

Transcript of video:

Family Voices Meeting at the White House July 7, 2011

On screen text: On July 7, three families were invited to the White House to talk about the how Medicaid impacts their lives. (photo of the families)

The meeting was arranged through Family Voices, a national non-profit organization that champions the rights of children with special health care needs.

(Photo of Kareem Dale with family members, focus in on 11-year-old Laura Rodgers)

Laura: I thought it was pretty awesome to get together at the White House. I think that's what any kid would think. But I thought about it in a different way because I know how Medicaid impacts kids like me because it really does make a difference in our lives.

(Focus moves to Rylin Rodgers, Laura's mom)

Rylin:

My husband and I are the parents of two wonderful children. Matthew is 14 and Laura is 11. Both of our kids have mitochondrial disorders, which is a form of muscular dystrophy, and in their case it impacts pretty much every system, so they have significant pulmonary, cardiac, GI and neuromuscular issues. My husband is a school teacher and we were very fortunate when our son was born to have very good health care insurance, and we were comfortable and confident that we would be able to meet the needs of our children. Within 6 months we were in rather significant medical debt, (onscreen text: **First year of Matthew's life: \$200,000 in out-of-pocket costs**) and that medical debt continued to accumulate for a number of years. We had to wait a number of years to have a slot in what's called a Medicaid waiver program which allows us to access Medicaid for our children in addition to their private healthcare. Both kids have been on it, Matthew for about 4 years and Laura for about 3. In that time we've been able to stop accruing significant medical debt and work on meeting their needs in a more appropriate way. But until that happened we really struggled, to the point of often not having enough money to pay for the other necessities of life, including food.

(Focus on Carissa Schlichting, a 14-year-old girl with Down syndrome. Photo fades into a photo of Carissa and her mom, Dianne Malley.)

Dianne:

From the second my daughter was born in Pennsylvania, we were provided with Medicaid as a backup insurance, (photo of Carissa with nurse having a medical checkup, onscreen text: **at the Pulmonary Hypertension Center, Columbia University Medical Center**) so throughout my daughter's life we've been able to get everything she needs to be a healthy person. (photo of Carissa and her sister with the nurse drawing blood. Onscreen text: **Sister Maeve holds Carissa's hand as the nurse draws her blood.**) She has a very complex and rare condition called pulmonary hypertension. The main symptom with pulmonary hypertension is tiredness, and it's a kind of tiredness that's hard for typical people to

understand, like people can be so tired that daily living activities like showering and so on can really drain them, so these medicines have helped her have the energy to live life. (photo of Carissa in a big piece of medical equipment. Onscreen text: **Carissa undergoes a pulmonary function test.**)

And then she told how she has sleep apnea. Any condition like that can make pulmonary hypertension much worse. (Shot of group of families at White House, focus in on Carissa and two girls behind her. Onscreen text: **Behind Carissa are her sisters Alecia and Maeve.**) But through Medicaid, she is on bipap and she has a night nurse daily who assists her with the bipap and makes sure her breathing is stable at nightly. And lastly she shared how having hearing aids she gets through Medicaid helps her in school to do better.

My daughter Carissa is 14, going into high school, she also happens to have Down syndrome, she's included in our local school, she's an active participant in our community and school plays, she plays basketball, she's at camp right now and all of these things are possible because I can access the health care that we need.

I always like to say when Carissa is doing well, that means my other children, myself and my husband also can have the opportunity to live full lives as well. (photo of Carissa and Dianne with Senator Menendez, onscreen text: **Carissa and her family pay a visit to Senator Menendez.**)

(Return to photo of families, focus on Meg Comeau)

Onscreen text: **Meg's daughter Sarah was born with a complex genetic disorder. Meg stopped working to care for her. Her family struggled financially until Meg learned of the Massachusetts Medicaid Buy-in program.**

(Photo of Meg holding infant Sarah. Onscreen text: **Sarah was born in October 1987.**)

Meg: We have always had private insurance and very generous private insurance as Sarah's primary source of coverage, but Medicaid has made a big difference to us in providing wrap-around services and wrap-around supports to her. Because we had that access, because we had those additional supports, Robert wasn't forced to stop working so that we could qualify for Medicaid based on income, we kept our private insurance for our entire family and we stopped the downward slide into medical debt and possible bankruptcy that we were on before we got access to Medicaid. I really think that because we've never had to make a choice between what we can afford and what Sarah needs— because we've always been able to get for her what she needs—she became medically stable relatively quickly in her childhood, and I was able to go back to school and to work as a result.

So this has had a really important impact on our family's financial stability, but also on Sarah's physical health and well-being, on *our* health and well-being—it's reduced the stress on Robert and I—and it's certainly allowed us the wherewithal to get the medical care that *we* need, and it's just improved the quality of our family's life tremendously.

Onscreen text: **What were your impressions of the White House meeting?**

Meg: Instead of approaching the meeting where we had information that we needed to *tell* the policymakers and the senior administration officials who were in the meeting, it was more of a two-way conversation, which I was really excited about. They were very receptive to the information we had to offer them, they asked great questions and follow-up, and they also gave us some information about what was going on from their perspective and how they were working to help defend Medicaid for kids with special health care needs and their families.

(focus shifts to Dianne Malley)

Dianne: The sense I got was that the administration is hugely supportive of maintaining Medicaid. They are almost surprised by some of the recent attacks on it and they very much were in support of us getting our stories out, because they feel many people don't understand the multiple faces of who really benefits and uses Medicaid

(Focus shifts to Rylin Rodgers)

Rylin: I left the meeting really feeling the sense of urgency and how critical it is for this message to get out. I think it's easy to look at Medicaid and think of it as a program for the very poor, which in fact it does provide much needed health care services to some of our nation's most vulnerable children, but it *also* is a *critical* part of the health care services and delivery system for children with special health care needs.

(photo of officials and families sitting around an oval table. Onscreen text identifying officials:

Kareem Dale, Special Assistant to the President on Disability Policy

Jon Carson, Director of Office of Public Engagement

Nancy-Ann DeParle, White House Deputy Chief of Staff

Sara Feuerstein, Staff Assistant to Kareem Dale

(Focus shifts to Laura Rodgers)

Laura: They asked us a lot about what would change if we didn't have Medicaid. One of the things I told them is I wouldn't have a computer so I wouldn't be able to write at all, because I can't write with my hands, that I want to be an author when I grow up. So I would never get the chance to do that.

Onscreen text: **From Laura's blog: I have BIG dreams and goals and I need a little help to reach them.**

Learn more at <http://bit.ly/WhiteHouseJuly7>

Onscreen credits:

Many thanks to the family members who attended the meeting and contributed their stories:

Rylin and Laura Rodgers

Dianne Malley and James Schlichting

Carissa, Maeve and Alecia Schlichting

Meg Comeau

And to the White House staff who met with them:

Kareem Dale, Special Assistant to the President on Disability Policy

Jon Carson, Director of Office of Public Engagement

Nancy-Ann DeParle, White House Deputy Chief of Staff

Sara Feuerstein, Staff Assistant to Kareem Dale

Many thanks also to Family Voices for coordinating the meeting!

Photos contributed by the families

Music: "Kids" by Creative Commons musician Pitx