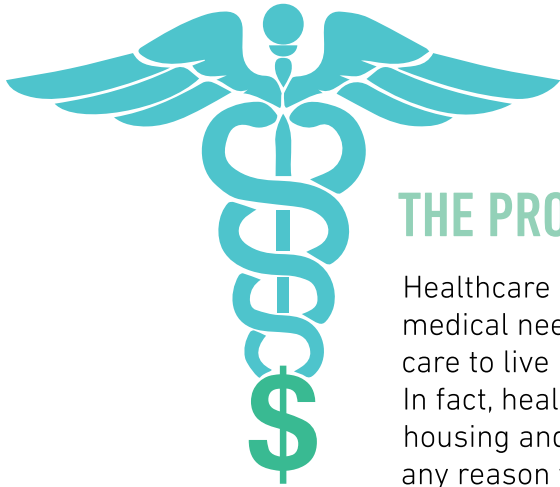


BEYOND COVERAGE:

Putting People First in Pennsylvania Healthcare



Put People First! Pennsylvania
2016



THE PROBLEM

Healthcare is a cornerstone of our lives. We all have medical needs, and we all need comprehensive medical care to live healthily, happily, and to our fullest potential. In fact, healthcare is so essential to our wellbeing that, like housing and education, it's a human right. There is never any reason to deny healthcare to anyone.

Healthcare isn't just necessary in our individual lives; it's necessary for our society. We're all better off when we all have access to dignified, quality care. A healthcare system that denies care to our friends, cousins, neighbors, coworkers, and people across town is a system that creates illness and insecurity.

Yet Pennsylvania's current healthcare system does just that: it denies people's access to needed healthcare. The result is widespread suffering in our communities. Even after the Affordable Care Act — also known as Obamacare — was passed, almost one million of us in Pennsylvania still don't have health or dental insurance.¹ Many of us have insurance, but are underinsured and still prevented from getting care by the high cost of premiums, deductibles, and co-payments. Hospitals and clinics in our communities are closing and people are being pushed into medical debt. It doesn't have to be this way.



CRISIS OF DEMOCRACY

98% of people we surveyed said that healthcare is a human right.

9 OUT OF 10 people we surveyed said that the government has an obligation to fulfill the right to healthcare.

9 OUT OF 10 people we surveyed say that the government is not fulfilling its obligation to ensure that we can all get the healthcare we need.

MORE THAN 4/5 people we surveyed feel that they have no say in the state's healthcare system.



KEY FINDINGS

HEALTHCARE COSTS ARE SERIOUSLY AFFECTING PEOPLE'S LIVES.

Over a six-month period in 2015 we surveyed 300 people in 43 of Pennsylvania's 67 counties. These findings just scratch the surface of the human toll of our healthcare crisis. We are continuing to survey people and document their stories. Here's what we've found so far.²

CRISIS OF HEALTHCARE COSTS AND ACCESS

Four out of five people we surveyed (82%) **said that last year's insurance rate increases affected their lives**, in many cases very seriously.

Almost half of people we surveyed (47%) **said that they had struggled to get care** because of the cost of deductibles.

More than two-thirds of people we surveyed (70%) said that their **health-care needs are not being met** by Pennsylvania's current healthcare system.

More than one in three people we surveyed (37%) **said that in the last 12 months alone, the cost of medical care has forced them to skip paying for basic things** like electric bills and groceries.

People reported having to make major life choices like switching jobs or staying in a relationship **in order to get health insurance**.

According to the Pennsylvania Department of Health, **12% of Pennsylvania residents reported that in the past year, they needed to see a doctor, but couldn't** because of the cost. That's more than 1.2 million people.³

The Department of Health also found that **one out of every nine adults in Pennsylvania** (16%) **are in medical debt**. That's 1.6 million people. **In Pennsylvania's Black and Latino communities, the rate of medical debt is even higher: one in four.**⁴

PROBLEMS WITH DENTAL INSURANCE

A third of people we surveyed (33%) **don't have dental insurance**.

A third of people we surveyed (35%) have **had to forego dental care because of the cost**.

14% of people we surveyed said they have developed a more serious condition because they couldn't get dental care, 11% had to skip paying for something they needed in order to pay for dental care, and 10% were forced to take on debt.

