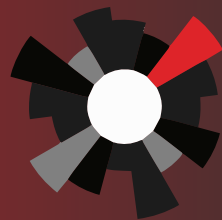


# A PUBLIC HEALTHCARE ADVOCATE FOR PENNSYLVANIA

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PARTNERS FOR  
DIGNITY & RIGHTS



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## ABOUT PUT PEOPLE FIRST! PENNSYLVANIA

Put People First! Pennsylvania (PPF-PA) 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 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 PARTNERS FOR DIGNITY & RIGHTS (FORMERLY NESRI)

Partners for Dignity & Rights believes that by building power together we can bring about a transformation in our country where all people live free and fulfilling lives. We believe in social movements and community-driven efforts that strive to ensure human rights and democracy. Our vision for human rights and democracy is broad and includes economic, social and cultural rights, as well as forms of participatory and inclusive democracy both within government and in community or worker-led institutions and programs. Because our current systems and structures breed inequity rather than human rights and democracy, we create and advance solutions and strategies for systemic change that address the intersection of racial, economic, gender and other forms of injustice.

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# INTRODUCTION

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Pennsylvania delivers great healthcare to some—the Commonwealth boasts some of the best hospitals and medical schools in the world—yet a shocking number of Pennsylvanians are denied needed care or are struggling with life-shattering medical bills. Appeals processes and legal aid are available, but the need far exceeds available support, and patients and residents at large are severely underrepresented in regulatory governance of the healthcare system. Insurance and hospital companies wield enormous information and power that enables them both to take advantage of individual patients and to bend the rules that govern the healthcare system in their favor. This situation has devastating health and financial consequences not only for patients and their families, but also for workers, employers, the state budget, and the economy at large. It also hurts legislators and public administrators, who lack effective information and tools to help constituents, to fully understand and monitor our fragmented healthcare system, and to develop policy solutions to steer things in a better direction.

COVID-19 has exacerbated each of these challenges. As of July 22, 2021, 27,813 Pennsylvanians had lost their lives to the virus and over 1.2 million had confirmed cases.<sup>1</sup> Outbreaks of the disease have hit residents and workers at nursing homes, prisons, jails, and detention centers especially hard. Fully half of Pennsylvania’s COVID deaths (more than 13,000) can be traced to nursing homes,<sup>2</sup> and state prisons are responsible for over 13,000 COVID-19 cases and 100 deaths among incarcerated residents and prison workers.<sup>3</sup> Half

of households lost a job, hours, or other income during the pandemic,<sup>4</sup> and an estimated 1,543,000 Pennsylvanians lost health insurance after they or a family member lost a job.<sup>5</sup> Essential workers like cooks, servers, and caregivers were heavily impacted by job losses. All this especially affects Black, Latinx and poor people, who are disproportionately incarcerated, whose work is undervalued, and who still face extra-high unemployment more than a year into the pandemic. <sup>6</sup>

The pandemic is a unique event, but the healthcare struggles the pandemic has helped expose are tragically routine—and all too often the direct result of the enormous power profit-driven healthcare companies hold over patients, healthcare workers and the whole healthcare system. Insurance companies deny people medical care, hospitals hand out crushing medical bills and shut down facilities without regard to community medical needs, drug companies price gouge patients and the State, and nursing-home and prison-healthcare companies understaff facilities and fail to adequately protect and treat their residents. It is nearly impossible for individuals and families to stand up to them. Existing appeals processes and regulations, though important, are not enough. Pennsylvanians need an advocate within government who can stand squarely on the side of patients, healthcare workers and the public when healthcare profiteers take advantage of people.



We propose creating a new state office housed within the Office of the Attorney General: an Office of the Public Healthcare Advocate. This state Office would be led by an appointed Public Healthcare Advocate, who with the support of their staff would play three key roles:

***Fight for Residents' Healthcare Rights:*** The Office of the Public Healthcare Advocate would investigate patterns of denied care or other forms of wrongdoing or negligence by healthcare companies affecting Pennsylvania residents, including brokering agreements with healthcare companies for the benefit of patients and recommending further investigation and litigation to the Attorney General when appropriate. It would also identify regulatory or administrative failures to regulators and lawmakers, and would represent patients, healthcare workers and the public as a class in administrative, legislative, and judicial proceedings hearings. The Office would also refer Pennsylvania residents whose healthcare rights are denied by any actor in the healthcare system, private or public, to available legal aid or, where third-party assistance is unavailable, would assist residents directly, thus providing Pennsylvanians with a single point of access to the Commonwealth's many healthcare appeals processes and legal aid resources. In all of this work, the Office would focus especially on reaching and representing communities that are systematically denied care and burdened with poor health outcomes, including people in rural communities and small cities, people who are incarcerated, people who are unhoused, people with disabilities, people of color and undocumented people.

***Advance Community Engagement and Education:*** The Office of the Public Healthcare Advocate would work with a Community Advisory Board made up of organizations representing poor and dispossessed working-class people

to create more spaces for everyday people to have a direct say in healthcare governance decisions that affect their lives, and would conduct proactive community outreach to help raise public awareness—especially in medically underserved communities—on healthcare needs, healthcare coverage, and healthcare rights. The Community Advisory Board would help collect testimony and data on residents’ healthcare experiences and would help the Office identify structural problems like cost barriers, denial of healthcare to prisoners, healthcare impacts of environmental devastation, lack of access to dental care, overbilling, insurance-rate increases, and hospital closures that affect people’s lives but that they are unable to solve on their own.

***Engage legislators and governmental agencies and hold agencies and the industries they regulate accountable:***

The Office would collect and document information on how the healthcare system is and isn’t working for people, and would report this information to the Attorney General, lawmakers and the public. It would work with the Community Advisory Board to co-produce policy recommendations for state agencies, the governor and legislature that are specifically designed to tailor healthcare benefits, processes, structures and mechanisms to meet underserved communities’ needs, and would advise legislators and agencies on drafting and implementing legislation and rules. It would help facilitate coordination and collaboration between state agencies with responsibility for different segments of the healthcare system to ensure that the State and industries are accountable to meeting the needs of Pennsylvania’s residents. The Office would initiate investigations into systematic wrongdoing or negligence, identifying regulatory or administrative failures, issuing reports and recommendations to state agencies, the governor and legislature, and, when appropriate, recommending further investigation and litigation to the Attorney General.

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**A Public Healthcare Advocate is a common-sense public solution that would directly benefit Pennsylvanians struggling to get care and would help address structural healthcare problems that people are unable to solve on their own. Institutionalizing the Advocate within government and granting them broad jurisdiction and powers—significantly broader than those of Pennsylvania’s existing advocates or ombudsmen—would, as we will argue below, increase residents’ access to care; increase community control over healthcare; improve population health; reduce harmful cost-shifting from private insurers onto patients, families, hospitals, and the state budget; increase racial equity in the healthcare system; and respond to the public’s demand for action to address rising healthcare costs and barriers to care.**

In the first section of this report, we share six stories from Pennsylvanians who have struggled with insurance companies, hospitals, and Medicaid to get the care they need. In the second, we discuss several critical problems that highlight the need for a Public Healthcare Advocate. In the third section, we highlight public advocates’ offices in Connecticut and Nevada that serve as strong models for Pennsylvania. In the fourth and final section, we lay out the details of our proposal, elaborating on the three key roles of the advocate and presenting several principles that are essential to ensuring a strong and effective Public Healthcare Advocate that is able to deliver what the people of Pennsylvania need.



# THE NEED FOR A PUBLIC HEALTH CARE ADVOCATE IN PENNSYLVANIA



**Much of the focus of healthcare reform is rightly on controlling costs and on providing a safety net for the hundreds of thousands of Pennsylvanians who remain completely uninsured, but in the Commonwealth's current fractured multi-payer healthcare system, insurance enrollment is neither a guarantee of care nor of financial security. Most people who are forced to forgo care and take on medical debt have some form of public or private insurance, yet still face problems using their insurance to pay for the care they need.<sup>7</sup>**

**Statistics reveal a breathtaking catastrophe unfolding across the state. Every year, over a million residents are priced out and forced to delay or forgo medical care. Insurance companies deny hundreds of thousands of residents' insurance claims every year,<sup>8</sup> and hospitals and other providers send more than 1.8 million residents a surprise medical bill.<sup>9</sup> More than 1.5 million Pennsylvanians are in medical debt,<sup>10</sup> and residents' total medical debt likely exceeds \$1 billion.<sup>11</sup> These statistics reveal an enormous public health and economic crisis, one that has only been heightened by the COVID-19 pandemic and by job losses and other economic pain from the recession.**

**Existing appeals processes and legal aid programs provide essential services to many Pennsylvanians, but are fragmented and underfunded, so are not reaching everyone in need, especially people who are incarcerated, people in rural counties, undocumented communities and people who are underinsured.<sup>12</sup> Nor is it enough solely to provide individual assistance to help people get the care and coverage they should have gotten to begin with: individual people are outgunned by healthcare industries. Everyday Pennsylvanians need an advocate to represent them in government and to help legislators and public administrators find ways to stop harms before they occur.**

**These statistics, however, don't demonstrate the very real pain inflicted by our current dysfunctional system. Every person represented by these numbers has a story, so we begin by sharing six stories from everyday working-class Pennsylvanians whose struggles with insurance companies, hospital companies, and Medicaid illustrate how devastating denied care and medical bills can be.**

## **Farrah Samuels, Philadelphia**

Farrah had a great job, a great home, a great family, and great health. Then after the Great Recession, she lost her home, her job, and her father all within three years. As she was working to support her family and put her life back together, Farrah was diagnosed with stage IV cancer and given three months to live.



