

## **Let's Take a Breath Before We Dive In**

Conversations about DEI rollbacks, systemic bias, and research inequities aren't easy. But avoiding them doesn't make these problems disappear, it just ensures they continue unchecked.

This chapter isn't about blame. It's about accountability. There's a difference.

Policies are not neutral. They are shaped by the values of those in power. When a government eliminates programs that support veterans, disabled Americans, rural communities, and maternal health under the guise of "bureaucracy reduction," the impact is not accidental. It's a choice. And the consequences will be felt in every sector of healthcare, from chronic disease research to rural hospital closures, from disability benefits to workplace protections.

These targeted sweeping changes are not just a partisan issue. It is a public health crisis in the making.

## **The Danger of Erasing Public Health Programs in the Name of "Bureaucracy Reduction"**

Framing federal health programs as "government waste" is a familiar political strategy, but it ignores who actually relies on these programs. These cuts are not about fiscal responsibility. The numbers show they will ultimately cost taxpayers more in lost productivity, increased healthcare burdens, and economic ripple effects.

By eliminating committees focused on health equity, chronic disease research, and workforce protections, this administration is not saving money. It is shifting the financial and healthcare burden onto patients, families, and local economies.

Rural hospitals already on the brink will close at an even faster rate. Maternal mortality rates, already abysmally high for Black and Indigenous women, will rise further. Chronic disease research will stall, leaving millions with debilitating conditions and no path to treatment. Veterans and disabled workers will have fewer protections and support systems.

This is not about efficiency.

## **Who Benefits from These Cuts?**

When policies like what we have seen in the Trump administration in 2025 are introduced, the first question to ask is: who gains and who loses?

Corporations gain. Fewer workforce protections mean they can cut corners without accountability. Insurance companies benefit because without federal oversight, they can more easily deny coverage for chronic illnesses. Politicians can claim they have "cut government waste" while ignoring the human cost.

The people who lose are those who rely on these programs to survive, disabled workers, rural patients, veterans, and anyone dealing with long-term illness. They are not gaming the system. They are people who were promised protections that are now being stripped away.

This is not about making the system fairer. It is about prioritizing those who already hold power while dismantling protections for those who don't.

## **Defining DEI Beyond the Buzzwords**

The term diversity, equity, and inclusion (DEI) has been deliberately twisted by bad-faith actors who portray it as a race-only agenda to stoke resentment and justify gutting protections. But DEI has always been about ensuring equal access to opportunity, not special treatment.

Veterans and military families benefit from DEI when it ensures hiring protections, healthcare access, and mental health support. Disabled Americans and those with chronic illnesses rely on DEI policies for workplace accommodations, medical research funding, and disability benefits. Rural communities depend on DEI when it funds hospitals, broadband access, and economic revitalization programs. Low-income populations are supported by Medicaid expansion, fair wage policies, and housing assistance. LGBTQ+ individuals rely on protections against medical discrimination, mental health resources, and community safety measures. Women's health and maternal care benefit from reproductive health access, workplace pregnancy protections, and policies aimed at reducing maternal mortality.

DEI policies exist because systemic barriers exist. When these policies are removed, those barriers don't go away, they just become harder to fight.

## **This Isn't About Politics, It's About Lives**

When government-backed research into chronic illness, health equity, and workforce protections is eliminated, the people who suffer are not abstract groups. They are our neighbors, families, and communities.

This isn't a debate about whether inequities exist. They do. The real question is whether we are willing to acknowledge and address them or if we are willing to accept a healthcare system that prioritizes profit over people.

The consequences of this executive order will be felt for years. The fallout won't just be in research labs and policy rooms. It will be in hospital emergency rooms, disability offices, and job markets across the country. This is the reality we are facing.

## **The Executive Order That Just Made Things Worse**

On February 19, 2025, the White House issued the Executive Order on the Reduction of Federal Bureaucracy, eliminating multiple advisory committees and programs under the claim of

cutting government waste. But what this order truly did was strip away critical health infrastructure, leaving millions of Americans more vulnerable than ever.

Among the casualties were the Office of Long COVID Research and Practice, the Secretary's Advisory Committee on Long COVID, and the Health Equity Advisory Committee. These initiatives provided oversight, funding, and policy recommendations for chronic disease research, disability protections, and healthcare equity. With a single decision, the federal government abandoned its role in addressing some of the most pressing health crises of our time.

The administration justified these eliminations as part of an effort to streamline government, reduce inflation, and eliminate inefficiencies. But these cuts do not save taxpayer dollars; they shift costs onto families, healthcare systems, and local governments, all of whom now have to absorb the financial and social burden of neglected health crises.

The end of federal coordination on Long COVID and infection-associated chronic conditions means millions of chronically ill patients no longer have national representation in research, treatment, and disability policy. The elimination of the Health Equity Advisory Committee dismantles federal efforts to address disparities in healthcare access, maternal mortality, and chronic disease treatment. Defunding research into chronic conditions disproportionately affects marginalized communities, exacerbating existing health inequities rather than solving them. The impact extends beyond individuals, these cuts weaken the economy, worsening workforce dropout rates and increasing healthcare spending as preventable conditions become crises.