STORIES FROM OUR COMMUNITIES



“THE STRESS ON OUR FAMILY IS REALLY EXTREME. WE HAVE LIVED IN FEAR WITHOUT ADEQUATE COVERAGE FOR OUR FAMILY, UNDER CONSTANT THREAT OF COLLECTION AGENCIES.” —TAMMY

Deirdre, Columbia County:

Deirdre is a farmer and educator whose passion is growing clean, healthy, affordable food for people in her community and helping people learn about the importance of organics and healthy eating. But this last year, the premiums on her Obamacare health insurance plan were raised by so much that she was forced to stop doing this work in order to get a full-time job just for the health insurance benefit. Deirdre's stuck in a less fulfilling job, and her community has lost a source of good food and education.

Sam, South Central Pennsylvania: Sam is a young adult who has struggled to meet their dental and mental health needs. Throughout their life, they have had a lot of dental work due to natural circumstances. After finding a free dental clinic, they had work done on nearly every single tooth in their mouth — almost \$20,000 worth — but they are worried about being able to meet their needs in the future. Sam is currently on their mother's insurance plan, which covers only one cleaning and one cavity filling per year. On top of that, Sam's mother has been abusive and controlling as a parent. Sam needs to establish independence, including finding their own insurance plan, but fears losing the little care they are guaranteed under their mother's plan. On top of dental care, Sam has serious mental health needs that they haven't been able to afford to get treated. They want to seek help, and think they might even need hospitalization, but they worry because none of their options, including Medicaid, will cover the care they need. “I'm so scared to do it,” says Sam, “because the only thing I can think about is how much it's gonna cost even for one day at the hospital.”



Jairo, Allegheny County: Jairo is an undocumented immigrant from Mexico who has lived in the Pittsburgh area since 1998. He is the father of two daughters and a baby boy, a leader in the Casa San Jose community, and a restaurant worker. In 2015, he was diagnosed with gallstones and urgently needed a cholecystectomy — an open gallbladder removal. Jairo looked for help everywhere, but was denied most forms of care by discriminatory laws and policies that disqualified him because of his immigration status. After suffering through months of pain and making payments to a private insurance company that then refused to cover his procedure, Jairo applied for Emergency Medical Assistance and qualified because of the urgency of his case. Jairo had to undergo a second procedure in early 2016, but had to wait until his condition was so bad that he again qualified for EMA. Jairo is still uninsured and experiencing health problems.



Kim, York County: Kim was born with a number of congenital abnormalities, and has undergone over 50 surgeries in his life. A few years ago, Kim was laid off from his job for not making quota and realized he needed to file for disability. He spent two long years filing paperwork and going through case reviews only to have his claim dismissed by a judge who ruled that his medical condition was irrelevant. As Kim gets older it's getting more difficult for him to get around. His orthopedic shoes alone cost over \$1,000. Kim gets by on food stamps and Medicaid. Despite his struggles, Kim is a member of his township's planning council and very involved in community life.

Tammy, Philadelphia County: Just before the Affordable Care Act was initiated, Tammy was dropped from her health plan while receiving care for her second pregnancy. Her replacement coverage didn't cover basic maternity procedures. Her claims were denied multiple times. Her insurance company, Independence Blue Cross (IBX), mistakenly opened multiple accounts under Tammy's name and deposited Tammy's insurance payments into the wrong account. When Tammy's medical providers billed IBX, the company refused to pay them because it looked at her other account and said it was past due. Every time Tammy contacted the insurance company to try to figure out what was going on, she faced a lack of transparency and poor customer service. Finally, one of the customer service reps told Tammy they'd found an account under Tammy's name and social security number where all her payments had been deposited, but they said there was no way for them to move the deposits to her active account. "I had so many accounts that I completely lost track," Tammy said. "Not one person helped me. I have spent hundreds of dollars in out-of-pocket expenses. The stress on our family is really extreme. We have lived in fear without adequate coverage for our family, under constant threat of collection agencies." Tammy is now embarrassed when she and her family go in to seek care from their healthcare providers, and she worries about what all the distress from the insurance company has done to the health of her baby.