Thanks to Medicaid, Farrah was able to undergo 18 months of treatment and fought her cancer into remission. Still, she needed ongoing medical care, so in 2011, Farrah signed up for a health insurance plan from Independence Blue Cross (IBX) on Healthcare.gov.

Farrah needed medicine, but because IBX had made multiple accounts for her, they were falsely saying that she had not paid her premium and refused to pay for her prescriptions. She spent hour after hour on the phone trying to resolve miscommunication between different departments at IBX. Finally after a pressure campaign involving months of calls by Farrah and by fellow members of Put People First! Pennsylvania, IBX escalated and resolved her case, giving her the coverage for which she had already been paying.

Then, in 2019, Hahnemann Hospital, where Farrah received her initial diagnosis and care, was closed by American Academic Health Systems in an attempt to profit off the redevelopment of the property, and without regard for the medical needs of Farrah and so many other people in Philadelphia. A Public Healthcare Advocate would help people like Farrah fight insurance companies when they refuse to fix their mistakes and would hold public hearings around hospital closures and fight for directly impacted communities.

Listen to Farrah's story in her own words: <https://www.youtube.com/watch?v=u6akmGR-I5I>



### **Kim Altland, York County**

Kim was born with congenital abnormalities that have required more than 50 surgeries. Because one of his legs is significantly shorter than the other, in order to walk, Kim needs custom-designed orthopedic shoes. In 2018, when he was on a Medicaid managed-care plan administered by Gateway Health, Kim needed to replace his old, worn-out shoes. But Gateway repeatedly denied coverage for the shoes, and there was no way Kim could afford the shoes on his own.

Put People First! Pennsylvania organized a call-in day in which dozens of people from all over the state entreated Gateway to pay for Kim's shoes. The next day Gateway relented and Kim got his shoes, but people who don't have the strong support network Kim had are not so lucky. A Public Healthcare Advocate would help people like Kim who are denied coverage for essential treatments, medicines, and medical equipment by Medicaid or by insurance companies.

Listen to Kim's story in his own words: <https://youtu.be/bosgU4mM1Bs>

## Danelle Morrow, Cambria County

In 2016, Put People First! PA member Danelle Morrow held a vigil to pay tribute to her mother, Marie Funk, and call attention to the negligent care Marie received in the last eight months of her life from Senior LIFE, a healthcare company that Pennsylvania's Medicaid program pays to provide healthcare to low-income seniors. Marie was in severe pain, but Senior LIFE's doctor insisted she needed neither medication nor diagnostic testing.

After months of pain for Marie and months of advocacy by Danelle, Marie finally received diagnostic testing and was diagnosed with cancer. Yet even then, Danelle was only informed weeks later by a doctor at another facility that Marie had stage-four terminal lung cancer and didn't have long to live.

Senior LIFE's doctor and staff had not only denied Marie pain medications and early testing: they had also treated her disrespectfully, telling her that the pain she was experiencing was only in her head. As Marie's health deteriorated, Danelle repeatedly asked Senior LIFE to provide more in-home personal care. They refused, insisting she was healthy enough to live independently at home. With no way to care for her mother at home, Danelle admitted Marie into hospice care. She died three days later.

Danelle and her family couldn't afford a funeral. The vigil they led with Put People First! PA members from around the state



provided a chance for her family and friends to say goodbye.

A Public Healthcare Advocate could have helped Danelle advocate with Senior LIFE to provide Marie with proper testing, medicine and care. If the Advocate heard similar stories from other Senior LIFE patients and families, they could initiate an investigation into Senior LIFE, recommend the Attorney General take legal action and provide recommendations to the Department of Health, Department of Aging and the state legislature on how to better hold Senior LIFE and other companies accountable so that they are not allowed to neglect patients' health in the future.

Read more about Danelle's story here: [https://www.putpeoplefirstpa.org/wp-content/uploads/2016/04/PPF-Newletter-Spring\\_Summer-2016.pdf](https://www.putpeoplefirstpa.org/wp-content/uploads/2016/04/PPF-Newletter-Spring_Summer-2016.pdf)



## **Richard Mosley, Delaware County**

Richard Mosley of Philadelphia was incarcerated for four years at State Correctional Institution (SCI) Fayette in LaBelle. Shortly after he arrived, Richard started having trouble breathing, and he wasn't alone. Prison doctors, employed by the private company Wexford Health Solutions, told Richard and other inmates who were experiencing respiratory and digestive ailments that their symptoms were psychosomatic and gave them allergy medications. Only after Richard

returned home to Philadelphia did his health begin to improve, but more than ten years later, his breathing still suffers.

After being released from prison, Richard learned that SCI Fayette was built on a toxic coal ash dump. Guards and nearby residents have been getting sick too, and between 2010 and 2013, eleven Fayette prisoners died of cancer. Richard and other people who were incarcerated had no practical way to hold Wexford or the Department of Corrections responsible for the negligent care they were receiving, nor for the environmental hazards caused by the location of the prison.

A Public Healthcare Advocate would help incarcerated people and their families appeal treatment decisions by prison healthcare companies and would provide much-needed transparency and accountability by reporting to the legislature and governor on the quality of care delivered to incarcerated people and the living and working conditions affecting the health of incarcerated people, corrections workers and neighboring residents alike.

Listen to Richard's story in his own words: <https://www.kalw.org/post/environmental-costs-prisons#stream/0>



## Summer Mills, Philadelphia

Summer Mills is a social worker who is raising four kids in Philadelphia. In the fall of 2019, Summer needed multiple root canals, a crown bridge, and a deep cleaning, but she had a problem: she had Medicaid, but the state legislature and the Department of Human Services had cut Medicaid adult dental benefits in 2011. Summer was forced to apply for a Benefit Limit Exception (BLE) with her Medicaid managed-care plan, Aetna Better Health, beseeching them to make an exception and cover her care. She was denied.

Put People First! PA took immediate action, and did a statewide call-in day to support Summer in appealing that denial. She was denied again. PPF-PA then reached out to a reporter at WHYY, who interviewed Summer and also contacted Aetna and its dental insurance sub-provider. One day later, Summer received a call saying her BLE was approved. But by that time, Summer's pain had grown so intense that she'd been forced to pay for the dental care she needed on a credit card.

A Public Healthcare Advocate would help people like Summer appeal their BLE denials, and would help address structural problems like the denial of dental care to millions of Pennsylvanians by gathering data and stories on people's dental health, holding hearings on the impact of the 2011 benefit cuts, and providing legislators with information on the medical, social and economic benefits that restoring dental coverage in Medicaid would bring.

Listen to Summer's story here:

<https://whyy.org/articles/for-adults-on-medicaid-getting-dental-care-is-an-uphill-battle/>

## Tammy Rojas, Lancaster County



In 2018, Tammy Rojas, a home health worker and long-time resident of Lancaster found out that her community's hospital, St. Joseph's Hospital, was being shut down by the University of Pittsburgh Medical Center (UPMC), its new owner. St. Joseph's (renamed Pinnacle) had served her community for 130 years, and without it, Lancaster city would be left with just one hospital.

Tammy was born at St. Joe's, her family worked at St. Joe's, and Tammy and many of her neighbors used St. Joe's for its life sustaining services like emergency care and mental health services. She knew that UPMC's decided to close the hospital based on its chase for profits, not on residents' medical needs, so as a member of Put People First! Pennsylvania she organized with fellow residents of Lancaster to fight back. Tammy and fellow PPF members attended city council meetings, met with elected officials, wrote letters to the editor, and took over a dozen public actions to call attention to the closure of the hospital and the impacts it would have on their community. Local officials voiced sympathy, but said they had no control, and UPMC closed the hospital anyway.

A Public Healthcare Advocate would help people like Tammy and communities like Lancaster city stand up to hospital giants, private equity firms and other profiteers when they buy up and shut down hospitals, clinics and other community healthcare facilities. The Advocate could help investigate community health impacts, hold hearings, summon corporate executives to testify, and make policy recommendations on how aging health infrastructure, especially in rural areas and small cities, could be maintained and modernized.

