

FINAL PROJECT REPORT

DECEMBER 2020

Increasing Access to COVID-19 Testing & Treatment in PA

Lessons Learned from PHLP's Outreach & Community Navigators

By Callie Perrone, Callie Kennedy, & Laurie Johnson-Wade *PHLP Outreach & Community Navigators*

COVID-19 has disproportionately affected marginalized communities, exposing and exacerbating health inequities. Barriers to testing and treatment further exclude vulnerable populations from accessing the care they need. In the fight to curb the pandemic and promote health equity, PHLP's Navigators contribute to an understanding of these barriers and advocate for more accessible alternatives.

Overview

The Pennsylvania Health Law Project (PHLP) is a non-profit legal aid organization that represents Pennsylvanians having trouble getting or keeping Medicaid coverage and services. As the designated state-wide health advocacy project of the Pennsylvania Legal Aid Network, PHLP has a single focus: to protect and advance the health rights of lowincome and underserved individuals.

PHLP serves thousands of individuals from across the state each year by providing free legal services; engages in education and outreach to consumers, advocates, and health care providers; and advocates for policies that ensure all Pennsylvanians can meet their basic healthcare needs.

In July 2020, PHLP received CARES Act funding to hire a small team of Outreach and Community Navigators to investigate the accessibility of testing and treatment among low-income and marginalized communities throughout Pennsylvania. With a focus on people who are on Medicaid or uninsured, the Navigators have worked to identify vulnerable communities struggling to get tested and treated for COVID-19, assess the availability of testing and treatment, target community outreach efforts to increase awareness of low-barrier COVID-19 resources, and help connect individuals to services.

In this report, mention of "testing" refers to diagnostic tests, which determine if a patient has an active COVID-19 infection. "Treatment" refers to medical care a COVID-19-positive patient requires, including methods and services to treat or relieve COVID-19 symptoms.

As our initiative comes to an end, we aim to share our work, lessons learned, and recommendations going forward in the hopes that others can learn from our experience and continue to advocate for equitable access to COVID-19 testing and treatment.

COVID-19 and Health Equity

While the COVID-19 pandemic has impacted all Americans, it has not impacted all Americans equally. COVID-19 has exposed and exacerbated underlying systemic inequities across the United States. Existing inequities in health status and healthcare access among marginalized communities have been compounded by COVID-19. Vulnerable populations including low-income households, racial and ethnic minorities, and undocumented immigrants have been hit hardest by COVID-19.

Black and Latinx populations in particular bear a disproportionate burden of every aspect of the pandemic. Federal, state, and local data consistently show that people of color account for higher rates of COVID-19 cases, hospitalizations, and deaths compared to their white counterparts. Additionally, the economic consequences of the pandemic have been most severe for low-income Black and Latinx households.

As a result of systemic inequities, including structural racism and historic disinvestment in communities of color, the same populations who are at higher risk of contracting COVID-19 have less access to testing and treatment. For example, people of color are overrepresented as low-wage frontline workers – who are more likely to be exposed to the virus and less likely to have paid time off or health insurance.

Pennsylvania mirrors the trends seen across the United States. Available data suggests that Black Pennsylvanians make up a disproportionate number of the state's COVID-19 infections, hospitalizations, and deaths. According to an August 2020 report on health disparities by the Pennsylvania COVID-19 Response Task Force, Black Pennsylvanians account for just 12% of the state's population, vet account for nearly one-third of cases and one-fourth of deaths for which racial data was reported. Black and Latinx Pennsylvanians are less likely to have health insurance compared to white Pennsylvanians. Undocumented communities experience uniquely high rates of exposure and low rates of insurance.

Low-income and marginalized Pennsylvanians – particularly communities of color – have suffered high COVID-19 infection and mortality rates, compounded by limited access to testing and treatment. Those most in need of COVID-19 testing and treatment face the most barriers to these key services. Those already struggling to obtain healthcare are further struggling to navigate care for COVID-19. In order to mitigate the spread of the virus and promote health equity, it is essential to ensure that low-income and marginalized Pennsylvanians have equitable access to COVID-19 testing and treatment.

