance program, but when he was diagnosed with prostate cancer last December he found that his insurance would not cover the cost of his treatment and recovery. A caseworker at Barnes-Jewish Hospital helped him to enroll in Barnard Free Skin and Cancer Hospital program, so that Quincy could receive treatment through the Siteman Cancer Center. At the time, he was not covered by Medicaid.

Quincy applied for Medicaid in May because he needs long-term treatment for his cancer. He makes only \$900 per month as a full-time state employee-less than \$11,000 annually. He has been unable to work while on unpaid FMLA leave, so his income is even more diminished.

At first, Quincy was denied Medicaid despite his income which for the last six months was less than \$3,000. Recently, however, he was found to be eligible and now receives Medicaid. Quincy depends on Medicaid for his follow-up medical visits and for his treatments for the next year.

Without Medicaid, Quincy would be unable to receive the treatment and regular testing he needs to ensure that his cancer stays in remission. Consequently, he would be unable to return to work and resume his position as a state worker. Cancer is a very serious condition that requires constant vigilance, especially since the rate of occurrence and death is higher for African American men than other demographic groups.

Without Medicaid, Quincy would not have access to the medications and treatments that give him the opportunity to recover and live long enough to enjoy his retirement.



### Kristen: Furthering Her Education

ST. LOUIS, MISSOURI

Kristen is a 30-year-old single mother of two sons. She's always had a job since she was 15 years old. Several months ago she was laid off from a good-paying office job that supported herself and her kids. She spent six months looking everywhere for a good job and just hasn't been able to find one.

She decided she needed to go back to school. She's currently taking classes at the University of Missouri-St. Louis, working towards her bachelor's degree in psychology.

Being a full-time student doesn't allow her to work full-time as well—not with two kids at home. She is working part-time at the corner store, but this doesn't provide enough to support the family through this transition period.

To make it through, Kristen and her sons have signed up for Medicaid, Temporary Aid to Needy Families and child-care assistance from the state. These are a lifeline; they will allow this family to get back on their feet.



### Sabrina: A Young Mother Strives for a Better Future

MEXICO, MISSOURI

Sabrina lives in Mexico MO. and has two children. Sabrina had Micheal (now age eight) when she just turned 15. Micheal was born with health problems requiring intensive care. During Sabrina's labor, Micheal aspirated meconium and had an infection in his lungs. He also could not digest food.

At 18 months Micheal started having seizures. He was diagnosed with febrile seizures that accompany high fevers. The doctors prescribed anti-seizure medication and that continued until he was three.

Micheal had behavior problems which led to an attention deficit hyperactivity diagnosis. He is on medications that calm him down and allow him to sleep. The medications cost nearly \$300 a month.

Katelyn (now age three) was born early by Cesarean section. According to her doctors her uterine position caused a birth defect in her leg. One leg is not developing and is smaller than the other. Shriners Hospital in St. Louis is evaluating her condition.

Sabrina also has health issues. She suffers from asthma and GERD, a chronic disease causing severe heartburn. In addition, her glasses are broken and she cannot afford to get them repaired. She has an allergic reaction to the cold that causes her to break out in hives. Sabrina estimates that her medication costs are over \$500 a month, which are covered by Medicaid.

Sabrina is a volunteer and dues-paying member of Grass Roots Organizing. She is learning about civic participation, self-advocacy, and being empowered to improve the system that she must depend on for help. She has been especially active in a voter registration project that GRO has been conducting in Mid-Missouri during the 2004 electoral season.

### Jerome: On His Way to Self-Sufficiency

ST. LOUIS, MISSOURI

Jerome Jackson is an 18-year-old young man who lives in Covenant House Missouri's Transitional Living Program. Jerome's mother kicked him out of the home four months ago. Since Jerome was a child he has had severe asthma. When Jerome was a child, his mother lost her job after being diagnosed with diabetes and a bone disease. Jerome required hospital

care for two weeks due to persistent asthma attacks. After the hospitalization, Jerome's mother enrolled them in Medicaid, which helps with his expensive medication for asthma, eczema, and numerous allergies.

Jerome graduated with his high school diploma from Normandy Tech. in December 2003 and is working with Covenant House Missouri's Garden Rangers program to earn a little money while searching for a more permanent job.

Jerome says that without Medicaid he wouldn't be able to afford the medications and he would probably die. He knows that without medications his asthma is unmanageable and he cannot function.