Read more about Tammy's story here: <https://www.putpeoplefirstpa.org/take-back-st-josephs-part-one-history/>



## Rica Phillips, Allegheny County

At the beginning of the COVID-19 pandemic, Pittsburgh resident Rica Phillips started having bad tooth pain. The pain got so bad that she couldn't function. "I was popping pills all day long to keep the pain away," Rica says, "and I couldn't get into see a dentist because of the pandemic. So by the time I did go in to the dentist office, the only thing they could do was pull my tooth."

Rica had already lost several teeth to diseases, and losing another one made it hard for her to eat. This difficulty eating has now given Rica intestinal problems, and one by one, more of her teeth are going bad. But because the State cut dental benefits for adults on Medicaid, Rica can't get a root canal to save her teeth, can't get dentures refitted more than once a year, and can't get all her teeth pulled at once so that her dentures would fit properly.

The pain Rica has been dealt isn't just physical. "Now I have my front tooth missing out my mouth," she explains, "and this is not just a health issue. This affects your being a person."

A Public Healthcare Advocate would help people like Rica appeal to get the dental and medical care they need, and could help provide critical information to the State and the public about how denying dental care can produce a cascade of medical, emotional and occupational problems—problems that could be entirely avoided by guaranteeing everyone dental care when they need it.





# FAILURES OF HEALTHCARE MARKETS AND GOVERNANCE

Unfortunately, these stories of everyday Pennsylvanians struggling in all sectors of the healthcare system without adequate institutional support are not exceptional. They reflect system-wide dysfunction in the following areas.

## Delayed and Forgone Care

Though uninsurance is of course a major problem facing Pennsylvanians (2.2 million Pennsylvanians are uninsured for at least a portion of each year),<sup>13</sup> most people who are forced to delay and forgo care are insured,<sup>14</sup> and people in all private and public insurance programs are experiencing problems.<sup>15</sup>

In 2016, Put People First! Pennsylvania and Partners for Dignity & Rights (then called NESRI) conducted a survey of more than 300 people in 43 counties, and found that one out of every eight respondents experienced a decline

in their health in the previous twelve months after costs forced them to skip medical care.<sup>16</sup> Four out of five of the people had insurance yet were still forced to skip care.

In a 2018 survey, Altarum found that two out of every five Pennsylvanians are forced to delay or forgo medical care every year. This was true even though 97% of those surveyed had insurance. In other words, close to half the population of the state is unable to get the care they need despite having insurance coverage. Every year, one in four Pennsylvanians skip going to the doctor or getting a medical procedure, one in four skip a medical test or treatment, one in five skip a prescription, one in six cut pills in half or skip doses of medicine, and one in ten have problems getting mental healthcare.<sup>17</sup>

There are a variety of circumstances that force people who have insurance to delay or forgo care, including gaps in coverage; prohibitively high deductibles, copays, and other out-of-pocket costs; insurance companies' denial of pre-authorizations for specific treatments; a lack of in-network specialists; a lack of in-network providers near where people live; a lack of transportation to medical providers;

a lack of linguistically, culturally and gender-appropriate information and care; difficulty understanding insurance plans' coverage, eligibility, and benefits; and jobs with no paid sick time or paid family leave. This is a complex set of problems requiring comprehensive policy solutions, but at the very least, Pennsylvanians would fare far better if they had better access to clear, accessible information and assistance with finding and navigating appeals processes, and if they had an Advocate in Harrisburg to document the nature of these problems, advocate for residents, and help legislators and public administrators develop solutions.

## Wrongful Denials of Coverage and Claims

Pennsylvania insurance companies do not release data on how many requests for pre-authorized coverage and insurance claims they deny each year, and the Pennsylvania Insurance Department, to our knowledge, neither collects nor reports this information,<sup>18</sup> but data from nationwide studies and from other states suggest how many wrongfully denied claims Pennsylvanians may be facing:

- A U.S. Government Accountability Office (GAO) study of other states found that **insurance companies deny between 11% and 24% of claims.**<sup>19</sup>
- A study of insurance claim denials in California found that **insurance companies rejected more than 26% of all claims submitted,** or

13.1 million per year. Claim-denial rates among the state's seven largest private insurance companies ranged from 5.9% to 43.9%.<sup>20</sup>

- In Maryland, a state with half the population of Pennsylvania, insurance companies consistently deny around 15.5% of claims, or 8 to 9 million claims every year.<sup>21</sup> Though many denials are due to technicalities like duplicate claims or missing information, a significant portion—some 50,000—are classified as “adverse decisions” in which an insurance company decides “a proposed or delivered healthcare service is not medically necessary, appropriate or efficient.”<sup>22</sup> If Pennsylvanians experience denied claims and adverse decisions at the same rate as Marylanders, **residents of the Commonwealth would experience roughly 100,000 adverse decisions every year.**
- In a nationwide survey, Kaiser Family Foundation and the New York Times found that one in five adults under 65 experience medical billing problems every year, and that one in four of those people had an insurance claim denied in the previous twelve months.<sup>23</sup> If those nationwide rates hold for Pennsylvania, that would mean that **1.4 million Pennsylvanians between the ages of 18 and 64 may be experiencing medical billing problems every year, including 370,000 people experiencing billing problems who were denied a claim by their insurance company.**<sup>24</sup>



When patients appeal adverse decisions, they have a good rate of success—two to three out of every five appeals are approved, the GAO found—revealing that a significant portion of denied claims are wrongful denials. Yet because complaint processes are obscure and confusing, rarely do patients contest denials. **Faced with 49,237 adverse decisions in 2016, Maryland residents filed just 5,598 grievances, leaving 89% of adverse decisions unchallenged.**<sup>25</sup>

Though figures for Pennsylvania are impossible to calculate without further data, all the available evidence suggests that wrongful denials of insurance claims affect tens of thousands of Pennsylvania

residents every year, and that few of these wrongful denials are currently appealed and reversed.

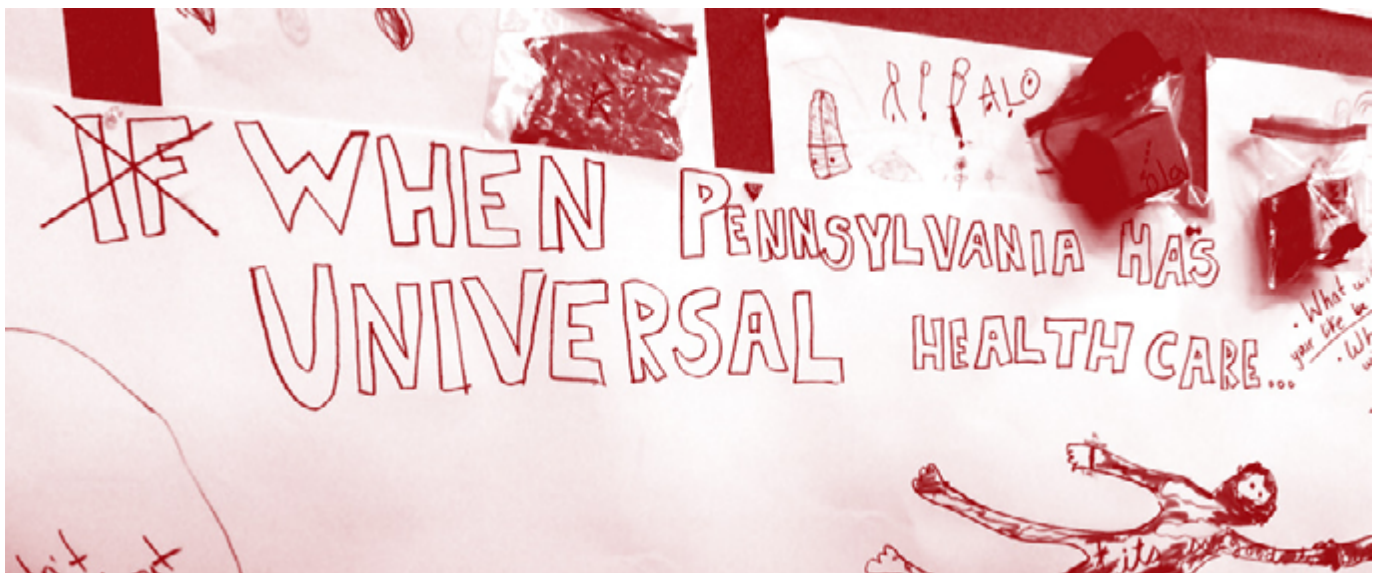
These wrongful denials force patients who are already struggling with illnesses to navigate bewildering and stressful changes in eligibility, coverage limitations, billing errors, and appeal processes, a gauntlet that far too many are unable to overcome on their own. This affects patients with chronic medical needs and their families most of all, and further erodes patients' health.

