

About this publication

We believe expansion of the Medicaid program offers the best opportunity for low-income working West Virginians to qualify for affordable health care. It is our hope that this publication will help in the effort to make affordable health care a reality for all our citizens.

We are grateful to Craig Robinson, Amber Crist, Karen Glazier and the other staff members at Cabin Creek Health Systems who helped us better understand the challenges of providing health care in our state.

We also greatly appreciate the guidance of Perry Bryant and Renate Pore of West Virginians for Affordable Health Care, who have long championed the cause of affordable health care and who know how health care issues affect so many in West Virginia.

We would be remiss if we did not acknowledge the work of Stephen N. Smith, whose West Virginia Healthy Kids and Families Coalition made Medicaid expansion a priority, and Ted Boettner and the West Virginia Center on Budget and Policy for helping make sense of the policy aspects of health care reform.

Finally, we thank Celena Roby, Heather Miller and Bill and Teressa Brown, who opened up their lives to offer testimony about the need for affordable health care.

Rick Wilson & Beth Spence American Friends Service Committee West Virginia Economic Justice Project March 2013

PART ONE

Trying to meet the Health Care Challenge

very Tuesday morning at 8 a.m.—before patients start to stream through the doors of the Cabin Creek Health Systems clinic at Dawes—the staff gathers for what they call a "huddle."

For the next hour, doctors, physician assistants, nurse practitioners, pharmacists, social workers, counselors and the director apply their collective knowledge and experience to some of the clinic's most challenging cases. This team approach to problem solving is both creative and reality-based—imagining how to best do what is possible for patients. At the end of the session, staff members plan follow-up: who will set up home visits or contact specialists or arrange for hospice care.

One of four clinics operated by Cabin Creek Health Systems, the clinic at Dawes has an impressive record of providing basic health care and preventive care for its patients. The medical staff runs into trouble when uninsured patients need to see specialists to confirm a diagnosis or to receive advanced treatment.

On a Tuesday morning in late February, the case brought to the huddle involved a 13-year-old girl who had injured her knee. The daughter of a coal truck driver whose family does not have health insurance, the girl was described as an athlete who

played soccer and softball. Since the injury, she had been trying to play past the pain.

An x-ray showed some abnormality in the knee, so the physician assistant (PA) adopted a conservative treatment approach, advising the girl to curtail her sports activities. She did, but the knee got worse instead of better, leaving the PA at a loss as to what to do.

"I don't know what's happening," he said. "She needs to see an orthopedist or to get an MRI."

If the girl's family had insurance, this would not be a problem. The clinic could refer her to an orthopedic specialist, who in all likelihood would order an MRI in order to ascertain the type of injury the girl has sustained and the treatment she needs. As it is, her family's income is too high for her to qualify for West Virginia CHIP (Children's Health Insurance Program), and she's too young to participate in West Virginia Connect, a health insurance program (soon to be discontinued) that operates on a sliding scale for working and uninsured adults.

"This kid is slipping through the cracks," the PA said.

Unfortunately, she is just one of many. "We have 100 cases like this one," a doctor said. "Sometimes we get them in to see a specialist, but that's only

in select cases. We're not designed to meet catastrophic needs. At times we have begged specialists to see our patients, and sometimes they will do it. But some of our patients have had to drive to West Virginia University or Marshall University because no one locally will accept them."

In this child's case, staff members decided to check with local orthopedic doctors to try to get someone to take a look at the x-ray and make a recommendation as to next steps. Staff members also will check with West Virginia Health Right, a free clinic for adults in Charleston, to see if the girl might be able to get treatment there.

The huddle reviewed some previous cases:

- A female patient had experienced symptoms suggesting she might have multiple sclerosis. Because she didn't have health insurance, the woman could not be referred to a neurologist to make a definitive diagnosis. She was left to worry about what was wrong with her. Clinic staff members made a number of calls and succeeded in getting a local neurologist to see the patient. The neurologist determined that the woman did not have MS, but was suffering from a rare spinal condition that required surgery. It wasn't a good diagnosis, but it at least gave the woman and her doctors some answers.
- Another patient who lacked health insurance had undergone a colostomy. Because he was unable to pay for the surgery, a lien was placed on his house by the local hospital where the procedure was performed. "He had anxiety before that," a doctor said. "Now he's being driven crazy by bill collectors." The man would qualify for Medicaid if the program were expanded.

