

Tony Coelho: Closing Remarks

The Perils of QALYs: Addressing Discrimination Against People with Disabilities and Serious Chronic Conditions

May 20, 2019

Thank you to everyone for joining us today.

As you can see, we have built quite a team here to carry forward what we started with the ADA.

This is my ministry – that those of us impacted by policies should have a seat at the table in creating them.

It is why I created the Coelho Center – to ensure that people with disabilities become lawyers and eventually judges that protect the ADA and disability rights.

To ensure that people with disabilities are building the technologies of tomorrow that will allow us to live and work in our communities.

I started PIPC in an effort to make research more patient-centered, with patient and people with disabilities at the table throughout the process so that it answered questions that matter to us.

Over the years, PIPC has grown to bring that same passion to engaging patients and people with disabilities in Medicare and Medicaid decisions about access to care.

I am worried that we get caught in the middle of the fight to lower health costs.

We should not lose access to care because others decide that we are not worth taking care of.

The very idea flies in the face of everything I have worked for in my life.

So I encourage you to use your voice in this fight against groups like ICER.

Last Fall, we communicated to ICER in person that their use of quality-adjusted life years (QALYs) was discriminatory and we asked them to do better.

Their response was to send out a press release calling QALYs the gold standard.

Discrimination is not the gold standard.

We can and we must do better.

And with your help, we will not let discrimination be the standard for how we determine access to health care.