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July 9, 2019

The Honorable Elijah Cummings
Chairman
House Committee on Oversight and Reform
Washington, DC 20515

The Honorable Jim Jordan
Ranking Member
House Committee on Oversight and Reform
Washington, DC 20515

**Re: Written Statement Submitted for the Record
Hearing: The Trump Administration's Attack on the ACA: Reversal in Court Case
Threatens Health Care for Millions of Americans, July 10, 2019**

Dear Chairman Cummings and Ranking Member Jordan:

We are Little Lobbyists, an organization of families across the country who have children with complex medical needs and disabilities. We seek to educate policymakers about our community so they can understand the real lives that are impacted by laws and policies they administer. We thank you for holding a hearing on this issue of critical importance to our families, and appreciate the opportunity to explain just how vital the Affordable Care Act (ACA) is to the livelihood of our children, and how they would be endangered if the Administration is successful in its efforts to have that law invalidated in its entirety.

In 2013, there were some 3 million children with medical complexities in this country -- a number that has certainly grown since then.¹ While specific conditions, diagnoses, and treatments may differ, there are also shared experiences common to many in our community: hospitalizations lasting weeks or months; frequent appointments with multiple different specialists; numerous medications necessary to keep our children alive; medical billing statements in the millions of dollars. But those are not the only shared experiences, and they alone do not tell the stories of our children. Families in our community also know what it is to savor every milestone that once seemed out of reach, to celebrate every birthday knowing that they are not guaranteed, to watch in awe as our children not only survive, but thrive.

Our children receive significant medical care, and our children have incalculable worth and potential. Both these things are true. And they are true, in large part, because of the ACA.

¹ Children's Hospital Association, Issue Brief: Defining Children with Medical Complexities, published October 11, 2013 (available at <https://www.childrenshospitals.org/Issues-and-Advocacy/Children-With-Medical-Complexity/Fact-Sheets/Defining-Children-With-Medical-Complexities>).

While repeal of the ACA in its entirety -- which the Trump Administration seeks in the *Texas v. U.S.* litigation now before the 5th Circuit Court of Appeals -- would be devastating to our families in a number of ways, below we focus on three specific provisions of the ACA that are essential to the livelihood of medically complex children and their families.

The ACA's Prohibition of Annual/Lifetime Limits on Care

Many of our children accumulated millions of dollars in medical bills before they took their first breath outside of a hospital. Thankfully, under the ACA, insurance companies are prohibited from taking insurance coverage away from our children if their care reaches a certain dollar amount. The emotional stress that comes with having a sick child in a hospital for weeks, months, or years is beyond description. Imagine adding to that the stress of constantly worrying whether it will be the next procedure, the next surgery, the next medication, that will take away your child's health insurance forever, and the guilt associated with rationing medical care for your child to avoid that possibility. This is not an abstract concern. Among our community are families whose children lost health insurance coverage before the ACA was enacted because an arbitrary dollar limit on care was reached.

Elimination of the ACA would usher in a return to these times. Parents of medically complex children would no longer have the security of knowing, for certain, that their insurance company cannot impose a cap on their child's health care, possibly before they ever come home for the first time. If this protection were eliminated, the financial impact on these families and the health impact on their children would be devastating.²

The ACA's Prohibition of Pre-existing Condition Discrimination

Medically complex children, by definition, have multiple pre-existing conditions, often since birth. With the ACA, our families have certainty that our children will not face unaffordable increased premiums, or be unable to find health insurance altogether, because of conditions they have. We are able to better focus on spending time with our children and getting them the care they need, and can avoid the medical underwriting that was a feature of health insurance before the ACA and was frequently used to deny care to those, like our children, with significant medical needs.

As with the issue of annual/lifetime limits, eliminating the ACA's pre-existing conditions protections takes away from our families a bright-line protection we desperately rely on.

² Notably, not a single "replacement" plan offered by Republican Members of Congress has included a provision banning insurer lifetime/annual limits on care, clearly signaling that should the ACA be struck down by the courts, any legislative fix reinstating this protection would be subject to a partisan fight, with our families caught in the crossfire.

Without these protections, our families will be at the mercy of insurance companies who will have every reason to deny necessary coverage for our children, or provide it only at an exorbitant cost. We note that many Republican Members of Congress have stated that they support protections for pre-existing conditions, and some have even introduced legislation claiming to do so in the event the ACA is struck down. However, we also note that despite these claims, every single Republican proposal offered thus far contains a fraction of the protections that the ACA currently provides, and would leave our families without the full measure of security they have under existing law. A requirement that insurers have to offer a plan to everyone (which many Republican proposals have included) is meaningless to our families without protections that the insurer cannot selectively exclude certain conditions from coverage or charge unaffordable premiums because of a pre-existing condition (protections that the ACA includes, and Republican proposals do not).

The ACA's Medicaid Expansion and Health Exchanges

While some medically complex children are eligible to receive health care through Medicaid (either traditional Medicaid or through State waiver programs), many of our children are not. If private employer-based insurance is either unavailable or insufficient to cover necessary medical care, families with medically complex children and disabilities depend on the ACA for their health care coverage, either through (1) Medicaid expansion or (2) the ACA health exchange marketplace. A court ruling eliminating the ACA, and thus these two programs, would immediately take health coverage away from tens of millions of Americans, including countless families with medically complex children.

We know, perhaps better than most, that the current system of health care in this country is in dire need of improvement. There are millions of Americans today without access to the quality health care services they need, and for millions more who have access it is in name only, as the care they have “access” to is unaffordable. These are real problems that demand real legislative solutions.

The outright elimination of the ACA by a federal court that this Administration seeks is not a step toward a solution. Rather, it would be a radical, destructive leap backward that would make the problems we already have even worse. Millions of more uninsured Americans is not a solution. Dramatically higher health care costs for the tens of millions of Americans with pre-existing conditions is not a solution. Even more surprise denials by insurance companies is not a solution. Dropped coverage for medically complex children with high medical bills is not a solution. We know this because these things were our reality before the ACA was enacted. For the sake of our children, so they can meet their fullest potential, we must see to it that it is not our future as well.

We appreciate the opportunity to provide this written statement, which we do so on behalf of all the Little Lobbyists families with children with complex medical needs, including:

- Isaac Crawley, who lost his insurance in 2010 after he met his lifetime limit just a few weeks after his first birthday, but got it back after the ACA became law;
- Myka Eilers, who was born with a pre-existing congenital heart defect and was still able to obtain health insurance;
- Timmy Morrison, who spent part of his childhood in hospitals both inpatient and outpatient because his insurance plan covers what is essential to his care;
- Claire Smith, who has a personal care attendant and is able to live at home with her family and be included in her community thanks to Medicaid;
- Simon Hatcher, who needs daily medications to prevent life-threatening seizures -- medications which cost over \$6,000 a month without insurance;
- Colton Prifogle, who passed away earlier this year, was able to spend his final days pain-free, with dignity, surrounded by love, because of the hospice care he received.

We thank the Committee again for holding this hearing. Should you have any questions for our families, please feel free to contact me at elena@littlelobbyists.org.

Sincerely yours,

Elena Hung
President and Co-Founder, Little Lobbyists