KEY PROBLEMS

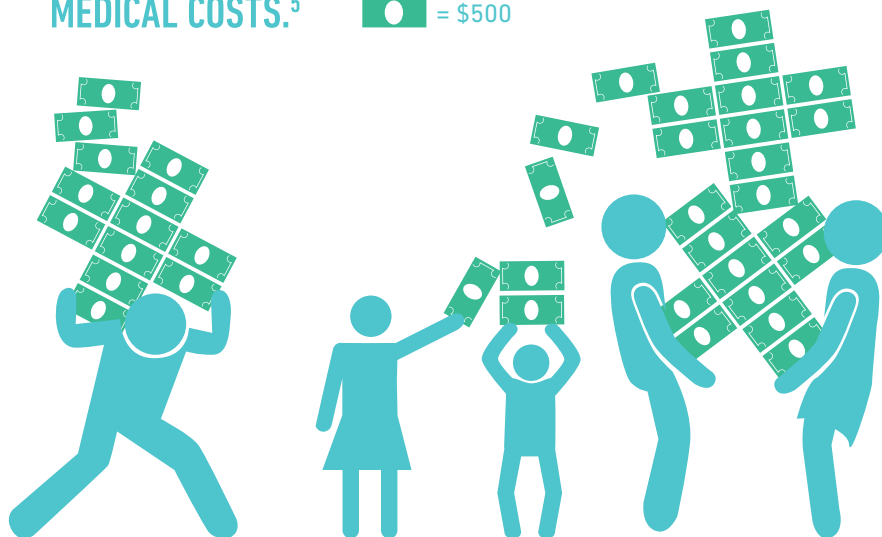
Commodifying our health:

The private health insurance system uses prices and fees to make healthcare available just to those who can afford it while putting up a barrier to everyone else. That's wrong. Our access to healthcare should depend on our medical needs, not on how much money we have.



BY LAW, INSURANCE COMPANIES ARE ALLOWED TO MAKE US PAY MORE THAN \$6,500 PER INDIVIDUAL AND MORE THAN \$13,000 PER FAMILY OUT OF POCKET EVERY YEAR ON TOP OF OUR PREMIUMS BEFORE THEY COVER ALL OUR MEDICAL COSTS.⁵

■ = \$500



Rate hikes: The Commonwealth of Pennsylvania regulates the cost of insurance plans sold on Pennsylvania's healthcare exchange. At the request of insurance companies, the State's Insurance Department approved premium increases of up to 27% in 2016. Four out of five people we surveyed (82%) said that year's insurance rate increases affected their lives, in many cases very seriously. However, the Department allowed these rate hikes to take place without holding a single public hearing to find out how these increases would affect people's lives. The following year, after eight months of organizing by Put People First! PA, the Department held the first public hearing ever on insurance rate increases in the Commonwealth. Public hearings are a step toward stronger democracy, the right to health, and economic justice, but are not enough on their own. Our government must serve our communities and the will of the people by holding private actors accountable to our rights, delivering public goods, and increasing transparency, accountability, and participation in all matters important to our lives.



Uncovered care: One of the ways that the health insurance industry makes money is by refusing to cover some of the healthcare we need. Obamacare finally forced insurance companies not to reject people for "pre-existing conditions." But most health insurance plans still won't cover dental care, mental healthcare, reproductive care, gender transition care, hearing aids, natural medicine, and many other forms of care that are part of what we need to live healthy, fulfilling lives. Currently, no insurance plans cover 100% of the care we need.

Out-of-pocket costs: Most of us who have insurance not only have to pay premiums, but also co-payments, co-insurance, deductibles, and other out-of-pocket costs that can run into the thousands of dollars. By law, insurance companies are allowed to make us pay more than \$6,500 per individual and more than \$13,000 per family every year before they cover all of our medical costs.⁵ That's on top of the premiums we already have to pay. Most of us simply cannot afford that. For those of us who are facing severe poverty, even a \$10 co-pay can prevent us from getting care. We need to remove these barriers to care by financing healthcare together through public tax dollars.



Discrimination against immigrants: More than 170,000 of us in Pennsylvania aren't allowed to sign up for Medicaid or insurance subsidies.⁶ We're being discriminated against because of our immigration status, which should have no bearing on our human right to healthcare.

