



Missouri Association for Social Welfare

Clock Ticks on Medicaid: Reform Must “First Do No Harm”

Part I: Analysis of Cuts & Principles for Reform

*Part II: Beyond the Numbers:
The Reality of Life After Medicaid Cuts*

**By Ruth Ehresman,
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Missouri’s Medicaid and State Children’s Health Insurance Program (SCHIP) will sunset in June 2008, as required by legislation passed in May 2005 by the Missouri Legislature. Plans for reforming these programs are in the making; at minimum some legislative changes must be made in 2007 if new Medicaid and SCHIP health insurance programs are to be up and running by June 2008.

The Missouri Budget Project and the Missouri Association for Social Welfare have:

- examined the results of 2004 and 2005 cuts in Medicaid and SCHIP,
- interviewed Missourians affected by the cuts and
- developed a set of principles to guide Missouri’s reform efforts.

True reform will require the cooperation of numerous public and private entities. It will require openness to new ideas. And, most of all, it will require a commitment to making decisions that support the common good.

Key Points

- Missouri’s Medicaid and State Children’s Health Insurance program sunset in June 2008
- In redesigning Medicaid, the strengths of the current program should be retained while improving components that do not support quality, efficiency and easy access
- Reform should result in more people having access to the health care they need
- Funding healthcare is an investment creating both long term and short term social and health benefits, increasing economic activity and creating jobs.
- The decisions to cut eligibility for Medicaid insurance in 2005 had immense scope: *1 of every 8 persons insured by Medicaid lost their health insurance*
- The 2005 cuts brought unintended negative consequences for children, the elderly and disabled and undermined the efforts of low income working families to support themselves

Principles to guide Medicaid and health care reform

The bedrock of all reform should be *First Do No Harm*. The responsibility for health care is a partnership among consumers, providers, employers and the government.

Reform must build upon what works in Missouri's publicly-funded state insurance programs and reform what does not.

The following principles are put forth as guidelines for policy makers as they develop new, comprehensive health insurance programs.

- Focus decisions about funding health care on maximizing investments rather than cutting costs. Tax dollars used for health care are investments in the future of all Missourians. These are wise investments, creating both long term and short term social and health benefits, increasing economic activity and creating jobs.
- Contain costs by taking advantage of price negotiations based on economies of scale, using advances in technology and controlling fraud at every level. Federal match of Medicaid dollars should be maximized as well.
- Support consumers in fulfilling their responsibility for making healthy life-style choices and being well informed about health care choices. Provide access to information and services that promote prevention, as well as a continuum of care, that extends across geographic and demographic boundaries.
- Structure consumers' cost-sharing so it is not a barrier to receiving either preventive care or treatment. Cost-sharing should not require consumers to make choices between health care and other basic necessities such as food and rent. No one with an income lower than the federal poverty level should be required to participate in cost sharing.
- Maintain and build on Missouri's strong public investment in health insurance for children.
- Focus reform on managing the health of consumers rather than on managing health care services.
- Fairly reimburse providers for their services. This will maintain a robust provider network and support delivery of high quality services.
- Create opportunities for employers to offer affordable insurance to their employees. Individuals who do not have access to affordable employer-sponsored insurance should have access to affordable public insurance.

- Require employers to pay a fair share for employees' health insurance. Any business/enterprise that receives tax credits or tax deductions should be required to contribute fairly to the costs of health insurance for their employees.
- Ensure a strong safety net for those who fall through the cracks. Even a reformed system will have cracks.
- Evaluate the success of reform strategies in terms of financial and human impact. Use evaluation outcomes to modify the course of reform.

Medicaid in 2006 is leaner

In May 2005 the Missouri legislature significantly reduced eligibility and services provided through the Medicaid public health insurance program.¹ Most provisions of the cuts took affect in or after August 2005.

Nearly 15 months after the Medicaid cuts began to take effect, it is possible to measure their impact. This report addresses the effect of the cuts from two perspectives. First it examines the data collected by the Department of Social Services. Second, to better understand the human cost of the changes to Medicaid, it highlights the experience of a sampling of real Missourians who were impacted by eligibility cuts, or who have lost services critical to their health.

According to the Missouri Department of Social Services historic data, 114,525 fewer individuals were insured by Medicaid in July 2006 than in August 2005.² **Nearly 1 in every 8 people insured in August 2005 lost their insurance by August 2006.** Many more retained eligibility for Medicaid insurance, but are required to pay a hefty monthly premium to participate in the “spend-down” Medicaid program.

