Patients, Families, and Communities COVID-19 Impact Assessment: Lessons Learned and Compelling Needs

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About the NAM series on Emerging Stronger After COVID-19: Priorities for Health System Transformation
This discussion paper is part of the National Academy of Medicine's Emerging Stronger After COVID-19: Priorities for Health System Transformation initiative, which commissioned papers from experts on how 9 key sectors of the health, health care, and biomedical science fields responded to and can be transformed in the wake of the COVID-19 pandemic. The views presented in this discussion paper and others in the series are those of the authors and do not represent formal consensus positions of the NAM, the National Academies of Sciences, Engineering, and Medicine, or the authors' organizations.
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Introduction

The health system exists to serve the most fundamental need of society: people's health and well-being. To do so effectively requires engaging people as a partnership proposition in all elements of health system structure and function. Patients, families, and communities represent a wide-ranging group of individuals and populations contending with a host of health conditions and engaging in the health system for prevention, screening, diagnosis, and treatment. Yet patients, families, and communities are not simply passive recipients of health services—they are also active partners in scientific research, collaborators for shared decision making in care and related matters, and advocates for the population health priorities salient to their communities. The 2017 National Academies of Sciences, Engineering, and Medicine (NASEM) report *Communities in Action: Pathways to Health Equity* shared the significance of the role of communities in promoting health equity. The report concluded that community-driven solutions are necessary, as communities are in a unique position to drive priorities and actions tailored to their needs that address many of the determinants of health [179]. In addition, the enhanced engagement of patients, families, and communities has been encouraged as a strategy in health policy change, research, and care delivery to improve the quality of

care and drive health equity [237]. Orienting the different health system sectors around the experiences, needs, and considerations of patients, families, and communities is a necessary precondition to achieve the values of equity, efficiency, and effectiveness.

Unfortunately, the U.S. health system has long fallen short of those aspirations, as evidenced by the persistent increase in health expenditures without commensurate improvements in population health [234]. Indeed, life expectancy in America has declined in recent years, a stark contrast with trends in other high-income countries [112]. Additionally, before the start of the COVID-19 pandemic, the United States grappled with other challenges, such as the misdiagnosis of patients and medical errors leading to thousands of preventable deaths each year [9,133]. Rather than occupying the center of the health system, many patients, families, and communities have been relegated to the periphery, as evidenced by challenges in achieving population health. Furthermore, longstanding disparities in health status and health outcomes affect communities of color; low-income populations; people with disabilities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities; people with limited English proficiency; and older adults [164].

It is amid this period of declining health and growing inequality in America that the COVID-19 pandemic struck. The public health emergency—which remains ongoing at the time of this paper's publication—has negatively impacted the lives of virtually every patient, family, and community throughout the nation and the world. The virus has taken a tremendous toll on the health of these groups, with 45,655,635 cases, 3,223,806 hospitalizations, and 740,348 deaths in the United States as of October 27, 2021 [274]. Additionally, the added stressors from the pandemic's upending of everyday life (manifesting in worsening mental health outcomes for nearly every population) and disruption to other types of necessary health services (e.g., chronic disease management) have made it even more challenging for patients, families, and communities to pursue and achieve health and well-being [32,85,196]. Altogether, the cumulative health effects of COVID-19 precipitated a full-year decline in average life expectancy in the United States during 2020.

The pandemic has also erupted the existing fault lines of race and class in the health system. Morbidity and mortality attributed to COVID-19 have disproportionately affected populations in the United States along the axis of age, income, social determinants of health (e.g., geographic location, education), race, eth-

nicity, gender and sexual orientation, and immigration status [95,162,191]. For example, declines in life expectancy due to COVID-19 were significantly greater for Black (2.7 years) and Latinx (1.9 years) populations compared to Whites (0.8 years), with the gap between Black and White populations representing the largest disparity in over twenty years [53]. Further, the impact of the pandemic on populations with multiple and intersecting identities (e.g., low-income rural residents, low-income women of color, low-income older adults of color) is probably more significant, as the groups are more likely to experience inequities and disparities.

Collectively, the devastating impact of and response to the COVID-19 pandemic underscores and illuminates the fragilities and inequities in health status and in the health system, as well as the disparities present in factors that significantly influence health and wellness (e.g., wealth, social determinants of health). However, the pandemic also presents leaders with an opportunity to implement comprehensive reforms to assure health and well-being *for all* by recentering the health system around patients, families, and communities and addressing the historical legacies and structural inadequacies across sectors contributing to the disparities in population health.

This discussion paper aims to provide a comprehensive review of the impact and implications of the COVID-19 pandemic on patients, families, and communities (see *Figure 1*). Importantly, this assessment seeks to offer the perspectives of sector leaders on the system's failures and opportunities for change, and elevate the stories and experiences of patients, families, and communities who have demonstrated remarkable resilience while bearing the myriad impacts of COVID-19. While this assessment will focus broadly on patients, families, and communities, it will substantively address the inequities that exist for marginalized populations, focusing on low-income populations, communities of color, and older adults and their family caregivers. This paper will highlight the interplay of patients and families, who comprise communities, and who are connected to the broader health system, as reflected in the socio-ecological model [148]. Identifying the progress and challenges faced by patients, families, and communities within the health system both prior to and during COVID-19 will allow for building on pandemic-era innovations and cross-sector collaborations to achieve meaningful improvements for all.
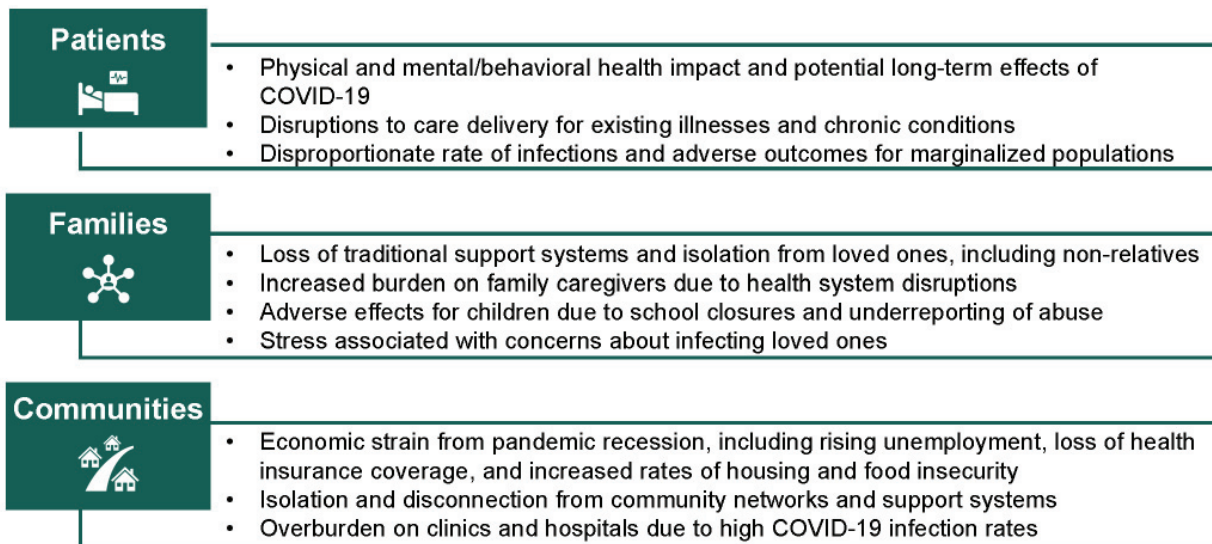
Patients
- Physical and mental/behavioral health impact and potential long-term effects of COVID-19
- Disruptions to care delivery for existing illnesses and chronic conditions
- Disproportionate rate of infections and adverse outcomes for marginalized populations

Families
- Loss of traditional support systems and isolation from loved ones, including non-relatives
- Increased burden on family caregivers due to health system disruptions
- Adverse effects for children due to school closures and underreporting of abuse
- Stress associated with concerns about infecting loved ones

Communities
- Economic strain from pandemic recession, including rising unemployment, loss of health insurance coverage, and increased rates of housing and food insecurity
- Isolation and disconnection from community networks and support systems
- Overburden on clinics and hospitals due to high COVID-19 infection rates

FIGURE 1 | Impact of the Pandemic on Patients, Families, and Communities

Pre-COVID-19 Experience of Patients, Families, and Communities

Over the years, there has been more focus on approaches to increase patient- and family-engaged care, address the social determinants of health, and improve patient-centered outcomes research. Yet, despite evidence of the positive benefits arising from increased engagement, patients, families, and communities, these changes are far from widespread and have not resulted in major population health improvements. Further, patients, families, and communities still faced critical challenges prior to the pandemic including gaps in access to key services and public health infrastructure and the constraints and consequences of structural and institutional racism. This section presents the pre-pandemic progress and challenges for patients, families, and communities (see *Table 1*).

Key Successes for Patients, Families, and Communities Prior to the Pandemic

Increase in Patient- and Family-Engaged Care
Patient-centered care focuses on providing care that respects and responds to patient preferences, needs, and values, and ensures that clinical decisions are guided by patient values [128]. In recent years, payers, providers, and policy makers have invested in several approaches to increase patient and family engagement in care delivery that include changing how care is delivered (e.g., development of Patient-Centered Medical Homes), paid for (e.g., moving away from fee-for-service to alternative payment models, developing value-based programs), and measured (e.g., development and use of patient-reported outcome measures) [43,70]. In addition, engagement across care settings has improved the salience of information sharing, supported the redesign of clinical facilities and care models, empowered patients to be represented on hospital and health system boards, and fostered changes to organizational culture [43]. Despite challenges in implementing patient engagement approaches (e.g., lack of shared guidelines or education on best practices for engagement), a growing body of evidence highlights the benefits of patient- and family-engaged care, including improvements to patient safety, perceptions of quality, medication adherence, functional status and recovery, and rates of medical errors [8,102,239].

Focus on Social Determinants of Health and Addressing Social Needs
Substantial evidence illustrates how the social determinants of health, including education, transportation, housing, and access to food, influence patient- and population-level health outcomes. In recent years, payers and providers have sought to improve the health care system's capacity to address the patient-level social needs through partnerships and integrated delivery models [179]. For example, payers are exploring federal demonstration models such as Accountable Health Communities to state initiatives to screen and refer for social needs through Medicaid managed care [22,73]. Likewise, health department partnerships con-

ceived and rolled out under the guidance of the Public Health 3.0 framework and care systems investments in social services, such as access to safe and affordable housing, illustrate cross-sector efforts to address the social determinants of health that impact patients, families, and communities [123,190]. Certainly, much more work is needed among payers, health systems, and providers, alongside patients and community-based organizations, to understand how to capture information on social needs, identify resources available, and support use by patients.

Improving Patient-Centered Research and Outcomes
The voices of patients, families, and communities are integral to research to ensure that the benefits are accessible to all patients and inclusive of the outcomes that matter most to them [198]. Models of community-partnered participatory research and patient-centered outcomes research—in which patients, families,

and communities are treated as active partners and included in question selection, data ownership, and outcomes dissemination—represent authentic approaches to improving the equity and benefits of research [134]. For example, the creation of the Patient-Centered Outcomes Research Institute (PCORI) seems to reflect a continued interest in and commitment to patient-centered comparative effectiveness research. Findings from PCORI-funded research projects on addressing disparities and improving health systems have been translated into practice to address various health and health care issues [199]. Likewise, the Food & Drug Administration's (FDA's) patient-focused drug development program has supported the use of patient experience data to ensure regulatory decision making better captures patients' perspectives [127].

Domain	Theme	Description
Progress Areas	Increase in Patient- and Family-Engaged Care	• Emphasis on patient-centered delivery models and patient-reported outcomes • Focus on care coordination and shared decision-making
	Focus on Social Determinants of Health	• New payment and delivery reforms to integrate health and social services • Creation of cross-sector partnerships to better meet community needs
	Improving Patient-Centered Research and Outcomes	• Advent of Patient-Centered Outcomes Research Institute • Increased uptake of community-partnered research practices
Challenge Areas	Underinvestment in Public Health Infrastructure	• Chronic underfunding of both preventive and emergency public health services • Variation in health department resources and capabilities • Lack of significant coordination between public health and health systems
	Access to Care	• Millions of Americans continue to be uninsured and underinsured • Uneven distribution of providers constrains patient access to health services
	Health Care Costs	• Persistent growth in health expenditures without commensurate gains in health outcomes • Patients are increasingly liable for a greater share of their health care costs
	Inequities and Structural Racism	• Longstanding disparities in population health for marginalized populations • Gaps in access, quality, and outcomes are the product of racist structures embedded within the health care system

TABLE 1 | Pre-Pandemic Experiences of Patients, Families, and Communities

Challenges Impacting Patients, Families, and Communities Prior to the Pandemic

Underinvestment in Public Health Infrastructure
Robust public health infrastructure at the local, state, tribal, and national levels is necessary to support disease prevention and health promotion. However, public health in the United States has traditionally operated separately and distinctly from other sectors and has long been chronically underfunded, with substantial declines in the share of national health expenditures dedicated to public health and its workforce over the past twenty years. The result has been a persistent inability to focus on coordinated and effective preventive services addressing the health and well-being of communities and has led to an increasing emphasis on medical care and interventions [124,207]. The chronic disinvestment in public health and significant heterogeneity in health department capacity across the country also affects preparedness for emergency situations. Indeed, funding for emergency preparedness has declined significantly despite multiple infectious disease outbreaks since the turn of the millennium [176]. Further, the underinvestment in public health has made it challenging to develop, build, and maintain effective and significant coordination between public health and health systems.

