

FROM COVERAGE TO CARE:

A PEOPLE'S REPORT ON
HEALTHCARE IN NEW YORK STATE



IN MEMORY OF **CATHERINE WOLF**

(MAY 25, 1947- FEBRUARY 8, 2018)

*"I am writing this by raising my right eyebrow,
which triggers a switch,"*

Cathy explained in her final letter championing the New York Health Act, days before she died, quadriplegic and ventilator dependent, after 21 long years with Lou Gehrig's disease.

Fighting for NY Health — "the most important battle of my life"—was personal for Cathy. It meant saving money, time, anxiety, and lives—"even mine."

A fierce advocate and warm friend with an extraordinary career, including 100 scientific articles and six patents, Cathy was also a published poet. She described her struggle to give herself voice, slowly, letter by letter: "Like an ancient chiseling words in Aramaic/ I will be heard."

In this collection of testimonials, hear our voices joining with Cathy's. Hear our stories recounting pain, anguish, frustration, and fear, made worse by our current healthcare system. Hear our stories of courage, constancy, resolution, resilience — and determination to win a healthcare system that meets our collective right to health. In loving memory of Cathy and our beloved healthcare advocates who lost their lives before we could make single-payer healthcare for all a reality:

Bernard Fetterly, Candice Hildebrant, Carrie Ann Lucas, Richard Propp, and Daniel Robert. We continue this work in their memory.

INTRODUCTION

The Campaign for New York Health (CNYH) is a statewide coalition dedicated to passing and implementing legislation for universal, publicly-funded healthcare in New York State. We bring together over 150 organizations, including community groups, labor unions, seniors, people with disabilities, nurses, teachers, patients, doctors, business leaders, faith groups, immigrants, and healthcare advocates, committed to the right to healthcare. We believe healthcare is a human right that should be accessible to all of us, not just those who can afford to pay.

Through this report, CNYH is lifting up the lived experiences of New Yorkers in the current profit-driven healthcare system. These data and testimonials reveal the unnecessary distress, sickness, and death that this healthcare system inflicts on patients, families, and communities around the state. No matter where you are from or what your background, the current health system—driven by greed—hurts all of us. It is especially harmful to marginalized communities: people of color, women, immigrants, LGBTQ people, and rural populations.

This report advances a vision of the future in which healthcare is treated as a right and a public good. When our democratic process truly reflects the will of the people, we will have a system of guaranteed healthcare securely in place.

METHODS

CNYH completed 2,409 Healthcare Rights and Access Surveys with residents all over New York state. CNYH trained volunteers on how to implement the survey, and collected results in person, over the phone, and online, mostly between August 2017 and January 2019. For a full explanation of the survey methods, see nyhcampaign.org/reportmethods.



FINDINGS

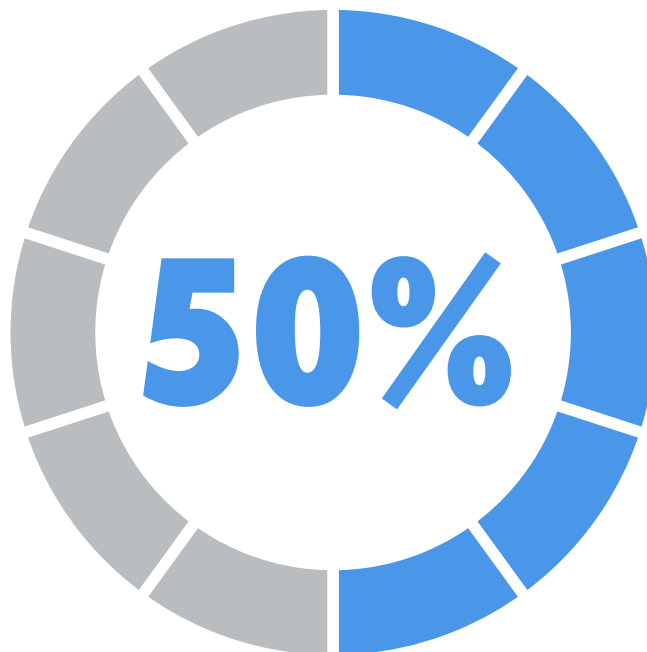
INSURED YET UNABLE TO GET CARE

Most respondents were insured at the time of responding to the survey, but **a striking number faced cost barriers and inadequate coverage that prevented them from getting medical care.** 50% of privately insured respondents reported skipping or delaying at least one type of care because of cost. Three out of four (72%) of these respondents skipped or delayed multiple types of care.