HUMAN RIGHTS STANDARD FOR CARE: 100% OF COSTS COVERED

PLATINUM ACA PLAN:
90% OF COSTS COVERED

YOU
PAY:
10%

GOLD ACA PLAN:
80% OF COSTS COVERED

YOU PAY:
20%

SILVER ACA PLAN:
70% OF COSTS COVERED

YOU PAY: 30%

BRONZE ACA PLAN:
60% OF COSTS COVERED

YOU PAY: 40%

CATASTROPHIC
ACA PLAN:

UNLIMITED OUT-OF-POCKET COSTS

INSURANCE SHOULD COVER 100% OF OUR HEALTHCARE NEEDS, but no private insurance plan does. This is because insurance companies spend our healthcare dollars on corporate marketing, needless administration, and putting money in their wealthy owners' pockets. This unjust system disproportionately affects the poor, as the less you can afford to spend on insurance premiums, the more money you must pay out-of-pocket and the more difficult it is to get care.

WHAT WE NEED

There's a simple solution: universal, publicly financed healthcare. Instead of paying our healthcare dollars to private insurance companies, we could pay our healthcare dollars into a publicly financed system. All the healthcare we need would be covered, and we would be able to make decisions about our own health together with our doctors. We wouldn't have to wonder how much a treatment will cost, compare confusing insurance plans, argue with insurance companies, worry about whether our doctors take our insurance, lose our insurance when we leave a job, or pay costly co-pays and deductibles.

Financing the whole system through public tax dollars would allow us to finance it equitably. We'd all pay in what we're able and all get the healthcare we need. Our whole state would be healthier because we'd have better access to care, and no one in Pennsylvania would ever be turned away again for lack of money. In fact, under this system we'd no longer be paying for the marketing, wasteful administration, or corporate profits that insurance companies take out of what we pay for healthcare now.

“IF WE PAID FOR HEALTHCARE THROUGH OUR PUBLIC TAXES INSTEAD OF PRIVATE PREMIUMS, OUR HEALTHCARE DOLLARS WOULD GO TOWARD OUR HEALTHCARE, NOT TOWARD PRIVATE PROFITS.”

This would actually cost Pennsylvanians less than the complicated, harmful system we have today. We already spend \$145 billion for healthcare in Pennsylvania every year,⁷ or an average of more than \$11,000 per person,⁸ but much of what we spend goes to private insurance companies and drug companies rather than directly toward our healthcare.

For every \$5 we spend on premiums, insurance companies take \$1 out for themselves, which they pocket as profits and spend on wasteful marketing, administration, and overhead.⁹

This makes healthcare far more expensive in the United States than any other country on earth. We spend 16% of our national income on healthcare, almost 5% more than any other country in the world, yet because our access to care is restricted and we're not guaranteed housing, clean environments, and other basic rights, we're still less healthy than people in other countries.

If we paid for healthcare through our public taxes instead of private premiums, our healthcare dollars would go toward our healthcare, not toward private profits. With public financing, we could also finance healthcare equitably, using progressive taxation to make sure that the wealthiest people and companies pay the most into the healthcare system and the rest of us pay less than we pay now, and only as much as we're able.¹⁰ Even though we'd spend less money, with public financing, nobody would ever be denied care for lack of money, our state would be healthier, and our whole healthcare system would be more transparent, democratic, and accountable to us, the people of Pennsylvania.



HEALTHCARE IS A HUMAN RIGHT

Right now in Pennsylvania our access to healthcare depends on factors like where we work, whether we work full time, how much money we have, and which country we were born in. This discriminates against part-time, low-wage workers, non-unionized workers, poor people, and immigrants. None of these things have anything to do with our medical needs.

Like all fundamental human needs — things like clean water, healthy food, safe housing, and a good education — healthcare is a human right. Each of our human rights is necessary to our ability to live healthy, fulfilling lives. Our government has an obligation to protect our rights, but nine out of ten people we surveyed said that obligation is not being met. We've always had to fight to secure our human rights, and we must come together to organize for our right to healthcare and our other fundamental rights.