Inequitable Access to Quality Care
Patients, families, and communities across America have long encountered barriers to accessing necessary health services. First, 14.5 percent of Americans lacked access to health insurance before the pandemic, with affordability cited as the most common barrier to coverage [45]. Second, when Americans have health insurance, their coverage may not encompass the full scope of their health needs. For example, 23 percent of Medicare beneficiaries are underinsured [234]. Likewise, many Medicare beneficiaries lack coverage for long-term services and supports [214]. Third, beyond questions of insurance, many communities suffer from a dearth of providers, with over 80 million patients and families living in Health Professional Shortage Areas [140]. A key area of need is behavioral/mental health [140]. There is a lack of parity in service capacity and financial structures between behavioral/mental and physical health, which impacts systems serving patients, families, and communities [235]. Relatedly, there often are not enough providers from diverse backgrounds [245]. Last, due to geographic variation, rural residents often have less coverage and do not receive recommended care when compared to urban populations [129]. Rural residents make up an estimated 19 percent of the US population, and within these communities, 80 percent of the population are considered medically underserved [126].

Increasing Health Care Costs
Even when patients and families can access care, the continually rising cost of care continues to be a deterrent for many communities. Indeed, premiums on average in 2020 exceeded $21,000 for families with employer-sponsored health insurance, while deductibles have risen at five times the rate of workers' earnings over the past decade [143]. High out-of-pocket costs for deductibles, coinsurance, and copayments can also deter patients from seeking necessary care, such as refilling prescriptions for medications and receiving needed medical treatments. Moreover, beneficiaries in Medicare's fee-for-service benefit program often have high out-of-pocket costs and/or no caps on out-of-pocket expenses, which increases their financial risk and the economic impact associated with receiving care for catastrophic illness. Additionally, "surprise billing," which describes significant out-of-pocket expenses for health services that were not apparent at the time of treatment, highlights how the cost of care can have long-lasting consequences on the health and well-being of families [151]. Increasing health care costs have significant impacts on families' abilities to build, maintain, and transfer wealth, which further negatively influences the health and well-being of future generations.

Inequities and Structural Racism in Health and Health Care
The persistence of inequities in health and health care is not the result of a broken system but rather the product of a "carefully crafted system functioning exactly as intended with social policies rooted in racism" [256]. Health inequities are fueled by social, environmental, and structural determinants of health that plague US society, including but not limited to generational and situational poverty; mass incarceration; police brutality; dysfunctional and uncoordinated educational, criminal, and health systems; inadequate transportation; poor housing conditions, capacity, and stability; poor nutrition and diet; and lack of health literacy [77]. Health inequities due to structural racism impact communities of color, including Indigenous, Black, Asian American and Pacific Islander, and Latinx populations and subpopulations.

The inequities that stem from structural and institutional racism affect both the health of communities and the experiences of patients and families with the health care system. Consider the case of residential segregation, a social policy with significant implications for the health of communities. In the 100 metropolitan areas in the United States, 68 percent of Black children and 58 percent of Latinx children live in neighborhoods with either low or very low social and economic opportunities compared to 27 percent of White children [6]. Wealth, a more comprehensive representation of collective economic resources than income, has increasingly been viewed as an indicator of individual and population health. Significantly, in 2016, the median wealth of White, Latinx, and Black families was $171,000, $20,600, and $17,100, respectively [38].

Similarly, housing instability, food insecurity, and other social needs are all more prevalent among communities of color, which are negatively associated with the health status of these populations. In addition, conditions such as obesity (47 percent for both Black patients and Latinx patients compared to 38 percent among White patients) and diabetes (19 percent for Black patients and 22 percent for Latinx patients compared to 13 percent among White patients) have greater incidence and prevalence among communities of color. These disparities in health status create the basis for disparities in health outcomes and life expectancy; for example, Black patients are twice as likely to die from cardiovascular disease as White patients, while cancer death rates are 19 percent higher for Black men than White men [54,78].

Yet despite long-standing documentation of the outcomes gap between communities of color and White patients, non-White patients continue to experience differential treatment in the U.S. health care system. Discrimination based on race or ethnicity is the most frequently reported type of discrimination by patients [186]. As noted in the Institute of Medicine report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,* and other articles, Black patients are less likely to receive preventive care (e.g., cancer screenings), accurate diagnoses (e.g., pain assessments), consistent and efficient treatment (e.g., wait times for surgery, practice patterns for myocardial infarctions), and supportive services (e.g., end-of-life care), illustrating the pervasive nature and devastating consequences of structural racism in the health care system [37,81,121,128,193,260].

Importantly, the impact of each of the existing challenges listed above on patients, families, and communities is magnified when evaluated through the lens of structural and institutional racism. While public health infrastructure is atrophying across America, the gaps are particularly dire among communities of color, with Black, Indigenous, and Latinx populations more likely than White populations to contend with neighborhoods with toxic sites; substandard plumbing; polluted air, waters, and lands; and insufficient access to fresh and nutritious food items. Likewise, of the more than 33 million Americans who were uninsured in 2019, Black and Latinx adults were more likely than White adults to lack health care coverage [45]. Even in areas where progress has increased patient and family engagement, communities of color continue to be left behind. Many value-based care programs disadvantage patients with greater social needs. For example, physicians caring for patients with more social needs scored lower under the Merit-based Incentive Payment System, while accountable care organizations serving minority patients were associated with poorer performance on Medicare quality measures [147,159]. Likewise, underrepresentation of communities of color is a long-standing problem for clinical research. For instance, mortality from cardiovascular disease is twice as high for Black patients compared to White patients, yet Black patients account for only 4 percent of study participants in cardiovascular clinical trials [55,146].

It is critical to note that intersectionality, or how social identities such as race, ethnicity, class, gender, and age "intersect," has a profound effect on health and health outcomes. The above-referenced examples highlight disparities by race and ethnicity; however, when race and ethnicity are combined with other characteristics, they can often produce increased and exacerbated health inequities and worse health outcomes. For example, a January 2021 report found that among older adults, Black and Hispanic individuals are three and two times more likely than White individuals, respectively, to report that their care preferences were not considered, making them more likely to report lower satisfaction and decline medical care [246]. Additionally, compared to one in six low-income White women, one in five low-income Black women are uninsured [182].

Consequently, while patients, families, and communities as a whole face discrete challenges, achieving the goal of enabling each member of US society to reach their full health potential requires grounding the challenges and opportunities for patients, families, and communities using the framework of health equity [179]. Only by redressing historical legacies and the

ongoing perpetuation of structural and institutional racism will the health care system be truly centered on the needs, experiences, and considerations of patients, families, and communities.

Patients, Families, and Communities Experiences During COVID-19

The COVID-19 pandemic has affected patients, families, and communities across America in myriad ways. However, the most fundamental consequences of the virus are health related. With persistently high infection rates and the susceptibility of specific populations to severe illness, COVID-19 has become the leading cause of death in the United States [16,257]. However, the health effects of COVID-19 (e.g., risk of hospitalization) and the response of the health system to COVID-19 (e.g., access to testing and treatment) were not equally distributed across all Americans. Indeed, the health outcomes of patients and families during COVID-19 was determined by a combination of both health (e.g., chronic diseases) and social (e.g., class, race, ethnicity, living conditions) factors, with evidence clearly demonstrating the virus's disparate impact on communities of color, low-income populations, and older adults.

Yet while the United States is one of the countries that leads the world in COVID-19 cases and deaths, these stark numbers alone do not adequately reflect or demonstrate the significant and wide-ranging impact the pandemic has had on patients, families, and communities [131]. COVID-19 has negatively affected multiple aspects of the lives of patients, families, and communities, including the severe economic conse-quences of the pandemic-related recession and the mental health toll from the disruption in relationships and social networks. To fully capture the experience of patients, families, and communities during COVID-19, this section will review the health consequences of the virus as well as the upstream and downstream effects on society. Key domains of focus include:

1. Disparities in COVID-19 infection rates
2. Disparities in COVID-19 morbidity and mortality
3. Disparities in COVID-19 testing, treatment, and vaccination
4. Impact of COVID-19 on caregivers and families
5. Impact of COVID-19 on behavioral health
6. Impact of COVID-19 on non-COVID-19 health conditions
7. Impact of COVID-19 on community-based services
8. Impact of COVID-19 on health and social equity (see *Figure 2*)

Disparities in COVID-19 Infection Rates

Over 45 million cases of infection have occurred in the United States as of October 27, 2021 [48]. Although COVID-19 has affected patients of all ages and backgrounds, adults between the ages of 18 and 64 have accounted for nearly 75 percent of cases. While children were thought to be less susceptible to infection, over 11 percent of cases are attributed to pediatric patients, although the likelihood of escalation to severe illness still appears lower [49]. In addition, infections have disproportionately affected select populations, including communities of color and individuals living in congregate settings. For example, the rate of COVID-19 infec-

Disparities in Infection Rates	• Elevated risk for essential workers • Increased transmission in congregate settings • Disproportionate infection rates among low-income individuals and minority populations	Behavioral Health	• Unprecedented increase in anxiety, depression, and suicidal ideation • Exacerbation of existing behavioral health issues, such as substance use disorder
Disparities in Outcomes	• Greater incidence of severe illness and fatalities among the elderly population • Increased risk for those with chronic diseases • Disproportionate burden of mortality and morbidity for communities of color	Non-COVID-19 Health Conditions	• Reductions in diagnostic screenings (e.g., colonoscopies, mammograms) and preventive health services (e.g., pediatric vaccinations) • Disruptions to chronic disease management
Testing, Therapies, and Vaccines	• Unequal access to diagnostic testing sites and longer waiting times for certain communities • Uneven distribution of therapies • Racial disparities in vaccination rates and access to vaccines	Community-Based Services	• Disruptions to home- and community-based care and services • Greater demand for social services and strain on community-based organizations
Caregivers and Families	• Emotional toll of visitation restrictions • Variation in COVID-19 discharge practices • Added burdens of new home and childcare responsibilities during lockdowns, especially for women	Health Inequities	• Exacerbation of COVID-19 by structural and institutional racism • Economic inequality of the pandemic recession • Ageism and neglect of long-term care

FIGURE 2 | Experiences of Patients, Families, and Communities During COVID-19

> **BOX 1 | Stories of Lived Experience: Impact of Being a Frontline Employee during COVID-19**
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> "Our community—the majority work in the service industry, and they are out providing you their food, cleaning the hospitals, and doing the sanitation. So they are very, very high risk of getting infected with COVID." – Sandra Rodriguez, Gulfton, Texas

tions is higher for Black (1.1 times), Latinx (1.3 times), and Indigenous (1.9 times) patients as compared to White patients [50]. This section will review the contextual factors contributing to disparities in COVID-19 infection, including the increased risk for (1) "essential" workers (of whom a disproportionately large percentage are people of color) and (2) patients and families living in crowded conditions with limited ability to socially distance [18,126].

Essential Employees are More Likely to be Exposed to COVID-19

Health care workers—clinicians, allied health professionals, and staff at health care facilities—are at substantial risk of exposure to COVID-19 due to their service on the front lines of the pandemic. However, their susceptibility to infection increased significantly due to prolonged shortages of personal protective equipment (PPE), with gaps particularly persisting for workers in nursing homes [167]. Over 3,600 US health care workers are reported to have died from COVID-19, with 67 percent of deaths affecting workers of color [106]. In fact, being a health care worker at a nursing home was one of the most dangerous jobs in America during the early months of the pandemic [167].