Although a number of state agencies run appeals processes, these processes are fractured, hard to find, and even harder

to navigate. When faced with an adverse decision by a major healthcare company, residents face a systematic lack of information and an imbalance of power that make it difficult to understand, much less overturn, wrongful decisions. Several nonprofit legal aid organizations and state agencies provide essential information and assistance to patients to help them navigate these processes. This is vital assistance that needs greater investment from the State. Yet the existing network of assistance is itself fragmented and insufficiently visible and accessible to most residents. As our estimates of wrongfully denied coverage and claims reveal, evidence strongly suggests that the vast majority of Pennsylvania residents who need help are neither getting legal assistance nor filing appeals.

An Office of the Public Healthcare Advocate would not replace appeals processes or existing legal aid programs.

Instead, the PHA would serve as a single point of access to legal aid statewide by referring people to assistance where it is available and by directly providing assistance to counties and populations who are not adequately served by other legal aid programs, including people in rural areas and small cities, people who are incarcerated and undocumented immigrants. In addition, the PHA would work within the government to help improve the administration of appeals. It would work with agency administrators to help better coordinate and streamline appeals processes and information resources for residents, to standardize and collect appeals data, and to help identify policy improvements for legislators to consider. Additionally, the office would work to investigate patterns and trends in claim denials for the purpose of interventions that result in greater accountability for healthcare industries and State agencies.



## **Unaffordable Bills and Medical Debt**

Far too many Pennsylvanians face impossibly expensive medical bills and medical debt. Our 2016 survey revealed that medical bills had forced more than one in three respondents to skip paying for basic needs like groceries or utility bills.<sup>26</sup> Four out of five of these people had insurance.

In its 2018 survey, Altarum found that one in three privately insured adults in the state had received a surprise medical bill in just the past 12 months, which adds up to 2.4 million people.<sup>27</sup> Residents reported being unexpectedly charged higher rates, out-of-network fees, and charges for services they did not receive. Though three in four privately-insured Pennsylvanians who received a surprise bill tried to resolve the bill with their provider or insurer, just one in eight took more than one step, and “very few reported taking actions that would escalate the issue beyond the insurer, doctor or hospital, such as: Filing an insurance appeal, Contacting a state government agency, Contacting state legislators or member of Congress, Contacting a lawyer [or] Filing a formal complaint.” Only 28% of surprise medical bills were resolved to patients’ satisfaction. Even more troubling is the fact that, as Altarum reported, “many respondents may not realize they have options for appealing these bills.”<sup>28</sup>

In a nationwide study, the Kaiser Family Foundation and the New York Times found that 44% of people with medical bill problems say the bills have had a major impact on their families.<sup>29</sup> People hit with

high medical bills report a number of major impacts on their lives:

- skipping further medical care,
- losing jobs,
- taking cuts in hours and pay,
- taking on extra jobs,
- cutting back on food and other essentials,
- having to move,
- having to stay in an abusive relationship,
- using up their savings,
- borrowing money,
- taking on credit card debt,
- sinking credit scores,
- drawing down retirement savings, and
- filing for bankruptcy.<sup>30</sup>

These financial pains both cause and amplify poverty, which currently impacts 4.7 million people in Pennsylvania who are living at or below 200% of the Federal Poverty Line, according to the Poor People’s Campaign.<sup>31</sup> They force otherwise financially stable households into poverty, and keep families who are already in poverty from being able to dig their way out. Everyone who is forced to make these kinds of decisions suffers strain on their budgets, their emotional health, and their relationships, and a foreclosing of their futures.

The State of Pennsylvania needs a comprehensive strategy to halt the rise in hospital, drug, and insurance prices and to guarantee residents the health and economic security they need, but establishing a Public Healthcare Advocate would be an excellent start. Through referrals and direct assistance, the

PHA could return tens of millions of dollars to residents every year by helping them negotiate medical bills with providers and appeal denied coverage and claims by insurance companies. Returning this money to residents would help keep people from falling down the economic ladder. As described below, in Connecticut—a state with a population less than a third the size of Pennsylvania’s—the Office of the Healthcare Advocate returned \$10 million to Connecticut residents in 2017 alone.<sup>32</sup>

## **Abusive Market Power and Hospital Closures**

Delayed and forgone care, surprise medical bills, and medical debt are often interpreted as problems for individual patients, leading to policies that promote individualized assistance like legal aid. Individual Pennsylvanians are struggling in very real, material ways, so individual assistance must be a core part of the Public Healthcare Advocate’s mandate. Yet at their root, barriers to care and spiraling prices are not individual problems, but structural ones. Individual patients and residents face enormous barriers that prevent them from engaging in regulatory governance processes to assert their needs, rights, and interests. Healthcare companies, on the other hand—especially insurance and hospital companies—wield enormous financial resources that they use to hire lobbyists, commission studies, and otherwise assert themselves in rulemaking and other regulatory processes. Just as individual patients face enormous disparities in information and power when faced with an adverse decision by an insurance or hospital company, patients and residents as a whole face information, time, and financial barriers that prevent them from asserting themselves in markets and in regulatory governance.<sup>33</sup> This gross underrepresentation of patients and residents in healthcare governance is why





Pennsylvania needs an official state Advocate to fight for patients and residents as a class.

The oligopolistic distortions of healthcare industries' power in markets and in regulatory governance is clearly illustrated by industry agglomeration, hospital closures, and problems in the nursing-home industry.

Over the last several years, both the hospital and insurance industries have made headlines for a historic wave of mergers and acquisitions that have consolidated ownership—and thus market power—among a handful of industry giants. The University of Pittsburgh Medical Center (UPMC), for example, controls 40 hospitals, 800 clinics, 30 senior communities and 92,000 employees, making it the largest private employer in the state.<sup>34</sup> In Western Pennsylvania it not only dominates the hospital sector, but also insurance: it is the single-largest private insurance, Medicare Advantage, and Medicaid HealthChoices insurance company across Western Pennsylvania, and is now the third-largest health insurance company in the state.<sup>35</sup> Through hospital buyouts and other moves, UPMC is extending its control across Central Pennsylvania too, and it is hardly the only hospital or insurance company extending its reach.

This corporate consolidation gives a few giant health care companies enormous market power, enabling them to drive up healthcare prices,<sup>36</sup> take advantage of patients, force doctors to affiliate with them, and lobby for favorable rules and regulations.<sup>37</sup> The Pennsylvania Attorney General has sued the University of Pittsburgh Medical Center (UPMC), for example, alleging that UPMC violated its nonprofit status by discriminatorily pricing patients out of care by “demanding up-front payments in-full from all Out-of-Network patients,” “transferring



medical procedures to its higher cost specialty providers,” and acting “in callous disregard of the treatment disruptions and increased costs suffered by its patients.”<sup>38</sup> Nor are the insurance and hospital industries alone: healthcare industries from pharmacy benefits managers to medical device manufacturers to diagnostics labs and dialysis clinics are all consolidating market power.<sup>39</sup>

More and more healthcare companies, including hospitals, nursing homes, and many of these other industries, are being bought up by private equity firms. These firms have no commitment to healthcare nor to Pennsylvania communities: their commitment is to their shareholders, and their goal is simply to squeeze healthcare workers, patients, and residents to extract profits. Yet as significant as they are, these buyouts have received too little legal scrutiny. Legislators and the public do not have enough information to properly understand them, and face pressure from industry lobbyists. Workers, patients, and community members who are affected have no effective way to engage in public decision-making about how healthcare providers should be owned, bought, and sold.

Meanwhile hospital companies have shut down hospitals in Ashland, Lancaster, Peckville, Philadelphia, and Sunbury, and for years have been closing and consolidating obstetric and other hospital units around the state.<sup>40</sup> Residents and healthcare workers in each of these communities have been deeply affected by the decision to close these hospitals,

yet have not had adequate voice in these decisions nor adequate assistance to find new sources of care. According to researchers at the University of North Carolina, at least five more Pennsylvania hospitals in rural areas alone are at high risk of being closed.<sup>41</sup>

Mergers, acquisitions, and buyouts are examples of structural features of Pennsylvania’s healthcare system that are creating problems for patients, healthcare workers, and the whole state, but which individual people who are affected are in no position to solve. Individual legal aid cannot help people who are denied care or forced to pay higher prices because of these and other structural problems, nor are almost any individuals able to successfully engage in existing regulatory decision-making processes, which privilege highly technical legal and economic knowledge over other forms of expertise. Even state officials suffer. Regulatory authority is so fragmented across state agencies that administrators are hamstrung in their abilities, and legislators and their staff do not have the time to cobble together and analyze information from so many agencies and industries, which is neither forthcoming nor clear.

Pennsylvania needs an Advocate institutionalized in the state government to advocate on behalf of patients, healthcare workers, and residents in regulatory matters, to document and report vital information and recommendations for legislators, and to help agencies coordinate across their fragmented jurisdictions.

## Economic Toll on Communities and the State

Insurance and hospital industry practices ranging from individual denied claims and overbilling to systemic abuses of market power take a cumulative toll on public health, workers, employers, the state budget, and the economy at large.