The table and graphs below show the change in the numbers of individuals enrolled in Medicaid over time. The graph shows that enrollment in Medicaid began to decline prior to August 2005 due to cuts in eligibility and services made in previous legislative sessions.

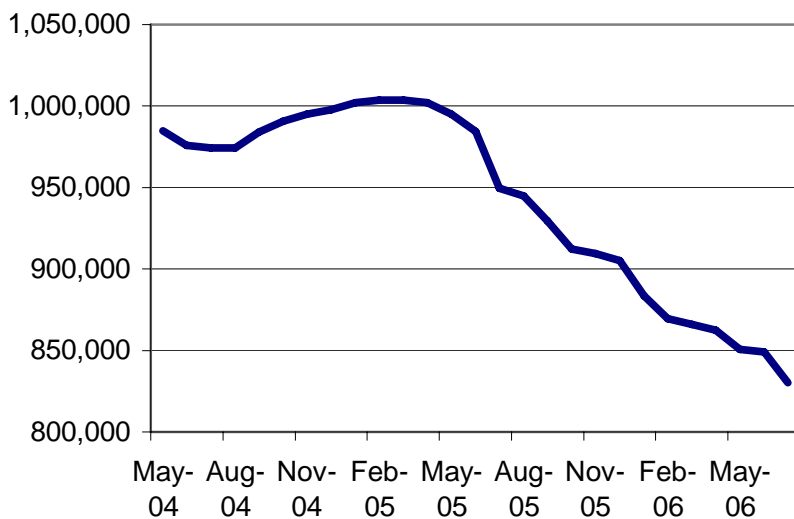
¹ See the *Missouri Budget Project*. “[The High Price of Budget Cuts: Thousands More Missourians Lose Health Care](#)” January 2006, available at www.mobudget.org

² Department of Social Services, Case Load Counter, October 2006. www.dss.mo.gov.

Table 1: Medicaid Enrollment August 2005 – July 2006

Population	Number enrolled in August 2005	Number enrolled in July 2006	Difference	Per Cent Change
Total	944,787	830,262	-114,525	-12%
Individuals with a disability	159,374	140,900	-18,474	-12%
Elderly	80,591	77,728	-2,863	-4%
Adults	141,044	86,210	-54,834	-39%
Children	535,156	488,549	-46,607	-9%
Pregnant women	26,839	38,875	+12,036	+45%

Medicaid/MC+ Enrollees (Eligibles)



Elderly and individuals with a disability lost coverage or pay burdensome premiums

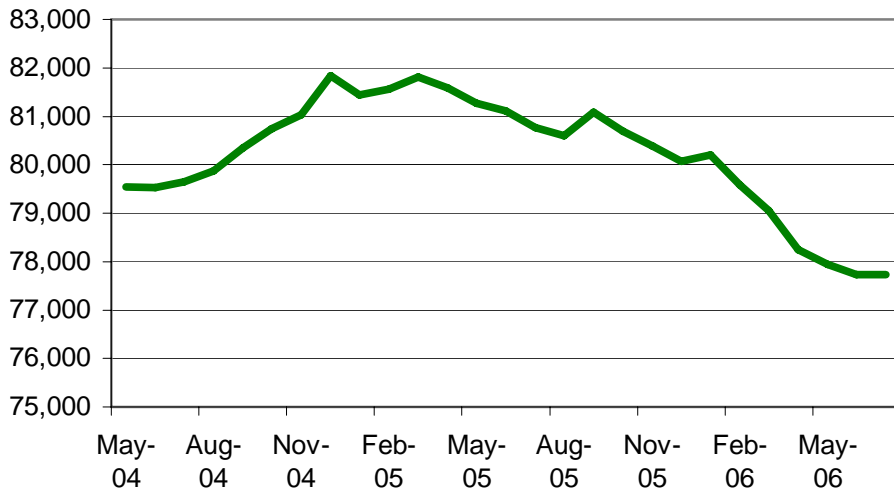
The graph below shows that the participation in Medicaid of the elderly and people with a disability has declined as a result of lowered eligibility levels. Some individuals who initially lost their eligibility continued to participate in Medicaid through the spend-down program. In the spend-down program, individuals may participate in Medicaid if they spend enough of their monthly income on medical services or goods to become income-eligible. They may also pay this amount up front, as a kind of premium. This allows them to be eligible for Medicaid at the beginning of each month.