Workers in other industries deemed "essential" by the government have also been at high risk of exposure to COVID-19. Over 40 percent of these frontline employees identify as people of color, and less than one-fifth of Black or Latinx workers possessed the capacity to telework (compared to one-third of White workers) [106]. These frontline occupations include jobs in direct care (i.e., day care providers, personal aides, and home health care), construction, hospitality, agriculture, and meatpacking [107,108]. A member of that community illustrates the impact below (see *Box 1*).

Unlike health care, many industries requiring workers to report in person may not have provided adequate PPE and did not develop or use physical distancing protocols, increasing the risk of COVID-19 transmission among coworkers and customers. For example, tens of thousands of meatpacking workers have been infected with COVID-19, with 87 percent of cases affecting people of color [259]. Likewise, direct care workers—who play a central role in providing home- and community-based services—have increased susceptibility to COVID-19 exposure due to their close contact with high-risk individuals. A significant proportion of direct care workers in the United States are women (>80 percent), people of color (60 percent), immigrants (25 percent), and those over the age of 55 (23 percent) [204,224]. Yet despite their substantial exposure and individual risk factors, most lack access to paid sick leave and were not included in the emergency provisions of the Families First Coronavirus Response Act, layering their health risks with added financial uncertainty [275]. Furthermore, workers in congregate living spaces, where there are high rates of COVID-19 transmission, were also likely to be infected. For example, nearly 4,000 cases were reported among prison staff in the spring of 2020 [211]. Likewise, many nursing homes—which account for over one-third of COVID-19 deaths—rely on staffing models where many workers are simultaneously employed by and required to travel between multiple homes. Modeling studies suggest nearly half of nursing home cases are linked to staff networks, leaving workers—the majority of whom are women—in an impossible bind: risk contracting COVID-19 or risk termination [20,62,88].

Lastly, the challenges facing essential workers were magnified for immigrant and undocumented workers, who may be less likely to notify the Occupational Safety and Health Administration about workplace safety concerns for fear of deportation [180]. They may also have concerns about being considered a "public charge," where until recently, receipt of public benefits would render them ineligible for legal permanent residence [92]. This fear of being deemed a "public charge" has haunted individuals like Maria and Francisco Garcia, who have worked the produce fields of the Coachella Valley for over 25 years. Maria and Francisco are undocumented, and their daughter Mariana is a U.S. citi-

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BOX 2 | Stories of Lived Experience: Impact of Isolating to Prevent Transmission to Family Members

"These were very sad weeks, behind plastic, without being able to hug or kiss them—this was the hardest part—away from your family, as if you have some kind of pestilence." – Rina Chivarria, Los Angeles, California

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zen. Recently, Maria and Francisco became eligible to apply to become Permanent Residents; however, with the rapid spread of COVID-19 in California's agricultural regions, they feared contracting the virus at work and jeopardizing their chance of becoming naturalized citizens if they seek medical care [25]. Additionally, undocumented individuals, *including* their U.S.-citizen spouses or children, are excluded from receiving direct cash relief provided by the federal government and may continue to work and increase the risk of exposure to COVID-19 to financially provide for their families [41].

Crowded Living Conditions Increase the Likelihood of Contracting COVID-19

Living conditions in which households or multiple individuals live together near one another are high-risk environments for the spread of infectious diseases. These conditions limit the capacity of individuals to distance themselves in the event one member of the household becomes sick. Location- and housing-based risk factors for COVID-19 disproportionately affect marginalized populations.

First, people of color are more likely than White populations to live in multigenerational households. This arrangement is especially true for immigrant communities, such as the Latinx population, where one in four live in multigenerational households [64]. The risk of infection is multiplied when considering the overrepresentation of essential workers in multigenerational housing, with such individuals reporting significant challenges with self-isolation during COVID-19 [64,271]. For example, Rina Chavarria, a meatpacking worker in Los Angeles who contracted COVID-19 while at work, had to isolate herself in a makeshift bubble consisting of a lower bunk bed sealed off with clear vinyl plastic and tape for two weeks to avoid infecting her 12-year-old son, who has bronchial problems (see *Box 2*) [272].

Second, people with low incomes living in poor housing conditions—as defined by cost, overcrowding, and inadequate facilities—are more likely to be infected. Analyses of over 3,000 counties in the United States found that a 5 percent increase in the number of households with poor conditions in a given county was associated with a 50 percent increase in the risk of COVID-19 incidence [11]. Relatedly, studies have also reported that a 0.1-point increase in a US county's Social Vulnerability Index—defined by the CDC to include factors such as poverty and housing conditions—was associated with a 14 percent increase in the incidence of COVID-19 infection [138]. Communities of color are overrepresented in the population of individuals living in poor housing conditions. For example, the proportion of Latinx families living in crowded conditions is nine times higher than White families in California, a state where infections have disproportionately impacted Latinx communities [143,262].

Third, congregate living facilities—including homeless shelters, correctional facilities, and nursing homes—became hotbeds for COVID-19 transmission. For example, testing at homeless shelters in major metropolitan areas in the spring of 2020 found resident infection rates to range between 17 percent and 66 percent in shelters with at least two confirmed cases, illustrating the ease of viral spread [172]. In jails and prisons—where justice-involved populations are disproportionately people of color—the known infection rate for COVID-19 is approximately 5.5 times higher than in the general population [227]. Furthermore, in nursing homes—which have been called "ground zero" for COVID-19 due to their high rates of infections and fatalities—severe outbreaks were more likely in facilities with higher shares of Black or Latinx residents [26,42].

Disparities in COVID-19 Morbidity and Mortality

The CDC estimates that about 20 to 30 percent of those with COVID-19 become acutely ill and require emergency department (ED) visits or hospitalizations, with approximately 5 to 15 percent of hospitalized patients requiring treatment in an intensive care unit (ICU) [96]. Several factors contribute to the likelihood that an infected individual will progress to severe illness, includ-

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ing preexisting health conditions and age. Notably, the burden of severe illness and fatalities is disproportionately higher for older adults and populations of color. This section reviews the disparities in health outcomes for patients following COVID-19 infection.

Increased Risk for Individuals with Chronic Illnesses

Individuals with preexisting conditions (e.g., cardiovascular disease), poor health (e.g., obesity), and unhealthy behaviors (e.g., smoking) are all at elevated risk for severe COVID-19. Indeed, almost 90 percent of those hospitalized for COVID-19 also had two or more chronic conditions, while nearly 75 percent of COVID-19 deaths occurred in patients with at least one preexisting condition [264]. For example, studies of Medicare beneficiaries found kidney disease, cardiovascular disease, and diabetes to be strongly associated with the likelihood of hospitalization due to COVID-19 [61]. Thus, while preexisting conditions may be one factor associated with increased risk for morbidity and mortality due to COVID-19, they may not be the sole cause of disparities in health outcomes among Black and Latinx Americans compared to White Americans. It is important to note that other factors, such as lack of consistent providers, lack of high-quality care, and experiences with systemic racism, may have a greater influence on health outcomes for communities of color [23].

Burden among Older Adults

Age is a substantial risk factor for COVID-19, with CDC analyses of laboratory-confirmed COVID-19 cases indicating that nearly 75 percent of deaths were attributed to individuals over 65 [263]. Compared to 5- to 17-year-olds, older adults 65 to 74 years are 40 times more likely to be hospitalized and have a 1,300 times greater risk of death due to COVID-19; older adults 75 to 84 years are 65 times more likely to be hospitalized and have a 3,200 times greater risk of death [51]. Several factors contribute to the increased risk of severe illness and death among older adults. First, older adults with chronic illnesses and functional limitations have an increased need for supports and services for activities of daily living and are at increased risk of exposure to COVID-19 [229]. Second, older adults are overrepresented in nursing homes (84 percent of residents), which account for over one-third of United States COVID-19 deaths [122,184]. Third, the prevalence of chronic illnesses is greater among older adults. However, the experience of seniors is not uniform. For example, older adults who are dually eligible for Medicare and Medicaid are hospitalized at four times the rate of Medicare beneficiaries, while hospitalization rates are higher for Black (fourfold) and Latinx (twofold) Medicare beneficiaries as compared to White patients [67,97].

Disparate Impact for Communities of Color

Evidence to date overwhelmingly illustrates the disproportionate morbidity and mortality from COVID-19 on populations of color of all ages. Compared to White and Asian American and Pacific Islander patients, Indigenous, Black, and Latinx individuals are approximately three times more likely to be hospitalized and twice as likely to die from COVID-19 [52]. While Asian American and Pacific Islander patients have been underrepresented in some analyses, and while race and ethnicity data may not capture the full diversity of this population, analyses of Epic health records suggest Asian American patients who test positive for COVID-19 were at greater risk for hospitalization (1.3 times) and death (1.2 times) than White patients [217]. The disparities in hospitalization rates between White patients and populations of color are even larger in adults under 65 [50]. Furthermore, recent studies indicate that children of color are five to eight times more likely to be hospitalized with COVID-19 than White children and more likely to develop a serious complication such as multisystem inflammatory syndrome [212].

Disparities in COVID-19 health outcomes reflect disparities in the underlying health status of marginalized populations in the United States. The prevalence of illnesses such as diabetes and cardiovascular disease—leading risk factors for severe illness from COVID-19—is greater at baseline for populations of color, contributing to their risk of poor outcomes from COVID-19 [162]. Marginalized populations also have less access to health care resources (e.g., insurance), and Black and Latinx individuals report poorer health literacy about COVID-19 [14]. Notably, studies suggest there is no difference in COVID-19 mortality when comparing hospitalized White patients to hospitalized Black patients [270]. Likewise, while one-third of COVID-19 patients admitted to the ICU are Black (even though Black individuals account for only 13 percent of the United States population), researchers did not find an association between race and death for COVID-19 patients receiving critical care [109]. However, this preliminary evidence should be contextualized to the historically unequal treatment and care quality provided to Black patients in the U.S. health care system, including for COVID-19, with early data and patient stories reflecting the disparate experience of Black patients seeking care for COVID-19 [84].

Additionally, the drivers of outcome disparities for communities of color must be understood considering the broader gaps in access to necessary health care resources that these populations face. Indeed, Black patients have poorer access to primary care physicians, experience local hospital closures at higher rates than their White peers due to residential segregation, and are sent to lower-quality nursing homes. These factors, together, may contribute to worse outcomes during the pandemic [94,100,153]. Patients of color also experienced worse outcomes in congregate facilities—a function of the staffing and resource shortages at nursing homes serving marginalized populations [173]. For example, COVID-19 outbreaks were more widespread at nursing homes with more patients of color, and nursing homes with a higher share of Black (1.6 times) and Latinx (1.3 times) residents were more likely to have COVID-19 deaths than those with low shares of patients of color [15,42,160]. Likewise, COVID-19 death rates are twice as high in prisons compared to the general population, with people of color accounting for most incarcerated individuals in the United States [225].

Challenges for COVID-19 Recovery

The morbidity associated with COVID-19 extends beyond the time frame of testing positive for the virus. Early evidence suggests that survivors of COVID-19 are confronting unpredictable trajectories with complex and long-term physical, cognitive, and emotional health consequences [24]. Almost all patients who are hospitalized and discharged have health implications that extend at least a few weeks. Because of their development of acute respiratory distress syndrome, patients who were treated using mechanical ventilation are at risk for lung injury [268]. Others have developed new complex problems, hypothesized to be due to hyperinflammation, affecting the heart, brain, kidneys, and lungs. In addition, those who have been hospitalized often experience "the post-viral syndrome" or "long-COVID" with persistent shortness of breath, fatigue, and, for some, cognitive deficits such as difficulty concentrating [44,114]. Anecdotal reports reveal that some otherwise healthy adults, even those not hospitalized, also report unresolved symptoms that require long-term rehabilitation and emotional support [252]. Ongoing observational studies at the National Institutes of Health examine the long-term consequences of this disease, which may influence health care delivery in the future [183]. Given the burden of disease and hospitalization rate for specific populations of color, the United States will likely also face disparities in the long-term impacts of the pandemic.

Disparities in COVID-19 Testing, Treatment, and Vaccination

Just as certain patients, families, and communities experience disparities in their risk of infection and likelihood of experiencing severe illness, marginalized populations have also faced inequities in access to diagnostic testing, contact tracing programs, and the resources available to self-quarantine [231,241]. Furthermore, even as the health care system developed new therapeutics and vaccines capable of significantly reducing morbidity and mortality, the uptake of new biomedical innovations was uneven due to gaps in access and low levels of trust among many patients, families, and communities. This section reviews the disparities in the COVID-19 response, which not only exacerbated the inequities in health outcomes for many populations but also hindered the safe reopening of communities, states, and the country.