The Health Equity Advisory Committee was a critical piece of the federal government's work to ensure healthcare policies considered disparities affecting racial minorities, rural communities, disabled individuals, and economically disadvantaged populations. Its removal is a deliberate step away from addressing health inequities. For years, the committee played a central role in tackling racial disparities in maternal mortality, chronic disease, and access to care. It provided essential policy recommendations on Medicaid expansion, healthcare workforce diversity, and equitable research funding. Without it, there is no longer a structured effort to ensure federal health initiatives reach those who need them most. The absence of this oversight does not make the system more efficient; it makes it easier to ignore the people already struggling to access care.

The administration claims that reducing government oversight will promote economic growth and innovation, but the cost of inaction will far exceed any potential savings. The loss of federal Long COVID efforts alone is projected to cost the U.S. economy \$3.7 trillion annually due to workforce dropout and increased healthcare expenses. Cutting health equity initiatives will accelerate racial and rural health disparities, increasing preventable deaths and overwhelming local hospitals. Eliminating research coordination slows medical advancements, forcing individual researchers, nonprofits, and state agencies to compensate for federal neglect.

None of these decisions reduce waste. They create a system where only those with wealth and privilege can afford to be healthy while the rest of the population is left behind. These cuts are

not about efficiency; they are about erasing decades of progress and leaving systemic barriers unchallenged. The people most affected by these changes will not be the ones who designed them, but the patients, families, and communities who have no choice but to live with the consequences.

## **The False Promise of “Efficiency”**

The word “efficiency” is often used to justify sweeping government cuts, but in this case, efficiency is not the real goal. The Executive Order on the Reduction of Federal Bureaucracy claims to streamline government by eliminating “unnecessary” programs, yet the programs that were cut are those that directly impact public health, disability support, and chronic disease research. If these cuts were truly about efficiency, they would be based on a cost-benefit analysis. Instead, they appear to be ideologically driven, targeting programs that serve the most vulnerable communities under the guise of reducing waste.

Eliminating research funding and advisory committees does not eliminate the problems they were addressing. Long COVID is still disabling millions. Rural hospitals are still closing at an alarming rate. Maternal mortality rates are still disproportionately high among Black women. Chronic illnesses like diabetes, cancer, and autoimmune diseases are still increasing. Stripping away the infrastructure designed to tackle these issues does not make the system more efficient. It makes it weaker.

One of the most damaging assumptions behind this order is that federal oversight is inherently wasteful. History proves otherwise. Programs that invest in public health save far more money in the long run than they cost upfront. Research into chronic disease prevention reduces hospitalizations and long-term disability expenses. Investments in maternal health lower emergency care costs and improve outcomes for future generations. Funding rural healthcare incentives keeps hospitals open in underserved areas, preventing massive economic losses in those communities. The cost of inaction is never zero. It is simply shifted onto patients, families, and local economies that are already struggling.

The administration argues that private industry and state governments will fill the gaps left by these eliminations. But without federal coordination, states and institutions are left scrambling to create their own fragmented solutions, many of which lack funding or expertise. When the federal government steps back, inequities widen. Wealthy states with progressive policies will continue investing in healthcare and research. Lower-income and rural states, many of which already suffer from physician shortages and underfunded public health systems, will be left behind.

This is not the first time “efficiency” has been used as a smokescreen for harmful policy decisions. Cuts to social programs have always been framed as necessary belt-tightening, yet they consistently result in higher costs elsewhere, whether in emergency healthcare spending, lost worker productivity, or increased poverty rates. If this administration were truly committed to efficiency, it would be looking for ways to make government programs work better, not dismantling them entirely.

What these cuts actually accomplish is the erasure of public health protections that some politicians have long sought to eliminate. They target policies that address systemic inequities while leaving untouched the programs that serve the wealthiest and healthiest segments of society. In the end, this is not about efficiency. It is about whose lives this administration considers worth protecting and whose it is willing to sacrifice.

## **Why I'm Covering Long COVID in Detail**

Before I dive into the specific impact on Long COVID, I want to make one thing clear: this is not about saying Long COVID is more important than the other devastating cuts in this executive order.

This administration targeted multiple critical public health priorities, maternal health, rural healthcare, disability research, veterans' medical access, racial health disparities, and more. Every single one of these areas is essential. Every single one deserves attention.

However, as a subject matter expert in Long COVID and infection-associated chronic conditions (IACCs), I have been deeply involved in shaping federal policy, research priorities, and legislative efforts on this crisis.

I've spoken directly with multiple NIH directors and top federal health officials about Long COVID policy. I participated in the National Academies of Sciences, Engineering, and Medicine (NASEM) Long COVID Definition Focus Group, helping refine how Long COVID is clinically defined. My training in Long COVID research methodology at the University of South Carolina's Patient Engagement Studio reinforced how critical patient perspectives are in shaping research design.

I have co-authored Long COVID research with top experts like Akiko Iwasaki at Yale and David Putrino at Mt. Sinai, ensuring that patient experiences are not just heard but integrated into scientific inquiry. I've collaborated with federal agencies like HHS and SAMHSA, addressing the intersections of Long COVID, disability policy, and mental health.

Beyond research and policy, I've helped shape or influence every single piece of Long COVID legislation introduced in Congress.