PHLP's Response: Outreach and Community Navigators

Recognizing the heightened need for COVID-19 testing and treatment in underserved communities, PHLP applied for CARES Act funding to conduct targeted research and outreach in order to better understand and address barriers to care. In July 2020, PHLP received funding and hired three Outreach and Community Navigators with the goal of improving equitable access to COVID-19 testing and treatment among low-income and marginalized Pennsylvanians.

Due to the parameters of CARES Act funding, PHLP's new initiative spanned from July -November 2020. Cognizant of our limited timeframe and capacity, Navigators targeted our efforts on Allegheny County, Philadelphia County, and the Capital Area – urban areas with a high concentration of vulnerable populations heavily impacted by COVID-19. In relation to the demonstrated need, Navigators prioritized low-income, Black and Brown, and immigrant and undocumented communities. Aligning with PHLP's health access framework, Navigators focused our resources on Medicaid recipients and the uninsured, as many vulnerable Pennsylvanians fall into these categories.

While COVID-19 testing and treatment opportunities are intended to serve all Pennsylvanians, marginalized Pennsylvanians often lack awareness of or meaningful access to these services. To help fill this gap, PHLP's Navigators functioned as signal-boosters – streamlining and amplifying existing lowbarrier COVID-19 resources and services, and helping vulnerable Pennsylvanians navigate a complex healthcare system. Navigators aimed to increase access to testing and treatment by increasing the availability of information, and ensure that community members have resources at their disposal to know where to get tested and what to do if they test positive.

To meet our stated goals, Navigators first identified vulnerable communities struggling to get tested and treated for COVID-19. Navigators then investigated the availability and accessibility of testing and treatment at the neighborhood level, connecting with local community organizations, testing sites, and health centers. We gained insights into community need through in-depth conversations with community partners.

Navigators engaged in resource mapping, focusing on COVID-19 testing sites. Navigators quickly discovered that while most sites can be found through an online search, available information lacks critical details that enable people to choose a testing site that adequately meets their needs.

We systematically reached out to hundreds of testing sites to gather information relevant to vulnerable groups – such as which sites offered free testing to people without health insurance and how results would be communicated. After compiling this information, Navigators developed resources specifically intended to be useful and accessible to low-income Pennsylvanians. Our resources highlight lowbarrier testing sites, meaning sites that minimize barriers that stand in the way of vulnerable populations getting tested.

Navigators also researched healthcare coverage for those in need of COVID-19 treatment and developed resources to help Medicaid recipients and the uninsured access coverage and care.

Finally, once this information was compiled, Navigators focused on getting the word out. Navigators created flyers, FAQs, and resource guides; populated the COVID-19 section on PHLP's website; and participated in panel discussions, webinars, and community resource fairs. Navigators partnered with trusted community organizations serving vulnerable populations to disseminate COVID-19 resources and information, as well as share how PHLP's legal services can benefit their community members.

Lessons Learned

Monumental efforts have been made across public, private, and nonprofit sectors in response to the unprecedented challenges posed by the COVID-19 pandemic. Despite progressive interventions, inequities in healthcare access remain. Throughout this initiative, PHLP's Outreach and Community Navigators have identified barriers that limit marginalized and low-income communities' access to COVID-19 testing and treatment; shared our findings with community groups, advocates, and government officials; and encouraged further action to address these barriers.

In sharing our findings with a wider audience, Navigators hope to increase awareness about the ways in which vulnerable Pennsylvanians are routinely prevented from accessing COVID-19 testing and treatment. By highlighting identified barriers, we hope that allies can continue to fill gaps in access and work towards more equitable solutions.

COVID-19 Testing

Across geographic regions, PHLP's Community Navigators have identified common barriers to getting tested that disproportionately affect low-income and marginalized Pennsylvanians. These individuals are likely to be enrolled in Medicaid or uninsured. Under state law, COVID-19 testing is currently free for all Pennsylvanians on Medicaid, and no prior authorization is needed to be tested.