Individuals who have testified at Medicaid Reform Commission hearings and other Legislative Committee hearings have consistently stated that participating in Medicaid

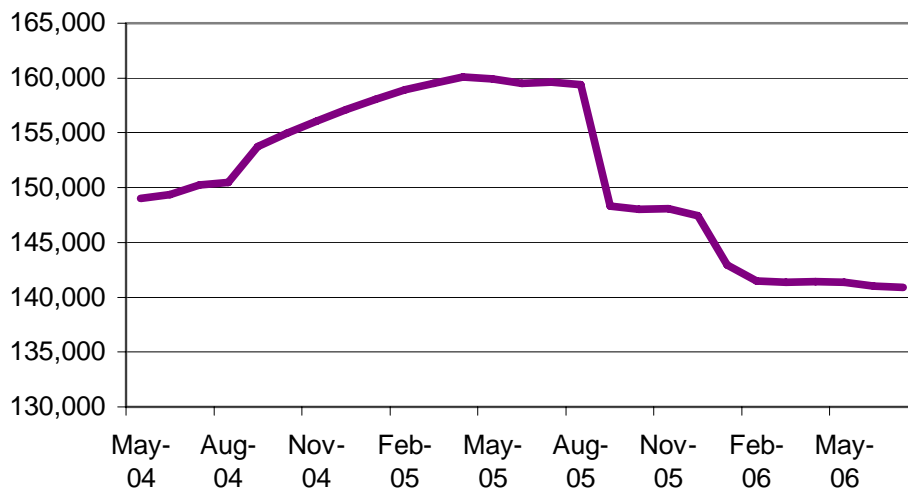
through spend-down is an enormous burden. The spend-down “premiums” consume a large amount of their disposable income, requiring them to make hard choices among medical care and heat, food or rent.

In August 2005, 11,880 persons were insured through the spend-down program. In July 2006, this number had almost doubled to 21,837.³

Elderly Enrolled in Medicaid



People with Disabilities Enrolled in Medicaid



³ Department of Social Services, Family Support Division/Division of Medical Services Management Reports for August 2005 and July 2006, p. 20

Low-income working parents are hardest hit

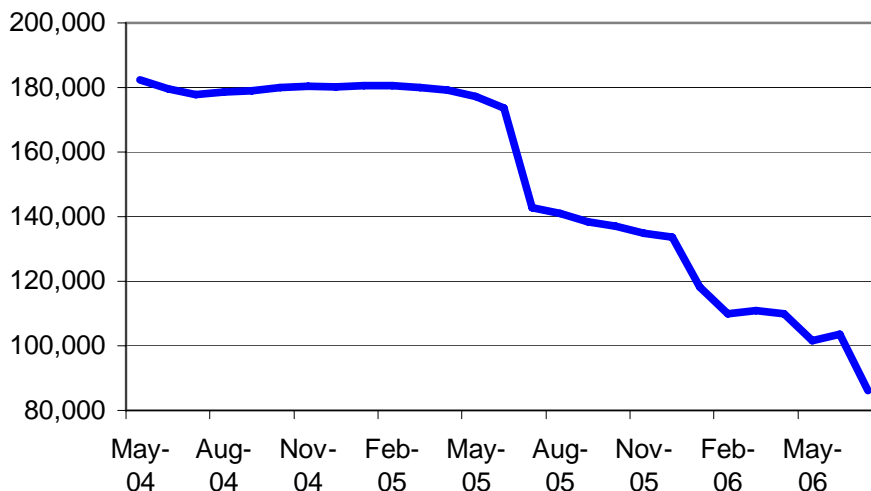
The 2005 Medicaid cuts were most severe for working parents, with 68,000 losing access to healthcare. Missouri made the deepest cuts nationally to this group; eligibility for working parents now stands at 17-22% of the Federal Poverty Level. Working parents are in the difficult position of either lacking access to employer-sponsored insurance or not being able to afford it when it is offered.

Recent census data shows that the number of uninsured Americans is at an all time high. In Missouri, the number of uninsured has grown from 9.9% (an average of 2000-2001 data) to 12.4% (an average of 2004-2005 data).⁴ These percentages do not reflect the full impact of the 2005 Medicaid cuts.

Census data show that low-income adults who lost Medicaid insurance because of eligibility cuts are likely to remain uninsured. In 2005, about 24% of those who were uninsured had incomes below \$25,000, and 45% had incomes under \$50,000. Only 8.5% of the uninsured had incomes over \$75,000.⁵

Parents who lost eligibility for Medicaid are also less likely to be insured by employer-sponsored insurance than individuals with higher incomes. In 2004, only 15% of adults with incomes under the Federal Poverty Level (\$19,307 in 2004 for a family of 4) had employer-sponsored insurance. Eighty-six percent (86%) of those with incomes 4 times the federal poverty level (\$77,228) had employer-sponsored insurance.⁶

Adults Enrolled in Medicaid



⁴ Current Population Survey. Table H105 at www.census.gov. August 2006

⁵ Current Population Survey. Table H106. at www.census.gov. August 2006

⁶ Kaiser Family Foundation, *Health Coverage in America-2004* at www.kff.org.