Gaps in Testing and Tracing Capacity

Access to rapid and accurate diagnostic testing was a significant challenge during the pandemic. At the peak of the pandemic, less than half of all laboratory tests were completed within three days, and some patients reported waiting weeks to receive results—delays that rendered diagnostic testing useless for health care decision making and health department contact tracing [119,155,170]. Even as the availability of testing improved, inequities persisted due to the uneven distribution of resources [231,241]. Although people of color were more likely to test positive for COVID-19, experience severe illness, and require hospital-level care, data from electronic medical records indicate that these same populations received COVID-19 tests at only slightly higher levels than White patients [217]. Furthermore, even though testing rates were slightly higher in the aggregate for people of color, the experiences of communities varied significantly across the country. For example, a national analysis of nearly 8,000 testing sites during the summer of 2020 revealed wait times for diagnostic testing to be longer in communities of color than in predominantly White communities [40,150]. These studies likely underestimate the true disparities in access, given that many laboratory records lacked demographic data [236]. Further, the lack of demographic data, in general, represents a major inequity that has been exacerbated by and has yet to be addressed during the pandemic. The stories from patients below during the pandemic help highlight the challenges of navigating a fragmented system with little support and poor communication (see *Box 3* and *Box 4*).

> **BOX 3 | Stories of Lived Experience: Challenges Faced by Elizabeth de Garcia and her Family in Navigating the Health System during the COVID-19 Pandemic**
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> Elizabeth de Garcia, who is from the predominantly Latinx community of Montgomery Village, Maryland, told the Washington Post that in order to get one of her brothers tested in April, they had to make two hospital trips and dozens of phone calls. De Garcia did not know of any free testing sites in her county. To her knowledge, the closest one was 27 miles, a two-hour bus ride from her apartment and an inherently risky activity in itself during the peak of the pandemic.
>
> SOURCE: [276]

Stories like Joe's show that without access to accurate and timely testing and the supports—such as paid sick leave and provision of housing to support isolation for individuals who test positive—one case can lead to additional community spread, more infections, and even deaths [277,278]. Indeed, even when populations could access testing, the effectiveness of contact tracing programs and supportive services for quarantine requirements were often lacking. Many of the populations at greatest risk for COVID-19 infection and severe illness (e.g., older adults, people of color) have limited access to phones, poorer access to technology such as broadband and smartphones, and challenges with health literacy, making them less likely to receive calls from contact tracers or be able to easily research support for quarantine outside the home [29,194,205].

Gaps in Access to Therapeutics and Vaccines

While tremendous investment and coordination by biomedical researchers and health product manufacturers and innovators enabled the development and emergency use authorizations of multiple COVID-19 therapeutics and vaccines in record time during 2020, new medical countermeasures were unevenly distributed among patients, families, and communities. For example, the initial allocation of remdesivir, an antiviral treatment for COVID-19, did not follow a clear methodology, leading to access delays for different communities [34]. Furthermore, while the United States vaccinated nearly thirteen million individuals during the first month of COVID-19 vaccine availability, the majority of vaccines went to White patients, with Black patients accounting for little over 5 percent of all vaccinations [195]. Although immunization campaigns remain in progress at the time of this paper's publication, the persistent variation in access to medical products during the pandemic reflects how COVID-19 has perpetuated long-standing disparities in access to care.

Impact of COVID-19 on Caregivers and Families

As of 2020, there were 53 million family caregivers to an adult or child with special needs [1]. An AARP research report found that the majority of caregivers are women (61 percent), with 61 percent being White, 17 percent being Latinx, 4 percent being Black, and 5 percent being Asian American and Pacific Islander [1]. Due to earned income (approximately 36 percent of caregiver households earn less than $50,000) and caring for two or more adults (24 percent), caregivers often experience greater financial strain, have competing demands of work, and suffer from high levels of emotional stress [1]. COVID-19 has further impacted, and even increased, the physical and emotional well-being of caregivers and families. These impacts range from the devastating restrictions for visitations in health care facilities to the evolving burdens of home and childcare responsibilities due to closures of schools and workplaces.

First, many family members have been unable to support loved ones isolated in hospitals and receiving treatment for COVID-19, since health care facilities have imposed restrictions on visitation to limit the spread of infection [253]. Further, for patients who succumb to COVID-19, caregivers and family members are not able to be there in person, with hospitals resorting to using tablet technologies and videoconferencing platforms to enable patients, families, and caregivers to say goodbye [118]. Bereaved families are the secondary victims of COVID-19, as they experience sadness, anguish, anger, guilt, and an increased trauma response due to the pandemic [101]. Reports estimate that for every loss due to COVID-19, approximately nine people are bereaved [264]. Additionally, as of July 2021, approximately 1.5 children per 100,000 in the United States have lost a primary caregiver due to COVID-19 [251]. The potential for long-term adverse stress reactions is enormous.

BOX 4 | Stories of Lived Experience: Challenges Faced by Joe Merlino and His Family in Navigating the Health System during the COVID-19 Pandemic

Joe Merlino lived with his elderly mother and a roommate, an essential worker whose workplace did not require regular COVID-19 testing, despite knowing some employees had been infected. Unfortunately, Joe and his mother began to experience more severe COVID-19 symptoms a few days after initial symptoms they attributed to allergies. After Joe called at least 12 different testing hotlines and scoured three different websites to figure out where he could get a test, he still had to wait four days before getting tested and an additional five days to receive the results. Unfortunately, his mother had to be hospitalized due to her symptoms, and she died.

SOURCE: [277]

Second, the impact of such restrictions has been particularly stark for nursing home residents, who are generally older and for whom prolonged loneliness and isolation are associated with functional decline [171,201]. For example, during the spring of 2020, many nursing homes imposed significant restrictions on visitations, with the lack of contact with family and limitations on social activities in the facilities negatively impacting the mental health of these patients. Indeed, some residents reportedly stopped eating and entered a state of despair because of social isolation, which a 2020 consensus study report from NASEM indicates can severely impact health and well-being [3,177]. Although visitation policies were later modified, guidelines continued to vary, creating challenges for patients and families alike.

Third, in an attempt to minimize the spread of COVID-19, hospital restrictions were also applied to other non-COVID-19-related areas. For example, many hospitals limited visitors for labor and delivery units [21]. Likewise, the pandemic disrupted many palliative care activities—for which caregiver and family involvement in end-of-life conversations can play an important role—adding to the emotional burden for patients and potentially dislocating them from their support systems [4]. Thus, while infection control policies were necessary to mitigate the risk of COVID-19 transmission, the downstream effects on caregivers and families had significant impacts.

Beyond visitation restrictions, families and caregivers faced additional challenges in supporting patients infected by COVID-19. For example, during the early months of the pandemic, local, state, and federal guidelines regarding whether patients recovered from COVID-19 and discharged from hospitals could be admitted to skilled nursing facilities varied and were frequently modified, creating confusion for patients, caregivers, and clinicians [7,68,101]. Many patients who otherwise would have been admitted to such facilities were subsequently sent home with substantially increased health care needs. Unfortunately, information needed to address these needs was often not communicated to primary or home care clinicians, due in part to the Centers for Medicare & Medicaid Services' (CMS') relaxation of discharge planning reporting requirements [68]. Early in the pandemic, caregivers' preparation for their responsibilities for patients suffering from the effects of this ravaging and unpredictable disease was conducted via phone, not in person. These added responsibilities without additional resources for caregivers came when many Americans were confronting other major stressors, including competing roles as parents and financial stress due to loss of jobs [161].

In addition to caregiving responsibilities, the upending of daily life for over a year (e.g., closure of schools and workplaces) has added to the stress of families. Families have had to navigate compounding challenges ranging from economic uncertainty, potential health impacts to loved ones, and supporting children with remote learning. As a result, the use of childcare centers has declined by over 50 percent during the pandemic, with COVID-19 requiring 67 percent of working parents to modify their childcare arrangements [268]. Parents have had to become homeschooling teachers and have few childcare options while managing caregiving for aging relatives [135]. Unfortunately, the increased burden of home and childcare responsibilities, as well as caring for relatives, has largely fallen on women. For example, one in ten women with children under the age of 18 years quit their jobs due to the pandemic, and ap-

> ## BOX 5 | Stories of Lived Experience: Impact of Suicide on Loved Ones
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> "As someone who has lost a loved one to suicide, I understand why it's such a taboo topic. There are layers of anger and guilt over their decision, but also sadness and confusion. Why did they do it? Why wasn't I enough? What am I going to do without them? Who am I without them? Am I really never going to see them again?" – Michael Bamarni, a man who lost a loved one to suicide
>
> SOURCE: [28]

proximately 30 percent of working mothers took time off work because of their children's school or lack of day care. Women who are Black, Latinx, or low-income were more likely to quit their jobs for reasons related to COVID-19 [143]. In addition, during the prenatal and postnatal time frame, people who are pregnant experience more burden, stress, and anxiety due to COVID-19, greatly impacting their mental health [175]. Further, in general, women have reported higher rates of symptoms of anxiety or depression during the pandemic than men, raising concerns about the long-term implications for gender equality in American society [71,196,247].

Impact of COVID-19 on Behavioral Health

As with other public health and financial crises, the COVID-19 pandemic has negatively affected behavioral health. The pandemic has exacerbated mental health distress and illness and substance misuse in people with existing conditions and facilitated the development of new conditions while increasing long-standing challenges in accessing best practice interventions.

Increased Mental Health Distress

Since the start of the COVID-19 pandemic, changes in daily life have been required by everyone in the United States. These changes have resulted in a notable increase in mental health distress, including anxiety, depression, and increased substance misuse. Certainly, these life changes have been more challenging for some. Reports of symptoms of anxiety or depression have quadrupled among adults between June 2019 and January 2021 [196]. Changes, such as physical distancing and stay-at-home orders, have made it more difficult for people to connect with others, resulting in increased social isolation and stress. The negative impact of social isolation, anxiety, and depression also include impaired executive function, accelerated cognitive decline, poor cardiovascular function, and

impaired immunity [188]. The stress of remote learning has affected the behavioral health of adolescents, with new diagnoses of attention deficit hyperactivity disorder increasing by 67 percent in March 2020 [189]. Likewise, greater baseline stress has disrupted sleep patterns for some individuals, increasing the incidence of insomnia symptoms and prescriptions for anti-insomnia medication [86,174]. Compared to 37 percent of men, 53 percent of women report negative mental health outcomes related to the pandemic. Older adults have been particularly affected, as their increased susceptibility to COVID-19 necessitated continued distancing despite the resulting emotional distress.

Social isolation is also associated with an increase in the risk of premature cardiovascular disease mortality [12]. There are also concerns about increased rates of suicide, driven by the increased rates of depression and anxiety. Suicidal ideation has more than doubled for adults, including evidence of greater risk for marginalized populations [254]. As the story below from Michael Bamarni, who lost a loved one to suicide, demonstrates the impact of these losses can be profound (see *Box 5*) [28].

Unsurprisingly, COVID-19 has also placed significant strain on families and communities. New stresses related to financial constraints with job losses, interruptions in usual health care, lack of childcare, lack of family supports, changes to education structures and online schooling, and concerns about child education and development for children with existing delays are present. Economic challenges have created additional stress for individuals and families who may struggle to cover basic necessities like food or housing [257]. As mentioned above, women have been significantly impacted by stress during the pandemic. Further, the stress is experienced in people of all ages. Children, especially school-aged youth, have also been negatively affected by family stress, lack of access to community

anchor institutions such as schools, and the limitations on outdoor activities, interpersonal development, and peer-to-peer connectivity. Studies have shown children living in higher-risk areas for COVID-19 to be at greater risk for psychological distress during the pandemic [104,210,266]. Distressingly, ED visits related to mental health have increased substantially for children (24 percent) and adolescents (31 percent) during the pandemic [156]. As the pandemic extends well into 2021, the prolonged disruption to school, social activities, and educational and developmental trajectories for children and young adults has raised concerns about the long-term mental health effects for this "lost generation" [157,228].

Lastly, while the pandemic has added to the stress of all Americans, the mental health impacts have been especially severe for low-income populations and communities of color. During the COVID-19 pandemic, low-income populations and households with job loss report higher mental illness rates than those who have not lost a job or who have not experienced income loss (53 percent versus 32 percent). In addition, Black and Latinx individuals have reported greater rates of anxiety or depressive symptoms. The mental health impact for essential workers—among whom people of color are overrepresented—has been particularly negative (e.g., nearly threefold increase in experiencing suicidal thoughts) [196]. The trends are particularly alarming considering that these populations already had worse access to mental health services than White populations before the pandemic [218].