That's why this section will break down the impact of this executive order on Long COVID, not because it's the only issue that matters, but because this is where my expertise allows me to provide the deepest insight. But make no mistake: the broader attack on health equity, research funding, and public health infrastructure will harm millions. If we don't push back against this now, the ripple effects will be felt far beyond any one disease or population.

Despite growing concern over Long COVID's impact, no prior research has fully quantified the true financial cost of inaction alongside the missed economic opportunity of medical innovation. This book presents the first comprehensive analysis that integrates NIH funding trends,

workforce losses, healthcare expenditures, and the untapped global market for a Long COVID treatment or cure.

## **The Cost of Inaction vs. Investment in Long COVID**

The decision to cut federal funding for Long COVID research is more than just a failure of public health policy, it is an economic and scientific disaster. In 2021, Congress allocated \$1.15 billion to the NIH RECOVER Initiative for Long COVID research, spread over four years. Despite the scale of the crisis, NIH slashed Long COVID research funding to just \$51 million in 2024, a fraction of what is needed to drive meaningful progress.

This decision comes as Long COVID-driven economic losses reach \$3.7 trillion annually. Even if NIH had increased its Long COVID research investment to \$10 billion over four years, it would still represent only 0.27% of the total economic losses. Instead of making even a modest investment in solutions, the government is choosing to absorb an avoidable financial catastrophe.

Beyond just economic losses, the U.S. is missing an opportunity to lead the world in post-viral and neuroimmune disorder research. If the NIH had the funding to accelerate treatment development, the U.S. could establish itself as the leader in post-viral syndrome research, pioneering breakthroughs for ME/CFS, POTS, and other chronic conditions.

## **Workforce Losses and GDP Impact**

Long COVID has removed an estimated 4 million Americans from the workforce, driving a \$572 billion annual loss in GDP. The average U.S. worker contributes \$143,000 per year to GDP, and without medical breakthroughs, these losses will compound over time. If workplace accommodations and medical interventions had kept even half of these workers employed, the economy could recover at least \$286 billion per year.

## **The Growing Healthcare Burden vs. the Cost of Investment**

The annual healthcare cost of Long COVID is projected at \$544 billion, covering hospitalizations, disability benefits, specialist visits, and lost earnings. Investing just \$50 billion annually in research, early treatment programs, and post-viral care clinics could significantly reduce this burden. The proposed investment represents only 9.19% of the total healthcare costs yet could yield exponentially higher long-term savings.

## **The Executive Order's Lasting Damage**

The new Executive Order dismantling the Office of Long COVID Research and Practice and eliminating the Secretary's Advisory Committee on Long COVID (ACLIC) removes the federal government's role in coordinating treatment, research, and disability support. Without a central research and policy hub, the stagnation of scientific progress will cost billions in missed funding opportunities and delay potential treatments.

By dismantling these federal Long COVID programs, the administration is guaranteeing higher future costs instead of reducing them. A \$50 billion annual investment in research, treatment, and workplace accommodations could have saved trillions in economic losses. Instead, by choosing to underfund Long COVID, the government is actively allowing \$3.7 trillion in annual damage to continue unchecked.

## **The Global Market Potential of an FDA-Approved Treatment**

The administration's failure to invest in Long COVID research does not just prolong suffering and economic collapse. It squanders an unprecedented opportunity to lead the world in treating a condition affecting millions globally.

If the U.S. were to develop the first FDA-approved treatment or cure for Long COVID, it would unlock an entire global market for post-viral illness treatments, with potential trillions in pharmaceutical sales. Long COVID is not just a U.S. issue, an estimated 65 million people worldwide are suffering from its effects. The country that leads in developing effective treatments or a cure will dominate the international medical and biotech industries.

If the NIH were to fund the development of an FDA-approved treatment, the U.S. could lead the world in tackling this crisis, generating billions in pharmaceutical sales while mitigating an economic catastrophe. Instead, the government is absorbing a \$3.7 trillion annual economic loss while reducing research investment to a fraction of what is needed. This is not just a failure of public health policy, it is a failure of basic economic strategy.

Instead, by abandoning research investment, the U.S. is ceding this opportunity to other nations that are ramping up their post-viral research efforts. Europe, Japan, and China are already making moves to expand research in infection-associated chronic conditions. If the U.S. fails to act, another country will step in to develop the next blockbuster treatment for Long COVID and similar conditions, leaving America behind in both healthcare and economic innovation.

The cost of inaction is not just measured in dollars. It is measured in lives lost, livelihoods destroyed, and the erosion of America's competitive edge in medical innovation.

## **What Gets Cut, Who Pays the Price**

By gutting advisory committees and slashing research funding, this administration is pulling support from areas that have historically been underfunded and misunderstood. This includes:

- Post-infectious illnesses such as ME/CFS, Long COVID, and POTS, which disproportionately affect women and marginalized groups. These conditions will see fewer clinical trials and treatment developments.
- Autoimmune diseases like lupus, rheumatoid arthritis, and multiple sclerosis, which already lack sufficient research investment, will fall further behind in medical advancements.

- Neurological disorders such as Alzheimer's, Parkinson's, and post-viral neurological complications, which impact millions of Americans, will receive even less funding for prevention and treatment.
- Disability accommodations and workplace protections will be undermined by the rollback of research into disability inclusion, leading to greater economic losses and fewer evidence-based policies to support disabled workers.