A wide variety of medical care was skipped or delayed by privately insured respondents: regular check ups (33%), prescription drugs (23%), mental health (22%), diagnostic testing (14%), and surgery (7%). Many privately insured respondents skipped dental (41%) and vision (24%), forms of care that insurance frequently does not cover.

Even those who have been most consistently insured throughout their lives reported skipping or delaying care at nearly the same rate as those with less stable insurance coverage (47% vs. 51%).

These findings reveal a crisis of underinsurance: insurance coverage is no guarantee of timely access to adequate and necessary care.



of all privately insured respondents reported skipping or delaying at least one type of care because of cost.

*My daughter has Type-1 diabetes and two other chronic autoimmune diseases which require frequent doctor appointments, labs, and daily medications. **Even with good coverage through my union, the costs are daunting.** The out of pocket costs for four of my child's medicines have each spiked up by between 241% and 2400%. We live with a constant stack of medical bills that we chip away at as we can.*

Ellen Wagget, Unionized Worker, Brooklyn



*Currently, our family has Highmark BCBS health insurance through my husband's job. Our premiums go up every year and our copays, which often exceed \$5,000 a year, are not included in our out-of-pocket maximums. **It's difficult to find in-network providers for most of the healthcare we need. Even with private insurance and a secondary Medicaid policy for children requiring special services, our family suffered severe financial difficulties, and ultimately had to declare bankruptcy.***

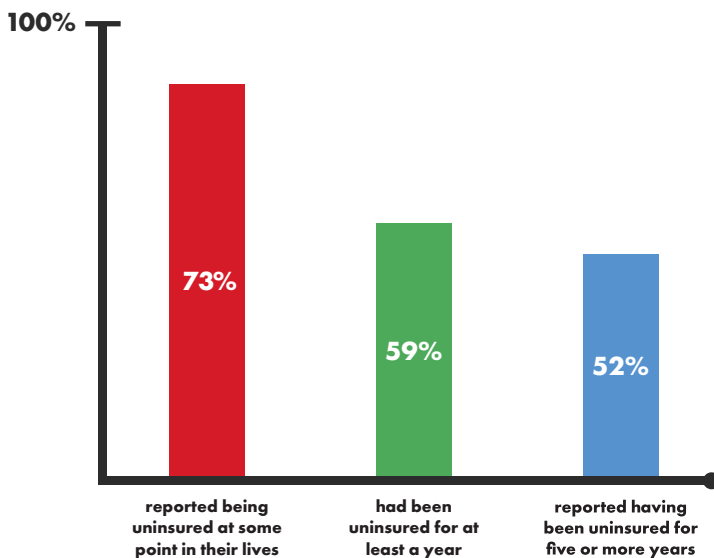
Mary Hobson, Suffolk County

UNINSURED AND INSECURE

An overwhelming number of survey respondents (73%) reported being uninsured at some point in their lives. Six out of ten (59%) had been uninsured for at least a year, and over half of respondents (52%) reported having been uninsured for five or more years. While most respondents (93%) were insured at the time of the survey, **lack of health insurance has been a fact of life for almost everyone.**

According to the U.S. Census Bureau, 1.1 million New York state residents were uninsured for the entirety of 2017,¹ and many more lost their coverage during the course of the year, when they lost or changed jobs, experienced a change in income eligibility, divorced, aged out of coverage, or lost a parent or spouse. More than 400,000 New Yorkers are barred from Medicaid, Medicare, and the individual marketplace because of their undocumented immigration status.

Without insurance, people are more likely to suffer from preventable illness, even death, and be faced with financial insecurity when struck by illness or injury.



*In 2007, I fell from a forklift and hurt my leg. **Because I was undocumented and did not have health insurance, I couldn't go see a doctor.** In 2011, I went to the emergency room for a pain in my stomach. **They removed my appendix, and I was charged \$8,000.** I made monthly payments but was only able to pay off half the bill because I lost my job due to another injury.*

Victor Hernandez, Monroe County

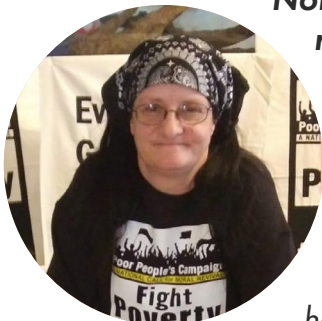


*When my husband was diagnosed with cancer at the age of 30, we had a young son, no health insurance, and an income of about \$35,000 a year. **It was only through the extraordinary generosity of family, friends, and even strangers that we were able to pay the tens of thousands of dollars that it cost to treat him.** This did not even include the lost wages from months of being unable to work, regular CT scans, blood work, and doctors visits he has needed for the last several years to stay cancer-free. **Even after we were finally able to get insurance with the Affordable Care Act, his tests and visits have not always been covered.***