HUMAN RIGHTS PRINCIPLES

Because we all rely on the healthcare system to meet our fundamental need for healthcare, the whole system has to abide by human rights standards. Specifically, a healthcare system that respects our rights must meet five key principles:

Universality Everyone has guaranteed access to comprehensive, quality healthcare

Equity Everyone contributes what they can and gets what they need

Transparency All information related to decision-making should be clear and accessible to all

Accountability The people are able to oversee and guide how the government is protecting and fulfilling our rights

Participation Everyone has a meaningful say in how decisions get made that impact us all



CRISIS OF DEMOCRACY

Pennsylvania's healthcare crisis isn't just about healthcare: it's a crisis of democracy. It seems incredible that we'd spend so much money on a healthcare system that doesn't meet our communities' healthcare needs, but we do. In our statewide healthcare survey, 98% of respondents said that healthcare is a human right. But you wouldn't know that from listening to the news or to most politicians. There's a reason for that. The health insurance, hospital and pharmaceutical industry profits by charging us more and more money and by restricting our access to care. They also exert enormous control over the media and over politicians in Harrisburg, protecting their interests at the expense of our health, our communities, and our dignity.

OUR MOVEMENT

Universal, publicly financed healthcare isn't a policy choice; it's a moral imperative. But powerful healthcare corporations stand in the way of what's right, and politicians can't and won't make such a big change on their own. The only way to get the healthcare system our families and communities need and deserve is if we, the people of Pennsylvania, stand up, organize, and demand change.

Put People First! Pennsylvania (PPF-PA) is an organization of everyday people all over Pennsylvania who are struggling to meet our basic needs. We are a vehicle for individuals and families across the state to unite for health and dignity. We believe that until we unite, we will not have a voice.

We chose to fight for the human right to healthcare for our first campaign at our first annual Membership Assembly in Schuylkill County in 2013. We are poor and working people who have been hurt by the cruelties of the healthcare system, and we're coming together across the state and across lines of difference to build the power to change what's politically possible. The only way anyone has ever won their rights is through struggle. We are organizing together to demand that our government value human lives over industries profit. We need to put people first.



TAKE ACTION!

AS A PENNSYLVANIA RESIDENT:

Talk to your family, friends, and coworkers about healthcare.

Share your healthcare story with people you know, and contact PPF-PA to share your story more broadly.

Share this report with people you know.

Contact us at (484) 619-2306 or info@putpeoplefirstpa.org to talk about organizing a free health screening clinic or healthcare know your rights workshop in your community.

Contact us and ask for pointers on speaking with your State Senator or Representative.

Become a member of PPF-PA by going to putpeoplefirst.org/become-a-member, join a local PPF-PA organizing committee or start a new one in your community.

Follow us: *Put People First - PA* on Facebook and *@PPF_PA* on Twitter

AS A HEALTHCARE PROFESSIONAL:

Share this report with colleagues or create a human right to healthcare committee at work.

Talk publicly about barriers to accessing healthcare and about the human right to healthcare for everyone in PA.

Contact us at (484) 619-2306 or info@putpeoplefirstpa.org to partner on hosting a free health screening clinic or healthcare know your rights workshop for your community.

Contact us and ask for pointers on speaking with your State Senator or Representative.

Become a member of PPF-PA by going to putpeoplefirst.org/become-a-member, join a local PPF-PA organizing committee or start a new one in your community.

Follow us on Facebook.

Donate to the Healthcare Is a Human Right Campaign by going to putpeoplefirst.org/become-a-member.

AS A LEGISLATOR:

Meet with your constituents to hear about their experiences with the healthcare system.

Share this report with your colleagues and other legislators about the healthcare system in Pennsylvania.

Organize a hearing on unmet healthcare needs.

Support healthcare legislation that advances universality and equality.

Contact PPF-PA at (484) 619-2306 or info@putpeoplefirstpa.org to hear more about how you can work with us in moving PA forward.

ACKNOWLEDGMENTS

Put People First! Pennsylvania extends deep appreciation to Deirdre, Jairo, Kim, Sam, and Tammy for their courage in sharing their stories, and to the hundreds of people across Pennsylvania who completed surveys to tell us about their healthcare experiences. We thank the National Economic and Social Rights Initiative (NESRI), particularly Ben Palmquist, whose support was instrumental through the development of our survey and this entire report. Thanks too to Dr. Jamie Longazel, Research Associate at the University of Dayton's Human Rights Center. Finally, we extend a special thanks to graphic designer Anastasia Cook for her beautiful report design, and to Nijmie Dzurinko, Eric Shapiro, Eliel Acosta, Noah Winer, Maddie Taterka, and Sean Jin for all of their contributions.