Increased Risk of Abuse
Intimate partner violence and child abuse and neglect are also exacerbated by structural and interpersonal changes resulting from the pandemic. This includes increased rates of abuse and neglect and related increases in mental illness such as depression, post-traumatic stress disorder, and substance misuse [169]. For example, female survivors of intimate partner violence were more than twice as likely to experience depression or anxiety [46]. In addition, victims of child abuse and neglect and other adverse childhood experiences are well documented to be at greater risk for mental illness, functional impairment, and onset of risky behaviors, especially in the absence of access to best practice interventions [243].

Consequently, the prolonged restrictions of the pandemic raised concerns about the potential consequences of intimate partner violence and child abuse

[219,269]. For example, domestic violence hotlines experienced greater traffic during lockdowns, and cases are suspected of having increased significantly during the initial quarantine period [125,247]. Likewise, advocates and experts are concerned about the potential increase in child abuse and neglect, as the pandemic has limited school- and community-based reporting, which are the primary means of risk detection [5,226]. For instance, child reporting agencies have highlighted a decrease in notifications ranging from 20 percent to 70 percent during the pandemic. At the same time, CDC data indicates that ED visits due to child abuse and neglect declined by 53 percent in the spring of 2020, raising concerns about victims "suffering in silence" [30,244].

Exacerbation of Behavioral Health Problems
In addition to increasing the incidence of anxiety and depression, the strain of COVID-19 has exacerbated existing behavioral health problems for many Americans and increased rates of substance misuse. More than 13 percent of adults reported "new or increased substance use" [75]. Alcohol sales have increased more than 25 percent, with new applications for online ordering and delivery increasing the ease of access [251]. Similarly, cigarette sales increased during COVID-19, outpacing tobacco companies' expectations [165]. In addition, opioid and stimulant use is on the rise across the country. A recent analysis of 500,000 urine drug tests showed an increase of 32 percent in use of nonprescribed fentanyl, 20 percent for methamphetamine, and 10 percent for cocaine from mid-March through May 2020. Collectively, over 81,000 Americans died from a drug overdose in 2020—a record for overdose deaths in a 12-month period [56].

Lastly, the negative health outcomes arising from intersections between COVID-19 and behavioral health have only been magnified for communities of color. For example, while the prevalence of substance use disorder is similar between Black and White populations, hospitalization and fatality rates were approximately 1.5 times higher for Black COVID-19 patients with substance use disorder than White patients [260]. Likewise, Black and Latinx people with mental illness or substance use disorders are incarcerated or experience housing instability at higher rates than the population at large [220]. Further, people with mental illness tend to be incarcerated rather than receive community-based interventions, and Black individuals in correctional care facilities are frequently less likely

to be diagnosed and referred for behavioral health compared to White patients [136,206,208]. Together, these trends highlight how structural and institutional racism both increase the risk of poor outcomes from COVID-19 (e.g., representation in high-risk settings) and the negative spillover effects for other dimensions of health (e.g., poor baseline diagnosis and treatment of mental illness) for communities of color.

Treatment Services for Behavioral Health

Despite the increasing rates of behavioral health concerns and conditions, access to treatment, services, and supports is in major shortage across the country, and the pandemic has further exacerbated this problem. Prior to the pandemic, projections indicated shortages in behavioral health practitioners (e.g., psychiatrists, psychologists, substance abuse and behavioral disorder counselors, mental health and substance abuse social workers, mental health counselors) by 2025. The need for behavioral health among Americans due to the pandemic will significantly outpace the addition of providers to the workforce and access to evidence-based care around the country [143].

One positive development during the pandemic was the new CMS flexibilities for telehealth, which supported an unprecedented expansion in virtual care offerings, including for behavioral health services [69,120]. Generally, telehealth options have been well received by people in need of behavioral health services and service providers. While telephonic and telehealth access is by no means a solution for the systemic shortage of behavioral health services and providers, virtual care platforms have been critical for extending access during the pandemic [260]. Access to telephonic services and telehealth must be balanced with the need for high-quality care. In addition, uptake of tele-mental health services has remained robust even after outpatient facilities reopened [168].

Still, transitioning to virtual support can be problematic for some patients. Therefore, care should be taken to address challenges such as building provider-patient relationships, overcoming language barriers, having privacy at home or in multigenerational houses, and providing access to and capacity for using technology, especially for older adults. Additionally, while changes in telehealth are beneficial, not everyone has access to high-speed internet connections or technology to support video-enabled visits (e.g., nearly half of seniors lack a smartphone), requiring regulatory flexibilities to address major barriers and providers to get creative with telephonic supports [202]. For example, in some

cases, patients have had to use the Wi-Fi services at local McDonald's parking lots to dial in to support groups. Indeed, early evidence suggests different rates of telehealth uptake across socioeconomic groups and differences in receptivity to audio- versus video-enabled services for different populations [76,93].

Impact of COVID-19 on Non-COVID-19 Health Conditions

Since March 2020, the COVID-19 pandemic has caused disruptions in care continuity for patients, families, and communities. Preventive care, screening, and chronic disease management have been modified to prevent the spread of COVID-19, and the implications for the health of patients and families are undeniable. Further, there have been disruptions to home- and community-based care, which have largely impacted families, older adults, and communities.

Challenges to Receiving Preventive Care and Screening

The closure of many physicians' offices during the spring of 2020 led to a significant decline in delivering many preventive health services. For example, while primary care appointments could still take place virtually, research has found the content of outpatient telehealth visits differs from an in-person visit, with lower rates of blood pressure level assessments (50 percent decline) and cholesterol level assessments (37 percent decline) for telehealth visits [13]. Likewise, rates of diagnostic services such as colonoscopies (88 percent decline) and mammograms (77 percent decline) decreased substantially during the spring of 2020 and continued to remain well below pre-pandemic baselines into the fall of 2020 [152]. It must also be reiterated that virtual primary care appointments are only available to some, with patients of color disproportionately experiencing barriers to telehealth access and primary care physicians. Some delayed or deferred care may represent waste or low-value care (e.g., age-inappropriate screenings), and the COVID-19 pandemic may yield new insights about overdiagnosis and the appropriateness of different health services [65,149].

Delays for various types of health services during COVID-19 are cause for concern. For example, children have had less access to routine health care and life-saving vaccines typically delivered at well-child visits, raising concerns about their vulnerability to illness in the future [2,223]. A particular area of concern is measles, which had begun to make a resurgence in the United States before the pandemic [197].

Changes to Chronic Disease Management

Experts in the spring of 2020 warned that COVID-19 might be accompanied by a second, "hidden" pandemic due to disruptions in chronic disease management [27]. Over 60 percent of Americans have at least one chronic disease, with illnesses such as cardiovascular disease and cancer accounting for most of the country's morbidity and mortality burden [57]. However, the pandemic presented many challenges to effective chronic disease management. First, many physicians' offices were closed during the spring of 2020, making it difficult for some patients to present for treatment services in person (SAMHSA, 2020). Some patients were also hesitant to seek treatment in the early days of the pandemic for fear of contracting COVID-19. Others who sought help had trouble obtaining resources, as facilities limited services (e.g., to individuals who were at high risk of contracting COVID-19) or even closed for multiple reasons (e.g., public health compliance, lack of PPE to protect the workforce, workers getting sick and experiencing burnout, transitioning to telehealth options).

Further, patients who had previously relied on clinical trials found their access to cutting-edge treatments for various health conditions reduced because of COVID-19. For example, a review of a nationwide database of trials estimated that from January to May 2020, there were 42 percent fewer oncology trials actively recruiting compared to a year prior [105]. In a starker example, at the University of Pennsylvania's Abramson Cancer Center, nearly 90 percent of cancer clinical trials suspended enrollment in spring 2020. Those that continued last April and May had less than a third of their baseline enrollments, limiting cancer patients' access to vital resources.

Emerging evidence illustrates the scope of disruptions in care continuity. For example, hospitalization rates for many chronic illnesses have declined, including heart failure (nearly threefold) and chronic obstructive pulmonary diseases (nearly fourfold) [32]. While declines could represent a response to previous overuse, the decrease in hospital admissions for emergencies such as stroke (49 percent reduction) and heart attacks (39 percent reduction) highlight the negative impact of deferrals on patient health [31]. Overall, 41 percent of adults report delaying medical care in the spring and summer of 2020, with COVID-19 playing a key role in many patients' decision making [10]. Distressingly, delays were more common for Black and Latinx patients than White patients—another example of how the pandemic is widening existing disparities in health outcomes [75].

Impact of COVID-19 on Community-Based Services
Beyond clinical needs, the pandemic has also significantly affected access to key community services, ranging from the needs of specific populations (e.g., older adults, the disabled) to the exacerbation of social needs and risks (e.g., food, housing).

Disruption to Home- and Community-Based Care

Direct care workers serve twenty million older adults and adults with disabilities who need assistance with activities of daily living (e.g., bathing, dressing) and other routine tasks (e.g., cooking, shopping) [224]. Recipients of home- and community-based services are disproportionately older adults and people of color, have chronic illnesses complicated by functional deficits compared to their peers, and are at increased risk for severe illness and death if they contract COVID-19 [57,240]. Unfortunately, most communities have no system for distributing PPE to or routinely testing these essential workers. Some, fearing the effects of the virus for themselves and their families, stopped working. Others, fearing losing their jobs and income, continue to put themselves and their clients at risk. Common themes emerging from qualitative interviews with a sample of such workers in New York City during the pandemic were feelings of being invisible despite their frontline responsibilities and anxiety over trade-offs they made related to their work and personal lives [242].

Impact on Patients with Disabilities

One in four adults in the United States lives with a disability, which encompasses many kinds of conditions, including physical (e.g., mobility limitations, sensory impairment) and cognitive (e.g., memory difficulties) disabilities [59]. While it is important to acknowledge the heterogeneity in communities with differing abilities in terms of risk level and access to resources, patients with differing abilities, in general, have experienced challenges during COVID-19. In addition, some disabilities increase the likelihood that individuals will contract COVID-19 and experience severe illness. For example, the nursing home population—which COVID-19 has disproportionately impacted—has high rates of physical (e.g., 80 percent requiring support for assisted daily living tasks) and mental disabilities (e.g., 48 percent suffering from some kind of dementia), for which support may have been less accessible during the pan-

COVID-19 Impact Area	Pre-Pandemic Disparities	Pandemic-Era Disparities
Risk of Infection	People of color were disproportionately affected by infectious diseases (e.g. HIV/AIDS) and respiratory illness (e.g. asthma)	• COVID-19 infection rates were significantly higher for communities of color
Risk of Severe Illness	The prevalence of chronic illnesses such as cardiovascular disease and diabetes was higher among communities of color	• The burden of morbidity and mortality from COVID-19 was higher among Black and Latinx patients
Population-Specific Needs	People of color were overrepresented in essential jobs, justice-involved populations, and homeless populations, and more likely to live in poorer-quality nursing homes	• Communities of color had higher rates of COVID-19 hospitalizations and fatalities in the subgroups of the elderly, nursing home residents, adults, and children
Access to Health Services	Communities of color are more likely to be uninsured and live in a primary care shortage area	• Communities of color lacked ready access to diagnostic testing and were vaccinated at slower rates compared to White patients
Mental and Behavioral Health	People of color have less access to mental health services than White patients	• Incidence of symptoms of anxiety or depressive disorder during COVID-19 were higher for people of color
Non-COVID-19 Care	Black and Latinx patients at increased risk of early incidence and progression of chronic diseases	• Black and Latinx patients were more likely to defer or delay non-COVID-19 care during the pandemic
Social Needs	Income and wealth building inequality, ageism, gender pay gaps, and environmental disparities were prevalent throughout different facets of American society	• The pandemic exacerbated economic (e.g., financial security) and social (e.g., housing, food) needs among marginalized populations

TABLE 2 | The Disparate Impact of COVID-19 on Communities of Color

demic [58,115]. Likewise, claims data analyses indicate that the risk of death from COVID-19 was nearly three times higher for patients with developmental disabilities and intellectual disabilities (e.g., Down syndrome) [89]. Yet despite their elevated risk, support has often been lacking. For instance, some states' guidelines for allocating ventilators—later amended after intervention from the Department of Health and Human Services—discriminated against individuals with disabilities [206]. Similar variation exists for states' prioritization frameworks for the COVID-19 vaccine [132]. The challenges are layered upon the pandemic-era disruption to daily routines and support systems on which people with disabilities may rely.