Melanie O'Brien, Henderson

At a recent job working at a hotel, I was paying \$100 a week for health insurance out of my paycheck, but **I could not afford the copays for doctor visits.** I have a worsening health condition that I haven't been able to get checked out. It has become so severe that I sometimes pass out and am rushed to the emergency room. **I have thousands of dollars in medical debt, which negatively impacts my credit score.** I also suffer from an enlarged heart, a condition that runs in my family. My sister Michelle had a similar condition, cardiomyopathy, and passed away in 2004. **She was covered by Medicare, but my family still struggled to pay over \$100 a month out of pocket for her prescriptions.**

Serena Seals, Syracuse



Not being able to afford regular dental care cost me my teeth. When I could afford to pursue treatment, they were rotten enough that I had to have them pulled. There have been many times I've had to seek treatment at an emergency room. **The services weren't covered by my insurance and I got referred to collection agencies, with huge impacts to my credit score.**

Becca Forsyth, Student, Elmira

Because of the cost, I had to delay treatment for cervical cancer. By the time I could get surgery, my cancer worsened into stage 2. At that same time, **I was forced into over \$50,000 of medical debt due to my son's chronic asthma,** which required several ambulance rides and ER visits. This was during a time when I lost my Medicaid coverage, and my son and I were both without health insurance for about two years. When I was laid off, I then qualified for Medicaid. **All the debt I was forced to incur during that time ruined my credit,** so I was unable to qualify for a car loan or a basic credit card for the next 17 years until the debt was charged off. My daughter is 10 years old and her school counselor says she fits the profile for dyslexia. Not one psychologist in my Medicaid managed care company's network does testing that can diagnose her. When I call, **they tell me they do not offer testing for patients with Medicaid because of the reimbursement levels.**

Lauren Manning, Albany



When I didn't have insurance during undergrad, I put off getting a root canal for several months. The pain became so unbearable, I had thoughts of suicide. Fortunately, I was approved for Medicaid and was able to get the surgery without charge. **I put off going to the dentist during undergrad because I was no longer getting coverage through my mom, and I didn't want to pay out of pocket for expensive dental appointments.**

Robertha, Medical Student, Syracuse



When I had Medicaid, I had to wait three months to get a shoulder surgery after an accident where my whole right humerus slid behind my shoulder, severely tearing cartilage, and ligaments. I went to the emergency room with intense pain and needed an MRI but **the insurance wouldn't cover it.** After I was able to get the surgery, years later **I was insured under the Marketplace, and the surgeon I had been seeing was no longer covered.** I was able to see him again years later when my insurance changed. The surgeon recommended a biopsy for a potentially cancerous growth. **The biopsy was not covered by my insurance, and I started to get bills** several months later for about \$400. I've ignored medical bills, **but I wouldn't have been able to pay rent, or even buy food, if I had to pay for the outrageous amount of money they charge people.**

Pauline Salotti, Patchogue

THE MARKETPLACE FAILS TO MEET HEALTHCARE NEEDS

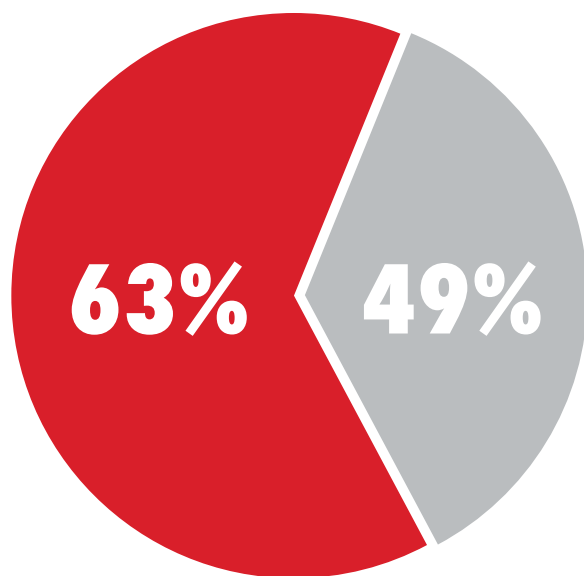
The New York State of Health, established under the Affordable Care Act, is a marketplace for people who are not eligible for public or employer-provided plans to purchase insurance.

Respondents who purchased plans through the individual marketplace were more likely than respondents insured through other types of coverage to report problems getting the care they need (63% vs. 42%) and skipping or delaying care due to cost (63% vs. 49%).

