HEALTH CARE’S 7 DIRTY WORDS

On December 16, 2017, participants in a meeting at the Centers for Disease Control (CDC) reported that an administration official had told them not to use any of these seven words: transgender, vulnerable, entitlement, diversity, fetus, evidence-based and science-based. Later, a spokesperson for the administration said that CDC was only told not to use those words in its budget documents, which, obviously determine the work the CDC has funding to do. And let’s be clear – the CDC, as explained in its mission statement, is “the nation’s health protection agency.”

That list – of seven banned words – evokes George Carlin’s 1972 Seven Dirty Words monologue, which became a major Supreme Court case about censorship and the First Amendment. That case emboldened Carlin and many others to keep using the words and to fight against censorship. The Seven Dirty words that the CDC can’t use aren’t “indecent” like Carlin’s monologue, which makes it even more frightening when the government attempts to ban them, but like the Seven Dirty Words case, the CDC banning should embolden us to talk about the important issues these banned words represent.

I want to start by saying that this is not intended to be a political rally. The conversation we need to have about health and poverty will be important and challenging whoever is in the White House or the governors’ mansions or in control of Congress. But unfortunately, health care has become a political football; decisions are being made for political points; and rhetoric has been substituted for analysis. We can’t afford this. There is work to be done and it requires that we work with facts and evidence, not with political bluster.
I am the Executive Director of the National Health Law Program (NHeLP). For almost 50 years, our mission has been to protect and improve access to health care for low income individuals, and we believe it is crucial to use those banned words and talk about the issues they represent. The things we are afraid to talk about are often the ones that matter the most.

Two years ago, the world lost Kyler Prescott. Kyler was a 14 year-old, transgender boy who battled against depression, bullying, and harassment by his peers. He went to the hospital seeking help because he was thinking about suicide. The hospital staff chided Kyler that he was "too pretty to be a boy" and kept calling him a girl, even when he and his mother repeatedly asked them to stop. Kyler committed suicide a few weeks later.1

In a recent National Transgender Discrimination Survey, 28 percent of participants postponed medical care due to discrimination.2 Those statistics aren’t going to change if we are afraid to talk about the health needs of transgender individuals or if, as the current administration is doing, we make it easier and easier for health care providers to discriminate against women, people of color, and LGBTQ individuals by claiming a religious reason for the discrimination.

Back to these 7 dirty words. The keys to understanding this bizarre directive are these two – evidence-based and science-based. You would think that science and evidence are exactly what the Centers for Disease Control -- and the rest of us who care about health -- ought to be talking about. There is science about what we need to do to address health inequities, to give an equal opportunity for health to our diverse population, but making policy based on that evidence may not be consistent with tax cuts and ending entitlements. So, if you take only one thing away from tonight, take this: don’t be afraid of the truth; demand the evidence and the science and you can change the world.

It is an honor to be delivering a lecture dedicated to the memory and legacy of Frank Porter Graham. Frank Porter Graham was committed to pursuing the truth. In his inaugural address as President of the University in 1931, Dr. Graham said that we must protect

the freedom of the scholar to report the truth honestly without interference …freedom to study not only the biological implications of the physical structure of the fish but also the human implications of the economic structure of society …freedom from the prejudices of section, race and creed . . . [and] freedom for consideration of the plight of the unorganized and inarticulate peoples in an unorganized world in which powerful combinations and high pressure lobbies work their special will on the general life.3

Those words should guide us today.

Why should you want to know the facts about health care in our country? Because our country’s future depends on it.

Imagine this. Imagine that no one figured out that you needed glasses until after you had been labeled as not very bright in school. Imagine that your single parent mother didn’t get cancer screenings and you lost her when you were 10 and bounced around with various relatives after that. Imagine that your father’s substance use disorder landed him in jail and you don’t have a relationship with him. Imagine that the stress of those losses has taken a toll on you, both mentally and emotionally, but instead of giving you support, your school kicked you out for acting up too much. You are on the school to prison pipeline instead of sitting here, a member of the UNC Chapel Hill community. That would be a loss, not just to you, but to our country and our world, because it would not be nearly as likely that you will be doing the thinking, the writing, the working that we are counting on you to do.

How many people’s contributions do we lose because our health system let them fall through the cracks? Why don’t we just provide health care for everyone? Do we think that the people who don’t have health care don’t matter as much? That it’s enough to get health care from the emergency room where they will treat anyone who shows up? Or do we think that people in poverty don’t deserve health care because they aren’t working as hard as the rest of us?

