

Good morning [afternoon], my name is Allison Doran. I am a member of the Greater Rochester Community of Churches' Interfaith Health Care Coalition. I am 26 years old and I was born with a rare genetic disorder called Oculodentodigital Dysplasia. I am here today to plead the inevitable conclusion that everyone needs health insurance, especially those with special needs like myself. Complete coverage is a necessity for individuals with disabilities. Many of the services that insurers refuse to cover, like durable medical equipment such as eyeglasses and wheelchairs, are the very things that people with disabilities need the most. Although Medicaid has been there for me in many ways it needs to work better for those of us with special needs. The current health care system is way too complicated. There is Medicaid, Child Health Plus, Family Health Plus, COBRA, Part D, waivers, and on-and-on—even the average, non-disabled person can't keep all these names straight, let alone all the rules that go along with them. Disabled individuals may have problems with using telephones or handling paperwork, making it more difficult for them to deal with telephone trees and the extensive documentation requirements. The bottom line is that it takes too much energy to find out how to get services and how to deal with miles of red tape around the health care system.

As I mentioned, I was born with a genetic disorder called Oculodentodigital Dysplasia. This rare neurological disorder affects approximately 7 out of every 10,000 babies who are born with Ectodermal Dysplasia Syndrome. When a baby has at least two types of abnormal ectodermal features such as malformed teeth or extremely thin hair then the child is diagnosed with Ectodermal Dysplasia. There are different types of Ectodermal Dysplasia. With some types the person may have no ability to naturally sweat or their eyes are close together on their face giving a cross-eyed impression. It

varies with every person. One person may be affected by a thin nose where another could have severe muscular weakness and pain in the legs.

The part of the syndrome that I have been affected with is called Oculodentodigital Dysplasia. My symptoms are thin, sparse hair, a thin nose, and weakness in my legs. The weaknesses in my legs always changes so I am constantly going to doctors and trying new treatments. Also, because my bone and muscle structure is not as strong as yours I can be injured easier and more severely than you. There is no cure for my disease. Living with this rare disorder has been a struggle for me and for my family, both emotionally and financially.

Two years ago my legs became so weak that I could not walk on my own and I was told by my doctor that I needed a wheelchair. My doctor recommended a wheelchair that has anti-tipper wheels on it so that I don't fall backwards when I go up on a curb or an incline. Because I am constantly going to doctor's appointments, my family agreed with my doctors that a wheelchair with anti-tipper wheels would be the safest thing for me. Little did I know that my battle with Medicaid was just about to begin...

I had two evaluations done by my physical therapist who agreed that a wheelchair with anti-tipper wheels would be the right fit for me and the best thing for my safety. All of my doctors wrote letters to Medicaid and I filled out all of the paperwork that was sent to me. Because I did everything they asked of me, I thought that would be the end of it and I would get my chair. I was devastated when I received a denial letter from Medicaid stating that they would not pay for an anti-tipper wheelchair. The doctors told them why I needed anti-tipper wheels...still this changed nothing. So for the next two years, I was on the phone with Medicaid multiple times a week. I was constantly sending and re-

sending letters from my doctors and all of the other information that they asked for back-and-forth. It was a very frustrating experience and it made me more tired than my disease already did. I would be on the phone for hours at a time. This went on for two years...still no chair, but I wasn't giving up.

One day I was out with some friends from the local MS chapter. We were on the bus and I was wheeling from my spot on the bus over to the lift to get off of the bus. Suddenly, wheeling onto the lift, I fell backwards in my chair. If the bus driver didn't see me and catch me just in time by pulling on the front of my chair, I would have fallen back onto the hard bus floor and smacked my head. I was so freaked out that I could not catch my breath and all I could think of was "Oh my god, I almost hit my head." I was terrified and very shook-up for days after that incident because I had been fighting for two years so that something like this wouldn't happen and now it had almost happened to me. At that point I saw two options for Medicaid in my eyes: they could either buy me the wheelchair that I needed for my safety or pay the hospital bill when I was recovering from a head injury. I should tell you that a head injury for me might not be the same as a head injury for you. My disease is neurological and a hit on the head could cause my legs to become weaker than they already are. I couldn't understand why Medicaid didn't see these two simple options as clearly as me.

At that point I decided that I needed to get the ultra-light wheelchair with anti-tipper wheels, even if it meant paying the difference myself between the cost of that chair and the chair Medicaid was willing to give me. I talked to five or six different people at Medicaid but no one would tell me what the difference in cost between the two chairs was. At that point I called my counselor at VESID, which stands for Vocational and

Educational Services for Individuals with Disabilities. My counselor knew what I had been going through. VESID helped me by doing all the paperwork and making the phone calls; something I had become too tired and too frustrated to do myself. VESID said that they would do whatever it took to get me the wheelchair that I needed, even if it meant that they would have to pay the difference. VESID did get me my chair eventually but they ended up having to pay not just the difference between the chair that I needed and the chair Medicaid was willing to give me, they paid the whole thing because even VESID could not get the information on the difference in cost of the two chairs from Medicaid.

In conclusion, although Medicaid has helped me with a lot of my needs, the wheelchair experience was horrific. I am here today to tell you what I think could be done to the Medicaid program in order to strengthen it so that neither myself nor others will continue to face these tiring, frustrating, and unnecessary experiences. First of all, we need better coverage and better coverage should translate into better care. I believe that if someone from Medicaid had taken the time to meet with me and learn about my life they would have clearly seen that I needed this special wheelchair. Also, I receive Medicaid through a managed care plan and so I don't have a case manager. That means that I talk to a different person every time that I call with a question or concern. I always write down the name of the person that I talk to but when I ask for that person the next time I call they tell me that the person is not there. The Medicaid program could be significantly strengthened if managed care plans were required to provide case management. Not only would this promote consistency and efficiency, but it would help

build a relationship between recipients and their worker so that better and more accurate decisions could be made regarding eligibility determinations and claims.

Lastly, I would advocate that the employee morale needs to be improved. I always feel as though I am a burden when I call the insurance company and I am often talked down to and rushed off the phone. If I could tell the people who work there one thing it would be “realize that you are making a difference in someone’s life.” If they knew that, or if someone told them that, maybe they would be happier with their jobs.

As I said, I am here today to plead the reality that everyone needs health insurance, especially those with special needs like myself, and that we need to create a better system than the one that we have now because it is simply not working.

Thank you for your time today.