Policy changes result in children losing coverage

As the Medicaid budget cuts were being made, there was fairly broad bipartisan support to protect children. In fact, children's participation in Medicaid (which includes both the traditional Medicaid program as well as the State Children's Health Insurance Program⁷, (SCHIP,) dropped dramatically. Two changes enacted in Senate Bill 539 in 2005 significantly affected children's participation in Medicaid: Premiums and Affordability Tests⁸.

Premiums

The first change required families with incomes of just over \$24,900 per year for a family of three (151% of the Federal Poverty Level) to pay premiums. Previous rules required that only families with incomes from 226-300% of the Federal Poverty Level were required to pay premiums. Although the premiums were modest (1%, 3% or 5% of the Federal Poverty Level, depending on the family's income), it appears that they contributed to children losing their health insurance. Research of other states' experience shows that premiums, even when modest, result in declining participation.⁹

Affordability Test

The 2005 legislation also required families with incomes over 151% of FPL to undergo an affordability test previously only required of families with incomes between 226 and 300% of the FPL. An "affordable" premium was defined as one costing \$342 or less per month. If a family had access to private or employer-sponsored insurance for a child, and the cost of the premium was \$342/month or less, the child would not be eligible for SCHIP. This was true even if the family could not afford the premium, or if the insurance offered did not cover a pre-existing condition of the child. This affordability test was slightly modified in July 2006 and the new affordability tests are \$209/month, \$255/month or \$375/month based on income. The Department of Social Services estimated that these changes would allow 5418 previously ineligible children to be eligible for SCHIP.¹⁰ At this point the Department of Social Services data does not reflect this projected change.

From the graph below, it is evident that the number of children insured through Medicaid/SCHIP began declining in April 2005. This was probably due to positive changes in the economy, as well as requirements for annual re-certifications of eligibility.

⁷ SCHIP is a component of Missouri's Medicaid program. In some states SCHIP is a separate program. In general, Missouri children are eligible for SCHIP if: family income is 300% of the Federal Poverty Level, or less; the child is uninsured; and the family does not have access to affordable employer-sponsored insurance.

⁸ [/www.senate.mo.gov/05info/BTS_Web/Bill.aspx?SessionType=R&BillID=22520](http://www.senate.mo.gov/05info/BTS_Web/Bill.aspx?SessionType=R&BillID=22520)

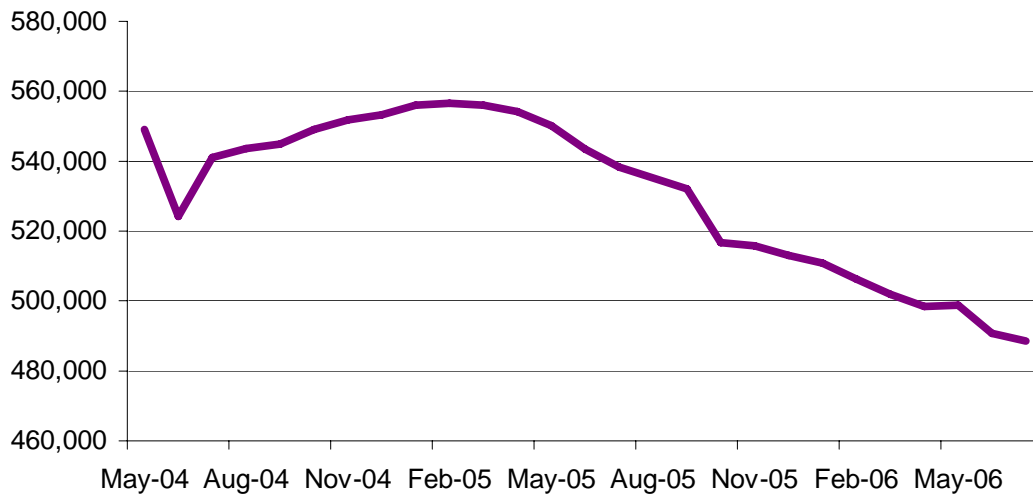
⁹ Leighton Ku and Victoria Wachino, *The Effect of Increased Cost Sharing in Medicaid: a Summary of Research Findings*, July 2005. Julie Hudman and Molly O'Malley, *Health Insurance Premiums and Cost-Sharing: Findings from the Research on Low Income Populations*, Kaiser Commission on Medicaid and the Uninsured, March 2003.