These cuts are not happening without impacting other areas. Chronic illnesses and disabilities already face systemic bias in research funding, with disproportionately lower investment compared to other diseases of similar prevalence and economic impact. The loss of dedicated federal programs will exacerbate these disparities, ensuring that millions remain underserved, undiagnosed, and untreated.

## **The Economic Fallout of Chronic Disease Neglect**

The financial toll of chronic disease is staggering. More than 60 percent of U.S. adults live with at least one chronic illness, and more than 40 percent have multiple chronic conditions. These diseases are responsible for the majority of healthcare spending, disability claims, and lost workforce productivity. Instead of investing in solutions, this administration's decision to eliminate critical research programs guarantees that costs will continue to rise unchecked.

- Chronic disease accounts for 90 percent of U.S. healthcare spending. Cutting research funding does nothing to reduce this burden. It only ensures that treatments and preventative measures remain out of reach.
- Chronic illnesses drive disability-related job losses, reducing GDP and increasing dependence on government assistance. The failure to invest in medical advancements means fewer people will regain the ability to work.
- Treating chronic conditions reactively rather than proactively drives up long-term costs for both the government and private sector. The cost of inaction is far greater than the cost of investment.

## **A Step Backward for Disability Rights and Health Equity**

The executive order doesn't just slash research funding. It dismantles the infrastructure that ensures medical progress is equitable. Advisory committees focused on health equity, disability policy, and public health were critical in shaping research priorities and ensuring that funding reached underserved communities. Their elimination means that decision-making power is now concentrated in fewer hands, with less accountability and less consideration for the populations most in need.

This is particularly alarming given that chronic illness and disability disproportionately affect BIPOC, low-income, and rural communities. These populations already experience higher rates of misdiagnosis, delayed treatment, and medical discrimination. Without targeted research and policy interventions, these disparities will only deepen.

## **The Bigger Picture: An Ongoing Pattern of Neglect**

This administration's decision to eliminate chronic disease and disability research funding is not an isolated event. It is part of a broader pattern of disinvestment in public health, scientific inquiry, and social support systems. The consequences will not be immediate, but they will be profound. Years from now, when preventable deaths rise, when disability rates continue to climb, and when the economic burden of untreated chronic disease becomes even more overwhelming, these cuts will be remembered as a turning point.

Investing in chronic disease research isn't just about healthcare. It is about economic stability, workforce sustainability, and the basic principle that all people deserve access to medical advancements that improve their quality of life. By eliminating these critical programs, the government is sending a clear message. Chronic illness and disability are not a priority.

The question is, how much longer can we afford to ignore the cost?

## **The Dismantle DEI Act: Expanding the Attack on Health Equity**

The executive order's cuts to chronic disease and disability research were only the beginning. Soon after, Congress introduced the **Dismantle DEI Act**, an aggressive move to eliminate equity-based policies altogether. This bill doesn't just defund DEI programs, it **bans** federal funding for research grants that prioritize racial health disparities. This is a direct assault on efforts to address conditions like sickle cell disease, maternal mortality, and chronic illnesses that disproportionately impact marginalized communities. Senator Rick Scott, a co-sponsor of the bill, made the intent clear:

"Democrats spent the past four years pushing policies that prioritized radical far-left ideology over merit-based policies... The American people don't want to foot the bill for a woke agenda they don't believe in." This rhetoric misrepresents what DEI actually does. It also threatens research that has historically relied on federal funding to correct systemic disparities. Without these resources, medical research will once again shift toward diseases that primarily affect wealthier, whiter populations, leaving millions behind.

The Dismantle DEI Act is built on a lie: that DEI only helps racial minorities. In reality, white rural communities, disabled veterans, and older workers are some of the biggest beneficiaries of DEI protections.

But the GOP wants to selectively erase DEI only where it benefits racial minorities, while keeping the parts that protect their core voting base.

## **They Support DEI When It Benefits Them: The Republican Hypocrisy on Equity Policies**

Many of the same politicians leading the charge against diversity, equity, and inclusion (DEI) programs have personally benefited from the very policies they now seek to dismantle. When

DEI policies assist veterans, disabled Americans, rural communities, and workforce protections, they defend them. But when those same principles are applied to racial and economic justice, they label them "woke" and push for their elimination.

A closer look at the Republican lawmakers who co-sponsored anti-DEI bills reveals a contradiction: many of them have also championed legislation supporting veterans, disability programs, and rural healthcare, issues fundamentally tied to DEI principles.

## Republicans Who Benefit from DEI While Attacking It

### 1. Veteran Benefits and Military Hiring Programs

- **Senator Tom Cotton (R-AR)** co-sponsored the *Dismantle DEI Act* but also backed federal workforce DEI initiatives that prioritize **veteran hiring preferences**.
- **Senator Josh Hawley (R-MO)** pushed for **DEI-based veteran mental health programs** while attacking racial DEI hiring policies.
- **Representative Mike Garcia (R-CA)**, a former Navy pilot, **supported hiring initiatives that favor veterans**, despite denouncing DEI in government hiring.
- **Senator J.D. Vance (R-OH)**, a vocal critic of DEI, has personally benefited from **DEI-based veteran entrepreneurship programs**.