• A 58-year-old woman suffering from chronic pain is a participant in the CAP program, designed for adults who do not qualify for other health programs and which is recognized locally by Charleston Area Medical Center. The patient, who has had several back surgeries, is being treated with opiates and sedatives. If she qualified for Medicaid, she also would be able to receive physical therapy and perhaps be able to reduce her dependence on the narcotics.

These cases represent just a small sampling of patients who have come into the clinic with major health issues and few resources. In many instances, they have delayed seeking medical care because they don't have health insurance.

Ensuring that all of these patients receive high quality health care is the major challenge faced by the dedicated professionals at Cabin Creek, who are in some ways making up a health care delivery system as they go along. The huddle, which draws on staff members' creativity, connections and compassion, is just one way in which Cabin Creek Health Systems utilizes a team approach to cobble together solutions for their patients.

Despite many stories that have had successful endings, however, staff members are frustrated with this random and piecemeal approach. They realize that without Medicaid expansion and full implementation of the Affordable Health Care Act, they will never be able to provide the highest quality of health care for every patient.

"People just aren't getting what they need," a doctor said. "There's just no system in place to get patients the help they need."

Why Medicaid should be expanded

he health challenges faced by many of Cabin Creek's patients are shared by thousands of West Virginians across the state. Indeed, many of the uninsured lack the good fortune of having a medical home and the services of dedicated professionals enjoyed by the former.

Ironically, many of our state's uninsured are working people. It is a paradox of the American health care system that many of those most difficult to insure—the elderly, the indigent, children, and people with disabilities—receive coverage through one of several public programs such as Medicaid, Medicare, and the Children's Health Insurance Program, while working adults without employer-provided coverage are often left to their own resources.

This gap in coverage exacts a heavy toll both on the uninsured and their families and on the public at large. In 2012, Families USA estimated that in 2010 over 26,000 adults aged 25 to 64 died prematurely because they lacked health insurance. West Virginia's share amounted to 223 early deaths, or about four per week.¹

Even aside from the loss of life and the suffering it entails, the financial costs of providing what care the uninsured receive is staggering. According to the West Virginia Hospital Association, in 2010, West Virginia hospitals absorbed \$279 million in

costs for caring for the uninsured whose incomes were below the poverty level. These costs are passed on to consumers in the form of higher premiums, adding as much as \$1,000 per year to the costs of family coverage.²

Fortunately, West Virginia is now in a position to reduce the number of uninsured residents by as much as half in one stroke of the pen by expanding Medicaid coverage to people earning up to 138 percent of the federal poverty level. This single decision by our governor would provide coverage to an estimated 120,000 uninsured working West Virginians.

Medicaid expansion was a key component of the Affordable Care Act and was originally intended by Congress to be implemented across the country. However, the United States Supreme Court in 2012 ruled the expansion to be an option rather than a requirement for states. By March 2013, 24 states and the District of Columbia had made the decision to expand, and 14 indicated opposition. The remaining states, including West Virginia, are undecided.³

As things now stand, Medicaid eligibility in West Virginia is confined to low income parents and children, people with disabilities, and people over age 65. The threshold for eligibility is very low, at around 35 percent of the federal poverty level. A

family of three, for example, can't earn more than \$7,000 per year to qualify. Expansion under the Affordable Care Act would result in the most significant increase in health care coverage since the creation of Medicare and Medicaid in 1965.

If implemented, the federal government would cover 100 percent of the costs of the expansion for three years and 90 percent thereafter. West Virginians for Affordable Health Care and Families USA report that, if enacted, by 2016 Medicaid expansion will increase economic activity in West Virginia by \$664 million and support the creation of around 6,200 new jobs.

ENDNOTES

¹ Families USA, Dying for Coverage: the Deadly Consequences of Being Uninsured, p. 2, 5. http://familiesusa2.org/assets/pdfs/Dying-for-Coverage.pdf

²West Virginia Hospital Association, Hospital Community Benefits Report 2012 (Charleston: West Virginia Hospital Association, 2012), available online at http://www.wvha.org/ WVHA/media/WVHAMedia/Media/Reports/HospitalCommunityBenefitsReport2012.pdf.

³ West Virginians for Affordable Health Care and Families USA, West Virginia's *Economy Will Benefit from Expanding Medicaid*, 7.