### Cheryl: A Helping Hand Gives Family Hope

NEOSHO, MISSOURI

In April 2000, Cheryl and her husband Shannon were employed full-time while raising their three children, aged 11, 13 and 14. Cheryl's job afforded the family medical insurance at a reasonable cost. Unexpectedly, Cheryl became ill and lost not only her income but the availability of health coverage. Cheryl faced surgery and a bleak outlook for future employment. Helplessness and hopelessness flooded Cheryl's thoughts which eventually led to feelings of utter despair and a bout with depression.

Cheryl and her husband separated, which only amplified the seriousness of the situation. Danielle, their 13-year-old daughter, suffered from chronic asthma and needed medication which costs \$200 per month. Though Cheryl had heard about Medicaid she knew little about the guidelines or how to seek assistance.

Early in 2001, Cheryl's children brought home an information packet from their school about the availability of Medicaid and MC+ in Missouri. Cheryl applied and within two months received a letter outlining the benefits of MC+ along with the cards and assigned numbers for each child. A huge burden was lifted.

Today Cheryl's health has improved and she has re-entered the workforce. She will soon be employed full-time and will qualify for health insurance through her employer. Cheryl's children remain covered under MC+ and she continues to strive for her ultimate goal... self sufficiency!



### April: A Young Woman Triumphs Over Adversity

ST. LOUIS, MISSOURI

April is 18 years old and lives in Covenant House Missouri's Transitional Living Program. April's mother enrolled her in Medicaid when she was a young girl. After several fights and living in a drug-infested home, April chose to move out. April came to Covenant House Missouri to live. She graduated from Roosevelt High School in May, 2004.

As a result of April's mother's drug use while she was pregnant, April has eye and ear problems. She is deaf in one ear and has repeated ear infections. She is unable to close one of her eyes and has annual check ups for both her ears and eyes. From ages 6-14, April was hospitalized for mental health problems. She attributes that to all the drama in her life.

If April didn't have Medicaid, she states that "I would have several bills that I wouldn't be able to pay and I would be really poor". She suspects that she would be in and out of the emergency room all the time.



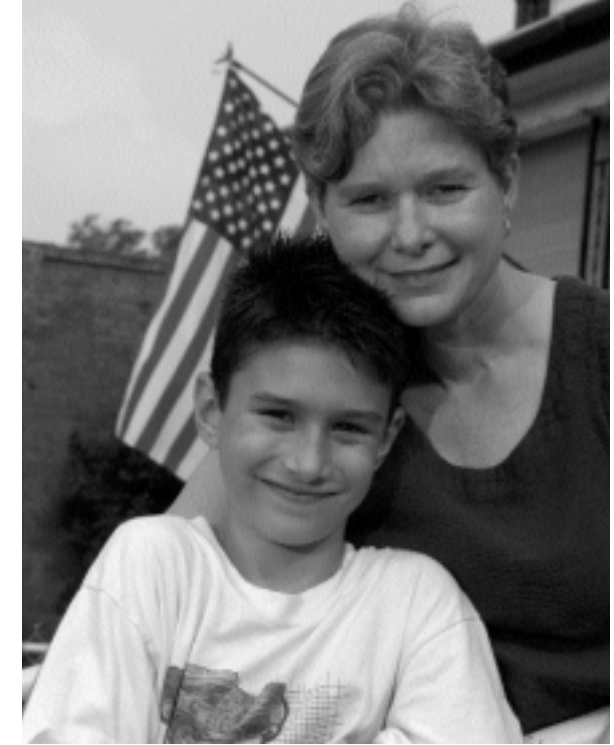
## Paula: Planning for Her Children's Future

ST. LOUIS, MISSOURI

Recently separated from her husband, Paula works full time as a certified medical technician at Creve Coeur Manor in St. Louis County. She has three children, ages 9, 11 and 15. Two have asthma, one has scoliosis and all three wear glasses. All are enrolled in the MC+ program which covers their doctor visits and prescriptions. Paula receives her health insurance coverage through her job. Her income is not enough to pay for her children's health insurance and still cover shelter, food and car insurance. She used to work overtime, but the bad economy has meant overtime hours have not been available the last seven months.

Paula is trying to save for her eldest daughter's college education. She diligently puts away her daughter's child support, only dipping in for true emergencies. Paula knows if the proposed asset tests came into being her kids would become ineligible and she too could not afford the proposed co-pays and premiums. She worries about what would happen to her children who have asthma.