¹⁰ Joel Ferber, *Measuring the Decline in Children's Participation in the Missouri Medicaid Program: An Update*, September 2006.

However, after August 2005, a disproportionate amount of the decline in children’s participation can be attributed to children in the SCHIP program. After August 2005, SCHIP enrollment fell by 31%, while regular Medicaid enrollment only decreased by 4%.¹¹ From this, it appears that the policies requiring more families to pay premiums and meet the affordability test were key factors in driving reduced participation.

Overall, the number of uninsured children in Missouri is growing. The Children’s Healthcare Campaign reports that in 2005, 8.2 percent of Missouri children were uninsured-- enough children to fill 2,200 school buses.¹² In 2002 six percent of Missouri children were uninsured.¹³

Children Enrolled in Medicaid



Medicaid population and expenditures in 2006

The policy changes enacted in 2005 have changed the mix of the population insured by Medicaid. The graph below is based on FY 2006 average monthly enrollment. It shows that more than half of those insured by Medicaid are children, and almost 75% of the current enrollees are children and adults without a disability.

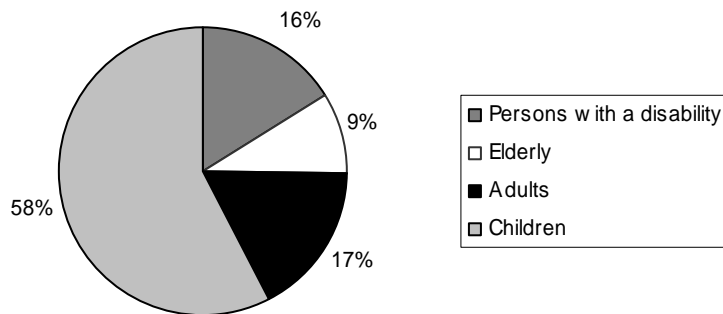
Expenditures show quite a different picture. The table and graph below show that persons with a disability and the elderly, although comprising just 25% of the total enrollees, account for about 66% of the expenditures.

¹¹ *ibid*

¹² Campaign for Children’s Health Care. *No Shelter from the Storm: America’s Uninsured Children*, September 2006

¹³ Annie E. Casey Foundation, Kids Count Online Data at www.aecf.org.

FY 2006 Average Monthly Medicaid Enrollment



Percent of Medicaid Expenditures by Category FY 2006

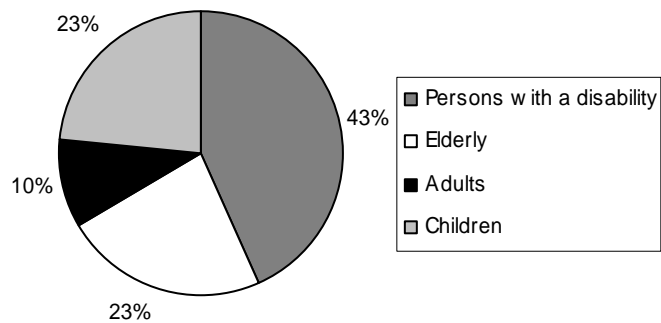


Table 2: Average Monthly Cost Per Enrollee Category¹⁴

	FY 01	FY 02	FY 03	FY 04	FY 05	FY 06
Elderly	1,192	1,216	1,236	1,253	1,409	1,281 ¹⁵
Individuals with a disability	1,138	1,180	1,176	1,197	1,261	1,304
Adults	146	164	206	235	264	296
Children	145	152	162	159	177	199

¹⁴ Presentation by Dr. M. Ditmore to the Kansas City Child Roundtable, 9/19/2006.

¹⁵ The drop in cost of insuring the elderly in FY 06 is attributable to Medicare Part B. *ibid*

The cuts in Medicaid disproportionately affected non-elderly adults without a disability and children. The cost to insure these individuals is much lower than to insure persons with a disability and the elderly. The result is that the Medicaid cuts created hardship for many of the elderly and individuals with disabilities who are still insured, and created large numbers of uninsured individuals without netting substantial financial savings in the budget.