Look at some facts. Almost no one in this country could afford regular health care without insurance and an even smaller number—the 1% of the 1%--could deal with the financial impact of a serious accident or illness without insurance. That’s why one of the significant impacts we have seen in states that have expanded Medicaid coverage to more people in their states is an increase in financial stability and a decrease in bankruptcies caused by medical debt. A study last November concluded that Medicaid expansion saved 50,000 people from bankruptcy in two years.4 In North Carolina, which has not expanded Medicaid, an Urban Institute study found that 27% of people in the state have medical debt in a collection process.5

We need insurance, but how do we get it? The biggest source is employer sponsored insurance. If you don’t get insurance through your job, what does it cost to buy health insurance? That varies, of course, but you can get an idea of cost from the health insurance plans available on the health insurance Marketplace set up under the Affordable Care Act.

In 2016, the average cost of the cheapest type of plan was $289.88 per month for a single person age 40 and the average deductible – the amount you have to pay for health care before insurance kicks in – was $6,092.6 That’s a total of $9,570. What does someone working full time at the federal minimum wage earn? $15,080 per year. So under the standard our government has set as fair pay, someone working full time can’t possibly buy health insurance and put food on the table.

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Look at jobs with highest Medicaid enrollment. According to a Kaiser Family Foundation study, the industry with the largest number of workers covered by Medicaid in 2016 was the restaurant and food service industry, perhaps some of the people who serve you on Franklin Street. These are people who are not getting health care through their employers but who don’t make enough to purchase insurance. Without Medicaid, they simply do not get essential health care. And anyone without health insurance is one major accident or illness away from bankruptcy.

A few years ago, I got a call from our former nanny. She was born in Guatemala and is a U.S. citizen. She was in the hospital, where she had gone because of severe abdominal pain. The doctors thought it was cancer and wanted to do a number of tests. She said no. She did not have health insurance. She checked herself out of the hospital and flew to Guatemala to get medical care. She was not going to see all that she had worked for, the home she had bought, the savings she had set aside to help her children, be lost to the enormous debt she knew she would have if she stayed here. That’s a very sad indictment of our health care system.

The United States stands alone among what are considered “developed” countries in not providing access to health care for all of its people. In fact, in most of the world, access to health care is treated as a fundamental right.

The Universal Declaration of Human Rights, adopted by the then-very-new United Nations in 1948, includes the declaration that “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care…” Led by Eleanor Roosevelt, the United States voted in favor of the Universal Declaration, but we also consider it non-binding – we don’t have to follow it.

We have declined to ratify the International Covenant on Economic, Social and Cultural Rights.

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9 “International Covenant on Economic Social and Cultural Rights (Chapter IV: Human Rights),” United Nations,
The state parties to the Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and commit to take steps that include: “The creation of conditions to assure to all medical service and medical attention in the event of sickness.”

No other country that claims to be a world leader has declined to ratify the Covenant.

Why is it so hard for us to understand what the rest of the world understands – that our country’s strength depends on the contributions of all of our people, not just the wealthy, and that, without access to health, we can’t make those contributions?

For those of you not steeped in health law, let me give you some quick background on publicly funded health care in this country. You probably know something about Medicare. Medicare provides health care for seniors and people with disabilities. Medicare is federally funded. It is not designed to help only poor people – Bill Gates will be eligible for Medicare when he turns 65.

Medicaid, on the other hand, is an essential part of the safety net. It is a joint federal/state system, with federal dollars matching state dollars. It provides health insurance to very low income people – generally eligibility is limited to people who make less than or slightly above the federal poverty level, which in 2017 was $12,060 for an individual and $24,600 for a family of four.

Medicaid provides coverage to more than 70 million people.

**WHY MEDICAID MATTERS**

About 1 in 4 people in the U.S. will use Medicaid at some point over the year. Medicaid covers

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Medicaid pays for various health services for about 40% of kids in the country and 45% of all births, 41% of adults who are HIV positive, and 62% of nursing home care. Medicaid is the go-to health insurance for abused and neglected children placed in state foster care systems, as well as for many children living with developmental and other disabilities and children with medically complex conditions.

Medicaid is the single largest payer for mental health services in the US and increasingly is the source of funding for substance abuse treatment. Medicaid is efficient and the evidence shows that it improves health outcomes.

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Medicaid is an entitlement, one of those dirty words. That means that anyone who satisfies the eligibility criteria gets enrolled and gets the covered services; it’s not a finite pot of money to be used until it runs out. It is really important to understand that entitlement is a good word, one that we should be proud of. Our country made a commitment in 1965, when the Medicaid statute was passed, that everyone eligible for health insurance under the statute would get it – these are our most vulnerable, another dirty word. If we change this, what happens when the budgeted money runs out? What happens when there is a Zika virus outbreak and thousands of children need care? Or what about the opposite problem -- a cure for a deadly childhood brain cancer is developed. Do we turn away the children who get to the state Medicaid office after the budgeted money runs out or tell them there is not enough money for them to get the cure?