### 2. Disability & Chronic Illness Policies

- **Senator Rick Scott (R-FL)** called DEI a "scam," yet **supported disability workforce incentives and protections**.
- **Senator Marco Rubio (R-FL)** backed **disability workplace protections** while co-sponsoring efforts to defund federal DEI offices.
- **Representative Elise Stefanik (R-NY)** voted to **expand disability accommodations in federal workplaces** while denouncing DEI programs.

### 3. Rural & Economic Development Policies

- **Senator John Cornyn (R-TX)** co-sponsored anti-DEI legislation while supporting **rural economic investment programs based on DEI principles**.
- **Senator Mitch McConnell (R-KY)** helped secure **rural broadband and healthcare funds**—initiatives that fall under DEI protections.
- **Senator Tommy Tuberville (R-AL)** voted for **rural hospital incentives**, a form of **targeted equity policy**, yet calls DEI "anti-American."

Additionally, several Republican legislators, including Rep. Brian Babin, Rep. Tony Gonzales, Rep. Richard Hudson, Sen. Mike Crapo, and Sen. James Risch, have sponsored or co-sponsored legislation supporting veterans, military families, individuals with disabilities, those with chronic illnesses, rural communities, and the elderly; groups that benefit directly from the principles of diversity, equity, and inclusion. Yet, their silence or endorsement of DEI rollbacks highlights a striking hypocrisy. While benefiting from and promoting policies rooted in equity for

these marginalized groups, they simultaneously support efforts to dismantle DEI initiatives that provide similar opportunities and protections for other marginalized communities. This contradiction underscores the selective application of equity when it aligns with political convenience rather than a genuine commitment to fairness and inclusion for all.

## **The Hypocrisy of "Merit-Based" Hiring**

Republicans argue that hiring should be merit-based, yet they refuse to eliminate legacy admissions at universities, which overwhelmingly benefit wealthy white students. If they truly believed in a level playing field, they would:

- Oppose corporate bailouts, which disproportionately benefit white business owners.
- End legacy admissions, where over 40% of white Ivy League students are admitted due to family ties.
- Support Black farmers receiving equal subsidies, after white farmers received \$28 billion in Trump-era bailouts while Black farmers were systematically excluded.

The same Republicans who rail against DEI in hiring have no problem securing policies that benefit their own demographics.

## **Who DEI Actually Helps**

- Disabled Americans: Workplace accommodations, federal hiring incentives, and NIH-funded chronic illness research exist because of DEI policies.
- Veterans & Military Families: VA hiring initiatives, mental health support, and educational benefits are rooted in equity principles.
- Rural Communities: Federal broadband funding, rural hospital grants, and economic investment zones exist because of equity measures.
- Older Workers: Anti-age discrimination laws and worker retraining programs are DEI policies in action.

If DEI were truly eliminated, these same Republicans' constituents would be among the hardest hit.

## **Tim Scott's Warning: Silence is Complicity**

Senator **Tim Scott (R-SC)**, the only Black Republican senator, once wrote in *The Washington Post*:

“Some in our party wonder why Republicans are constantly accused of racism—it is because of our silence when things like this are said.”

His words remain relevant. Many Republican legislators who have benefited from equity-based policies remain silent as their party dismantles DEI initiatives. Their selective support for DEI, only when it benefits their own constituents, exposes the deeper hypocrisy at play.

## **Betting on Public Ignorance**

Many of these lawmakers rely on their constituents not knowing how DEI policies actually work. The same disabled veterans, rural communities, and small business owners they claim to fight for would lose federal protections if DEI were dismantled entirely.

This is not about fairness. It is about prioritizing those who already hold power while dismantling protections for those who don't.

DEI initiatives played a crucial role in increasing the number of BIPOC scientists, researchers, and medical professionals in STEM fields. These programs weren't just about representation, they were about ensuring that diverse lived experiences informed research, particularly in chronic illness, maternal health, and public health disparities. However, with these rollbacks, mentorship programs, recruitment efforts, and funding for underrepresented researchers are disappearing overnight.

This isn't just about equity. It's about the future of scientific progress. Without these pipelines, entire research areas will be set back by decades, particularly in fields like infection-associated chronic conditions, autoimmune diseases, and health disparities research. The loss of these initiatives makes it harder for diverse scientists to enter, stay in, and lead the field.

Senator Tim Kaine has spoken out against these reversals, stating that they are part of a broader attempt to weaken public institutions.

*"These actions are shameful and harmful not only to you, but to Americans across the country that you serve,"* Kaine wrote in a letter to federal workers, condemning the erosion of diversity and equity commitments.

This is where institutions face a choice. Some will use these rollbacks as an excuse to abandon their DEI commitments entirely. Others will recognize what DEI has always been about: ensuring ethical, effective, and inclusive research that reflects the communities it serves.

The real test will be how institutions respond. Will they allow these cuts to erase decades of progress? Or will they take a stand and ensure that DEI remains a pillar of scientific integrity?

Institutions that choose the latter will define the next decade of scientific progress.

## **MAHA, RFK Jr.'s Healthcare Plan, and the Political Determinants of Health**

The Make America Healthy Again (MAHA) initiative, spearheaded by Robert F. Kennedy Jr., is positioned as a plan to expand healthcare access. However, its merit-based framework aligns with broader DEI rollbacks under the Trump administration, selectively applying equity while undermining health protections for marginalized communities.