As noted, in our 2016 survey we found that one in eight respondents' health declined after costs forced them to delay or forgo care. A significant portion of Pennsylvanians thus needlessly suffer poor health, forcing people to live through pain and reducing people's productivity as workers, community members, and caregivers. The Kaiser Family Foundation/New York Times survey found that 29% of people who are struggling to pay medical bills end up losing a job or having to take a cut in hours or pay.<sup>42</sup> Job losses, income losses, and lower worker productivity not only harm affected workers, but also

employers, the statewide economy, and the state's tax revenue. The Centers for Disease Control and Prevention reports that "indirect costs of poor health including absenteeism, disability, or reduced work output may be several times higher than direct medical costs" and that, on average, "productivity losses related to personal and family health problems cost U.S. employers \$1,685 per employee per year."<sup>43</sup>

In addition, the wrongful denial of claims by insurance companies directly and indirectly shifts costs onto public programs. Overall, hospitals in Pennsylvania absorbed \$761 million in unpaid medical bills in 2017,<sup>44</sup> more money than the entire budget of the Pittsburgh public school system.<sup>45</sup> Although many of these costs cover care for people who are uninsured, a significant portion no doubt arise from patients who have insurance but have had a claim denied or been hit with a surprise out-of-network bill for anesthesiology



or another treatment. Hospitals shift these costs by charging higher prices to other patients' insurers (which ultimately raises insurance premiums for workers, families, and employers) and also onto the State, which directly and indirectly covers uncompensated care through the Tobacco Settlement Fund, Medicaid, county and municipal health departments, and public assistance programs. The Kaiser Family Foundation estimates that nationwide, state and local health and public assistance programs cover, on average, 32% of public spending on uncompensated care, and Medicaid covers another 25%.<sup>46</sup>

Rather than investing money in Pennsylvania's public health and economy, the State is stuck spending money to ameliorate damage that should never have occurred in the first place. A Public Healthcare Advocate could help document the public health and economic toll of harmful healthcare industry practices and agency failures and inefficiencies, report this information and policy recommendations to legislators, and, through referrals and direct assistance for patients, could return millions of dollars to residents and the State. As described below, Connecticut's Office of the Healthcare Advocate returns millions of dollars to Connecticut residents every year by helping them appeal denied coverage and claims, and has saved the state's Medicaid and CHIP programs millions of dollars by holding insurance companies accountable to paying their enrollees' claims.<sup>47</sup>



## Public Action Thwarted by Lack of Information and Bureaucratic Complexity

Given the ever-growing cost of care and its devastating effects, it is no wonder that healthcare is voters' single biggest concern. An October 2018 poll by the Kaiser Family Foundation found that 71% of voters name healthcare as a "very important" priority, placing healthcare ahead of the economy, jobs, gun policy, and immigration as voters' single most important issue. The high cost of care, in particular, is a worry that resonates with voters of all political stripes—Republican, Democratic and Independent. Voters want solutions, and with Congress unable to deliver, they are looking to state legislatures for action.

Institutionalizing patient and public voices in healthcare governance is essential to counteract the enormous disparities of information and power controlled by insurance, hospital, and other healthcare companies, which enable them not only to take advantage of individual patients, but also to shape the whole healthcare system in ways that drive up healthcare prices, deny care, and otherwise harm people across the state.

Legislators hear from constituents about healthcare problems all the time, but, like residents, are hampered by not having a single, clear office to which they can refer people.<sup>48</sup> On a policy level, the fragmentation of healthcare makes it too difficult for legislators to amass adequate information to fully understand the complex operation and

regulation of the healthcare system, much less to develop effective solutions. And in a time of widespread public anger and distrust in public institutions, an effective, visible public advocate would also help restore public faith in public officials and state government.<sup>49</sup>

Public administrators, meanwhile, are burdened and hamstrung by the fragmentation of responsibilities across the multi-payer insurance system and many different kinds of providers. For example, at least eight different state agencies regulate one or more health insurance sub-sectors, operate a complaint or appeals process for patients, provide information and direct assistance to patients, and/or collect data on and recommendations for improving healthcare system:

- The Pennsylvania Insurance Department (PID) regulates most private health insurance plans, provides information to residents on insurance companies' internal appeal processes, and operates a complaint process;
- The Department of Human Services (DHS) operates Pennsylvania's Medicaid program, handles appeals on denials of Medicaid enrollment or care, and adjudicates some denials and disputes reported to the Department of Aging;
- The Department of Aging runs a free health insurance counseling program (APPRISE) for Medicare patients and the Long-Term Care Ombudsman program;

- The Department of Corrections' Office of Inmate Grievance and Appeals runs a grievance process for people incarcerated in state prisons, working with the Bureau of Health Care Services to evaluate healthcare grievances. Since 2016, the Department has also maintained an Office of Health Care Systems Advocate and Office of Mental Health Advocate to assist incarcerated people in filing healthcare grievances.
- The Department of Labor and Industry (L&I) regulates workers' compensation insurance, covering people with work-related medical needs, and manages a complaint process;
- The Department of Health regulates managed-care plans, funds and oversees county and municipal health programs, and collects health statistics, among other activities;
- The Department of Drug and Alcohol Programs oversees county-level drug and alcohol treatment programs, including grievance and appeal processes operated by county authorities;
- The Attorney General runs a complaint process investigating reports of provider abuse and fraud in Medicaid; and
- The Patient Safety Authority reports on and makes recommendations to improve patient safety across the state's healthcare system.

This is, to our knowledge, an accurate and fairly comprehensive picture of healthcare regulation in Pennsylvania, yet in our months and years of research leading up to this report, and our many interactions with state officials, we still find the regulatory regime immensely labyrinthine, opaque and confusing. Individuals struggling to understand how decisions are made and where they can go to advocate for themselves barely stand a chance.

Given this fragmentation and complexity, policy solutions that focus on providing individuals with more information and options backfire by adding to the information overload and bureaucratic complexity that already overwhelm people. They also fail to acknowledge and address the systemic challenges—imbalances of information, legal knowledge, time, and money—that prevent the overwhelming majority of individuals from engaging in administrative governance. Pennsylvanians need a single clear and trusted point of access for individual information and assistance, which will help them understand their situations and appeal wrongfully denied claims across the entirety of the health insurance system. These forms of support must be housed in the office of a permanently institutionalized advocate who can speak on behalf of people's collective needs and rights in administrative processes and policymaking.

In short, legislators lack the information and tools they need to help constituents and understand and monitor the full breadth of the healthcare system and

also face pressure from industry lobbyists; public administrators suffer from fragmented jurisdiction and inadequate assistance with cross-agency coordination; and residents suffer both individually and collectively as they struggle to appeal claims and advocate in healthcare governance decisions that affect their lives. In the face of all this—and even more so during the pandemic and sudden recession—residents desperately need help getting care and getting their bills paid, voters are demanding action, and public officials need better information and new tools. A Public Healthcare Advocate holds the promise to meet voters’ demand for action with a solution that delivers real benefits to constituents and lawmakers alike.



# MODELS FROM OTHER STATES

A public advocate is a proven model for promoting accountability and effectiveness in both public and private healthcare systems. Pennsylvania already has advocates, ombudsmen,<sup>50</sup> and commissions that advocate on behalf of the public and/or assist people with complaints in several policy arenas, including the Long-Term Care Ombudsman Program and Child Advocate (both housed in the new Office of Advocacy and Reform), the Patient Safety Authority, the Pennsylvania Office of Consumer Advocate (for utilities), and the Pennsylvania Human Relations Commission (covering discrimination in employment, housing, commercial property, education and public accommodations). These programs each hold lessons for the Public Healthcare Advocate, but are significantly narrower in scope and weaker in powers than the Advocate we are proposing.

Several other states—California, Connecticut, Maryland, New York, Nevada, North Carolina, Ohio, Texas, and Vermont—have some version of a public advocate who assists patients with their health insurance plans.<sup>51</sup> These states' models vary significantly, however, and two states' offices, Connecticut and Nevada, stand out as especially robust, effective offices that have made a substantial difference in residents' lives.

# CONNECTICUT'S OFFICE OF THE HEALTHCARE ADVOCATE

Connecticut's Office of the Healthcare Advocate (OHA) was created by statute in 1999. In the years since, the Office has established itself as an indispensable resource for the public and for lawmakers.

Since 2005, the OHA has provided direct assistance on over 69,000 cases for residents. In so doing, it has returned over \$117 million to residents by helping them secure insurance coverage and dispute insurance companies' wrongful denials of their claims.<sup>52</sup> In 2018 alone, the OHA fielded 5,000 calls and complaints from the public and, by helping patients to dispute erroneous bills and appeal wrongfully denied claims, returned \$13 million to Connecticut residents.<sup>53</sup> With a population three to four times as large as Connecticut, Pennsylvania could expect a similarly structured Office of the Healthcare Advocate to return over \$40 million a year to state residents.