The Stories behind Health Care Reform



Celena Roby



Celena Roby with sons Daniel and Ryan, photos courtesy of Celena Roby.

n 2008, after she was held captive and brutally beaten in the bathroom of her own home, Celena Roby fled her life as domestic violence victim and began to chart a new course as a survivor. She escaped with \$12 in her purse and her two young sons in tow.

Celena, now 35, had been a stay-at-home mom with virtually no work experience except for a job in a grocery store deliwhen she was in high school. For eleven years, she lived in terror, every aspect of her life controlled by a man who made all the decisions, including "when I sat and when I slept."

Once out of the abusive relationship, Celena began to stitch together a new life.

A former teacher helped her rent an apartment. She worked at odd jobs, two or three at a time, to make ends meet. She celebrated her ability to take care of herself and her children, now 11 and 15. She made the first friends of her adult life. She became an advocate, her name attached to legislation (Celena's Law) that created the misdemeanor offense of unlaw-

ful restraint for abusers who hold victims against their will.

But Celena couldn't leave the past completely behind. The attack left her with serious injuries to her head and eye, and escaping the abuse meant she no longer had health insurance.

"I have health issues I still face today, long-lasting effects of domestic violence," she said.

Not long after the attack, Celena was hospitalized when she experienced numbness in her arms and legs. Her symptoms worsened, and at one point, she had to use a cane to walk.

Finally, after months of testing, she was diagnosed with Reflex Sympathetic Dystrophy, a chronic condition characterized by pain and swelling. RSD generally develops following nerve damage or trauma.

"It stemmed from my head injury," Celena said.
"I have to have a CAT scan on my brain once a year to monitor the area that was injured. And I have to have treatments in my spine twice a year for the Reflex Sympathetic Dystrophy. The treatments have given me 90 percent improvement in my mobility, but I have to do them twice a year, probably forever."

Because her out-of-pocket expenses are so high, Celena sometimes delays getting the medical treatment she needs. "It costs too much," she said. "I have to decide whether to get that or food or shoes for my kids."



Once she has had a treatment and racked up enough medical expenses, Celena qualifies for a temporary Medicaid card.

"The frustrating part is I can only get it for six months," she said. "I can go tomorrow and get a spinal treatment and meet the spending requirement. So I go to the Department of Health and Human Resources with \$5,000 or \$6,000 in bills. They approve the medical card for six months. But it expires just at the time I need the next treatment."

Celena would qualify for Medicaid if the program were expanded. She worries that other domestic violence victims may hesitate to leave abusive situations because they would lose their health insurance.

"I had never been independent," she said. "I really wanted to do it on my own. I've worked really hard, and it's frustrating that I can't get medical care."



Heather Miller with son, Tyler

Heather Miller

s a parent educator with the Upper Kanawha Valley Parents as Teachers Program, Heather Miller offers young women a wealth of information and a listening ear as they cope with pregnancy and motherhood.

"I love this job," said Heather, 36, and the mother of a nine-year-old son. "I go into homes and work with families from pre-natal to kindergarten. We do activities based on the age of the child. We also conduct screenings and help them get an idea of what to expect with their pregnancy or with their children's developmental issues."

Part of her job involves encouraging young mothers-to-be to get proper prenatal care and to make sure that their babies have their health needs met.

But Heather herself has no health insurance.

"My husband had health insurance for 20 years through his job," she said. "He does commercial and residential heating and cooling, and for years he dreamed of becoming a small business owner."

About a year ago, the couple took the leap and launched the new business. While they are confident it will succeed, one thing they had to sacrifice was health insurance. Heather, whose own job is guaranteed only for a year at a time, said she is thankful that her son, Tyler, is covered through the Children's Health Insurance Program (CHIP).

Both Heather and her husband have chronic health issues that require ongoing treatment.

"In 2005 I started having a heaviness in my

chest," she said. "People said it was probably panic attacks, but I had never felt that way before."

After a four-day stay in the hospital during which she underwent a battery of tests, she was diagnosed with sarcoidosis, an autoimmune disease in which tiny clumps of abnormal tissue form in the organs. As is common with most cases of sarcoidosis, Heather's lungs were affected.