Testing is also available for people who do not have health insurance, but it may not be free. In order to provide free testing to the uninsured, health care facilities must submit claims for COVID-19 testing to the Health Resources and Services Administration (HRSA). However, free testing alone is not enough to ensure equitable access. Navigators have identified the following barriers to COVID-19 testing:

- The majority of testing sites throughout Pennsylvania require an appointment in order to get tested. Some sites only take appointments online, while others take appointments over the phone. Walk-ins are rarely welcome. This makes internet access a frequent prerequisite for getting tested, which disproportionately limits access for low-income and marginalized communities. Many testing sites require completion of a health questionnaire or telehealth screening prior to testing, and send results via web portal – factors that additionally prevent people without internet from accessing testing at these sites.
- Internet access is often needed to locate nearby testing sites, and learn about their cost, hours, and eligibility requirements. Testing information changes frequently, and internet access is often necessary for up-to-date information. Even for those with internet access, a high degree of digital literacy is needed to navigate and retrieve information regarding where to get tested, which prevents those with low digital literacy, as well as limited English proficiency speakers, from accessing this information.
- Many testing sites are drive-through only, making them inaccessible to people without cars. Additionally, a lack of safe transportation options prevent people without cars from accessing walk-up sites that are not within close proximity to home.
- Testing sites commonly require a referral from a Primary Care Provider (PCP) in order to get tested. This is particularly a barrier
- for people without health insurance, who are less likely to have a PCP to obtain a referral from, and more likely to incur a hefty fee from a PCP visit. Additionally, many people without access to reliable primary care may feel unmotivated to get tested for COVID-19 because, in case of a positive test result, they do not have resources for the appropriate treatment or follow-up care. Even for people who already

have a PCP, the need for a referral can make an already stressful process more complex and cumbersome.

- With the exception of Philadelphia and Pittsburgh, Pennsylvania's testing sites are **few and far between**. Of the existing sites outside of these major cities, very few are low-barrier. For example, there are currently only nine testing sites in all of Dauphin County, only two which are in downtown Harrisburg. Nearly all sites in the county have requirements that may limit access for vulnerable populations, such as requiring a car, an appointment, or a PCP referral. This scenario is not unique to Dauphin county.
- In our efforts to identify COVID-19 testing sites accessible to marginalized populations, PHLP's Navigators have come across misinformation, incomplete information, and a general lack of available information. For example, some testing sites charge for a mandatory health screening prior to the test yet do not clearly communicate that a fee is associated with testing. Instead, they advertise that their testing is "free" without the disclaimer that one of the required features of testing does in fact come at a cost. Even when testing site information is accurate and available, it is not always easy to find, user-friendly, or comprehensive.

In addition to the overarching barriers above, Navigators identified the following barriers to testing that particularly affect undocumented and status-vulnerable immigrants:

- Language access has been a persistent issue. Information on testing is most readily available in English. Those who are not comfortable reading in English face barriers to learning where, when, and why to get tested.
- Though the law protects consumers' right to interpretation when receiving health care, the increase of telemedicine makes it more difficult for limited English proficiency speakers to have their language needs met.
 For example, testing sites often have an automated call menu in English that is

difficult for limited English proficiency speakers to navigate. Additionally, front desk staff may not be able to understand patients' language needs over the phone, whereas before the pandemic many immigrants and refugees were accustomed to bringing a card stating their language needs to their appointment.