Elevated Social Needs and Strain on Social Services
The health care consequences and financial strain of the pandemic have exacerbated the social needs of many families and communities. For example, millions of families faced housing instability (with thousands reporting evictions despite the CDC's moratorium), while rates of food insecurity doubled during COVID-19 [187,230]. These needs were often magnified for people of color, with food insecurity rates nearly twice as high for Black and Latinx families compared to White households [113]. Community-based organizations (CBOs) have played a key role in supporting the needs of patients and families during the pandemic, from coordinating with public health departments around COVID-19-related health needs to pivoting operations to virtual- (e.g., benefits counseling) and home-based (e.g., meal delivery) platforms [182]. However, increased demand for social services coupled with the logistical obstacles of the pandemic have created chal-

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BOX 6 | Stories of Lived Experience: Health Care Disparities during COVID-19

"I was crushed. He made me feel like a drug addict. And he knew I was a physician. I don't take narcotics. . . . I put forward and maintain that if I was White, I wouldn't have to go through that."

– Dr. Susan Moore, a Black doctor who died from COVID-19 and reported undertreatment for pain

SOURCE: [185]

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lenges for CBOs. For one, while some programs (e.g., meal delivery) increased due to demand, others have declined (e.g., transportation support). Additionally, the majority of CBOs report losing revenue during CO-VID-19, and staff layoffs coupled with declining volunteer support have constrained CBO capacity [72].

Impact of COVID-19 on Health and Social Equity
While the sections above note the distressing breadth of the pandemic's impact on patients, families, and communities, they also illustrate how each stressor and consequence of COVID-19 for the sector as a whole has been magnified for marginalized populations (see *Table 2*). It is necessary to emphasize that the pandemic did not cause these disparities so much as magnify existing inequities embedded into the structure of American society and the health system. Specifically, during the pandemic, the effects of structural and institutional racism, economic disparities, the gender gap, ageism, and environmental disparities have been felt by patients, families, and communities. The alarming effects of these inequities point to the need for the identification of approaches to improve the health and well-being of all patients, families, and communities.

Inequities and Structural Racism Exacerbates Impact of COVID-19 on Many Patients, Families, and Communities
Early in this paper, the authors detailed the impacts of structural and institutional racism on the health of communities of color and discussed the disparities in contracting, testing, contact tracing, and morbidity and mortality associated with COVID-19. Since structural and institutional racism are intertwined in all facets of the policies and systems in the United States, the impact on housing, education, employment, health care, the justice system, and other areas is evident. When combined with COVID-19, structural and institutional racism has ultimately led to the increased spread,

worse health outcomes, and compounded risk factors that make the virus more dangerous and deadly for communities of color. In addition, the policies and systems in place across the nation reinforce stereotypes, discrimination, and unequal distribution of resources and are even more grossly magnified because of CO-VID-19. For example, housing practices that have led to segregation and low-income neighborhoods are exacerbating the impact of COVID-19 on patients, families, and communities [273]. Likewise, educational systems in low-resource neighborhoods may have experienced more challenges instituting remote learning. With fewer eligible children receiving free or reduced school meals, schools may have found it more challenging to provide lessons to children who may now be going hungry [35,79].

Further health care disparities prior to COVID-19 exist in large part due to bias and discrimination. During the pandemic, these same biases and discriminatory practices could influence whether patients of color are turned away from hospitals, admitted, and treated. This was the case with Dr. Susan Moore, who experienced racial discrimination while undergoing treatment for COVID-19, despite being a physician herself (see *Box 6*) [185].

Race-based discrimination has also been especially severe for Asian Americans and Pacific Islanders, who have reported greater exposure to stigma in surveys conducted during the pandemic [158]. Hate crimes against Asian Americans and Pacific Islanders have risen by nearly 150 percent during 2020, even as overall reporting of hate crimes declined [60]. Patterns of bias, discrimination, and stigma during the pandemic reflect the structural racism embedded against Asian Americans and Pacific Islanders in various facets of American society, including the health system, where disparities have long been masked due to the monolithic treatment of the diverse communities that comprise this population [99].

FIGURE 3 | Impact of COVID-19 on Patients, Families, and Communities' Relationship to the Health System

Ultimately, the United States has yet to see and understand the long-term effects of this pandemic on the already fragile health system and associated social determinants of health as it relates to communities of color. Further, the pandemic will likely magnify and exacerbate the challenges caused by structural and institutional racism in education, wealth, health, and other areas for people of color for years to come unless action is taken.

Economic Disparities are Worsening

The pandemic and associated physical distancing protocols spurred a national economic collapse, resulting in unemployment rates reaching a peak of nearly 15 percent in April 2020—the highest level of job loss since the Great Depression—and continuing to be twice as high as pre-pandemic rates as of December 2020 [33,90]. The vast majority of those who have become unemployed are in low-wage service industries. This group remains vulnerable to the downstream impacts of the pandemic—lack of access to food, housing instability, and financial insecurity—that are likely long term [91]. Further, millions of laid-off workers became uninsured during the pandemic recession, precipitating a nearly 9 percent increase in Medicaid enrollment (more than six million new beneficiaries) [66,261]. Additionally, over 250,000 individuals signed up for coverage after several state-based marketplaces opened special enrollment periods in 2020 to enroll newly uninsured, and an estimated 9 million Americans are eligible to participate in the special spring 2021 enrollment period [139,163]. The gender gap in employment losses due to COVID-19 is staggering, with women's participation in the labor force now at the lowest rate in over thirty years [87]. Compared to men, who lost 4.4 million jobs, women have lost 5.4 million jobs during the recession. Intersections between gender, race,

ethnicity, and income have resulted in Black and Latinx women experiencing higher rates of unemployment, lower earnings, and lower rates of contributions to retirement plans than White women and even wider gaps compared to White men. While the long-term impacts of the pandemic recession are unknown, it is likely that widening disparities by race, ethnicity, gender, wealth, and income will have significant consequences for communities, states, and the nation.

Impact of COVID-19 on Patients, Families, and Communities' Relationship to the Health System

Many patients, families, and communities experienced a lack of trust in government and science during the pandemic due to historical legacies of injustice and the disparate impact of the aforementioned challenges during COVID-19. This section will examine how the pandemic affected patients, families, and communities' trust in science and medicine and their relationship to other sectors of the health system. Areas of focus include:

1. Public trust
2. Evidence-based science communication
3. Cross-sector relationships (see *Figure 3*).

Public Trust

Americans' trust in key public institutions and leaders—including the government and health system—was already at a generational all-time low when COVID-19 struck [203]. In addition, inconsistencies in communication and an uneven pandemic response have negatively impacted patients, families, and communities' trust in the health system. Based on feelings and instinct, this mistrust takes on many forms, including general unease, hesitancy, or suspicion, and can hinder outbreak containment efforts, from adherence

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BOX 7 | Stories of Lived Experience: Communicating Science to the Public

"I think there are a lot of people who don't understand the scientific thought process well—being able to recognise the difference between current theories and established information. . . . I think if people understood the process of establishing theories better, they'd be more supportive." – John Hartwig, a professor of chemistry at the University of California, Berkeley

SOURCE: [154]

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to public health restrictions to hesitancy surrounding vaccines.

Growing mistrust among patients, families, and communities during COVID-19 must also be understood in light of historical and persistent racism in the health system. The past role of the scientific enterprise in mistreating marginalized populations (e.g., Black Americans and the Tuskegee syphilis study) and the present-day injustices experienced by communities of color in their interactions with American medicine (e.g., racial disparities in access to and quality of care) are important context for understanding patterns of mistrust during COVID-19 [130,144]. For instance, some fear that efforts to disseminate vaccines early to Black or other communities of color may be a way to use this historically disenfranchised group as "unwitting test subjects" [130]. One conspiracy theory circulating in Spanish on social media suggests that local testing sites are reusing dirty test swabs to deliberately infect people [232]. While the spread of fear, misinformation, and confusion can cause mistrust to flourish, these examples illustrate that the seeds of mistrust were planted well before the start of the COVID-19 pandemic.

Beyond the impact of structural racism, other reasons for mistrust and fear include the influence of anti-science or anti-vaccination movements, the unprecedented dissemination of misinformation and disinformation on social media, and the politicization of expertise—all of which are further detailed in the subsequent subsection [215,248]. Mistrust has only made it more difficult to provide patients, families, and communities with the best information and care at the right time and will continue to hinder efforts at preventing, diagnosing, and treating COVID-19. Ultimately, this mistrust will greatly negatively impact the health of patients, families, and communities for years to come.

Evidence-Based Science Communication

As a novel pathogen, the evidence base for COVID-19 has rapidly evolved throughout the pandemic as leaders in research, clinician care, and policy making sought to understand the mechanisms of transmission, impact of infection, differential risk for sub-populations, and effectiveness of new medical countermeasures. While the extraordinary rate of scientific progress during the pandemic should be celebrated, leaders from all sectors encountered challenges with effectively communicating the dynamism of scientific research and data and its influence on practices and policies in an accessible manner for the public. This is exemplified by a statement from John Hartwig, a professor of chemistry at the University of California, Berkeley (see *Box 7*) [154].

Challenges for communication were especially amplified for patients, families, and communities due to the politicization of expertise, with surveys revealing stark differences in perceptions of pandemic response and scientific understanding of COVID-19 along politically partisan lines [216]. While differences in health literacy may affect people's ability to understand nuances about COVID-19 and information on vaccines, the politicization of information and expertise has had a clear impact on the actions of patients, families, and communities, as demonstrated by an anonymized patient story shared by the dean of Clinical Affairs at Baylor University (see *Box 8*) [166].

While this patient at Baylor University ultimately recovered, he saw three members of his family become hospitalized for COVID-19, with one family member later passing away [166]. This story is sadly not unique in the United States during COVID-19. In a May 2020 survey, more than two-thirds of Americans reported worrying about the volume of fake news and false information being spread about the virus, with close to half commenting on the difficulties of finding reliable and trustworthy information about COVID-19. The updated January 2021 survey noted that less than one in four respondents have good information hygiene

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BOX 8 | Stories of Lived Experience: Perceptions of the Pandemic Response

"'I thought it was all a big hoax—the government trying to take control of things.' He knew people in other parts of the country had the virus, but he did not personally know anyone who had it. He didn't even know anyone who knew anyone who had it. The response of media and civic leaders seemed overblown. 'It was a big nothing. Thankfully, it seemed now it was behind us. We were opening back up. We had beaten the virus.'" – Central Texas resident, who became ill with COVID-19

SOURCE: [166]

(e.g., verifying information, engaging with the news, not amplifying unvetted information). Misinformation has been amplified by social media with negative consequences for each stage of pandemic response, from a climate of fear around lockdowns to wearing masks to hesitancy surrounding vaccination campaigns, as Dr. Sandra Quinn explains below (see *Box 9*) [36].

Cross-Sector Relationships
As illustrated by the other discussion papers in the *Emerging Stronger After COVID-19* series, each sector of the health system has encountered its own distinct challenges during COVID-19. However, these different challenges share a common denominator: they all affect the health and well-being of patients, families, and communities. Consequently, it is worth highlighting select examples to illustrate the importance of centering the challenges and lessons of the pandemic through the lens of patients, families, and communities.

For example, a bright spot of the pandemic has been the remarkable advances in scientific research and product development for COVID-19. However, many of the populations most affected by COVID-19 (e.g., racial and ethnic minorities, older adults) were the least represented in key clinical trials [47,116]. At the level of the public health system, the experiences of many patients, families, and communities during COVID-19 went unrecorded due to inadequate collection of demographic information, including patient-level data on race and ethnicity. For the patients who did become infected, access to care delivery was affected by biases built into clinical algorithms and gaps in access to primary and specialty services. For example, there were no ICU beds available in nearly half of the nation's lowest-income communities; yet only 3 percent of the highest-income communities had the same problem [137]. Challenges with delivery should be interpreted in the context of challenges with quality and safety, including the variation in nursing home environments for patients of color and the inadequate attention of measurement systems to social needs and environmental risks.

Collectively, these examples illustrate how the experience of patients, families, and communities during COVID-19 must be understood in the context of their relationships with other sectors—and how improving population health and health equity during the COVID-19 pandemic and beyond will require a fundamental recentering of each sector around the perspectives of patients, families, and communities.