Surely, you are thinking, we wouldn’t turn people away from a lifesaving treatment even if they didn’t have insurance! Surely they would get the treatment, perhaps in the emergency room! About a year ago, I received a call in my NHeLP office in D.C. A young mother, who had no health insurance, had been diagnosed with an aggressive cancer and her doctor said that her only hope was to start chemotherapy immediately. The hospital would not give her the chemotherapy because she had no way to pay for it. Could we help? And we did. Our managing attorney in D.C. spent a day and a half making calls and getting her enrolled in Medicaid. There was no question whether the D.C. Medicaid budget was big enough to cover her care. She was entitled to be enrolled in Medicaid. Only after getting verification of Medicaid coverage, the hospital started the chemotherapy.

When you hear about efforts in Congress to pay for the $1.3 trillion deficit created by the tax bill by going after “entitlements,” think about the young mother in my story but put your mother or your brother or your child in her place and you will understand what’s at stake. Will they be turned away or refused lifesaving care, even if they are eligible for it, because the pot of money that was set aside at the beginning of the year ran out?

The Medicaid entitlement is tremendously important but it has been limited – to certain categories of people: seniors needing long term care, people with disabilities, pregnant women, children and their caregivers -- and the income limits for these categories differ—some are significantly below the federal poverty level.
The drafters of the Affordable Care Act (ACA) confronted a challenge – lack of access to health care for so many people was costing our country too much, in poorly used health care resources and in the harm to too many individuals – but our private market instincts were too strong for universal health care to succeed. So they built on what we had. The idea behind the Affordable Care Act was that we would have a seamless, if somewhat patched together, system that would make health insurance available to everyone in the country (except undocumented people, who are left out of this and other protections). Under the ACA, traditional Medicaid remains the bedrock, on which the rest of the system is built.

In the diagram below, you’ll see that different categories of beneficiaries have different income cut offs. These cutoffs differ state to state so this chart shows average income cut offs, some below the poverty level and some slightly above.

The line in the diagram represents the insurance Marketplace created by the ACA where people with incomes at 133%* of FPL could purchase insurance. Between 133% and 400% FPL, the federal government pays some of the cost of the premiums. Above 400% of FPL, you can still buy insurance on the Marketplace but you don’t get premium assistance.

You can see that there’s a gap—people not eligible for traditional Medicaid, who make too little to be eligible for assistance in purchasing insurance on the exchange. That’s where Medicaid expansion comes in.

*Because of the ACA methodology for counting income, the eligibility threshold is sometimes described as 138% of the FPL. In states that have not expanded Medicaid, Marketplace Subsidies are available starting at 100% FPL.
Medicaid expansion fills in that gap – it extends Medicaid beyond the tradition categories to include coverage for low income adults who aren’t caring for children, and covers people above the income caps on the other categories, up to 133% of the federal poverty level. For many low income adults, that means that they have access to regular health care for the first time; that they don’t have to fear losing everything they have if they get sick; that they can get regular treatment for high blood pressure or diabetes and be able to work.

That was the plan – a way to cover everyone. In 2012, the Supreme Court said that it has to be optional for states to expand Medicaid. Thirty-two states and the District of Columbia have chosen to expand Medicaid. Low income adults and others in the coverage gap in states that have chosen not to expand Medicaid are out of luck. The Kaiser Family Foundation estimates that nationally, nearly two and a half million low income uninsured adults fall into the “coverage gap” between where Medicaid ends and ACA coverage begins. Nearly nine in ten people in the coverage gap reside in the South.¹⁵ This is an example of evidence losing out to politics. The federal government pays over 90% of the cost of the Medicaid expansion but states are turning down that money and leaving the low income people in their states uninsured. The slides below show North Carolina’s Medicaid eligibility limits. Coverage for Adult caregivers is limited to 39% of the Federal Poverty Level. If North Carolina expanded Medicaid, almost 400,000 people would get insurance coverage.

