

**Hearing: Texas v. U.S.: The Republican Lawsuit and Its Impacts on Americans with
Pre-Existing Conditions
Subcommittee on Health (Committee on Energy and Commerce)
February 6, 2019**

**Answers to Additional Questions from Subcommittee
Elena Hung, Co-founder of Little Lobbyists
March 19, 2019**

1. The ACA prevents insurance companies from imposing annual or lifetime caps on coverage. Ms. Hung, you shared the stories of your daughter and other children who spent the first months of their lives receiving significant medical care.

a. Can you describe just how expensive this care can be and what would happen if insurance plans were once again allowed to impose lifetime or annual caps on coverage?

Thank you, Congresswoman Dingell for your question on annual and lifetime caps on coverage.

In 2014, I had a healthy pregnancy and a great birth experience; but fifteen minutes after she was born, my daughter Xiomara required 100% supplemental oxygen support and was rushed to the Neonatal Intensive Care Unit, where she spent the next five months of her life. During that time, she required two major surgeries (placement of a tracheostomy and gastrostomy feeding tube), countless medical procedures and testing, and medications. Her hospital bills from these five months were close to \$3 million, which was all covered by our insurance plan.

Many people do not understand how expensive high level medical care can be. I have heard from many Little Lobbyists families -- families with children with complex medical needs and disabilities -- that an extended hospitalization of more than 60 days in the intensive care unit can cost over a million dollars. Moreover, the need for high level medical care often continues for many of our children once they are discharged from the hospital and go home. They need follow up procedures, surgeries, medications, durable medical equipment, and ongoing medical care.

If insurance plans were once again allowed to impose lifetime or annual caps on coverage, many children like Xiomara could be kicked off their plans before they are even discharged from the hospital. This is actually one of the main reasons families like mine started speaking up and formed our organization in order to educate others.

My friend and Little Lobbyists co-founder Michelle Morrison understood firsthand how the cap on lifetime and annual limits saved her family from bankruptcy. Her son Timmy was about three months old when he surpassed \$1 million worth of bills. He was still in the Neonatal Intensive

Care Unit at the time and would remain there for another three months. Because of the Affordable Care Act, his insurer covered everything and Timmy continued to receive the care he needed to survive and thrive.

For more on lifetime limits and Timmy's story, please see Sarah Kliff's Vox article: The Obamacare provision that saved thousands from bankruptcy (March 2, 2017)
<https://www.vox.com/policy-and-politics/2017/2/15/14563182/obamacare-lifetime-limits-ban>

2. Ms. Hung, you noted Medicaid's importance for children with complex medical conditions, especially its ability to provide therapies and long-term services and supports that allow independence.

a. If Medicaid funding was significantly cut, what effect would that have on children with complex medical conditions and their independence?

Thank you, Congresswoman Debbie Dingell for your question on Medicaid's importance for children with complex medical needs.

Medicaid is a life-saving program for children with complex medical needs and disabilities. I say this without exaggeration: Medicaid can be the difference between life and death.

Medicaid covers care that many private insurance plans do not. It covers therapies and long term services and supports that our children need to thrive. Therapies, including physical, occupational, speech, and feeding therapies, help children achieve independence.

Medicaid also covers private duty nursing, which is usually not included in insurance plans. Some medically complex children, like my daughter, require a skilled caregiver to be at their side at all times.

A Medicaid program, sometimes known as the "Katie Beckett waiver," enable children who would otherwise be hospitalized and are certified as requiring hospital or nursing facility level of care to receive medically necessary and appropriate services in the community.

Without this level of home care services, our children face the alternative of unnecessary prolonged stays in hospitals, nursing facilities, or other long-term facilities. Notably, the cost of these community-based services is also less than the cost of institutional care.

If Medicaid funding was significantly cut, children with complex medical needs and disabilities would be severely harmed. They would miss out on medically necessary care that enable their independence. They would be unable to live at home with their families, unable to participate in their community, unable to go to school with their peers.

Our children deserve a shot at life and Medicaid provides that.