Paula wants people to know she works hard every day. She wants her children to go to college and she would like to pursue further education so she can get a better job.



## Kim: A Teacher Struggles To Make Ends Meet

ST. LOUIS, MISSOURI

Kim is a single parent of a nine-year-old son. When she was pregnant she received Medicaid, and her son was covered after birth. When she began to teach full time in the late 1990's, the eligibility levels were raised so he continued to be covered. Kim's income is \$30,000 a year and she is approaching her fifth year as a full time high school teacher.

Kim's son has been seeing the same doctor since birth and all his well baby visits were covered. He has only been sick one time. From strep, his kidneys shut down and he had to be hospitalized. Medicaid covered his follow-up visits for six months and now he uses it for basic visits twice a year, immunizations and dental checks.

Kim uses her Medicaid benefits to get basic care for her son and has only gone to the emergency room when her physician directed her there.

If Kim's son did not receive Medicaid, her insurance costs would double to \$280 a month plus co-pays. She currently pays for health insurance for herself. After paying her bills, Kim has no expendable income and says the only place she could cut is food and she currently shops at a discount grocery. For recreation she and her son only attend free entertainment or go to parks.

When asked about her dreams, Kim says she would love to see her son get a college education, be able to take vacations and rehab her house.

## Kaye: Giving Back To the Community

MEXICO, MISSOURI

Kaye Miller is 47 and lives in the Chevy Chase public housing complex in Mexico MO. Her family has a history of severe illness. Kaye's mother died at 37 from cancer and she also had heart disease. Kaye's father was 39 when he died from a heart attack (he had heart disease from the age of 25). Her grandmother died from heart disease at 40.

Kaye has had chronic asthma all her life. Her severe allergies set off the asthma attacks. She must take treatments from a breathing machine, take oral medications, steroids and inhalers.

Even with her health problems, Kaye worked all of her life. While at work for TCI cablevision in 1990, Kaye fell from a telephone poll three days before Christmas. Her foot was shattered and she has had five surgeries with two bone transplants and permanent metal plates. The nerves are so damaged that she can't step flat on her foot and she wears a walking cast all of the time except at night. She can't stay seated or stand for long because either will cause extreme pain. At the end of most days her foot and ankle swell beyond recognition.

Kaye has been on Medicaid since 1995. It took her several years to obtain general relief Medicaid. She has no source of income. She estimates her asthma medications alone cost nearly \$400 a month and without Medicaid there is no way she could pay for them. Her doctor is testing her for a more advanced and expensive treatment to control her asthma.

Kaye is a volunteer for several organizations in Mexico. She is a long time volunteer for the Audrain County Crisis Intervention Services (ACCIS). She is also a dues-paying member of GRO-Grass Roots Organizing. In addition she cares for her grandchildren and step-grandchildren and helps out with kids at the local church.



## Felicia: Keeping Herself and Her Kids Healthy

ST. LOUIS, MISSOURI

Felicia works at Christian Care Home, a nursing home in the city, where she has worked as a certified nursing assistant (CNA) for the last two years. Working full time she makes just over \$18,500, barely enough to support her family.

Felicia is a single mother of six children ranging in age from 9 to 17 years. She does not have health insurance coverage through her job because she doesn't earn enough to afford it. Single coverage alone would cost about \$78 a pay period. To cover her children would cost \$260 per week—both are sums she cannot afford.

Felicia's children are healthy. They are all covered under Medicaid, making it possible for them to get regular check-ups and vaccinations, dental and vision care. Felicia suffers from asthma as well as other health problems. She also depends on Medicaid to get treatment and medicine for her ailments. Without Medicaid, she would not be able to afford routine care for children, nor prescriptions and care to keep herself healthy.

As a CNA, Felicia has been injured on the job. The rate of injury among health care workers is high and it is very difficult to secure worker's compensation when injuries occur. Without health insurance, Felicia is at even more risk on the job. If she is injured, she has to depend on Medicaid to fund her recovery so that she can continue to work and take care of her family.

## Shirley: Speaking Up For a Living Wage

ST. LOUIS, MISSOURI

Shirley is a certified medical technician who has worked at the Tower Village Northside nursing home in St. Louis for over 18 years. She works full time and makes \$545 dollars every two weeks. On that income, Shirley must feed, cloth and shelter her family which includes four children, ages 6-14.

