

Chairman's Corner: Trump Medicare Drug Plan Would Hurt Most Vulnerable

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The Trump administration proposed an “international pricing index” intended to reduce drug spending under Medicare Part B by replicating the rates negotiated in other countries. It seems like a commonsense solution: Why should America pay more than other countries? The truth, however, is more complicated: lower foreign prices emerge from one-size-fits-all health care systems that drive patients to use certain drugs while refusing others, irrespective of individual needs.

This is a compromise Americans have always rejected. Lowering the reimbursement rate that Medicare pays for drugs is meaningless if patients are denied access to the right drugs.

In America, we want doctors and patients driving treatment decisions, not bureaucrats.

Recently, I've been reminded of what we accomplished when President George H.W. Bush signed the Americans with Disabilities Act in 1990, providing legal rights for people like me — who has epilepsy — to live and work equally. But President Bush's passing also serves as a reminder for what we could lose if we don't advocate for disability rights — if we start importing policies that discriminate against so-called high-cost patients.

I'm all for reforms to reduce drug prices and improve affordability. I've consistently advocated for a seat at the table for patients and people with disabilities in creating a health care system that pays for high-quality care. Data and information from personalized and precision medicine can tell us what treatment works for whom to both improve access and lower prices.

What I'm not for, however, are policies that systematically disadvantage those most vulnerable. In effect, the administration proposes to smuggle in the same discriminatory coverage standards and formularies that I and many other leading advocates have fought for the last 30 years.

Other countries limit access to medications using one-size-fits-all thresholds based on quality-adjusted-life-years, or “QALYs.” QALYs seek to quantify the extent to which a treatment

extends life and improves health on average — but in practice, these algorithms discriminate by assigning higher value to people in “perfect health” than people in less-than-perfect health. Treatments for older individuals with fewer years to live or for people living with disabilities fare badly under algorithms that say, “you’re not worth it.”

In the United Kingdom, people with multiple sclerosis, cystic fibrosis, and rare childhood diseases are routinely in the news for being denied access to life-changing medications. In Canada, less than 40 percent of medicines launched globally between 2008 and 2012 were available by 2013. And 95 percent of new cancer drugs are available in the United States, compared to as low as 8 percent in Greece. Imagine rejoicing in the development of innovation, only to be told that you or your loved one can’t get it.

For me, this issue is personal. I’m 76 with epilepsy — old and disabled — a deadly combination if I were to be judged by a QALY. Yet, I am more active than ever. I chair the Partnership to Improve Patient Care; I am on several boards of directors; and I recently launched the Coelho Center on Disability, Law, Policy and Innovation at my alma mater, Loyola Marymount University in Los Angeles, to ensure continued progress in the disability rights movement.

I’m not done, and hopefully the health care system isn’t done with me either.

Earlier this year, U.S. Health and Human Services Secretary Alex Azar spoke sensibly when he expressed skepticism with foreign reference pricing, saying he preferred alternatives that “keep patient choice and patients at the center.”

It is profoundly upsetting they are now trying to import these countries’ policy decisions, which will no doubt end as badly for people with disabilities and serious conditions in the United States as they have for those overseas.