DEI programs have played a critical role in addressing systemic healthcare disparities, ensuring funding for diseases that disproportionately impact Black, Indigenous, LGBTQ+, disabled, and

low-income communities. But this administration has selectively embraced equity in certain policy areas while dismantling it in others. Nowhere is this clearer than in MAHA's contradictions.

## **The NIH and Research Funding Cuts**

One of the most damaging aspects of MAHA is its alignment with federal cuts to health disparity research.

- NIH has begun stripping funding from universities conducting groundbreaking research on chronic conditions and pediatrics, despite these institutions leading medical advancements that improve health outcomes for vulnerable populations.
- MAHA shifts the focus of federally funded research to economically burdensome conditions rather than those disproportionately impacting marginalized communities.
- Chronic illnesses like ME/CFS, POTS, Long COVID, and autoimmune diseases will see even fewer resources, reinforcing the longstanding racial and socioeconomic biases in medical research.
- Kennedy's insurance reform proposals make disability coverage harder to access, increasing the financial burden on patients with chronic conditions.

These policies mirror broader DEI rollbacks, removing protections for communities that already struggle to access adequate care.

## **The Shift from Advocate to Enforcer of Rollbacks**

Robert F. Kennedy Jr. built a reputation as an environmental advocate, exposing corporate negligence and fighting for public health protections. Yet, in his role as Secretary of Health and Human Services (HHS), his policies now reflect the very system he once challenged.

His Make America Health Again Commission, created under Trump, focuses on childhood chronic illnesses but fails to address the systemic inequities driving health disparities. Changes in medication access, insurance coverage, and federal research funding are now disproportionately affecting the communities he once claimed to protect.

Even Kennedy's own campaign rhetoric highlights these contradictions. His Make America Healthy Again PAC, founded by former staffers, promotes preventative care and environmental integrity while simultaneously embracing policies that strip healthcare protections from marginalized communities.

With 60 percent of U.S. adults living with chronic disease and only 12 percent being metabolically healthy, structural barriers to care are a far greater determinant of health than merit. MAHA's approach fails to address this reality.

## **Contradictions on Chronic Disease and Health Policy**

Kennedy has long spoken about his personal commitment to chronic disease research. His public statements have emphasized his belief that the childhood chronic disease epidemic is among the most pressing health crises in America.

Yet, his own policy decisions contradict this stance.

Kennedy publicly acknowledged that some of his children have battled Lyme disease, even describing their experiences with facial paralysis and severe symptoms. This personal connection has shaped his interest in the disease's origins, yet his own policies now eliminate the very research funding that could improve treatment.

He has even promoted debunked theories about Lyme disease being a bioweapon from Plum Island, only to later backtrack during his Senate confirmation hearing, saying he never believed Lyme disease was created as a biological weapon.

## **Shifting Stances on Vaccines and Mental Health Medications**

Throughout his career, Kennedy has been a vocal critic of vaccines, linking them to autism and other chronic illnesses despite overwhelming evidence refuting these claims. During his confirmation hearings, he pledged to uphold existing vaccine policies and maintain the structure of federal advisory committees.

Since taking office:

- He has postponed meetings of the Advisory Committee on Immunization Practices (ACIP) and announced plans to overhaul its membership.
- He assured Senator Bill Cassidy that he would not alter childhood vaccination recommendations but later suggested that the vaccine schedule must be reevaluated.
- He has targeted mental health treatments, launching efforts to scrutinize SSRIs (selective serotonin reuptake inhibitors), commonly used antidepressants, going as far as calling users addicts and suggesting these medications pose a public health threat.

## **Vaccine Injury: Acknowledging the Reality While Avoiding Misinformation**

Vaccine injury is real, though rare. The National Vaccine Injury Compensation Program (VICP) has awarded over \$4 billion to individuals with legitimate claims, proving that adverse effects do occur.

But Kennedy's decades-long approach, leaning into conspiracy theories rather than advocating for transparency and improved monitoring, has alienated experts who could have strengthened this conversation.

Now, as HHS Secretary, he has the opportunity to fund research into overlapping immune dysfunction conditions like Lyme disease, ME/CFS, Long COVID, and even vaccine injury itself.

Instead, he has supported the elimination of federal programs and research funding, calling into question whether he will stand by his past advocacy or allow these critical areas to be erased.

## **The Larger Pattern of Policy Reversals**

Kennedy's shifting stance on chronic disease, vaccines, and healthcare equity is part of a larger pattern, one where political convenience dictates policy instead of scientific integrity.

At one point, Kennedy recognized systemic inequities in environmental health. He fought against corporate pollution, exposing how Black, Indigenous, and low-income communities were disproportionately affected.

Now, his healthcare policies reject that very framework.

The same logic he once applied to environmental degradation, that systemic inequities drive health disparities, is missing from his approach to healthcare access, disability protections, and chronic disease research.

I believe a man who has spoken so boldly in the past, about medical science in a way that conflicts with the majority in his field, has it in him to navigate this appointment in a way that stands firm with his past promises to many key issues that need protections. We are early into his time in this position, and I am holding out hope that the weight of the situation will hit him now or after he likely will be removed from this position, as historically the Trump administration goes through directors of various agencies at a high rate.

When systemic biases are ignored, the status quo remains intact, favoring those who have always had access while excluding those who need support the most.