ABOUT PUT PEOPLE FIRST! PENNSYLVANIA

Put People First! Pennsylvania gives voice to everyday people who are struggling to meet our basic needs. We define our basic needs as things we need to live healthy and fulfilling lives, like education, housing, healthcare, jobs at living wages, food, and a healthy environment. We're a membership organization made up mostly of people who know from our life experience that poor and working people need to unite and have a voice. No one else is going to do it for us. We're building, county by county, all across Pennsylvania. We're urban and rural. We're multiracial. We're politically independent. Until we unite, we don't have the power to change things.

ABOUT NESRI

In partnership with communities, the National Economic and Social Rights Initiative (NESRI) works to build a broad movement for economic and social rights, including health, housing, education, and work with dignity. Based on the principle that fundamental human needs create human rights obligations on the part of government and the private sector, NESRI advocates for public policies that guarantee the universal and equitable fulfillment of these rights in the United States.

- ¹ "In the U.S., Uninsured Rates Continue to Drop in Most States," Gallup, August 10, 2015, <http://www.gallup.com/poll/184514/uninsured-rates-continue-drop-states.aspx>
- ² For an explanation of our methods and full results from our survey, visit www.putpeoplefirstpa.org/2016surveymethods
- ³ Pennsylvania Behavioral Risk Factor Surveillance System, Pennsylvania Department of Health, 2014, <http://www.statistics.health.pa.gov/StatisticalResources/EDDIE/Pages/EDDIE.aspx>.
- ⁴ Ibid.
- ⁵ U.S. Centers for Medicare & Medicaid Services, <https://www.healthcare.gov/glossary/out-of-pocket-maximum-limit/>
- ⁶ Pew Hispanic Center, <http://www.pewhispanic.org/2014/11/18/unauthorized-immigrant-totals-rise-in-7-states-fall-in-14/>
- ⁷ According to the U.S. Centers for Medicare & Medicaid Services, Pennsylvania's healthcare expenditures were \$97.414 million in 2009. Healthcare expenditures increased at an average rate of 5.7% in the Commonwealth from 1991-2009, and are projected to increase at a national rate of 5.8% from 2014-2024. At a 5.8% rate of growth from 2009 to 2016, Pennsylvania will spend \$145 billion on healthcare expenditures in 2016. (National Health Expenditure Data, Centers for Medicare & Medicaid Services, <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/index.html>)
- ⁸ Based on Pennsylvania's 2014 population 18 years and older of 10,018,509 (U.S. Census Bureau, 2010-2014 American Community Survey 5-Year Estimates, http://factfinder.census.gov/faces/nav/jsf/pages/community_facts.xhtml).
- ⁹ U.S. Centers for Medicare & Medicaid Services, <https://www.healthcare.gov/health-care-law-protections/rate-review/>
- ¹⁰ Though Pennsylvania's constitution does not allow progressive income taxes, in which people with higher incomes are taxed at a higher rate than people with lower incomes, Pennsylvania could implement a wealth tax on unearned income from dividends, interest, capital gains, tenants' rent and other sources. Financing health care through a combination of a wealth tax and income tax would make sure that the people who benefit the most from our people, land and economy pay the most back into the health and wellbeing of our state, and that no one is ever again required to pay more into the healthcare system than they are able. (See <http://www.newsworks.org/index.php/local/essayworks/93900-how-to-create-a-progressive-income-tax-in-pennsylvania> for more on a wealth tax in Pennsylvania.) Employer taxes could also be structured progressively to make sure that big businesses pay more than small ones, and that businesses that benefit Pennsylvania by paying living wages to their employees pay less than businesses that exploit their workers through sub-living wages. (For more on progressive payroll taxes, see <http://www.nesri.org/resources/equitable-financing-plan-for-vermonts-universal-health-care-system>.)

PUT PEOPLE FIRST! PENNSYLVANIA

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