Shirley is covered through her employer's insurance program but says that if her children were on the plan it would cost half her monthly income. So she enrolled her children in the MC+ program. She uses the program for regular visits to the doctor and necessary prescriptions. Shirley says if the proposed co-pays or premiums went into effect she could not afford to keep her kids covered and they would become uninsured.

Shirley struggles to pay for basic necessities. If she pays her gas bill, then she may be late on the electric bill; she describes it as "robbing Peter to pay Paul". That, she said, is what her 18 years of working life has been about. She would like to have real cost of living wage increases as opposed to the nickel and dime raises she has had over her 18 years. Shirley says wants to stand up and be counted. She wants lawmakers to know the real choices many working people have to make and she wants them to know she is not the only one who makes these choices.



## Ilene: The Gift of Independence

ST. LOUIS, MISSOURI

Ilene is a quadriplegic. On December 8, 1996, while visiting a relative, she was asked to answer the door. There were two young men asking for another family member. When Ilene did not get them the information they needed, she was shot twice in the face. After leaving the hospital, Ilene was sent to a nursing home where she lay for six weeks in one spot, never being turned. It was there she got skin break-downs and had to get skin grafts. The second nursing home was not any better. It was there she lay in her waste for six hours.

After leaving the nursing home, it took six months for the wounds to heal. Ilene lived with a relative for eight months, and then moved to her own apartment. Medicaid personal assistance services are vital for Ilene. First she used a home health agency, but it did not meet her needs. Ilene enrolled in the consumer-directed Personal Assistance Services program and is able to live independently and be active in the community. This Medicaid in-home service gives her independence and control.

This program is not optional for Ilene. If this Medicaid service were to be cut, she would end up in a nursing home. She is certain that she would lose all her independence and in one year, there is no doubt in her mind and heart that she would be dead.

Ilene also uses Medicaid for her durable medical equipment, physical therapy, prescription drugs, dental and optical services. With her limited income, she would not be able to afford to go to the dentist or pay for her eyeglasses. Ilene has already felt the effect of previous Medicaid cuts. She now must pay for over-the-counter medication and medical supplies out of pocket. One month, her supplies ran \$100—an amount that is impossible for her to cover and still have enough for her bills. Additional Medicaid cuts would be a burden that she could not sustain.

## Melody: Preventive Care Keeps Her and Her Son Healthy

ST. LOUIS, MISSOURI

Melody is a single parent with a 16-month-old son. She was pregnant as a student, with no income, so she was eligible for Medicaid. She is finishing her sophomore year at Harris Stowe and is working part-time at a grocery store for \$7 an hour.

Melody uses Medicaid for eczema medication, well- women doctor visits and birth control. If she didn't have prescriptions for the eczema she would blister all over. Her son uses Medicaid for his well-baby visits, asthma treatments and prescriptions. If she did not have Medicaid she would not be able to go to the doctor for basic, preventive health care for herself and her son.

Melody's dreams are to graduate from college and get a good job. She would like to see her son grow up healthy and get a college education. Melody recently talked to an instructor who had traveled to Amsterdam. She became sick and had to be transported to the emergency room, where they ran tests and kept her overnight for observation. She was so worried how much it was cost, particularly being in another country. When she received the bill it was only 50 US dollars. She couldn't believe it. She found out that they had health care for all their citizens in Holland. Melody says she wishes we had health care for all in the USA.



## Chanda: Battling Life-long Health Conditions

LADONNIA, MISSOURI

Chanda is 28 years old and has been on Medicaid her whole life. Chanda was born without hip joints, a condition that has left her with a permanent disability.

Her mother knew something must be wrong when Chanda couldn't walk and they found out about her condition when she was just a year old. The first treatment was to do tracking, attaching weights to her legs to see if the joints would develop. That did not work and when she was just two-and-a-half years old Chanda had her first surgery to construct a hip joint.

At 13 Chanda was having trouble again as her hips would give out with normal activity. Shriners Hospital in St. Louis replaced the hip that had not been worked on when she was small. Her mother made sure that Chanda was on Medicaid and a patient at Shriners as her condition had to be monitored for deterioration. When Chanda is 30 to 40, both hips will have to be replaced.

Chanda has half of a pelvis due to the hip reconstruction. This could have been life-threatening when she was pregnant with her daughter.