Those on marketplace plans skipped or delayed nearly all types of care at higher rates than other respondents: regular check-ups (44% vs. 30%), prescription drugs (27% vs. 23%), mental health (29% vs. 20%), diagnostic tests (23% vs. 12%), dental care (49% vs. 40%), and vision (37% vs. 24%), with nearly 40% developing more serious conditions as a consequence (37% vs. 33%).

Those with marketplace insurance plans were more likely to have problems paying medical bills (55% vs. 44%), especially paying premiums (63% vs. 26%), deductibles (55% vs. 29%) and bills out of pocket (56% vs. 38%) than those with other types of coverage.

Despite public subsidies and increased regulation, those with marketplace private insurance plans are struggling to afford and access care.



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Every year, insurance companies say they have to raise premiums. I have the least expensive plan on the Marketplace and pay \$386 monthly premium. My annual deductible is \$4,000, and last year I paid \$2,000 dollars out of pocket for treatment for an autoimmune disease and did not reach the deductible.

Katie Barrett, Retired, Marcellus

I am currently insured through the Marketplace with the least expensive Bronze plan. I pay a monthly premium to Univera for health insurance but I still have to pay out of pocket for most healthcare because the deductible is so high.

Bridge Rauch, Buffalo

THE BURDEN OF HIGH COSTS

Many respondents reported problems paying bills out of pocket (40%), deductibles (31%), co-pays (31%), and premiums (29%). Respondents in the greater New York City area were more likely than other respondents to report having problems paying medical bills (52% vs. 43%) and skipping or delaying care because of cost (55% vs. 49%). Similar findings are reflected in nationwide studies: The Kaiser Family Foundation and New York Times found that one in four adults under 65 runs into problems affording medical bills every year. Two out of three of these people are insured, yet their insurance plans' out-of-pocket costs, coverage exclusions, and denied claims make the care they need unaffordable.²

When New Yorkers don't get the right care when they first need it, they can develop more advanced, complex—and often more costly—illness, putting unnecessary strain on families, communities, and the health system. 33% of respondents reported developing more serious conditions after delaying care. This phenomenon contributes in large part to why the US has some of the worst health outcomes in the developed world. According to the Organisation for Economic Co-operation and Development, out of 37 comparable countries, the US ranks 34th in infant mortality³ and 28th in life expectancy,⁴ despite spending significantly more on healthcare than any other country.

The costs of the current healthcare system go beyond delayed care, poor health outcomes, and medical bills. A survey by Kaiser Family Foundation and New York Times found that 18% of people who are struggling to pay medical bills were unable to meet basic expenses like rent, food, and utilities. 41% had to take on a second job or work more hours, and 17% had to move or change their living situation. 59% used up all or most of their savings, and 34% took out credit card debt.⁵ **Nationwide, medical debt is the single leading cause of personal bankruptcy.**⁶

Insurance premiums for the average employer-sponsored four-person family plan in New York cost \$21,317 per year in 2017, up more than 25% since 2016, and up 55% since 2008.⁷ In 2017, the average household with employer-sponsored insurance paid \$5,878 of these premiums plus another \$3,200 in out-of-pocket costs. The Congressional Budget Office projects that insurance premiums will continue to rise at an average rate of 5% per year over the next decade,⁸ faster than workers' wages. **If lawmakers do not act to control the cost of care, both employers and workers will be paying more every year.**⁹



1 OUT OF 3
RESPONDENTS DEVELOPED
MORE SERIOUS CONDITIONS
BECAUSE OF DELAYED CARE



I was hit by a car and broke six ribs. The ambulance took me to the ER and they gave me some Tylenol and discharged me the next day even though I was in great pain.

The hospital made me sign a document that would have put a lien on my house to cover the overnight stay if the insurance would not reimburse them. In the past, **when I've visited the ER without insurance, it ruined my credit score and I couldn't get a car loan.**

Gary Bonaparte, Retired Ironworker, Syracuse



Out of pocket costs range from \$30 to \$60, which is difficult on a fixed income for the majority of people with disabilities on SSI and Medicaid. Sometimes I

have to go without muscle relaxants that people with cerebral palsy might use to control muscle spasms or water pills that take care of the swelling in my legs that accumulates

from sitting all day. I have lousy vision and

Medicaid does not cover the glasses I need so I buy readers from the drug store. Also, I have swelling in my legs from sitting in my wheelchair and I need special socks. However, Medicaid only pays for these socks for people with type 2 diabetes, not people with edema like me. **It is difficult to find a dentist who accepts Medicaid.** Because of my disability, I struggle to brush my teeth and need deep cleaning. At one time, I was unable to afford a root canal and it resulted in having a tooth pulled.