- Many testing sites require patients to provide proof of identity. Undocumented immigrants face the added barrier of privacy concerns related to testing and contact tracing. While COVID-19 testing and contact tracing are safe and secure processes that should not affect an individual's immigration status, further outreach and support are needed to communicate this message and assuage fears. Testing sites must become more aware of and accommodating of these privacy concerns, and appropriately address people's hesitation to show ID or share personal information like address and date of birth.
- Employment concerns are a significant deterrent to accessing testing and quarantining effectively. Low-wage workers who are ineligible for or face barriers to obtaining paid sick leave may avoid testing knowing they cannot afford to stay home from work if sick. Fear of losing employment for testing positive and missing work is also a deterrent, which still occurs despite being an illegal employment practice. While these employment concerns are not limited to undocumented workers, undocumented workers are particularly vulnerable to rampant exploitation at work and have limited options for recourse.
- Some communities of color experience stigma and shame around testing positive for COVID-19, in part due to the racist rhetoric blaming the spread of the virus on Chinese and Asian people as well as immigrants.

COVID-19 Treatment

While there is currently no widely available antiviral treatment for COVID-19, Medicaid covers a broad range of services that treat or relieve COVID-19 symptoms, including: diagnostic tests, prescription drugs, emergency ambulance transport, and hospital care. The U.S. Department of Health and Human Services will reimburse health care providers for providing COVID-19 treatment to uninsured Pennsylvanians so that they can seek care without cost burden.

In Pennsylvania, no one can be denied medical assistance for COVID-19 testing, diagnosis, or treatment because of their immigration status. Emergency Medical Assistance (EMA) is available for people ineligible for Medicaid, such as undocumented immigrants. COVID-19 is a recognized Emergency Medical Condition; therefore, EMA can cover COVID-19 testing, diagnosis, and treatment for those who qualify.

While affordable treatment is available, it is important to recognize challenges that prevent low-income communities from accessing care. Navigators have identified the following:

- Misinformation is a deterrent to seeking care, especially regarding cost and coverage. It is crucial that vulnerable Pennsylvanians understand their options for seeking treatment, and do not delay treatment for fear of incurring medical bills. More outreach is needed to ensure that Medicaid recipients, EMA recipients, and the uninsured population have accurate information at their disposal.
- With regard to recovery, it is often a challenge for low-income families who may live in multigenerational or multifamily households to safely isolate when a member becomes sick.
- Obtaining sufficient medical care after testing positive is especially challenging for undocumented individuals who do not have health insurance. More **education and outreach** are needed regarding the availability of Emergency Medical Assistance. This outreach should include the fact that using EMA is not a public charge risk.
- Even with these interventions, obtaining reliable care for longer-term complications of COVID-19 is harder for the uninsured and underinsured.

Looking Forward

Although CARES Act funding for PHLP's Outreach and Community Navigator initiative expired on November 30, 2020, the need for accessible COVID-19 testing and treatment is growing. As of late November 2020, COVID-19 infection and hospitalization rates in the US are reaching record highs, with marginalized communities disproportionally affected. While we can anticipate many changes in the coming months, including the first COVID-19 vaccines, the need for low-barrier testing and treatment will remain long after a vaccine becomes available. Additionally, vaccine distribution efforts will likely pose similar issues of access for low-income Pennsylvanians that must dually be considered and addressed.

As our initiative comes to an end, one thing is clear: more work is needed to ensure that marginalized communities have equitable access to COVID-19 testing and treatment. To further reduce gaps in access, PHLP recommends targeted outreach and education to provide marginalized communities with sufficient information and support to navigate COVID-19 services, increasing the number and capacity of low-barrier testing sites in highneed areas, enacting paid sick and family leave, and the continuation and expansion of free COVID-19 testing and treatment for Medicaid recipients and the uninsured. These efforts must consciously and consistently reach across language barriers and the digital divide to ensure access for all. This work necessitates a coordinated approach between state and local government, healthcare systems, and nonprofit organizations, as well as close partnership with community-based organizations that have earned the trust of community members.

Going forward, we hope that others will build upon and expand the scope of our initiative. PHLP's Navigators primarily focused on lowincome, Black and Brown, and undocumented adults in Pennsylvania's urban areas. In addition to a continued focus on these communities, we recommend extending research and outreach into other vulnerable communities: including people living in rural areas, senior citizens, people experiencing homelessness, people recently released from incarceration, and people experiencing substance use disorder. Additionally, while our research has been largely qualitative, we encourage others to engage in more quantitative data-driven approaches. Finally, whereas PHLP played a role in highlighting existing barriers to equitable access, we hope others engaged in the fight for health equity can advocate for and enact meaningful changes to reduce these barriers.

