



Advocating for Kids with Complex Medical Needs
& Disabilities

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March 23, 2021

House Committee on Energy and Commerce Hearing:

Building on the ACA: Legislation to Expand Health Coverage and Lower Costs

Testimony of Laura LeBrun Hatcher

Greetings Chairwoman Eshoo, Chairman Pallone, Ranking Members Rodgers and Guthrie, and members of the committee. Thank you for inviting me here today to share my family's story with you.

My son, Simon, has the best laugh you've ever heard. He loves to watch the Muppets and play the drums – sometimes at the same time. Simon was born in 2006, before the Affordable Care Act became law. He had a brain bleed in utero, and when he was just 2 weeks old and in need of emergency brain surgery, I learned about the limitations of our private health insurance – about lifetime caps on care, and the danger of losing coverage because of “pre-existing conditions” my child was born with.

Through Simon's early years his diagnoses piled up – hydrocephalus, cerebral palsy, epilepsy, autism, a unique genetic disorder – and so did our medical bills. With each ride in an ambulance, and each stay in the pediatric intensive care unit, my anxiety increased. I was afraid for my little boy, and I was afraid of losing his health insurance. I was terrified of reaching his rapidly approaching lifetime cap on care, and I had no idea what we would do when we hit it.

So, it felt like a miracle when the Affordable Care Act passed. I no longer had to worry about his health insurance dropping him because he needed a high level of care. For the next 7 years, as Simon grew up, I grew more confident in my ability to care for my medically complex child, to get him what he needed to survive and thrive.

Then, on May 4th 2017, that confidence was shattered when the Republican-led House of Representatives voted to repeal the health care protections that saved my child's life.

At first, I was devastated. Then, I found other families like mine. We're called the Little Lobbyists – named after an article about a six-year-old boy named Timmy who came to Capitol Hill to ask Congress to save his health care. Simon and I joined Timmy, Xiomara, Abby, Emma, Josephine, Teddy, Claire, and so many more amazing kids with complex medical needs and disabilities and their families. Together we advocate for the health care, education, and inclusion our families need to survive and thrive.

And that is why I am here today. Though there's still a case in the Supreme Court threatening the ACA, it seems that for now ACA protections – which we've worked so hard to save – have survived. As our country begins to recover from this deadly pandemic and the horrific, disproportionate toll it has taken on marginalized communities – especially disabled, Black, Brown, and Indigenous people – it is time for us to work together to help all our families thrive.



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So let me tell you a little more about my family.

Last year, after being on a waiting list for 9 years, Simon qualified for a Medicaid waiver thanks to Medicaid expansion in my state. We finally have coverage for things our insurance would not fully cover – like medicines to prevent Simon’s seizures, the pulse oximeter he needs to sleep safely, and the walker he uses to get around. Simon also has access to Home and Community Based Services. At 14, with the help of a direct support professional, he was able to get his first taste of independence.

In addition to being Simon’s mom, I’m a self-employed graphic designer. My husband, Brian, is also a designer. Recently, Brian lost his job, and with it our employer-sponsored insurance. But, thanks to the Affordable Care Act, and the assistance of a knowledgeable navigator, we were able to purchase health coverage for our family through the exchanges – despite the fact that ALL of us have pre-existing conditions. Because of the ACA, we’ve been able to turn an unforeseen and scary event into an opportunity for Brian to join me in building our family business.

But, COVID has been tough on business - many projects have been cancelled or postponed. It’s also been tough on Simon. Simon lost his direct support professional at the beginning of the pandemic because there simply wasn’t enough funding for Medicaid services, for the PPE and support his staff needed. Online school has also been terribly difficult for him, but Simon can’t safely return to the classroom until he has access to a pediatric vaccine.

Fortunately, Congress has offered us a lifeline with the American Rescue Plan, and I want to personally thank you for that.

You voted to support funding for Medicaid, for Home and Community Based Services that people with disabilities like my son need to stay in their communities and out of deadly institutions. You voted to encourage states that have not yet expanded Medicaid to do so, so more people like Simon can access the life-saving care they need.

In addition to more support for small businesses like mine, Congress built on the ACA. By expanding subsidies to eliminate the “cliff” my family fell off of, I’m able to think about our future with the confidence of knowing we will not pay more than 8.7% of our income on health coverage - even if our business grows, as I really hope it does!

I’m asking you to make these provisions permanent. My family, and so many others, need the certainty and security that comes with affordable health care. Thanks to the ACA, and to the American Rescue Plan, I’m able to sleep a little better, and continue dreaming my American Dream – where my family succeeds with a small creative business and my son with complex medical needs and disabilities survives and thrives in his community, in his country, where we all belong.

Thank you.