Agnes McCray, Syracuse



My husband Joe is a diabetic and on Medicare. **We paid \$6700 in co-pays on his drugs last year and will be paying more this year.**

Katie Barrett, Retired, Marcellus



In contract bargaining, our union had to take concessions on wages and other benefits in order to keep our members healthcare coverage, which was very costly to workers. If you're making \$14 or \$15 an hour, how can you afford a \$4,000 deductible?

We need to take healthcare off the bargaining table.

Ray Trudell, Retired Steelworker, Solvay

For decades, I worked for the Dutchess County School District and paid into the employer's insurance plan, never going to the doctor or using the insurance. Then in my forties, I started to develop a range of health issues. At first, Blue Cross Blue Shield would pay for the treatments that helped me, such as my chiropractor. But then, **as it started to become clear that my condition was chronic and not "fixable," they started to deny coverage for everything except my yearly physical. I am paying \$14,000-15,000 per year out of pocket for the medical treatments.**

Maria Quakenbush, Dutchess County



I currently have Medicare but went without health insurance in the past. Once I became disabled, I had to wait two years before I got Social Security Disability and Medicare. **I depleted all my funds including my 401k while waiting, I had no health insurance for 2 years and had problems getting the healthcare that I needed when I was unemployed.** When I was diagnosed with congestive heart failure, I had problems paying my medical bills and lost my house as a result. Since then, I have saved enough to buy a used trailer to live in, but I am still struggling due to the increases in Medicare premiums.

Tim Brown, Retired, Ontario County

THE HEALTH INSURANCE SYSTEM RESTRICTS CHOICE AND FREEDOM

New Yorkers who rely on insurance through an employer, spouse, or parent report not having the freedom to make significant life choices as they wish, for fear of losing insurance or access to covered providers or services. 46% of respondents with employer-based insurance and 37% of all respondents said that they have stayed in a job only to keep their health insurance, a phenomenon referred to as “job lock.” **When workers do change jobs or fulfill other obligations like caring for a loved one, they often lose their insurance coverage.**

Ten percent of New Yorkers surveyed rely on insurance through a spouse or parent. People whose insurance coverage is tied to another person are at risk of losing their coverage in the event of a death, divorce, or other life event, and may remain in unwanted or abusive relationships in order to maintain coverage. Women, children, and transgender people are especially vulnerable because they face higher rates of employment and wage discrimination and domestic violence than men. We found that 11% of women and 15% of transgender respondents rely on a spouse or parent for coverage, compared to 7% of men.



We cannot afford to provide health coverage to our staff, though it is our deep desire to do so. The costs of premiums for ourselves and for our staff would be more than our total net profit by orders of magnitude. If both of us were to work full-time on our business, we could grow it significantly, but with two small children, and a complicated health history, we must prioritize quality health insurance and therefore divide our work time. One of us is employed full-time elsewhere and our family has healthcare coverage through the employer's plan. Health coverage is a major reason for continuing to work full-time while trying to grow our business. Once we train our staff and they develop skills with us, they understandably want to work for a company that can provide them with health benefits. So, as a small business it is very difficult to retain our most valuable staff.

**Sarina Prabasi, Owner, Cafe Buunni,
New York City**

Many of my farmer colleagues work another full-time job just for the health insurance. Last year my income was low enough that I qualified for Medicaid. The insurance system causes people like me unnecessary stress and worry. With my small business, my income changes every year, so I don't know if I'll be on Medicaid or buying insurance in the future. And, when you have to reapply every year for insurance, you are constantly jumping through hoops and changing your plan. I never know if my doctor will accept the new insurance or if I will have to change doctors. I start with one specialist and I can't follow through with them the following year. **There is no continuity of care in this system and the worry of bills is always in the back of my mind.**

**Nancy Morelle, Vegetable Farmer,
New Hartford**



I work in a union shop and my employer cannot provide affordable insurance. We are chronically understaffed, so any sick leave is highly disruptive. Insurance for preventative care can help workers and employers when it's affordable or guaranteed. I haven't had teeth cleaning in 5 years due to high costs.

**Matthew Stupak, Barista, Service Employees
International Union Local 2833, Ithaca**



Health insurance costs have become prohibitively expensive for both my small company and our 18 employees. **Although the company pays half the premiums and funds the very high deductible through an HRA, some of my employees pay as much as 20% of their income for family health coverage.** When my uninsured mother had a heart attack and could not get follow up care, her delayed care created huge medical bills for our family and made her health problems worse.