This direct patient assistance also saved the State of Connecticut over \$7 million since 2012, and an average of \$1 million a year from 2016 through 2019.<sup>54</sup> The OHA has also worked to assist the legislature, governor and state agencies to improve systems and policies by collecting and reporting data, responding to requests for information, tracking and testifying on bills, and reducing cost shifting from private insurance companies to the State.

All this has established the Office as a trusted resource among the public and lawmakers from both parties. As the Altarum Center for Value in Health Care reports, "The office receives widespread support among the state legislature. The OHA is considered a trusted resource that legislators and their staff can turn to for information."<sup>55</sup> Staff in the Office of the Healthcare Advocate report that they have also earned respect from across the executive branch and from the Connecticut public at large.<sup>56</sup>

The OHA is led by the Healthcare Advocate, who is recommended by an advisory committee, nominated by the governor and confirmed by the legislature to a 4-year term. The Healthcare Advocate oversees a staff of lawyers and other professionals. It began with two staff members at the Office's outset and has grown to 19 staff today.<sup>57</sup> Though administratively housed within the Connecticut Department of Insurance (DOI), the OHA has been insulated from DOI oversight to ensure its effectiveness as an industry watchdog. The OHA is not funded through the appropriations process, but rather through an earmarked fund financed by an assessment on all companies selling health insurance plans in the state.



# NEVADA'S OFFICE OF CONSUMER HEALTH ASSISTANCE

Nevada's Office of Consumer Health Assistance (OCHA) was created in 1999. It was initially created to help injured and ill workers appeal adverse decisions by workers' compensation insurance companies, but the legislature has expanded its role significantly over time.<sup>58</sup> The Office now assists people who have insurance through an employer, managed care, individual insurance plans, workers' compensation, Medicare, Medicaid, or the Public Employees' Benefits Program as well as people who are uninsured.<sup>59</sup> OCHA also houses two special offices: the Bureau for Hospital Patients, which mediates and arbitrates medical billing disputes between patients and hospitals, and the Nevada Office of Minority Health and Equity, which works with community partners to advocate for and conduct public education with people of color, people with disabilities, and LGBT people, all communities confronted by unique barriers to care.<sup>60</sup> The Office is housed within the Department of Health and Human Services, and the Advocate is appointed by the governor.

OCHA is financed through a mix of funding streams. The Bureau for Hospital Patients is funded by a tax assessment levied by the Advocate on private hospitals with more than 49 hospital beds.<sup>61</sup> The portion of the Office's costs associated with assisting people with workers' compensation is funded through workers' comp taxes assessed by Nevada's Division of Industrial Relations, and the portion associated with assisting people with Medicaid is drawn

from Medicaid funds. OCHA also receives an allocation from Nevada's tobacco settlement fund and sometimes secures federal grants. The remainder of the Office's remaining budget is appropriated by the legislature from the State General Fund.<sup>62</sup>

Over the last four years (FY 2016-2019), OCHA fielded 49,862 inquiries from residents, providing them with information and referring them to services. In 10,519 cases, OCHA provided people direct assistance to help them resolve insurance and billing problems and to get care at out-of-state hospitals for rare diseases.<sup>63</sup>

The Office enjoys broad support from legislators. In recent years, the Legislature has passed at least three bills by unanimous or near-unanimous votes that have further institutionalized the Office and expanded its purview and powers.<sup>64</sup> Legislators routinely refer constituents to OCHA, and OCHA staff work with legislators to help draft legislation.<sup>65</sup> "The office does great work and a great job of helping people," said Assemblywoman Ellen B. Spiegel in a recent Assembly hearing before relating a story about a constituent who "had recently changed insurance companies and was having problems finding an in-network provider who could continue his care, chemotherapy, and cancer treatment." The Assemblywoman's office passed along OCHA's phone number, and OCHA soon helped the constituent secure a same-day appointment with an in-network medical provider.<sup>66</sup>

# A PUBLIC HEALTHCARE ADVOCATE FOR PENNSYLVANIA



# The Role of the Advocate

The Office of the Public Healthcare Advocate would hold three core mandates: to fight for residents' healthcare rights, advance community education and engagement, and engage legislators and government agencies and hold agencies and the industries they regulate accountable. The Public Healthcare Advocate would lead this work with support from staff and from a Community Advisory Board (as described further on page 43-44). The Office of the Public Healthcare Advocate would be housed within the Office of the Attorney General and would report to the Attorney General.

## Fight for Residents' Healthcare Rights

- **Investigate, Document and Report:** The Office of the Public Healthcare Advocate would investigate patterns of wrongdoing or negligence by healthcare companies and regulatory or administrative failures that harm Pennsylvania residents. In its investigations, the Office would be authorized to compel data and information sharing from public agencies and private companies, broker agreements with healthcare companies on behalf of patients and residents, independently initiate investigations, and, when called for, recommend further investigation and litigation to the Attorney General. The Office would report to the Attorney General, but would also consider investigating problems identified by legislators and the Community Advisory Board. The Office would be required to publish annual reports as well as special reports sharing findings from investigations. These reports would be submitted to the Attorney General and also the governor, legislature and Community Advisory Board, and would be made available to the public.
- **Advocate:** The Office of the Public Healthcare Advocate would advocate for patients and residents as a class in administrative, legislative and judicial processes, including participating on commissions, councils, committees, boards, working groups,

hearings, and other bodies. The Advocate would represent patients, healthcare workers and the public in these proceedings and would also work with community-based organizations to bring more everyday people into governance to advocate for their own rights, needs and interests

- **Refer and Assist:** The Office would refer Pennsylvania residents whose healthcare rights are denied by any actor in the healthcare system, private or public, to legal aid. The Office would thus not replace any existing appeals processes or legal aid services. In communities underserved by existing services, such as in rural communities and small cities and among people who are incarcerated, the Office would provide assistance directly. All Pennsylvania residents would be eligible to receive information, referrals, or assistance regardless of immigration status, housing status, native language, or any other factor. The Office would provide people with referrals and assistance for all manner of healthcare problems, including problems with public or private insurance plans (including employer-sponsored plans, individual plans, workers' compensation, Medicaid, Medicare, public-employee plans, etc.), with lack of insurance, or with a hospital, clinic, senior home, pharmacy, or any other kind of healthcare provider. The Office would also accept inquiries and complaints from minors as well as surrogates calling on behalf of the patient. By providing both referrals and direct assistance for all healthcare problems residents are facing statewide, the Office would thus provide Pennsylvanians with a single point of access to the Commonwealth's many healthcare appeals processes and legal aid resources.
- **Advance Equity and Inclusion:** In all of its work, the Office would focus especially on reaching and representing communities that are systematically denied care and burdened with poor health outcomes, including people in rural communities and small cities, people who are incarcerated, people who are unhoused, people with disabilities, people of color and undocumented people, and non-union healthcare workers.

## **Advance Community Engagement and Education**

- ***Co-Create Spaces for Participatory Governance:*** The Office of the Public Healthcare Advocate would work with a Community Advisory Board made up of organizations representing poor and working-class people to create more spaces for everyday people to have a direct say in healthcare decisions that affect their lives. Together, they would develop and convene public hearings and other mechanisms designed to give people—as patients, healthcare workers and members of the public—the ability to play a role in shaping both policy and operational decisions that determine things like which public health needs receive public funding and where hospitals and clinics are opened or shut down. The participatory governance mechanisms would enable residents to testify about their healthcare needs and experiences, identify pervasive problems, shape policy priorities, and help hold both healthcare companies and public agencies to account.
  
- ***Conduct Proactive, Targeted Community Engagement:*** The Office of the Public Advocate and Community Advisory Board would collaboratively develop and execute public education, outreach, and engagement strategies to help raise public awareness on healthcare access, healthcare coverage, and healthcare rights, focusing especially on medically underserved communities including people in rural communities and small cities, people who are incarcerated, people who are unhoused, people with disabilities, people of color and undocumented people, and non-union healthcare workers. The Office would provide grants to community-based organizations to conduct outreach and education activities.

## **Engage Legislators and Governmental Agencies and Hold Agencies and the Industries They Regulate Accountable**

- ***Document and Report:*** The Office of the Public Healthcare Advocate would assist public officials by collecting and documenting information on how the healthcare system is

and isn't working for people and reporting this information to the Attorney General, lawmakers, regulators and the public. The Office would focus on documenting systematic healthcare problems affecting Pennsylvanians that people are unable to solve on their own such as barriers to care, access to dental care, overbilling, insurance-rate increases, hospital closures, healthcare access and quality in state and local prisons and jails and environmental health. In conducting its research, the Office would work with the Community Advisory Board to develop participatory research approaches to collaboratively and effectively document residents' healthcare experiences and to help the Office identify under-reported dynamics, regulatory or administrative failures, and policy priorities. The Office would provide grants to community-based organizations to conduct research including collecting data and recording testimonies.