Chanda knew she had a delicate situation with her pregnancy. Her doctor assured her that she was fine and her pregnancy went along normally until she developed toxemia. The doctor performed a Caesarean-section and told her that due to the condition of her pelvic girdle if she had gone into labor her uterus would have exploded and killed both her and the baby. She wanted the doctor to perform a sterilization procedure that would prevent her from ever having to go through this life-threatening situation again; however, Medicaid would not pay for it because she was only 19.

Chanda has accomplished things many of us have not. She went to college and obtained a master's degree in social work while raising her daughter. Chanda is a case worker for child protective services in Missouri.

Her disability benefits will continue for five years, but then she will no longer have that safety net. "The future scares me," Chanda says. Eventually she will be forced to have both hips replaced. Will her health insurance cover the procedure? She doesn't know.



## Carol: “Optional” Services Keep Her Independent

ST. LOUIS, MISSOURI

Carol is a 62-year-old woman with hemiplegia resulting from a severe stroke in 2001. She also suffers from exhaustion related to heart failure. Prior to the stroke, Carol worked as a licensed professional nurse (LPN). She had raised seven children, and had a house and car.

Carol was admitted to a nursing home where she remained after her rehabilitative services ended because her family could not care for her. Most of her children live outside the St. Louis area, work full time, and could not provide the assistance Carol required. She also lost her home and car since she was unable to make payments. While in the nursing home, Carol suffered emotional and physical abuse from staff. Many times her medications were given incorrectly. She survived the nursing home experience due to her own nursing knowledge. If she had not questioned the care, she could have died.

About eight months after the stroke, Carol's condition began to improve but she remained in a nursing home. She could not move into assisted living, because residents are required to be able to exit independently in case of an emergency. Eventually she received vocational training but was not able to get a paid position, because she lived in a nursing home being funded through Medicaid.

Carol was able to leave the nursing home in 2003 because of personal assistant services (PAS) and finding accessible housing. Carol's personal assistant (five hours a day) is covered by Medicaid. If funding cuts result in the loss of her personal assistant, Carol would have to return to a nursing home (funded through Medicaid). This terrifies her! She would have to return to a setting where she has no control over her own well-being or life choices.

If optional services are cut from Medicaid, she could lose her physical therapy and affect her chances for increased independence. When Carol was in the nursing home, several teeth had to be pulled. Now, she can't wear her bridge and can't get a new one because it was considered cosmetic. If dental services become optional under Medicaid, her oral health could further decline.

Carol recently paid off her glasses (\$205 over three months). Medicaid covered the exam, but not the glasses. If optical services were cut, the cost of the extensive eye exam would have been too much.

Carol takes 12 medications to maintain her health, which she will be on for life. If increased co-payments are implemented, the cost to Carol could easily be over \$100 a month. This is significant considering her income consists of her Social Security and part-time employment at minimum wage. Her employment allowed her to afford glasses and fund transportation to medical appointments and work. If her medical costs continue to increase, Carol may have to choose between her supplies, medications and medical visits. Without the services she needs, Carol's health would decline— along with her quality of life, independence, and active contribution to her community.



## Lacy: Staying Healthy Keeps Her On the Job

KIRKSVILLE, MISSOURI

Lacy is a 25-year-old woman who receives services through the Department of Mental Health provided by Learning Opportunities/Quality Works, Inc., in Kirksville, Mo. She has received services to increase her independence since July of 1998.

Some of the goals Lacy wants to reach include cooking healthy meals, attending doctor appointments, maintaining her employment at a local motel, budgeting, balancing her checkbook, and getting proper exercise. Currently Lacy is also working to obtain her driving permit.

Lacy's life has become safer since she became Medicaid-eligible. Until about three years ago, Lacy had been denied services due to her husband's income. Though she suffered through a lot of pain and discomfort due to chronic health problems and allergies, she was unable to get proper care because she could not afford the treatment. Advocates worked hard for Lacy, including her regional center case manager and support staff from LOQW. She was finally accepted for Medicaid benefits. After receiving treatment, Lacy is able to work and exercise; both of which help her to be healthy and more active in her community.

Recently, Lacy discovered a spot on her left cheek just below the eye. A dermatologist diagnosed her with skin cancer at age 25. Support staff was able to attend appointments and be with Lacy during her surgery, which required eight stitches to rejoin the skin tissues around the area removed.

Without Medicaid, Lacy could not maintain her employment at a local motel. Since receiving services, Lacy is healthier, physically and mentally. She does not have to worry as much about where or how she will get money to pay for health care and the support she needs to remain independent.