In the spring of 2012, Solicitor General Don Verrilli argued in the Supreme Court about the constitutionality of various aspects of the Affordable Care Act. In his summary to the Supreme Court after three days of argument, Solicitor General Verrilli described health care as essential to the enjoyment of liberty that is at the heart of our country’s design. He said:

we've been talking about . . . problems in the economic marketplace that have resulted in millions of people not having health care because they can't afford insurance. There is an important connection, a profound connection, between that problem and liberty. And I do think it's important that we not lose sight of that. That in this population of Medicaid eligible people who will receive health care that they cannot now afford under this Medicaid expansion, there will be millions of people with chronic conditions like diabetes and heart disease, and as a result of the health care that they will get, they will be unshackled from the disabilities that those diseases put on them and have the opportunity to enjoy the blessings of liberty. . . . In a very fundamental way, this Medicaid expansion, . . . secure[s] the blessings of liberty. 16

Solicitor General Verrilli was echoing an understanding expressed by Franklin Roosevelt in 1941, in what has become known as his Four Freedoms speech. Roosevelt said that, in countering the threat of totalitarianism, “there is nothing mysterious about the foundations of a healthy and strong democracy. The basic things expected by our people of their political and economic systems [are] simple” and they include “freedom from want,” including “opportunities for adequate medical care.” 17

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16 Florida v. Department of Health and Human Services, No. 11-400 (March 28, 2012) at 81-83.
Frank Porter Graham used similar language in 1934, in support of federal legislation for unemployment compensation, security for children and mothers, and health and disability insurance. Dr. Graham said: “Social insurance is indispensable to security against unemployment, sickness and old age. These millions of human beings provide the life and labor necessary to industrial civilization, but our modern civilization, with its fragmentary view of human beings and human society, makes but little provision for the security of their labor, sickness and old age.” 18

If we agree that we cannot write off a huge chunk of our population as not deserving or needing health care, as not deserving or needing to enjoy the full blessings of liberty, then we have our work cut out for us, because leveling the playing field – giving everyone an equal chance to be healthy – means tackling complex intertwined problems of poverty and inequality. It means having intelligent debates about the hard issues in health care and not being afraid of using honest words, science, evidence and facts.

You may have heard recently that the Department of Health and Human Services (HHS) has allowed Kentucky and Indiana to change their Medicaid programs to impose work requirements and require very low income people to pay premiums and cost sharing. NHeLP has sued HHS to block the Kentucky waiver.19 We have evidence about what happens when you require very low income people to pay premiums or co-pays when they use health services. They don’t get health care. Parents who have to choose between going to the doctor and putting food on the table for their children provide the food. And parents who don’t go to the doctor themselves are less likely to take their children to the doctor.20

Work requirements don’t help low income people find jobs. They just get people off of the Medicaid rolls. Kentucky expects over 97,000 Kentuckians to lose health insurance as a result of the changes HHS has approved.21 And that’s not because people aren’t working. Among Medicaid adults who do not qualify for insurance on the basis of a disability, 60% are working themselves; 64% have at least one full time worker in their home and 86% have multiple people in the home who worked full time at some point in 2016.22

A big problem with conditioning Medicaid enrollment on satisfying a work requirement or paying a premium that depends on your income is the near certainty that people entitled to Medicaid will get dropped from the rolls and locked out of coverage because they can’t keep up with the administrative challenge, especially because states like Kentucky and Indiana are not planning to put a lot of money into making the work requirement and new premium system easy to navigate for low income people. But there’s another fundamental flaw in the work requirement approach. Work requirements don’t help people get steady jobs because they don’t address the obstacles many low income people face in getting and keeping a job. Those obstacles include:

**The difficulty of finding jobs or being laid off.** In Kentucky, for instance, jobs are so hard to find that the Department of Agriculture waived the work requirements for the state’s SNAP program in 100 of the 120 counties in Kentucky.23

**Homelessness.** Homelessness adds obstacles to employment on top of whatever physical, mental and substance abuse problems contributed to homelessness in the first place – practical problems like keeping up with paperwork and using a computer.

**Having been incarcerated.** Over 70 million Americans, or nearly one in three U.S. adults, has an arrest or conviction record. 60 to 75% of formerly incarcerated individuals are jobless up to a year after release. A Department of Justice study documents over 26,000 state and federal laws and regulations that restrict the employment options of people with criminal records and, in addition, found that “most employers are reluctant to hire applicants with criminal records – 63% of employers interviewed probably or definitely would not be willing to hire an applicant with a criminal record.”24 Yet we know that one factor that significantly increases the chances that someone returning to the community will succeed is being enrolled in health insurance before he or she walks out of prison.25 Looking at that evidence tells us that we should tackle these issues, not pretend that holding health care hostage will make them go away.

Back to the dirty words.

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Fetus may be on the list because we don’t want to talk about reproductive health. What’s the evidence? Reproductive health care is essential health care. And it impacts poverty. The American Journal of Public Health just published the results of a 5 year study showing that being unable to terminate an unwanted pregnancy caused reductions in full-time employment, an increased incidence of poverty, more women raising children alone and greater reliance on public assistance. Those facts may not make the abortion conversation easier, but they are undeniably relevant to the link between health and poverty and what we do about both.