- **Issue Recommendations and Advise on Policy:** The Office of the Public Healthcare Advocate would work with the Community Advisory Board to co-produce policy recommendations that are specifically designed to tailor healthcare benefits, processes, structures and mechanisms to meet medically underserved communities' needs, and would advise legislators and agencies on drafting and implementing legislation and rules. The Office would also respond to requests for information from the legislature, governor and state agencies, and could work with lawmakers to help draft legislation and rules.
- **Facilitate Cross-Agency Coordination:** Because regulation of Pennsylvania's healthcare sector is so fragmented, the Office of the Public Healthcare Advocate would help state agencies that hold responsibility for different segments of the healthcare system to coordinate and collaborate among one another, and would help ensure that agencies are holding industries accountable and meeting the needs of Pennsylvania's residents. The Office would help agencies streamline and coordinate their healthcare appeals processes and information and assistance related to these appeals, help standardize data collection, and help agencies harmonize and improve their rules, regulations, processes and practices to improve protections and outcomes for residents.

# PRINCIPLES FOR AN INDEPENDENT, EFFECTIVE, AND ACCOUNTABLE ADVOCATE

There are dozens of federal, state, and local public advocates and ombudsmen in operation across the country. Some of these positions are independent, effective, and accountable to the public interest while others have too small a scope, are vulnerable to political attack, or are otherwise unable to meaningfully protect public interests. We have identified the following elements as important for the creation of an Office of the Public Healthcare Advocate in Pennsylvania. We developed these principles by reflecting on our members' healthcare experiences, reflecting on our engagement with the Insurance Department and other state agencies, reviewing recommendations from legal scholars and the United States Ombudsman Organization,<sup>67</sup> interviewing experts, studying the structure of existing public advocate offices (particularly Connecticut's Office of the Healthcare Advocate and Nevada's Office of Consumer Health Assistance), and speaking with staff from those two offices.

## Public

Advocates that operate within the government as official public offices carry much more authority than nonprofit or volunteer advocate programs. Connecticut's and Nevada's public offices have greater powers of investigation and reporting than Vermont's nonprofit Health Care Advocate, for example, and carry greater authority among lawmakers than New York's network of roughly two dozen nonprofit advocates.<sup>68</sup> At the same time, the Connecticut and Nevada offices are complemented by nonprofit legal aid organizations. In Connecticut, for example, the OHA directly assists residents with private insurance problems, but refers residents experiencing problems with Medicaid to other organizations.<sup>69</sup>

A Public Healthcare Advocate in Pennsylvania should be established as an official State office within the Office of the Attorney General—one that complements and supports but does not replace the investigations, assistance, outreach and other work conducted by the Attorney General and by nonprofit legal aid organizations.

## **Creation by Legislative Statute**

Creation of the Public Healthcare Advocate by legislative statute, rather than by executive order, is important for establishing an office with sufficient scope and powers, creating an earmarked funding stream, enabling the office to hire sufficient staff to effectively fulfill its mandate, protecting the Advocate from erosion or dissolution by a future administration, and building legislative support for the Advocate.<sup>70</sup> Connecticut and Nevada both have strong legislative statutes, and both states' offices enjoy bipartisan support from legislators.<sup>71</sup>

## **Clear Mandate to Equitably Serve the Public**

The legislation creating the Office of the Public Healthcare Advocate must give the Advocate and staff a clear mandate to promote the healthcare needs, rights, and interests of Pennsylvania residents at large, and especially of the communities who face the most significant barriers to healthcare and to fair treatment in the healthcare system. The statute creating the Office of the Public Healthcare Advocate should recognize healthcare as a human right, and should recognize the State's obligation to equitably uphold this right. It should also emphasize equity and name specific groups who have experienced historical and ongoing structural discrimination in healthcare and health outcomes, and who must be centered in the Office's advocacy, reporting, and community collaboration: poor and working class people, rural and small-city communities, Black, Indigenous and other communities of color, immigrant communities and undocumented people, people currently or formerly in prisons, people in healthcare facilities, people who are unhoused, elders, women and children, LGBTQ people, and people with disabilities, addiction, or mental health needs, people with chronic disease, and survivors of trauma and abuse.



## **Adequate, Earmarked Funding**

In order to ensure the efficacy of the Public Healthcare Advocate in fulfilling its duties over time and to insulate it from political attack, the legislature must designate an earmarked, non-lapsing fund that is not subject to the annual appropriations process, and must designate sufficient revenue to the fund to enable the Advocate and their staff to fulfill their duties.<sup>72</sup> This includes providing sufficient funds for the Office to hire enough employees to fulfill its mission, and pegging salaries for the Advocate and staff to the official salary scale for State employees.

To ensure the efficacy of the Office and to protect it from appropriations battles and defunding, we recommend financing the PHA through a tax on all hospital companies and companies offering health plans or workers' compensation plans in the state (including insurance companies, managed care organizations, mutual benefit associations, self-insured employers, etc.). Connecticut, for example, finances the Office of the Healthcare Advocate through a tax assessment on all companies selling health insurance plans in the state, including health insurance companies and hospital and medical services companies.<sup>73</sup> Nevada finances its Office of the Consumer Health Advocate in part through assessments on hospitals and workers' compensation insurers.<sup>74</sup> Texas finances its Office of Public Insurance Counsel through an assessment on all insurance companies and health maintenance organizations operating in the state.<sup>75</sup> As in Connecticut, the Office's annual budgetary needs should be determined by the Advocate, and then the level of the tax assessment should be automatically adjusted in order to raise the necessary revenue.

## **Universal Access and Comprehensive Scope**

Pennsylvanians experience problems across the full breadth of the state's healthcare system. Residents frequently move in and out of eligibility for different public and private insurance programs, 2.2 million Pennsylvanians find themselves uninsured at some point during the course of each year, and people experience problems with every form of insurance and every kind of medical provider.<sup>76</sup> Therefore, it is important that the Advocate have the authority and resources to be able to assist all residents experiencing healthcare problems regardless of their insurance status and regardless of

where in the healthcare system they are experiencing problems. This means that the Advocate must be authorized to advocate for and assist people with all forms of public and private insurance plans (including employer-sponsored plans, individual plans, workers' compensation, Medicaid, Medicare, public-employee plans, etc.), people who are uninsured, and people experiencing problems with a hospital, clinic, senior home, pharmacy, or any other kind of healthcare provider. Assistance must be made available to all residents free of cost and regardless of insurance status, immigration status, homelessness, native language, or any other factor. The advocate should also accept inquiries and complaints from minors as well as surrogates calling on behalf of patients.<sup>77</sup>

The Office of the Public Healthcare Advocate should serve as a single, unified point of access for information and assistance with resolving healthcare problems.<sup>78</sup> People who call with requests for assistance that are covered by other public or nonprofit service providers will be referred to the appropriate agency or organization. The Advocate would provide direct assistance to communities who are not sufficiently served by existing legal aid infrastructure.

To make universal access a reality and fully representative of community needs, the Advocate must be required to collaborate with the Community Advisory Board (described below) to develop proactive strategies to reach and support communities facing the greatest obstacles to healthcare for poor and working-class communities, especially rural and small-city communities, Black, Indigenous and other communities of color, immigrant communities and undocumented people, people currently or formerly in prisons, people in healthcare facilities, people who are unhoused, elders, women and children, LGBTQ people, and people with disabilities, addiction, or mental health needs, people with chronic disease, and survivors of trauma and abuse.<sup>79</sup> To achieve this, the Advocate should co-develop and co-execute education, outreach, and engagement strategies with the Community Advisory Board, make grants to community-based organizations to conduct outreach and education efforts, and help coordinate outreach and education among state and county agencies.<sup>80</sup> More generally, the Advocate

must be made visible and accessible to residents through proactive efforts including public advocacy, regional offices, diversity of personnel, toll-free phone access, regular visits to rural areas, and use of multiple forms of media.<sup>81</sup> Insurers, providers, and all other healthcare companies and agencies should be required to notify people about the Advocate when they make an adverse decision.

The more visibility the Advocate achieves, the more people will know that the Advocate's services are available to them; the more accountability the Advocate will be able to bring, the better Pennsylvania's healthcare system will work, and the more trust the public will hold in public officials.

## **Community Accountability**

In order to provide the Advocate with an ear to the ground and to hold the Advocate accountable to patients and communities, the legislation creating the Advocate should also create a Community Advisory Board with designated representatives from specific poor and working-class communities and community-based organizations. The Advocate and Office staff should be required to meet with the Board at least quarterly, and to submit all the Office's reports to the Board in addition to the Attorney General, governor and legislature. The Advocate should also be required to consult with the Board when choosing who to nominate for the position of Advocate, and should only be allowed to make a recommendation when a full Board is seated.

The Office of the Advocate should be required to work with the Board to identify and prioritize issues for investigation and advocacy, receive information and reports to be included in the public record, conduct community-based research documenting these problems, open up spaces in administrative and legislative governance for meaningful public participation, and co-develop and co-execute public education, outreach, and engagement strategies. It should also be required to make reports and data available to the Board in an accessible, understandable format to enable them to effectively conduct community education and advise the Office. These strategies should be designed to inform the public—and especially communities facing health injustices—

about their healthcare rights and to give these communities a meaningful degree of institutional power in healthcare governance.

