

Testimony of Ady Barkan

Before the U.S. House of Representatives Committee on Oversight and Reform

March 29, 2022

Good morning Chairwoman Maloney, Representative Bush, and Members of the Committee. Thank you for holding this hearing and inviting me to testify.

My name is Ady Barkan, and I am the Co-Executive Director of Be A Hero, an organization whose mission is to win health justice in America.

As you can see, I am currently in bed. I live in California, and it is rather early here. And because I am living with the neurological disease ALS, which has left me almost completely paralyzed, it takes me a very long time to get ready in the morning.

So, I am grateful for your grace in permitting me to participate from bed. But I am even more grateful that it is my bed, in my bedroom, in the home I share with my wife and our two young children. I am able to live at home because I have twenty four hour home care. Without it, I would be forced to live in a nursing home, separated from the people I love. I don't know if that would be a quality of life that I would be willing to tolerate. Home care is literally keeping me alive.

Three years ago, I came to the Capitol to testify in the Rules Committee at the first ever hearing about Medicare for All.

I was emaciated, weighing about a hundred pounds, down from one sixty. I had trouble breathing, and was sweating even though the room was cold.

Every month, my body deteriorated further. I felt like I was dying.

Later that year, I had to decide whether to get a tracheostomy, a procedure to implant a breathing tube into my windpipe, to compensate for my failing diaphragm. But I didn't know how I would be able to pay for the care that would allow me to stay alive. My insurance had already denied me a ventilator, stating that it was experimental, and then two weeks after that, they rejected access to an FDA approved ALS drug.

Even good health insurance, which I have, does not cover the long-term home care I need to survive. Paying out-of-pocket would have left my family bankrupt quickly. And so for too long after my diagnosis, my wife, Rachael, and I tried to get by without home care, which put the burden on her to care for both my young son and me.

We eventually secured 24-hour home care after suing my health insurance company in federal court. Home care has been life-changing, allowing me to participate in my family's life in ways I

thought were no longer possible for me. My daughter Willow was born 6 months after I gave my testimony, and now I'm a father to two beautiful, wild children.

But it shouldn't take a seasoned activist, a team of lawyers, and the generosity of strangers and friends to get the health care you need to survive. The reliance on crowdfunding to afford health care is a uniquely American tragedy. My outcome is the exception, but the challenges we faced, fighting insurance companies for services we are rightfully owed, are not.

We spend such absurd amounts on health care, and we get such bad outcomes for our money. The high costs of care and infuriating bureaucracy burdens all of us, including nurses and doctors, working families and small businesses. The only people who benefit from this absurd system are the corporate executives who profit off of our pain, and spend inordinate amounts of money trying to stop you from making life much better for your constituents

We've allowed greedy health care corporations to set the parameters of what we can expect of our health care system, and because of it, we've been forced to normalize the fate of bankruptcy, illness, and death. It's shameful that in the richest country in the world, we choose to inflict so much suffering.

Since that first hearing about Medicare for All, our country has been through the worst public health crisis in a century.

The pandemic has revealed and exacerbated the existing inequalities in our profit-driven health care system. It has hit hardest on disabled people, poor people, black, Latino, and indigenous people, and especially people who live at the intersections of these categories. And 1 out of 3 COVID-19 deaths in the US are related to gaps in health insurance¹.

Nearly a million Americans have already died from the Coronavirus. How much more is necessary to shock our legislators into action? When we lost 3,000 lives on 9/11, we responded by reorganizing our national security system, launching a global war on terror, and conducting two massive invasions and occupations. Three hundred times more people have died in this pandemic, but we have not marshaled our national energy to build a better health care system. It is a scandal and it is a shame.

But in the last two years, we've also seen glimmers of what's possible when our government takes action to prioritize people over profits, and works to guarantee care for all. Congress subsidized the [Affordable Care Act](#)² marketplace plans, leading to unprecedented enrollment,

¹ Stan Dorn & Rebecca Gordon. "The Catastrophic Cost of Uninsurance: COVID-19 Cases and Deaths Closely Tied to America's Health Coverage Gaps", Families USA. 4 Mar. 2021, https://familiesusa.org/wp-content/uploads/2021/03/COV-2021-64_Loss-of-Lives-Report_Report_v2_4-20-21.pdf.

² Keith, Katie. "Record High ACA Enrollment at 31 Million Americans: Health Affairs Forefront." *Health Affairs*, 7 June 2021, <https://www.healthaffairs.org/doi/10.1377/forefront.20210607.367870/>.

and paid states to keep millions more people on [Medicaid](#)³. As a result, More Americans have health insurance than ever before. Taxpayers funded vaccine research, and then, our government made vaccines easily accessible to all at no cost. And recently, our government made rapid test kits available to all Americans who requested them, free of charge.

These programs and many others are at risk of ending if Congress does not fund them and when the pandemic emergency policies expire. Instead of returning to the status quo, which fails all of us and especially our most vulnerable communities, we should build on the progress we have made during the pandemic.

The American people deserve so much more, and so much better. Our seniors and disabled children and adults deserve to live at home, not be warehoused in institutions. Working people deserve high quality care regardless of their income or their employer Marital status.

The people of rural America deserve good mental health care options, good community clinics, good accessible hospitals. And so do the residents of poor urban America, and the people who live on Indian reservations.

And seniors on Medicare deserve care also for the parts of their body above their necks, which means their teeth and eyes and ears and minds.

We can and must do better. We know what the solution is. A system that brings everyone in, and abandons no one. Where we are patients and people, not opportunities for profit.

The road to reach the better world of our imagination may be long. And there are many obstacles in our way. But our north star is clear. It is time for America to guarantee comprehensive, affordable health care to all. The best way to do that is By enacting Medicare for All. If each one of us continues to demand better, if together we build an even more powerful movement for health justice, then I know that someday we will get there.

Thank you.

³ Bradley Corallo and Sophia Moreno. Published: Mar 03, 2022. "Analysis of Recent National Trends in Medicaid and Chip Enrollment." *KFF*, 3 Mar. 2022, <https://www.kff.org/coronavirus-covid-19/issue-brief/analysis-of-recent-national-trends-in-medicaid-and-chip-enrollment/>.