"We had health insurance at the time, but even so I paid hospital bills for years," she said. "I still have to see a lung specialist to keep an eye on things. I have periodic chest x-rays and at times I have to take steroids."

Her husband, who is 41, has high blood pres-

sure. He also suffers from a form of osteoporosis that causes the cartilage in his joints to deteriorate faster than normal and leaves him in constant pain.

"We have no choice but to go and pay out of pocket for doctors' visits and medications because we have to have them," Heather said. "Medicaid expansion would greatly free up our income for other monthly necessities such as food, utilities, vehicle upkeep and clothing.

"Medicaid expansion would mean that families like mine who want to pursue starting their own businesses will feel freer knowing they can do so because they'll have the possibility of medical coverage," she said.

Bill & Teressa Brown

he suspected skin cancers growing on his face—especially the one at the corner of his eye—are never far from Bill Brown's thoughts. Bill, 53, works full time driving a coal truck. Unfortunately, these days he doesn't haul enough loads to pay for the health insurance his company offers its employees.

And Bill is not the only one in his family with critical health care needs. His wife, Teressa, 46, suffers from Ménière's disease, an inner ear disorder that affects hearing and balance.

The illness has become so debilitating that Teressa was forced to quit her job as assistant manager of a convenience store in the eastern Kanawha County community where the couple lives.

Not long ago, Bill was making approximately \$2,000 every other week, an income that placed him above eligibility guidelines for Medicaid. Now, with a slowdown



in the coal industry, his take-home pay has been cut in half, down to \$1,000 or less every two weeks. That's still too much for the family to qualify for Medicaid under current guidelines. Private insurance through Bill's company would cost the couple more than \$1,900 a month, leaving them unable to pay for rent, utilities or food, they say.

It has been more than a year since Bill learned about the potential seriousness of the growths on his nose and near the eye. A dentist who removed some of his teeth in May 2012 expressed particular concern about the one in the corner of his eye. Shortly after that, Bill went to Cabin Creek Health Systems for a required Department of Transportation physical examination. The doctor performing the exam also suspected cancer and recommended that Bill see a specialist to have the growths removed.

Removing them could cost as little as \$2,400 if there are no complications. However, the couple was told the price tag could be more than \$20,000

if the cancer has grown into Bill's eye or nasal cavity.

"I haven't had anything done because I just can't afford it," Bill said.

While Bill's situation causes ongoing worry and stress, Teressa's quality of life has deteriorated significantly since she was diagnosed with Ménière's in 2008.

"I went from being a person who worked 40 to 60 hours a week to a person not able to function," she said. The Ménière's episodes, which involve vomiting, dizziness, excessive perspiration and severe headaches, are occurring with greater frequency.

Teressa visited the only specialist in the state who would agree to treat her. "He wants to do injections in my ear every week for five weeks that may or may not work," she said. "There's no guarantee."

"They cost an average of \$1,500, and he said I would need \$300 cash for each visit," she said. "I

would have to be able to get all five weeks done. I couldn't take a week off. That means I would have to pay \$1,500 over the five weeks. And we just don't have it."

Medicaid expansion would mean that Teressa and Bill Brown could get the potentially life-saving medical treatment they need.

"We're not asking for a handout," Teressa said. "Let the state put us in a program so that we can pay \$25 for a doctor's visit or \$40 for a specialist. I'm begging for the health of myself and my husband."



Other Stories

Many West Virginians who would benefit from Medicaid expansion are hesitant to share their stories publicly. Here are some examples:

- A young mother of three children, all under the age of 10, owes \$8,000 in medical bills because she's had to make eight trips to the emergency room during the past four years to get relief from painful kidney stones. The woman, who has been without health insurance since she turned 18, makes only about \$400 a month, but even this minimal income puts her over the current Medicaid guidelines. As a result, she isn't able to get standard treatment to break up the stones and specialized treatment to address the underlying causes. Her only option is to keep going to the emergency room.
- A 62-year-old uninsured man who has been diagnosed with diabetes, high blood pressure and recurring kidney stones, says he is financially unable to retire and hasn't had employer-sponsored health insurance for many years. "I cannot afford to pay the high insurance premiums," he said. In 2008 his 58-year-old wife was hospitalized when she came down with Rocky Mountain Spotted Fever. "The hospital put a lien on our home for the \$20,000 hospital bill," she said. "If I can't make the monthly payment, the hospital said that they would take our house."
- A 37-year-old single mother of one daughter works full time but cannot afford the health insurance offered by her employer. "There have been many times I would just let my sickness go because I didn't have the money to pay," she said. "Or I would go and self-pay and now I have tons of medical bills against me. My mom had her first heart attack at 34. If I could afford to pay for medical coverage, I would."
 - A 54-year-old woman works as an in-home care-