Call for Action in 2007

With Medicaid/SCHIP's sunset just 18 months away, 2007 will be a critical year to take action. As plans for redesign and reform move forward, we urge policy makers to examine the results of the changes made in 2005. What have we learned? Did the policy changes give us the results we want? In recent surveys, Missourians have expressed deep concerns that the 2005 cuts hurt children and parents, elderly persons and individuals with a disability.¹⁶ The Medicaid reform process offers an opportunity to do better. We can and must engage in an honest, open dialogue among public policy makers, businesses, health care providers, insurance companies, and those whose lives will be affected by Medicaid reform. Above all, we must ensure that "reform" brings improvement and that we first do no harm to the health and well being of Missourians.

¹⁶ Missouri Budget Project, "2005 Statewide Survey Results: Missourians Strongly Oppose Health Care Cuts", available at www.mobudget.org

Beyond the Numbers: The Reality of Life after Medicaid Cuts

The report “Clock Ticks on Medicaid” provides the statistics of the Medicaid cuts. It is critically important to examine what these numbers mean in the lives of the Missourians who were directly impacted. Limiting eligibility for Medicaid insurance and cutting services has had a devastating affect on working parents, children, the elderly and people with disabilities.

In October 2005, the Missouri Association for Social Welfare and the Missouri Budget project, with the cooperation of more than 20 organizations statewide, distributed a survey, asking those insured by Medicaid what the policy changes would mean for them. More than 2,400 individuals responded to that survey.¹⁷ Almost half of those who responded did not know how they would cope with losing their health insurance or services. Almost a third of those responding said they would likely cut back on food or rent. After the survey was distributed, gas and other energy costs rose significantly, compounding the difficulty of stretching meager resources. The following section contains excerpts from interviews that MASW or MBP had with real Missouri families who have been affected by the cuts. Their experience must be taken into account by policy makers in order to thoroughly assess the impact of the cuts.

These vignettes show that hardship shows no favoritism. Men, women and children throughout Missouri share stories that are distressingly similar.

Women and children first?

Frances is a single mother of three. She lives in Independence where she works full-time in a low-income job to support herself and her children. When Frances learned about the Medicaid cuts in 2005, she grew anxious about losing her house. Private insurance premiums consume about 20 percent of her income, even before factoring in taxes, monthly utilities bills, and the cost of raising her three children.

Frances has not lost her home, but losing Medicaid coverage has placed undue stress upon her family’s well-being and health. “The Medicaid cuts have financially hurt this family,” she admitted. “I have insurance through my provider, and I pay a biweekly premium. But a lot of the time I can’t afford the copays, and so sometimes I go without seeing a doctor.”

Recently Frances was unable to put together the cash for a co-payment, and couldn’t find anyone to lend her the money, so she canceled a doctor’s appointment to check her high blood pressure. “That was not the first time we went without,” Frances said. “My son’s

¹⁷ See *Missouri Budget Project and Missouri Association for Social Welfare*, “Losing Health Care in Missouri, Survey Results: Impact of 2005 Medicaid Cuts”, October 2005 available at www.mobudget.org and www.masw.org

toes became infected; they became red and swollen. It took me a while to get the copay together then, too, and he was limping around by the time he saw a doctor.”

Frances often skips her own check-ups in order to take her children to the doctor. This sounds admirable, but it increases the chance of her becoming seriously ill, and not being able to fill her role as the family breadwinner.

“It’s dental care too,” Frances said. “My kids are only covered for cleaning and a six month checkup. My four-year-old has caps - how can I replace or repair those if there’s a problem? These things are not covered. And myself - I know I need dental work, I feel it every time I eat, but I can’t afford that.”

My son’s toes became infected; they became red and swollen. It took me awhile to get the copay together then, too, and he was limping around by the time he saw the doctor.

“At least emergencies should be covered. God forbid I have an emergency - it costs a hundred dollars for the copay. Who has that? And some places request it before they provide services,” she says shaking her head, “and that is not right.”

“If I could speak to the legislators, I would tell them not to be so strict on what people make in order to get Medicaid. We’re a family of four - I’m the only income - and I have a house, a car and other bill payments to consider. Not to mention I have children to clothe and feed.” Frances’ voice saddens and she admits that speaking of these things depresses her. “All this has really increased the stress on my family.”

Frances is a single parent, but two-parent families also struggle. **Jerry and Teresa**, who live in a tiny town in south central Missouri experience similar challenges in taking care of their own health and caring for their teen-age children. Teresa has suffered with pain from a bad tooth for some time, but can’t find a dentist to treat her. Even though they have two growing teens, they’ve had to cut back on food in order to pay for health services and prescriptions. Jerry is fearful of the future. “Our utilities have been disconnected before and I am afraid it will happen again.”