The implications of PHLP's findings are not limited to the COVID-19 pandemic; nor are the health inequities faced by vulnerable populations. Our findings speak to broader and deeply entrenched issues of racial, ethnic, and income-based disparities in healthcare access. The needs of low-income and marginalized communities must be considered and addressed in every area of the U.S. healthcare system, and often overlooked barriers to equitable access must be identified and eliminated.

We hope the work and insights of PHLP's Outreach & Community Navigators contributes to ongoing conversations and action to promote health equity throughout the COVID-19 pandemic and beyond.

Our Resources

Visit www.PHLP.org and click on the COVID-19 tab to view our Resource Center, Testing Site Guide, and FAQs.

Helpline

Need help resolving an issue with Medicaid coverage or services? Call PHLP's Helpline for free legal assistance.

1-800-274-3258

8:00 AM to 8:00 PM Monday, Wednesday, & Friday

Individuals who believe they were wrongfully billed for COVID-19 testing or treatment may call PHLP's Helpline.

Recommendations

As PHLP's initiative comes to an end, we encourage other decision-makers, advocates, and community leaders to advocate for and enact the following recommendations:

- Increase the number and capacity of low-barrier COVID-19 testing sites statewide. Low-barrier testing sites are those that provide free and sliding scale testing, welcome walk-ins, do not require a doctor referral, do not require a car, provide alternatives to telehealth visits and online registration for those without internet access, accept alternatives forms of identification that do not disclose immigration status, and provide resources and services in various languages.
- While PA state and many local governments already provide COVID-19 testing site locators that can be retrieved by web or hotline, information is limited. These resources must be expanded to include critical details about accessibility (Is testing free? Are walk-ins welcome?). Information should be centralized, comprehensive, user-friendly, and up-to-date.
- Continue and expand access to free COVID-19 testing, treatment, and vaccination when available, for Medicaid recipients and the uninsured.
- Ensure COVID-19 resources and services are tailored to non- and limited English proficiency speakers, including flyers, websites, automated call menus, and the provision of healthcare.
- Increase outreach and education to communicate that COVID-19 testing and contact tracing are safe and secure processes that should not affect immigration status.
- Enact paid sick and family leave so individuals can seek COVID-19 testing and treatment without fearing income loss or job loss.
- Prioritize funding for community-based organizations (including community health centers) as hubs for COVID-19 outreach and education, testing, and vaccination. Community-based organizations are often best suited to serve as trusted messengers and service providers among community members.

FOR MORE INFORMATION, PLEASE CONTACT:

Callie Perrone, MSW, MSSP, Outreach & Community Navigator, at cperrone@phlp.org Laval Miller-Wilson, Esq., Executive Director, at lmillerwilson@phlp.org

References

<u>https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html</u> <u>https://www.governor.pa.gov/wp-content/uploads/2020/08/20200813-COVID-19-Health-Disparity-Report.pdf</u>

https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-covid-19-key-findings-available-data-analysis/ https://www.nejm.org/doi/full/10.1056/NEJMp2024897

https://www.newyorker.com/news/our-columnists/the-black-plague

https://nlihc.org/resource/new-survey-finds-covid-19-economic-impact-most-severe-low-income-adults-and-people-color

<u>https://www.npr.org/sections/health-shots/2020/09/23/914427907/as-pandemic-deaths-add-up-racial-disparities-persist-and-in-some-cases-worsen</u> <u>https://policylab.chop.edu/sites/default/files/pdf/publications/PolicyLab-Survey-Immigrant-and-LEP-Communities-During-COVID-19-Pandemic.pdf</u> <u>https://whyy.org/articles/racial-disparity-grows-as-the-coronavirus-disproportionately-claims-black-lives-in-pa-jersey-and-delaware/</u>