Resilience of Patients, Families, and Communities in the Face of Adversity

Despite the many physical, psychological, and emotional challenges and hardships described in this paper, patients, families, and communities continuously reflect strength and emerge more resilient even as the

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BOX 9 | Stories of Lived Experience: Challenges with Communicating COVID-19 Messaging

"We have forces that undermine science, contradictory messages day in and day out that create skepticism and diminish trust in government." – Dr. Sandra Quinn, professor and chair of the family science department at the University of Maryland

SOURCE: [36]

> **BOX 10 | Stories of Lived Experience: Community Collaboration and Resilience in Support of Individuals during COVID-19**
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> In April 2020, as the spread of COVID-19 was accelerating, five community-based nonprofits formed the Latinx COVID-19 Collaboration. They saw a clear need, as Latinx individuals comprise 15% of San Francisco's total population but make up almost 50% of the city's COVID-19 cases. The collaboration includes a broad range of providers, ranging from mental health and immigrant rights nonprofits to organizations serving children and seniors. The collaboration has focused on implementing a COVID-19 response that integrates community-level prevention education, testing, and contact tracing with access to health care and supportive services, particularly housing, cash support and food. To strengthen and sustain its efforts, the collaboration has developed partnerships with San Francisco's Department of Public Heath, the Office of Economic and Workforce Development, and a variety of private philanthropies.

pandemic persists. Patients, families, and communities have not only adapted but found ways to thrive despite the adversity, trauma, and tragedy experienced because of the pandemic. Studies demonstrate that psychological resilience for individuals during the pandemic is due to modifiable factors that are pivotal to coping, including going outside, exercising, planning day-to-day routines, and praying [145,265]. Certainly, individuals deemed as essential by the federal government have continued to work tirelessly to support others. Families have found ways to be close to each other despite physical distancing through using video-based programs and applications to celebrate important moments. Communities have cultivated coping and resilience through supports for patients and families. One example is the resurgence of mutual aid groups who support neighbors with COVID-19 by providing food delivery and supplies, which has helped to address the immediate needs of individuals in their communities. These informal efforts and grassroots organizing have helped to overcome existing gaps in social networks in ways that government or large institutions have been unable to do [208]. Within communities, food banks and drives have been developed and scaled to address food insecurity. Collaborations such as those with NYC Health + Hospitals, the NYC Department of Health and Mental Hygiene, and other city agencies have created hoteling programs, where patients with COVID-19 can isolate and receive food and medical supplies while recovering [117].

Additionally, there are ongoing efforts to study and strengthen existing collaborations. For example, a safety-net health system in San Francisco leveraged partnerships to repurpose existing systems and en-sure that the most marginalized are receiving all of the community services and resources for which they are eligible [39]. Likewise, partnerships between key stakeholders from the academic medical center, the state department of health, and the homeless shelter network in Arkansas developed a streamlined referral process and quarantine strategies for individuals who are homeless [111]. CBOs are recognizing the needs in their communities and banding together to address them, as the example below makes clear (see *Box 10*) [279].

As the pandemic continues, and even after, and as leaders in the health system address the challenges, coping and resilience will be essential to overcoming the effects of the pandemic. The lessons learned by the exemplars above, and the many more that exist, represent the fortitude that exists among patients, families, and communities.

Transformative Policy, Regulatory, and Legal Changes for Improvements to Patients, Families, and Communities

The challenges faced by patients, families, and communities are multifaceted and wide ranging. Yet, there are opportunities to leverage the resilience displayed during the pandemic, the existing resources of the sector, and collaboration across the health system to improve the health and well-being of all people in the United States during and after the pandemic. Foundational to achieving system-wide transformation will be ensuring that America's post-pandemic health policy roadmap is centered around the needs, interests, health, and well-being of patients, families, and communities. This section outlines priorities for policy making, regula-

tory guidance, and legislation to transform the current health system into one that centers patients, families, and communities; supports the existing resiliency at the broader community level; and ensures efficacy, effectiveness, and equity. The key domains for transformation include:

1. Facilitating active, continued, and meaningful engagement with patients, families, and communities;
2. Building and restoring trust through improving communication, working with trusted sources, and translating scientific practices;
3. Prioritizing investment in solutions designed to advance health equity;
4. Realigning care approaches to meet the needs of patients, families, and communities; and
5. Examining critical intersections and implementing aligned solutions between patients, families, communities and other sectors.

Facilitate Active, Continued, and Meaningful Engagement with Patients, Families, and Communities

The core and foundational elements of the U.S. health system (e.g., financing and payment policies, care delivery practices, and decision making) were not developed or initially implemented in consultation or collaboration with patients, families, and communities. While efforts to engage these groups have certainly improved, the COVID-19 pandemic has emphasized the challenges and needs of patients, families, and communities are not well understood. Achieving active, continued, and meaningful engagement can bring about substantive and powerful changes that improve the health of the community and its members. Meaningful engagement of patients, families, and communities requires mobilizing resources, shifting power structures, redistributing resources, influencing and changing original systems of thinking, and shaping relationships among partners. Meaningful engagement can be catalytic and serve as the foundation for changing policies, programs, and practices [63].

Meaningful engagement also requires that leaders across all sectors engage those who use and are impacted by health and health care services. In particular, partnerships and collaborations with patients, families, and communities should include those who are most often left out, those who are often not well represented or well treated, and those who often have solutions to the challenges impacting them (e.g., communities of color, low-income populations). These communities should not just be asked to provide input along the margins or "rubber stamp" decisions made by others but be actively and consistently involved in the codesign of the system and collaboratively engaged in such topics as payment reform, performance measurement, quality improvement, health and biomedical research, use of digital health, and data sharing. Engagement with patients, families, and communities creates trust, facilitates multidirectional learning and inclusivity, and builds on the inherent resilience and strength of communities leading to healthier people and transformed health systems. For example, some coordinated care organizations (CCOs) in Oregon have been working to meaningfully engage patients and families [191]. CCOs are local and exist through partnerships with care providers, community members, and health system stakeholders that take on risk and financial responsibility for providing person-centered care and improving patient outcomes [191]. While this model continues to improve and build on lessons learned, it intends to place the patient at the center and shift power within the existing system to ensure that partners are equally involved in redesigning the system.

Further, as trust between patients, families, and health care teams in hospitals and other health care settings needs to be rebuilt, accelerated implementation of evidence-based strategies to improve engagement and prevent unnecessary and stressful breakdowns in communication are critical. Lessons can be learned from the Transitional Care Model and applied to other settings during and post pandemic to improve patient education, medication management, patient and family engagement, follow-up care, and health care provider accountability and engagement.

Additionally, fostering trust between patients, families, and digital health developers and users can ensure that care practices are aligned and meet the direct needs of patients, taking into account potential barriers. For example, as telehealth, artificial intelligence, and machine learning innovations are designed, implemented, and evaluated, full and equitable engagement of patients and families can enhance trust and potentially lead to improved patient outcomes.

Federal and state legislative bodies could also assist and play an active role in ensuring that all sectors engage critical participants. This could be done by requiring such participation when allocating funding, training, and assistance, enabling community members to collaborate on policy solutions and guidance for policy

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BOX 11 | Considerations for Facilitating Active, Continued, and Meaningful Community and Health Care Engagement with Patients and Families

- Orient transformation efforts across all sectors of the health system and ensure alignment with the community's focus on the experiences and needs of patients and families.
- Affirm commitment to and investment in programs for patient-centered research, measurement, and care delivery.
- Leverage incentives and regulatory guidance to improve the representation of patients, families, and communities in decision making and governance across the health system.

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makers and other government agencies. Policy makers could also reaffirm their commitment to existing programs and initiatives across the health and health care sectors, such as quality and safety (e.g., patient-reported outcomes at CMS) and biomedical research (e.g., patient-focused drug development at the FDA). Further, lessons about how to effectively engage patients, families, and communities can be leveraged from methodologies used for community-based participatory research and patient-centered outcomes research, including approaches on multidirectional learning and use of financial incentives to recognize participation (see *Box 11*).

Building and Restoring Trust through Improved Communication, Trusted Sources, and Translation of Scientific Practices

The COVID-19 pandemic has underscored the historical and contemporaneous drivers of a lack of trust among patients, families, and communities in the different sectors of the US health system. Restoring trust is a prerequisite for the health system to achieve meaningful improvements in the health and health outcomes of patients, families, and communities. Therefore, in addition to the priority action listed above of orienting health system transformation around the experiences of patients, families, and communities, policy makers and system leaders should also consider the following actions to overcome mistrust and distrust, especially among marginalized and under-resourced populations.

First, restoration of public trust can occur with leaders following crisis communication principles laid out by the CDC and endeavoring to separate political aims from science-based and health-related messages. A unified and agreed-upon strategy for communication and outreach into communities that lack trust can

help to build back a sense of inclusion. Health sector leaders should recognize that communication cannot take a one-size-fits-all approach and that messages must be tailored and translated to various communities and populations. As such, leaders working with patients, families, and communities must examine and test effective strategies and messages to communicate various topics as society continues to learn from the lessons of the pandemic and as system-wide transformation is hopefully accelerated due to COVID-19. Particular attention should be paid to adaptations in these strategies and messages to address unique trust issues of communities who are most impacted by structural racism and inequities, bearing in mind the unique experiences and history of interaction with the health system in the community.

Second, sector leaders should be mindful of not just the information and messages being communicated but also who is communicating the information. Early in the pandemic, there was strong public demand for expert voices, as people wanted to hear from the most trusted sources of information: scientists (83 percent), doctors (82 percent), and national health officials (77 percent) [82]. More information from scientists, doctors, and national health officials is needed, and it is important for these experts to also dedicate time and effort to educating the public on how the scientific process works: making observations, creating a hypothesis to explain them, and testing that hypothesis by making more observations. Science, and the policies informed by that science, must follow the path suggested by factual observations, and communication to the public that decisions and approaches may change as more observations are made is critical [238].

Third, further consideration of trusted sources of health and scientific information beyond scientists, doctors, and health officials should be considered. As

> **BOX 12 | Considerations for Building and Restoring Trust through Improved Communication, Trusted Sources, and Translation of Scientific Practices**
>
> - Separate scientific and medical messaging from political aims and incorporate the CDC's best practices for crisis communication.
> - Empower scientists, doctors, and public health officials and dedicate resources and training to improve communication to different segments of the public.
> - Partner with community leaders beyond health professionals and invest in diversifying the pipeline of health leaders to improve communication with marginalized people and families.

of January 2021, the public's view of trusted sources shifted to still include scientists (69 percent), as well as people in the local community (62 percent) and employers (60 percent) [83]. Translated and tailored messages can also be reinforced with patients, families, and communities by those viewed as reliable, credible, trustworthy, knowledgeable, and having the interest of the community in mind, such as religious leaders, community health workers (CHWs), and employers. For example, CHWs and the CBOs that often employ them, have played a critical role during the pandemic, serving as first responders and closing gaps in contact tracing, testing, and vaccination for communities of color [213,255]. Given the lack of diversity among the health and health care workforce, building a pipeline of professionals, such as CHWs and non-clinical patient navigators, throughout the health sector can further lead to effective communication and built trust (see *Box 12*).

Prioritizing Investment in Solutions Designed to Advance Health Equity
Addressing the systems of inequity exposed by COVID-19 requires that first and foremost, individuals, caregivers, and members of communities, especially people of color and of lower socioeconomic status, be empowered as active partners in the design, implementation, and evaluation of health equity policy solutions. Human-centered design principles can be used to achieve solutions to complex, multifaceted issues, such as those in health and health care, through codesign where being people-centered—focusing on the needs and abilities of people—is critical. Further, recognizing the influence of intersectionality requires the empowerment and active engagement of individuals and people with intersecting identities to develop solutions that address the root causes of inequities.

Second, leaders, including mayors, governors, congressional representatives, chief executive officers (of nongovernmental organizations, health systems, digi-

tal health development companies, and many others), must take actions within their sphere of influence to advance health equity. These and other leaders should move beyond merely describing the factors that affect health and investigate the most effective way to measure health equity among patients and communities [80]. To track the progress made, there is a need to develop robust measures and measurement systems that capture performance in advancing health equity (e.g., federal, state, and local systems that collect standardized, valid data about an individual's demographics, including race, ethnicity, health-related social needs, and community's social determinants, and also enable aggregate and stratified reporting of these data). A 2019 National Academies consensus study offers examples of how policy makers and system leaders can better leverage data and digital tools to integrate social care into health care delivery [178]. Likewise, 2016 guidance for academic medical centers on assessing outcomes and communicating the value of biomedical research for the sector could be expanded to prioritize a broader constellation of social, political, and economic levers central to measuring efforts to advance health equity [110]. Approaches such as these would foster the resilience of the entire health system by ensuring greater access to real-time data for early action and could be accelerated by federal funding or mandates, although there is also a role for private funders.