Grim choices for those with a disability

Ron lives in a small town in central Missouri with Connie, his girlfriend and primary caregiver. **Ron** suffers from ALS, or Lou Gehrig’s Disease. He is almost completely paralyzed and has been on a feeding tube and a ventilator for the past three years.

When he was healthy, Ron worked as a heavy equipment operator and had private insurance. After a routine check up, Ron’s insurance provider noticed a high level of liver enzymes: predicting that Ron would become a liability, they canceled his coverage.

Ron was treated for exhaustion over the next few months by another doctor. Only when he and Connie raised enough money to see a specialist did they discover he had ALS.

Ron applied for disability, but he was told that although he could no longer operate heavy machinery, he could learn a new skill and get a job behind a desk. For two years, *Ron* and *Connie* struggled to pay his accumulating healthcare costs. Because his illness prevented him from working everyday, he and *Connie* sold many of their possessions to make ends meet.

Two years later, when *Ron's* health had deteriorated and the sale of his possessions left him destitute, he was declared disabled. He quickly applied for Medicaid, and is currently paying four hundred and eighty five dollars a month for his spend-down premium. "That's almost half of my disability check," says *Ron*. *Ron* was told that since ALS was a terminal illness, he would not be sent to a rehabilitation center, but should "go home and die."

Ron moved into *Connie's* home. Though a paid caregiver is there for nine hours a day, *Connie* cares for *Ron* the remaining fifteen hours. Her time is not reimbursed. Medicaid paid for *Ron's* stationary ventilator, but will not pay for a portable ventilator. Because of this, *Ron* is trapped within *Connie's* home and has not left it in eighteen months. In the event of an emergency, he will not be able to leave the home to see a doctor.

When asked why he will not allow Medicaid to place him in a nursing home, *Ron's* eyes glisten. *Connie* reads his lips. "He feels that if they won't pay for sufficient care in his home, they won't pay for sufficient care in a nursing home. He believes they want to move him to a nursing home so he'll die sooner and cost them less money. He says they're compromising his life for profit."

Delores is a middle aged woman in a suburban community. Although she has a variety of ailments including obesity, fibromyalgia and Rheumatoid arthritis, she lives independently with the aide of a caregiver. *Delores* says that the loss of her caregiver due to Medicaid cuts "has been devastating and words cannot even describe the impact on my life."

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Now *Delores* relies on friends and neighbors to help her with basic household chores and shopping. She also relies on her aunt to help her shower once each week. If her aunt can't come over, *Delores* just doesn't get a shower that week. *Delores* shared that she is incontinent, and missing a shower causes a lot of discomfort, even if she attempts to bathe with a sponge. "To me, the most important part of Medicaid that needs to be protected is the personal attendant program," says *Delores*.

Delores is eligible for Medicare, and she could also be eligible for the Medicaid spend-down insurance. However, with her limited income she cannot afford to spend \$266 every month for her spend down premium, and she cannot afford the copays to see specialists that are required by Medicare. So even though she has referrals, she misses appointments with pulmonary specialist and specialists to treat her rheumatoid arthritis.

Delores went on to say, “If treatment can’t be done at a clinic, then it can’t be done because I can’t afford it.” If given the opportunity to speak to Missouri Legislators she would ask them to “restore the MAWD program and lower the cost of spend down premiums.”

A middle aged woman like Delores, *Lynda* lives in an urban area. She too knows the pain and fear of putting needed treatment on hold. Lynda has a grouping of brain aneurisms. She needs to be examined regularly to monitor these, as well as to monitor her seizures.

Lynda cannot afford to pay her spend-down premium every month. If she can’t pay the spend-down, she can’t see her doctor. “The Medicaid cuts made my priorities change,” Lynda says wistfully. “My first priority is getting prescriptions so I can function, then seeing a doctor so I can maintain my health. Then I worry about my rent and food. But fear about not being able to fill my prescriptions and being sick but not being able to see my doctor makes my condition worse.”

“There are people who are not on their medications because they can’t afford it. People with multiple sclerosis, with their nerves all messed up, and they’re in terrible pain without their shots.” Her face becomes serious, “I know a man who has not had his shot in over a year.”

Wherever hearings about reforming Medicaid Assistance for Workers with a Disability (MAWD) program, men and women have shared intimate stories about their struggles to work.

Kathie, a remarkable woman from Poplar Bluff tells her story, as well as the story of her clients and friends, with clarity and humor.