These policies will extend far beyond this administration, shaping research funding, healthcare access, and medical advancements for years to come.

Leaders must decide now:

- Will they allow these reversals to dictate the future of healthcare?
- Or will they resist the pressure to abandon equity in favor of convenience?

The choice matters.

## **Trump's History of Firing Those Who Challenge Him**

It is worth noting that Trump's previous administration was infamous for firing officials who pushed back on policies they found legally or ethically questionable.

Agency leaders, scientists, and even cabinet members were dismissed for raising concerns, providing dissenting expert opinions, or refusing to enact harmful policies.

This administration is following the same playbook, eliminating advisory committees, oversight mechanisms, and research funding that don't align with Trump's preferred political narrative.

If Kennedy truly believes in his past advocacy, he will have to push back against these pressures. If he doesn't, he risks becoming another casualty of an administration that does not tolerate dissent.

## **Lessons from History: When Progress Depends on Compliance**

This rollback of DEI policies is not the first time institutions have attempted to erase progress. History shows that without strict enforcement, many institutions revert to the status quo.

Following *Brown v. Board of Education*, many states refused to desegregate schools. Some districts shut down entirely rather than comply. It took federal intervention, including the deployment of the National Guard, to enforce desegregation in cities like Little Rock, Arkansas. Without government enforcement, millions of Black children would have remained locked out of quality education.

During the Obama administration, the Department of Justice introduced consent decrees to reform police departments with documented histories of racial discrimination and excessive force. These decrees forced departments to implement bias training, civilian review boards, and new use-of-force policies. When the Trump administration took office in 2016, these oversight measures were rolled back, leaving it up to local governments to decide whether to continue them. Many departments abandoned reforms as soon as federal enforcement disappeared.

These examples prove a hard truth. Institutions cannot always be trusted to do the right thing without external pressure. The same applies to DEI. Without ongoing scrutiny from researchers, patient advocates, and the public, institutions will continue to deprioritize equity for the sake of convenience.

## **Building a Future Where Equity is Unshakable**

The next phase of DEI and research equity must be institution-proof. This means embedding equity so deeply into institutional policies that dismantling it would require massive restructuring.

Establishing independent funding sources for marginalized communities and research on chronic conditions that disproportionately affect them.

Creating community-led oversight models that track progress and hold institutions accountable, even when government protections disappear.

This analysis is not intended as an irreparable condemnation of Donald Trump, the Republican party or Robert F. Kennedy Jr., but rather as a necessary correction that highlights gaps in understanding of the complexities of healthcare. They have not undertaken the intentional work of immersing themselves in communities of color or deferring to experts with a more complete and inclusive perspective. Their positions afford them the ability to change course if they so

choose, embracing the insights of marginalized communities and fostering more equitable healthcare policies that acknowledge and address systemic disparities.

But let's be clear: the problem isn't confined to one party. While the Biden administration positioned itself as a champion of equity, its failure to adequately fund Long COVID research and disability protections left millions without support. As discussed elsewhere in the book, their inaction deepened the crisis for disabled Americans, demonstrating that political rhetoric rarely aligns with real-world commitment. True accountability means challenging both sides when they fail the communities they claim to serve.

This is not a passive fight. Institutions that fail to act now will not just lose public trust. They will be remembered as part of the problem. The roadmaps for sustaining equity exist. The question is whether institutions will use them or whether the next generation will be forced to fight the same battles all over again.

**Note:** The views expressed in this work are those of the author in their capacity as a **subject matter expert, researcher, and federal policy advisor** with extensive experience in Long COVID and chronic disease policy. This analysis does not represent the official stance of any government agency, advisory committee, or affiliated institution. References to policy discussions, legislative efforts, and economic analyses are based on publicly available data, original research, and expert insight.

## **Sources**

### **Verified Economic and Public Health Data:**

- **Long COVID Economic Impact:** Estimated \$3.7 trillion annual loss due to workforce dropout, increased healthcare costs, and lost productivity. ([Harvard Economist David Cutler, 2022](#))
- **Workforce Losses from Long COVID:** 4 million Americans out of work due to Long COVID disability, costing \$572 billion annually in GDP loss. ([Brookings Institution, 2022](#))
- **Annual Healthcare Costs of Long COVID:** \$544 billion in additional healthcare spending due to hospitalizations, disability benefits, and specialist visits. ([Harvard Economist David Cutler, 2022](#))
- **Projected Savings from Research Investment:** A \$50 billion annual investment in Long COVID research and treatment could significantly reduce these costs. ([NIH, 2024 budget projections](#))

### **Federal Policy & Research Cuts:**

- **NIH Long COVID Funding Cuts:** NIH slashed Long COVID research funding from \$1.15 billion over four years to just \$51 million in 2024. ([NIH RECOVER Initiative, Federal Budget Reports](#))
- **Executive Order on the Reduction of Federal Bureaucracy:** February 19, 2025, eliminated the Office of Long COVID Research and Practice, the Secretary's Advisory

Committee on Long COVID, and the Health Equity Advisory Committee. ([White House Executive Orders Archive, 2025](#))

- **Dismantle DEI Act:** Introduced in 2025 to eliminate race-conscious health equity research funding and DEI-based federal initiatives. ([Congressional Records, 2025](#))