Third, multisector partnerships with the leaders mentioned above and organizations should be developed and structured to prioritize equity. Not only should equity be characterized as an outcome or goal of the partnership, but it should be integrated into all aspects and components of the collaborative function and strategy, such as inputs, processes, activities, and outputs. For example, it is important that tools such as health impact assessments are refined and expanded to allow policy makers to understand, in advance, the effect of any proposed local, state, and federal policies

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BOX 13 | Considerations for Prioritizing Investment in Solutions Designed to Advance Health Equity

- Empower patients and families as active partners in the design, implementation, and evaluation of organizational and community health equity policy initiatives, particularly through human-centered design principles.
- Invest in robust digital tools and data systems for collecting and measuring health inequities and progress to advance equity.
- Develop and structure multisector partnerships around health equity.
- Engage with leaders outside the health system to develop strategies for addressing the root causes of inequity, including social, economic, and environmental drivers of health.

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on equity before these policies are implemented. It is also important to evaluate the impact of these policies on equity after implementation, so stakeholders can understand where they were effective, why they were effective, and which policies need to be adjusted.

Last, leaders across all sectors should work collaboratively to create solutions that address the root causes of inequity, including social determinants of health and the structural and institutional racism that is the underpinning of American society. While strategies associated with interventions at an individual level (e.g., addressing food security, transportation) enable some progress, addressing the root causes of inequities through federal- and state-level policies and legislation at a population level will have the greatest impact on advancing equity. Social and economic policies and legislation outside of health and health care for populations most affected by structural and institutional racism, such as those dedicated to increasing opportunities for wealth, education, and housing, can significantly impact health outcomes. A state and federal legislative focus on equity will ultimately improve health outcomes and reduce the need and use of health care (see *Box 13*).

Realigning Care Approaches to Meet the Needs of Patients, Families, and Communities
The toll of the COVID-19 pandemic on behavioral health access and treatment, long-term care, community-based care, and social needs is evident. As society emerges from the pandemic, transforming and realigning how the health system approaches and meets the needs of patients, families, and communities is crucial.

First, care approaches must focus on prevention. Strategies and programs targeted to supporting community mental health (e.g., Mental Health First Aid,

trained CHWs), reducing social isolation, addressing adverse childhood experiences, and providing care to people coping with the loss of loved ones should be expanded and accelerated into widespread use. These programs, which can prevent the long-term consequences of stress reactions due to the pandemic, when developed alongside patients, families, and communities, can provide the supports that are oriented to real, not perceived, needs. Further, new investments must be instituted to develop multipronged strategies targeted toward improving the accessibility and use of preventive screening (e.g., public service announcements coupled with direct outreach from trusted clinicians and CHWs). These investments should be focused on populations with low incomes and communities of color to avert the worsening health impacts that were exacerbated due to the pandemic.

Second, revamping home- and community-based services (HCBS) care is necessary to advance the lessons learned from the pandemic and translate them to post-pandemic activities that will benefit patients, families, and communities. The disproportionally high rates of COVID-19 infections and deaths among older populations have further highlighted the need to invest in the organization, funding, and regulation of long-term care services to ensure that individuals receive needed services in the most appropriate setting. There is an opportunity to assess lessons learned from state use of Medicaid flexibilities to address the needs of HCBS during COVID-19 or other pandemics and explore what can be permanently implemented to support long-term services and supports [17]. Further, increased investment in HCBS would enable more long-term care recipients to remain in their homes. In addition, current innovations, such as increased flexibility in telehealth reimbursement, support this modal-

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> **BOX 14 | Considerations for Realigning Care Approaches to Meet and Engage the Health-Related Needs of People and Their Families, and Strengthen Community Capacity**
>
> - Support the expansion of prevention programs focused on both primary care and behavioral health.
> - Increase investment in home- and community-based services, including supporting the ability of patients to age in place and increasing resources available to Medicaid-financed caregivers.
> - Implement payment reforms to increase coverage and access for behavioral health services.
> - Expand networks of community health workers and peer providers to improve care coordination.
> - Enhance the health professions workforce through a greater focus on diversity, cultural sensitivity, and scope of practice.

ity of service provision. Policies that require that a fixed share of Medicaid HCBS payments be directed to caregivers through wage floors and wage pass-throughs would help ensure better pay and improved benefits for Medicaid-financed caregivers. Additionally, regulators should shore up infrastructure for community services (e.g., senior centers, home-delivered meals, legal assistance) given the distressing experiences of many seniors during COVID-19 (e.g., food insecurity, loneliness) [98,249].

Third, with the increased need for behavioral health services due to the impacts of the pandemic, providers need to be prepared to deliver more care at higher quality. Medical home models, such as Vermont's Integrated Health Services Model, can provide care that "is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety" [280]. This model facilitates and provides full integration of care to address patients' behavioral and primary care health needs, all while building strong patient and provider relationships [280]. Other opportunities include a shift to reimburse behavioral health providers more for the care provided, especially given the need to increase providers and access post pandemic; full implementation of mental health parity law; expanded flexibilities, such as tele-behavioral health; and new practices, such as expanded availability of take-home medications for opioid use disorder [222]. As the pandemic has made clear, safety net behavioral health providers operate on thin margins and have struggled to stay afloat during COVID-19. Enhanced Federal Medical Assistance Percentages for behavioral health services, increased investment from private and public payers, and encouragement of up-

front payments to these providers would improve access to care, expand the reach of the "Money Follows the Person" demonstration to people with behavioral health needs, increase access to community-based services, and reduce unnecessary use of institutional care [70]. Relatedly, regulators should align Medicaid with the policies of other health plans to support a crisis response continuum that is community-based and diverts from costly sites of care (e.g., acute care and corrections settings) as outlined in SAMHSA's National Guidelines for Behavioral Health Crisis Care [221].

Fourth, aligning with the needs of patients, families, and communities requires an examination of who should and can provide care. There is a need to increase the pipeline of providers from diverse backgrounds including by race, ethnicity, language capacity, age, sex, and gender identity to improve access, trust, and communication, and provide culturally appropriate care [245]. Clinician investment and training should focus on building a workforce prepared to address the unique stressors of diverse subgroups such as women, people with low incomes, populations of color, and their intersecting identities, as well as developing infrastructure and metrics to assess the quality of services provided. In many cases, patients, families, and communities want to receive care from those who act as liaisons between them and the health system, such as CHWs and peer providers. Encouraging maximum use of Medicaid/insurer-supported peer providers and ensuring a career ladder for them that is similar to what is in place for CHWs would grow the workforce and allow for more diverse providers facilitating coordination that meets the needs of those seeking care.

Last, further addressing the needs of patients, families, and communities would require changes to clinical practice. Specifically, clinicians should be able to continue to practice across state lines, and the telehealth flexibilities recently afforded by CMS, which have helped reduce traditional barriers to care, should be institutionalized (see *Box 14*) [19].

Examining Critical Intersections and Implementing Aligned Solutions between Patients, Families, and Communities and Other Sectors

Transforming the patients, families, and communities sector ultimately cannot occur without intersection and alignment with the other eight health and health care sectors, as identified by the *Emerging Stronger After COVID-19* paper series. As such, there must be coordinated efforts across all sectors to engage patients, families, and communities and build trust. While successful implementation of each of the priority actions highlighted above will require collaborations with the other sectors, it is necessary to call out the need for additional alignment with specific sectors, particularly in the context of pandemic response. Select examples of intersections with other sectors are discussed below.

First, public health approaches and collaborations must be a core and prioritized focus of the health system. Traditionally, public health has operated separately and distinctly from other sectors and has not been integrated into responses to social and medical challenges (e.g., homelessness). As the United States moves forward with addressing COVID-19 and preparing for future pandemics, public health authorities should develop emergency response plans in conjunction with patients, families, and communities and other sectors. This would allow for proactive consideration of key questions of access (e.g., testing), mitigation, and equity (e.g., distribution of vaccines). Furthermore, proactive partnerships with patients, families, and communities would equip state and local public health leaders to better communicate to the public and partner with grassroots leaders and influencers to design targeted campaigns to combat potential misinformation in a crisis. Lessons learned from developing emergency response plans should be leveraged to facilitate collaborations between public health and other sectors to confront other pressing health care needs faced by people in communities.

Second, the research sector and public health sector should collaborate to expand patient-centered research for emergencies. For example, it would be beneficial for sectors to dedicate funding for studying strategies for community-based, culturally appropriate contact tracing and financial support for isolation and quarantine of low-income individuals to guide the response to future infectious disease outbreaks. Additionally, it will be important to build on the infrastructure developed during COVID-19 and increase access to clinical trial networks for marginalized populations to ensure biomedical research and research through health product manufacturers and innovators reflect the communities bearing the greatest health burdens.

Third, leaders from care delivery organizations, health plans, and digital health need to work together to improve the collection and exchange of health care data both at baseline and in emergencies. Partnerships with patients, families, and communities will be key, as data collection efforts are more likely to be successful and mitigate historical distrust of the health care system when they include community members and organizations with established relationships with local residents and leaders. As previously noted, valuing patients, families, and communities requires collecting data that fully captures their experience. Developing infrastructure to collect data elements such as race, gender, sexual orientation, ethnicity, primary language, age, and socioeconomic status is critical to engage and inform patients, families, and communities. Further, developing frameworks to support the equitable development, implementation, integration, and evaluation of artificial intelligence and machine learning can support health stakeholders in the real-time use of these data to improve health outcomes, minimizing the opportunities to widen the chasm of disparities.

Fourth, intersections between payers and patients, families, and communities are critical for supporting family caregivers. Specifically, programs such as Medicaid Cash and Counseling and policies such as tax credits and paid leave for family caregivers would improve the quality of life for caregivers and their families. Likewise, coverage reforms for long-term care and support services would increase access to HCBS [200]. Beyond caregivers, payers and regulators could also support patients by investing in the health care workforce in their local communities. For example, developing reimbursement strategies for CHWs could both strengthen baseline health promotion efforts and improve preparation for emergencies.

Last, efforts of alignment are needed among patients, families, communities, health payers, state and local public health, and care delivery to ensure that

> **BOX 15 | Considerations for Examining Critical Intersections and Implementing Aligned Solutions between Patients, Families, and Communities and Other Sectors**
>
> - **Public Health:** Partner with patients, families, and community organizations in developing plans for responding to public health emergencies and other public health challenges.
> - **Research:** Improved representation of marginalized individuals and families in studies of public health interventions and development of medical countermeasures.
> - **Digital Health:** Modernize infrastructure for collecting and exchanging data, including demographic and social elements relevant to patients, families, and communities.
> - **Payers:** Expand coverage of home- and community-based services and implement payment reforms for community health workers.

significant resources are available to communities to address COVID-19, as well as to protect and save lives after the pandemic recedes. Under current federal statutory authority, federal Medicaid support is established retrospectively based on poverty levels within a state [74]. As a result, the percentage of federal financial support for the Medicaid program does not automatically increase as demands for services rapidly increase during profound health or economic crises, especially at a time when state revenues may be rapidly decreasing. Instead, Congress must act to increase the federal Medicaid percentage, putting the fate of this lifeline program in difficult and sometimes lengthy political processes. Congress could consider developing an automatic federal funding increase for the Medicaid program during health or economic crises, sometimes referred to as "countercyclical" Medicaid funding mechanism, similar to federal funding for unemployment insurance. When increases in federal support are triggered through this funding mechanism, the increases also could be tied to maintaining eligibility and benefits in the program through a "Maintenance of Effort" requirement, thereby ensuring increased federal support results in protected and expanded access to Medicaid coverage (see *Box 15*).

Priorities Moving Forward

This paper presents a comprehensive review of the available evidence regarding the multidimensional challenges that patients, families, and communities are confronting during the COVID-19 pandemic. This assessment reflects that patients, families, and communities are further impacted by the multisectoral responses to the COVID-19 pandemic that, in some situations, have supported those affected and, in others, exacerbated the problems. The proposed priority actions in this paper are by no means a panacea to fix the

US health system but rather touch on key issues that have been put into stark light by the COVID-19 pandemic. The pandemic has made it clear that the American public health system is underfunded, health coverage is piecemeal, and marginalized groups experience a higher rate of illness than others while struggling to access needed care. There are necessary changes, both short- and long-term, that all sectors involved in the US health system must make to improve the overall health and well-being of our nation and its people. Centering the needs of patients, families, and communities must be at the core of all proposed changes. Elected officials, doctors and scientists, public health experts, the private and public sectors, communities, families, and each of us as individuals must work together at the national, state, and local levels on these actions. Together, all of us can build on the resiliency that exists within individuals, families, and communities; partner with health systems and those at the local, state, and national levels; and foster true enduring and meaningful transformational change. The suggestions above spotlight how to improve sector-wide performance from a systems and governing level. Stopping the pandemic is everyone's responsibility, and applying the necessary changes to accomplish that goal will result in the transformation of the health care system into one where science, digital tools, incentives, and culture are aligned for continuous improvement, innovation, and equity, with individuals and families active participants in all elements.

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