Betty Warrick, Business Manager, Yorkville Sound, Niagara Falls

WOMEN, PEOPLE OF COLOR, TRANSGENDER PEOPLE MOST IMPACTED

The current health system drives health inequities in myriad ways: through uninsurance and underinsurance, inequitable distribution of healthcare resources, and a reimbursement system that favors privately insured patients and their communities. These inequities often fall along gender, race, and geographic lines. The survey revealed alarming results for women, transgender people, and people of color, communities more likely to experience barriers to healthcare.

Among the people surveyed, women were more likely than men to face problems getting needed care (47% vs. 38%), have difficulty paying medical bills (47% vs. 42%), skip or delay needed care (53% vs. 45%), and develop more serious conditions because of skipped or delayed care (35% vs. 29%).

Women are disproportionately adversely affected by the failings of the current health system. The US maternal mortality crisis is one of the most stark and tragic aspects of inequality in women's health. American mothers die at the highest rate in the developed world, and this rate has been worsening in recent years. Maternal deaths in similar nations have been decreasing in the same period. There are stark racial disparities when it comes to this crisis: Black women in New York State are four times more likely than white women to die from pregnancy-related causes, and in New York City, they are 12 times more likely to die.¹² **Inadequate access to quality, timely care throughout women's lives and a lack of healthcare resources in poor and Black communities are just some of the complex causes of maternal mortality.**

Problems reported by transgender people were also notable in the survey results. Although the number of transgender people we surveyed was relatively low (39 individuals), the overwhelming majority reported experiencing problems getting the care they needed (69%), paying medical bills (67%), skipping or delaying needed care (77%), and developing more serious conditions because of delayed care (64%). The rates at which transgender individuals skip or delay specific types of care are much higher than among cisgender people, with over half skipping dental care (62%), regular check-ups (59%), prescription drugs (54%), and mental healthcare (62%). Transgender respondents also reported struggling to afford healthcare costs at a substantially higher rate than others (67% vs. 45%).

Hispanic respondents were more likely to be uninsured (26%) than non-Hispanic ones (5%). They were more likely to have problems paying medical bills (53% vs. 45%), especially paying bills out of pocket (44% vs. 40%). Hispanic people were also more likely than others to report discrimination when trying to access healthcare (19% vs. 11%).

Although we only had 20 respondents who identified as American Indian or Indigenous, 70% have had problems getting needed care, 60% have skipped or delayed needed care, 65% had problems paying medical bills, 50% have had problems paying bills out of pocket, and 70% developed more serious conditions because of delayed care.

Discrimination is common in the health system. 14% of people of color reported discrimination in the healthcare system vs. 10% of white people. 12% of women and 36% of transgender people reported discrimination in healthcare vs. 9% of men.

Not all health providers like trans people or understand our health needs, and health insurance companies make us jump through pre-authorization hoops to access medications our doctors prescribe. Univera would not approve a testosterone patch that my doctor recommended instead of an injectable. Univera only wanted to cover the injectable because it is less expensive. The insurance companies exist to make a buck off our needs and to make money for their CEOs.

Bridge Rauch, Buffalo



My family has gone years without dental or proper vision coverage. **I didn't have insurance for short periods during my 3 pregnancies and the medical debt still follows me today.**

Sara Palmer, Buffalo



I see the challenges my clients face by not having access to quality health care coverage.

Women and children are suffering from preventable health issues because of this.

Not being able to afford necessary medication for pre-existing medical conditions impacts their mental, physical and social well-being. If we want to see an improvement in the health of our women and children in New York State, we need to ensure that every New Yorker has health care coverage. This is one action that can help address the maternal and infant health disparities that I fight every day to eliminate.

Sequoia Kemp, Certified Birth and Postpartum Doula, Public Health Worker, Syracuse



I stayed at a job that was emotionally and physically exhausting to keep my health insurance.

But even with the insurance, I couldn't afford my birth control prescriptions due to the high deductible. My depression and anxiety became more severe when I delayed mental healthcare because I couldn't find affordable treatment. My current plan does not provide reimbursements for seeing out of network providers so I pay out of pocket. The in-network options are not LGBT competent and it's important for me to see a provider that can provide care that is affirming to LGBT people and people of color.

Frances Huang, Health Educator, Brooklyn



On several occasions, I have been discriminated against in the healthcare system because of my race and because of being a Medicaid recipient. After delivering my son, the doctors wouldn't believe me when I hemorrhaged. I almost died due to blood loss. It was known that my pregnancy was high risk because of having gestational diabetes. My son was supposed to go into the NICU as part of the birthing plan but instead, we were sent home. When I go to the doctors, I feel like there is institutional racism. I am not listened to. I don't feel respected as a black woman. Most physicians do not even use my name when we meet (i.e. "Hello Ms. Manning".) I say I am in pain or experiencing certain symptoms, why don't they believe me?