Four years ago Kathie developed degenerative disk disease. Her spine began to fuse at the base of her neck and at the bottom of her back, restricting her movement and ultimately disabling her. Through Medicaid insurance, Kathie received her pain medication and also

the services of a personal attendant.

When Medicaid was cut, Kathie lost her personal attendant. “My life became very difficult when I lost my attendant,” Kathie explains. “With my attendant’s help, I could shower everyday, but now I shower maybe once in ten days. It’s hard for me. I spend two hours getting myself undressed, climbing into the shower, cleaning myself, and then dressing myself. And then I have to go to work!” Kathie laughs. “Sometimes I’ll show up wearing the weirdest outfits because I was too exhausted to put on matching clothes.”

“But I’m very lucky,” she says. Her employer, a local independent living center, provides her with private insurance, and raised her pay twice so she could afford her health costs. “There are people who are not on their medications because they can’t afford it. People with multiple sclerosis, with their nerves all messed up, and they’re in terrible pain without their shots.” Her face becomes serious, “I know a man who has not had his shot in over a year.”

But Kathie tempers the grimness with humor. “Someone asked me what we were doing in Missouri now that our Medicaid was cut,” she says. “I told them, ‘buying tombstones!’”

Kathie ticks off her monthly medical expenses: she pays two hundred dollars in copays for prescriptions; one hundred dollar installments on an electric wheelchair she purchased on her own; and ten dollar copays for Doctor’s visits. Recently, there was a computer error at a hospital she visited, and a debt collection agency charged her fifteen hundred dollars more than her bill. She paid this money, and now that the error has become apparent, the agency will not pay her back.

Things have been bad this year,” she says, “and I’m one of the lucky ones.”

Fortunately, Kathie’s insurance is covering two surgeries on her back. “I should be getting better soon,” she says, her voice filling with optimism. “I went in for the first surgery a few weeks ago, and the doctor said he pulled out the biggest cyst he had ever seen. Oh, thank the Lord, I thought.”

Kathie is currently at home, using the sick leave and vacation days she saved for two years to convalesce. Her daughter-in-law lives across the street and helps Kathie for four to eight hours a day. “She massages me so I don’t freeze up, and she helps with my mother, who lives with me.” Kathie’s mother has Alzheimer’s. “My daughter-in-law is not reimbursed for the time she spends caring for us.”

For Kathie, there are two things that are most important to her when it comes to healthcare. “We need our personal attendants,” she says. “I have to drive to work, and sometimes that’s dangerous. Out of the four people I work with who are disabled, I’m the best off. They’ve lost their personal attendants too, but still have to drive to work.”

“But the preventative medicine is the most important thing,” Kathie asserts. “If you can’t go to the doctor, then you can’t get medicine when you need it, and so you get sicker. A lot of people died because of these cuts.”

The golden years?

Helen is an elderly woman who lives in Saint Joseph with some family members. She is disabled, and lost her Medicaid coverage in 2005. Helen’s coping strategy is simple and cruel. “I will quit taking my medicine in order to survive,” she says with conviction. Helen’s household depended upon the supplementary insurance Medicaid provided to make ends meet.

Now, in 2006, Helen has gone months without seeing a doctor. “I can’t afford to see the doctor,” she admits, “and so I suffer.” Helen is on Medicare Part D, but fears she will soon lose access to her medications. “I can’t receive prescriptions from a doctor that I can’t see,” she explains. “And so, in about one or two months, I won’t be getting medications for my diabetes, cholesterol, or high blood pressure.”

Access to medicine is an issue Helen feels strongly about. “I take medicines that could cause liver and kidney problems, and that’s why I have to see a doctor every few months, to make sure the medicine saving me isn’t hurting me,” she says shaking her head. “People need their medicines. Probably a lot of people have died because they had to choose between house bills or rent or medicine or food. Many people choose not to take their medicines to afford those other things. You shouldn’t have to make those choices.”

Helen appears to be the victim of bureaucratic snafus as well. “They (Department of Social Services) had me paying fifty six dollars for spend-down, but then, three months ago, they quit taking it out. I called my caseworker and was told that if they stopped taking it out, that meant I was not covered anymore. But I didn’t receive a letter saying I wasn’t on Medicaid. And I had an injury last year, and I was on Medicaid at the time, but now I’m receiving the bills and collection agencies have been assigned to my debt.” “I’ve tried to call the Division of human health and services, but I usually can’t get through. I’ve been trying to call them for a year, but it’s always a bad time for them when I do,” she laughs a short, tired laugh. “I guess I’m between a rock and a hard place.”