The Members of the Community Advisory Board should be appointed by the Attorney General to represent poor and working-class communities. The Attorney General should be directed to select people from community-based organizations that represent people from poor and working-class communities, especially people from rural and small-city communities, Black, Indigenous and other communities of color, immigrant communities and undocumented people, people currently or formerly in prisons, people in healthcare facilities, people who are unhoused, elders, women and children, LGBTQ people, and people with disabilities, addiction, or mental health needs, people with chronic disease, and survivors of trauma and abuse.

## **Public Accountability**

The Public Healthcare Advocate should report to the Attorney General, and should be required to submit an annual report to the Attorney General, governor, legislature, and Community Advisory Board, and to make these reports available to the public.<sup>82</sup> These reports should include metrics on the Office's activities such as case volume, stakeholder surveys, outreach and education activities, participation on committees and working groups, legislative recommendations and outcomes, and any shadow reports produced by the Community Advisory Board. The reports should also quantitatively and qualitatively document residents' healthcare outcomes, including such measures as the number of residents with and without health insurance, rural and urban access to healthcare providers and hospitals, appeal success rate, financial returns to residents and the state, stories from patients, healthcare workers, and residents, and feedback from the Community Advisory Board and other community representatives. Data should be disaggregated by income level, race/ethnicity, immigration and citizenship status, insurance status and type of insurance, county of residence, and other relevant demographic information to ensure that no Pennsylvania communities are left behind.

## **Sufficient Powers of Investigation and Advocacy**

The Public Healthcare Advocate should be given sufficient powers to fulfill their mandate and meet the healthcare needs of Pennsylvanians and to promote universal inclusion, equity, accountability, transparency, participation, and due process in the healthcare system. These powers should include broad jurisdiction to make information available to lawmakers and the public, including authority to obtain all relevant documents related to claims, to collect data, to initiate own-motion investigations into appealed cases and systemic problems with agencies and profiteers, to issue reports to the governor and legislature, and to make these reports available to the public.<sup>83</sup> The Advocate should also be able to refer appropriate cases to the Attorney General for potential litigation.<sup>84</sup>

As described above, the Advocate should be empowered to advocate on behalf of residents, both insured and uninsured, as the voice of patients and the public in commissions, councils, committees, boards, working groups, hearings, and any other administrative, legislative, and judicial proceedings, and to convene public hearings and other forums for direct public engagement in regulatory and legislative deliberation.

## **Intra-Governmental Collaboration**

A public advocate is not a regulatory agency with powers of enforcement. Therefore, its ability to effect improvements in the health insurance system lies in its ability to investigate, report, and make recommendations to the Attorney General, legislature and governor and in its ability to work in collaboration with existing administrative agencies.<sup>85</sup> The Advocate and the Office's staff should, as mentioned, participate in commissions, councils, committees, boards, working groups, hearings, and proceedings relevant to patients' health insurance needs. They should also submit comments and testify on relevant legislation, have the authority to convene agencies for information-sharing and joint planning, and be able to collect and help standardize data across agencies. The Public Healthcare Advocate should also receive referrals from legislators and administrative agencies and should refer residents to state, county, municipal, and nonprofit health and

social service programs and other available services. By serving as a conduit between communities and lawmakers, the Advocate can help legislators, the governor, and public administrators better understand and prevent pervasive problems in the healthcare system and identify and implement actionable solutions.

## **Independence**

In order to hold private insurance companies accountable and protect the rights and interests of patients, the Public Healthcare Advocate should be insulated from political pressures.<sup>86</sup> This requires administrative and budgetary independence from the insurance industry and the Insurance Department (whose mandate to ensure the profitability and solvency of the insurance industry can come into conflict with patients' rights and interests) as well as the Department of Human Services, Department of Labor & Industry, and all other agencies managing public insurance programs or regulating private insurers.<sup>87</sup> The PHA could conceivably be housed within an existing agency such as the Office of the Attorney General, but must be administratively and budgetarily insulated from pressure from the governor and the agency.

Appointing the Advocate, and doing so to a fixed term of office, would help hold the Public Healthcare Advocate accountable to the people of Pennsylvania and make sure that it operates transparently. Appointing, rather than electing, the Advocate would help insulate the Office from industries' ability to influence elections.<sup>88</sup> Connecticut, for example, has a strong appointment process in which an independent, nonpartisan Advisory Committee submits a list of candidates to the governor, the governor nominates a candidate from the list, and the legislature votes to confirm the nominee. If the governor fails to nominate a candidate within sixty days, the Advisory Committee's top pick is automatically sent to the legislature as the nominee. We propose granting the Community Advisory Board this power to submit a list of candidates from which the governor must select a nominee. We also recommend that the Advocate be granted a sufficiently long term of office to allow the Advocate and their staff to identify problems and develop solutions.<sup>89</sup> The term should span two governors' terms; we recommend a term of at least six years.

**Pennsylvania should have terrific healthcare infrastructure, but this system simply isn't working for everybody. Far too many residents are denied care or are struggling with mounting medical bills and debt, and governance of the healthcare system is far too complicated for everyday people to take part in shaping decisions. The healthcare system is far too fragmented, and the insurance and hospital industries hold too much information and power, for everyday people to be able to advocate effectively on their own. Legislators and public administrators suffer too. Legislators have inadequate information and tools to see how the whole system is really working for people, and administrators' jurisdiction is so fragmented that they are limited in what they can achieve.**

**We call on the Governor and the General Assembly to pass legislation to create a Public Healthcare Advocate to advocate for residents and their communities, serve individual patients, assist lawmakers, and hold healthcare profiteers and public agencies accountable. Amidst a healthcare crisis marked by spiraling costs, persistent barriers to care, abusive practices by healthcare giants, a global pandemic, and clear public demands for action, a Public Healthcare Advocate is a necessary and common-sense solution.**

# **CONCLUSION**

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12 This bureaucratic fragmentation creates headaches for administrators, costly redundancy and inefficiencies, gaps in service, and distrust of public institutions. It also hurts residents by producing a confusing array of complaint and grievance processes spanning insurance companies and various

public agencies. Public information and patient assistance provided by state agencies and by nonprofit legal aid organizations—including AIDS Law Project, Community Legal Services, Legal Clinic for the Disabled, Pennsylvania Health Access Network, and Pennsylvania Health Law Project, among others—is absolutely critical in helping many people navigate these processes. Legal aid programs need more funding. Yet the sheer scale of denied claims in Pennsylvania makes it clear that far too many residents are not being served. Though data on denied claims is not publicly available for the Commonwealth, data from other states suggests, as described below, that Pennsylvanians may face somewhere on the order of 17 million denied claims and 100,000 adverse benefits decisions every year. In the face of so many adverse decisions, appeals processes are too fragmented, inscrutable, and inaccessible to come close to meeting residents’ needs, and though the existing network of state and nonprofit assistance provides critical support to many, it is also too fragmented and underfunded to serve everyone who needs support. This is especially true for poor and working-class people Pennsylvania communities facing the greatest barriers, and especially including rural and small-city communities, Black, Indigenous and other communities of color, immigrant communities and undocumented people, people currently or formerly in prisons, people in healthcare facilities, people who are unhoused, elders, women and children, LGBTQ people, and people with disabilities, addiction, or mental health needs, people with chronic disease, and survivors of trauma and abuse. These disparities are further amplified because poor and working-class people’s lives are not fixed: people often move in and out of eligibility for employer-sponsored insurance, Affordable Care Act subsidies, workers’ compensation, Medicaid, or Medicare during the course of a year, and thus move in and out of eligibility for different appeals processes and different legal aid programs all the time. Pennsylvanians need a single point of access to refer them to legal aid or, when outside aid is not available, to provide direct assistance.

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- 86 Estes et al. (2004), p. 114, supra note 72.; Gottehrer et al. (2000), p. 360, supra note 72; International Ombudsman Institute (June 2017), p. 3-4, supra note 70; Reif (2004), p. 399-401, supra note 70; Von Tigerstrom (1998), p. 36, supra note 75; United Nations Center for Human Rights (1995), p. 10-17, supra note 72.; Barkow (2000), p. 45-49, supra note 72.
- 87 For the requirements to which Pennsylvania's Consumer Advocate for utilities is held, for example, see Pennsylvania Statutes Title 71 P.S. State Government § 309-2. Office of Consumer Advocate (Adm. Code § 902-A).
- 88 International Ombudsman Institute (June 2017), p. 4-5, supra note 70.; United Nations Center for Human Rights (1995), p. 10-17, supra note 72.
- 89 Altarum (May 2018), supra note 51; International Ombudsman Institute (June 2017), p. 5, supra note 70.