Lauren Manning, Albany

HEALTHCARE WORKERS WITNESS UNEQUAL CARE

401 of the respondents (17%) work or have worked in a clinical setting, and many observed problems with the current healthcare system firsthand. **65% of these respondents report witnessing different treatments for patients based on their health insurance status.**

73% of healthcare worker respondents observed a patient delay or refuse healthcare because of costs, and 44% said that concern about the cost of care has negatively affected their relationships with patients.

Insurance status and cost dictate the type of care that patients receive and undermine the relationship between healthcare professionals and their patients.



I've seen my patients skip or stretch medications in order to save money.

This often happens with seniors on Medicare who don't have Medicaid and cannot afford their copays. If they don't have Medicare Part D, some seniors are paying \$200 to \$300 per month on medication. Some have to choose between food or medication.

*I didn't see one of my patients for five years after she retired and lost her employer-provided insurance. She came to me with a massive bump/lesion on her chest. She had stage 4 breast cancer. **With insurance and regular doctors visits, we would have caught her cancer and minimized her suffering.***

**Frances Ilozue, MD,
Family Physician, Buffalo**



I deal with insurance company obstructions on a daily basis as I try to help people with their mental health, substance use disorders and pain treatment. Most of my patients struggle with addiction and homelessness. Our practice is constantly under financial pressures because of the demand and focus on our patients getting and maintaining health insurance. The focus of my work often has little to do with being a physician. I feel more like an administrator or paperwork manager. **For my patients, a lapse in insurance or denial of a medication means an inability to access life saving treatment.**

**Sunny Aslam, MD, Addiction and Pain
Psychiatrist, Syracuse, NY**



As a registered nurse who performs bedside care in the hospital, I have seen patients delay or refuse healthcare because of cost.

Sometimes that has affected my relationship with my patients. Lapsed insurance and new brand name medications that are not covered are two examples of issues that consistently delay care, usually on discharge, increasing length of stay in the hospital.

**David Aguasca, RN,
Orange County Regional Medical Center**

LONG-TERM CARE & SUPPORT

Long-term healthcare and support services for people with disabilities and seniors who need assistance are expensive and not covered by commercial health insurance plans or Medicare. Medicaid covers many of these essential services, but it requires people to impoverish themselves to qualify for benefits. This financially devastates families and severely limits the freedom of individuals who rely on these services.

Many people try to fill these gaps in long term care by caring for their loved ones themselves, but they do so at a cost: their responsibilities at home make it difficult to maintain employment and obtain health benefits.



***I was left without an aide for a year when traditional aide services covered by Medicaid did not fit my needs.** Not having an aide is like not having the correct amount of air going into your lungs.*

Agnes McCray, Syracuse



*I help take care of my father, who has Alzheimer's, so I've been looking for flexible and part-time work, but **most part-time jobs don't offer health insurance.***

Serena Seals, Syracuse

THE SOLUTION

PEOPLE ARE READY FOR GUARANTEED HEALTHCARE

Most people we surveyed overwhelmingly support a universal, publicly financed, single-payer system, and the vast majority do not view the current healthcare system favorably. 94% believe that healthcare is a human right, and 46% state that the human right to healthcare is not protected in New York.

The overwhelming majority voiced their support for a single-payer system: 95% said that we should make sure that everyone in New York can get the healthcare they need, 91% believe that the government has an obligation to protect the human right to healthcare, and 84% support the idea of a universal, single-payer healthcare system.

A universal system of publicly funded, guaranteed healthcare, often referred to as “single-payer healthcare,” is the most equitable and affordable way to achieve comprehensive coverage for all, freedom of choice, quality care, accountability, and fair payments to healthcare providers. A health system that pays for care, not increasing profits, will save lives and money, benefiting the health of our people, as well as our whole economy.

The Campaign for New York Health is committed to creating a health system based on the following principles:

UNIVERSALITY: Everyone is included and can meet their healthcare needs.



Covers all New York state residents regardless of employment, financial status, race, age, disability, sex, sexual orientation, gender identity, immigration status, or other status.

COMPREHENSIVENESS: Full benefits and choice of provider.



Fully comprehensive, covering all medically necessary care, including dental, vision, hearing, reproductive and mental health, as determined by the patient and healthcare providers; promoting primary and preventive care and care coordination, and including long-term care and support services.