- giver making \$9 an hour with no benefits. She has worked since she was 16 years old and for most of that time has had no health insurance. "I have to pay rent, utilities, food and keep a car running to go back and forth to work," she said. "I am not complaining. I am blessed compared to a lot of people who are worse off."
- A domestic violence victim has been diagnosed with hepatitis c and was recently hospitalized because of gall bladder problems. She and her son live on a total monthly income of \$1,000. The woman needs to see a specialist but can't afford it. Medicaid would allow her to get the treatment she needs.
- A 43-year-old divorced single mother works as an assistant manager for a grocery store chain. "I work 40 hours a week to pay utility bills and keep food on the table," she said. "Sometimes my paycheck barely covers that." Her employer offered health insurance, but, "by the time they took out the insurance payment and I paid the co-pays, I was in greater debt."
- A 33-year-old working woman has not had health insurance for more than five years. "I have had to go to the hospital ER and have tests at the hospital. On our limited income, I cannot afford to pay," she said. "I have had some health issues that I have not addressed because I have no insurance."
- A 56-year-old woman who is a server at a steak house describes herself as "a working West Virginia citizen who has worked all my life at minimum wage, which is a joke. I cannot afford health insurance and pay to live in my home and pay my bills. Please help the people who really need help."

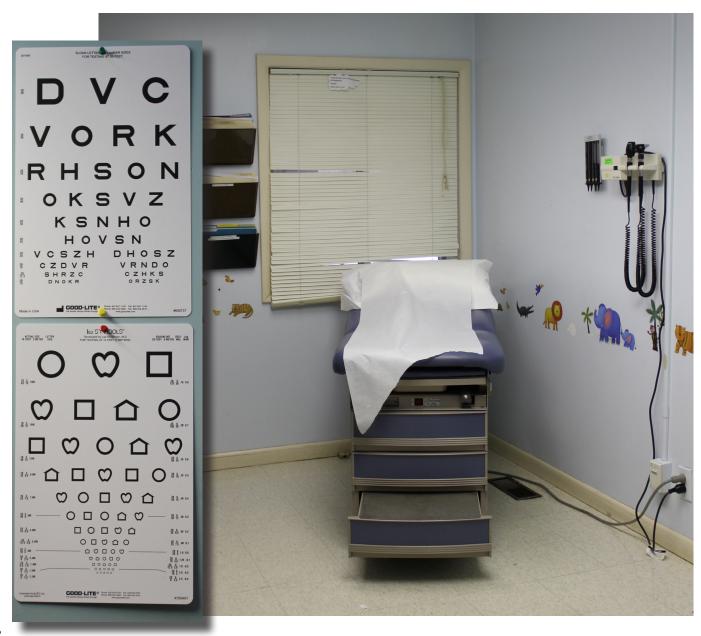
PART FOUR

Medicaid expansion: a win all the way around

y any measure, expanding Medicaid is a win all the way around. Lives will be saved and the quality of life will be improved for tens of thousands of West Virginia families.

Health care providers and other consumers will find relief from bearing the costs of uncompensated care. And West Virginia's economy will benefit from the influx of new dollars, new jobs, and a healthier workforce.

This momentous decision rests with West Virginia's governor. We hope that the information and stories of the lives of real West Virginians here will help to make that decision easier.



Affordable Health Care Resources

West Virginians for Affordable Health Care has a wealth of information on their website:

http://www.wvahc.org/

Find out if you will qualify for Medicaid Expansion or sign a petition supporting Medicaid Expansion by visiting:

http://www.medicaidexpansionwv.org/

The West Virginia Healthy Kids and Families Coalition also has many resources on their website: http://www.wvhealthykids.org/

The West Virginia Center on Budget and Policy also has valuable information about health care: http://www.wvpolicy.org

The American Friends Service Committee

The American Friends Service Committee is a humanitarian organization that has operated programs in West Virginia since the 1920s. You may reach us at:

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