And if diversity is a banned word, you can be sure that we can’t talk about what race and racism have to do with health, but we should. If we weren’t so busy batting back efforts to cut health care, we could get down to the serious business of health equity. Health equity isn’t just about dismantling current barriers to health care. We can do that, though it’s harder than you think. Not so many years ago, people of color weren’t admitted to white hospitals. That has changed; there is still discrimination in access to health care but now it’s harder to see. For instance, in programs designed to divert young offenders from the criminal justice system into mental health services, the courts tend to see the white kids as good kids needing healthcare and the black and brown kids as bad kids needing punishment. That’s one of the reasons why diversity is important – we come together with different perspectives and life experiences and we help each other see and understand what we would not see and understand alone.

Health equity is about ensuring an equal chance to be healthy. And that involves taking on the structural barriers to health – inequalities in education, income, neighborhoods. In New Orleans, the life expectancy varies by 25 years across neighborhoods that are just a few miles apart and the same is true for Richmond, Virginia and many other cities. So does the chance that someone born in those neighborhoods will go to prison.

The challenges to giving everyone an equal chance to be healthy are significant. How to tackle the fact that black mothers in the US die at three to four times the rate of white mothers. That people subjected to expressions of racism, sexism, hate and bigotry actually get sick from that hate.
That it’s hard to stay healthy when you are homeless but as our cities gentrify, there is an increasing lack of low income housing. That our prisons are full of people who landed there because of medical conditions – substance abuse disorders often compounded with mental health challenges.

We can’t solve these challenges if we are forbidden to acknowledge that there are vulnerable individuals and communities that need more attention than they are getting from the powerful in this country. What would happen if we invested more, not less, in these vulnerable communities? One expert predicts that in the U.S, a 1% increase in social spending would add up to 16 million additional years of life across the US population. And a study published by the CDC recommends that if we want to protect our children from abuse, we support families by investing in subsidized child care, a living wage, paid family leave and paid sick leave. What if we made those investments?

You, the best and the brightest, look at what is working and do more of that. Demand the evidence and learn from it.

Some cities have figured out that they can reduce health care expenses by providing subsidized housing to people who would be on the streets. Health care providers are increasingly interested in putting some money into the “upstream” factors like safe housing and nutrition, because those investments pay off in better health outcomes for lower health care costs. A doctor in San Francisco is figuring out what works in helping children with Adverse Childhood Experiences (ACE’s) overcome the effects of trauma – and it starts by recognizing the trauma and talking about it. There is promising research on how schools can help children develop the social and emotional skills to be resilient and to learn. At NHeLP, we convened experts from a wide range of federal programs that provide benefits that impact child health, experts who don’t always work together. In addition to our expertise in accessing health care, experts in housing, food and nutrition, education, homelessness and poverty, juvenile justice, child and family support, the environment, and more are now sharing knowledge and developing resources so that communities in North Carolina, South Carolina and Virginia have new tools to overcome the multiple obstacles to health for their children.

These are good starts. What else can we do to empower communities to break out of the intertwining effects of poverty, underperforming neighborhoods, poor education, and lack of health? What questions do you think we should be asking?

The effort to give everyone in this country an equal chance to be healthy is going to take all of us – lawyers who hold the powerful accountable in court; public health professionals; policy makers; industry leaders; medical professionals; community leaders and funders. And you young people don’t have to wait. Pursue your passions now and use them for good. Grow vegetables in the Hope Garden. Push to protect the environment. Hang out with people whose backgrounds are different from yours so you learn to see what others see. Fight for everyone’s vote to count. Ask questions of people running for office. Make sure that health care is on their agendas and that they deal with science, with the evidence, not with political rhetoric.

I want you to walk out tonight inspired to make sure that everyone is healthy enough to enjoy our liberty; your skills are needed. But also walk out with this message: We won’t make real progress if we afraid of the facts, if the people who should be leading the effort must pretend that there are no transgender people with health care needs, if fetus is too scary to say, so we don’t have an honest conversation about the importance of reproductive health, if the Medicaid entitlement becomes a dirty word, instead of something we protect with all our might because there are vulnerable people in our diverse country who matter just as much as the wealthy. We can make progress if we insist that science and evidence must not be banned or ignored. They must be the foundation of our policy. Science and evidence can’t be owned by Democrats or Republicans. Let’s have the courage to tackle the important challenges we face with science and evidence and not with political rhetoric or ignorance.