### Chronic Disease & Research Equity Impact:

- **Chronic Disease and U.S. Healthcare Spending:** Chronic diseases account for 90% of healthcare spending and drive most disability-related job losses. ([CDC Chronic Disease Report, 2023](#))
- **Disparities in Federal Research Funding:** Studies show diseases affecting women and marginalized communities receive disproportionately low NIH funding. ([JAMA, 2023: NIH Grant Data Reports](#))

### Missed Economic & Scientific Opportunities:

- **Global Market for Long COVID Treatments:** An estimated 65 million people worldwide suffer from Long COVID, presenting a multi-trillion-dollar opportunity for the first country to develop an FDA-approved treatment. ([World Health Organization, 2024](#))
- **Research Investment & Economic Leadership:** If the NIH were properly funded, the U.S. could lead global innovation in post-viral and neuroimmune disorder treatments. ([Congressional Research Service NIH Report, 2025](#))

## Groundbreaking Long COVID Economic and Research Calculations

This serves as a repository for the original economic and scientific impact calculations presented in *DEI Delusion: The Hidden Impact of Research in BIPOC Communities*. These calculations quantify the staggering cost of government inaction on Long COVID and the lost economic potential of a U.S.-led medical breakthrough.

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### The Cost of Inaction vs. Investment in Long COVID

#### 1. NIH Long COVID Research Funding Cuts vs. Economic Losses

- **Congress allocated:** \$1.15 billion to NIH RECOVER over four years (2021-2024).
- **NIH cut funding to:** \$51 million for 2024.
- **Annual economic losses due to Long COVID:** \$3.7 trillion (Brookings, 2022).

#### Math Breakdown:

- If NIH had increased investment to **\$10 billion over four years**, that would be:
  - **\$10 billion ÷ 4 years = \$2.5 billion per year**
  - **\$2.5 billion ÷ \$3.7 trillion annual loss = 0.27%** of the total economic losses.
- Instead of making even this modest investment, the government is **absorbing a \$3.7 trillion annual loss**.

## 2. Workforce Losses and GDP Impact

- **Total U.S. workforce out due to Long COVID disability:** 4 million people (Brookings).
- **Average GDP contribution per worker:** \$143,000 per year.

### Math Breakdown:

- **Total GDP loss:**
  - **4 million workers × \$143,000 = \$572 billion annually**
- **Potential GDP recovery if 50% of workers were accommodated or treated:**
  - **50% of 4 million = 2 million workers**
  - **2 million × \$143,000 = \$286 billion annual recovery**

This shows that **workplace accommodations and medical interventions could recover at least \$286 billion per year**.

## 3. Healthcare Costs vs. Prevention and Treatment Investment

- **Annual healthcare cost of Long COVID:** \$544 billion (Harvard Economist David Cutler).
- **Proposed annual research and treatment investment:** \$50 billion.

### Math Breakdown:

- **Percentage of healthcare cost that would be covered by this investment:**
  - **\$50 billion ÷ \$544 billion = 9.19%**

This means a **relatively small 9.19% investment could significantly reduce the overall burden**.

## The Untapped Market of Long COVID Treatments

- **Estimated global Long COVID patient population:** 65 million (WHO, 2024).
- **Potential revenue if an FDA-approved treatment captured even 10% of the global market:**

## Math Breakdown:

- If treatment costs **\$10,000 per patient** and captures **just 10% of the global market**:
  - **65 million × 10% = 6.5 million treated patients**
  - **6.5 million × \$10,000 per patient = \$65 billion in potential revenue annually**
- If the treatment remains **on the market for 10 years**, that's:
  - **\$65 billion × 10 years = \$650 billion in total market potential**

This is a **trillion-dollar economic opportunity**, and yet the U.S. is failing to invest in research that could dominate this industry.

## The Bottom Line: Short-Term Cuts, Long-Term Financial Disaster

- A **\$50 billion annual investment** in research, treatment, and workplace accommodations could have **saved trillions in economic losses**.
- Instead, by dismantling federal Long COVID programs, the administration is **choosing to let the U.S. economy absorb a \$3.7 trillion loss annually** rather than making **targeted investments in solutions**.
- This is **not** a budget reduction—it is a **long-term economic crisis**.

## Sources for Calculations

These sources were used to verify and construct our original calculations:

- **Long COVID Economic Impact:** [Brookings Institution](#)
- **Workforce Losses from Long COVID:** [Brookings Institution](#)
- **Annual Healthcare Costs of Long COVID:** [Harvard Economist David Cutler](#)
- **NIH Long COVID Funding Cuts:** [NIH RECOVER Initiative](#), [Federal Budget Reports](#)
- **Executive Order on the Reduction of Federal Bureaucracy:** [White House Executive Orders Archive, 2025](#)
- **Global Market for Long COVID Treatments:** [World Health Organization](#)
- **Chronic Disease and U.S. Healthcare Spending:** [CDC Chronic Disease Report, 2023](#)
- **Disparities in Federal Research Funding:** ([JAMA, 2023](#); [NIH Grant Data Reports](#))

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- **Journalists, policymakers, and researchers** are encouraged to cite and build upon these groundbreaking calculations.
  - For media inquiries and further analysis, visit [www.BIPOCEquityAgency.com](http://www.BIPOCEquityAgency.com)