Full choice of healthcare providers, with access to all qualified providers in New York state with no restrictive networks.

EQUITY: Funded fairly, based on ability to pay, with access to high quality care assured for all New York residents. The wealthiest will shoulder most of the costs of a fairly financed healthcare system.



Incorporates community healthcare needs assessment and planning to ensure that needed healthcare services are available and accessible in every community in the state.



Public planning of healthcare facilities to assure that all residents have access to high quality healthcare in their communities.

ACCOUNTABILITY AND TRANSPARENCY: The people running the plan will be accountable to the people of New York. The plan will be run according to public policies and laws.



All policies, data, and processes related to the design, decision-making, management and operation of the plan are open, clear and accessible to all.



The plan is accountable to the people it serves, not to insurance company executives or stockholders.

PARTICIPATION: Everyone has a meaningful voice in decisions that impact us all.



The health system includes meaningful public participation in all decisions affecting people's access to care.



Inclusion of all residents in the plan guarantees the highest quality of coverage and care.

CRISIS IN DEMOCRACY: WHY DON'T WE HAVE UNIVERSAL, GUARANTEED HEALTHCARE?

Despite their overwhelming support for a guaranteed healthcare system, two-thirds of survey respondents (64%) felt they do not have a say in decisions about our healthcare system. **The political process in New York State is dominated by corporate interests—insurance companies, pharmaceuticals, and the hospital industry—who profit from the costly, dysfunctional healthcare system, deny essential care to millions of New Yorkers, and thwart the public will.**

Since CNYH started collecting data for this report, a coalition of these corporate interests has been fighting tooth and nail to sow fear and doubt about a publicly-financed and accountable healthcare system. Their lobbyists wield undue power in Albany, blocking legislation for universal, single-payer healthcare from becoming law. **We hope this report, which is intentionally rooted in real people's experiences with healthcare, helps to counter their misinformation campaign.**

CONCLUSION

This survey finds powerful evidence that New Yorkers are paying far too much for a health insurance system that is not meeting their needs. The thousands of conversations captured in this report reveal that people are both struggling to get care and pay their bills at extraordinary rates. **We simply cannot afford the status quo.**

A health system that is driven by profit—not by public health needs—cannot handle the most pressing health problems facing us as individuals and as a society. It cannot guarantee universal, equitable access to comprehensive care while controlling system-wide costs and protecting people from insurance, hospital, and drug costs they cannot afford. It is slow to respond, if at all, to the HIV, opioid, and maternal and infant mortality epidemics, the racial and geographic inequities in health, and the needs of people with disabilities. Instead, our current system duplicates services in profitable areas, while creating “care deserts” in less profitable, higher need areas. Commercial health insurance companies “cherry pick” the patients who are the healthiest and least likely to need care.

We need a health system designed to care for all New Yorkers, with special attention to meeting the needs of those who need healthcare the most.

Health insurance companies distribute the costs of New York’s healthcare system unfairly onto the sickest people and generate profits by limiting essential coverage and putting up barriers to care. They leave millions of people without comprehensive coverage like dental, vision, hearing, mental health, and long-term care. They create barriers to accessing care with co-pays, deductibles, denials, and prior authorizations.

If we cannot get healthcare when we need it the most, what is the point of having health insurance at all?

TAKE ACTION FOR THE HEALTHCARE WE NEED

NEW YORK RESIDENTS:

- 🍏 We need legislative action. Call your state legislators and urge them to support the NY Health Act.

www.nyhcampaign.org/contact_your_senator

- 🍏 Volunteer to organize your community in support of universal healthcare:

www.nyhcampaign.org/volunteer

- 🍏 Our stories are our most powerful evidence for putting the current health system on trial. We need your help. Tell us how you and your community are impacted. Together, we can demand healthcare as a human right!

www.nyhcampaign.org/story

- 🍏 For more ideas on how to get involved, go to

www.nyhcampaign.org/action

EVERYONE:

- 🍏 Did you know our fight in New York is part of a national campaign? Go to www.medicare4all.org to join the national movement to bring guaranteed healthcare to the entire country!

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ENDNOTES

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CAMPAIGN FOR

NEW YORK HEALTH

The Campaign for New York Health is a statewide coalition dedicated to passing and implementing legislation for universal healthcare in New York State. We represent over 150 community and labor organizations made up of nurses, teachers, patients, doctors, union members, business leaders, faith and immigrant rights community, progressive political organizations, healthcare advocates and providers. Healthcare is a human right that should be accessible to all of us, not just those who can afford to pay.

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