

“My Experience Testifying before or Meeting with Legislators”

When I was growing up, politics were always a presence in our home. My father, a political consultant, taught us about the importance of government, the effect legislation can have on our lives, and why we should always stand up for what we believe in.

As I grew older and made my way in life, politics became a topic for polite conversation rather than a part of my day-to-day reality, which was now my son. But last year, these two things collided in an unexpected way. I was asked to speak in front of the Maryland State Appropriations Committee, which was planning to cut funding for the salary increase for the caregivers who look after my son Max. For years I had been fighting for my son – whether it was to improve his educational opportunities or to make decisions about the medical procedures he needed, I told myself that I was no different than any other parent. But the truth is I am different, because my child has special needs, and sometimes, it feels as though getting support for his care is an uphill battle.

But even this fight was different. These were elected officials who lived in a world that always seemed so complicated; a world full of political party agendas and controversy. They were men and women who spoke the language of the law and by being in the political spotlight seemed to be unapproachable and in some ways even untouchable. For the committee, this was just another budget line item on their checklist. How would I explain to them that Max’s caregivers were crucial to his independence? Could they possibly understand that the loving care my son received from his aids not only helped him physically, but emotionally as well? Would it be possible to convey how much I depended upon them to keep my son safe as well as provide him with the opportunities that I could not? When I thought about everything that Max had been through in his life, things became clear and the lessons my father taught me all those years ago made sense. My choice was simple because there was no other choice.

So I stood up and told my story.

As a mother there are always doubts about whether the decisions we make are the right ones, but for me there was never any question that children

like Max are viewed differently and that needed to change. So I stood up and told my story.

As a parent, it doesn't matter who you are or what your job title is. It doesn't matter how much income you make or what level of education you reached. It doesn't even matter what your political beliefs are. All that matters is that you stand up for what you believe in – you stand up and fight for what is best for your child. So I stood up and told my story.

I like to think that my father was watching over me that day giving me the strength to speak without faltering.

I like to believe that in the eyes of the committee, I put a name and face to all of the children like my Max who should never be discounted or thought of as being different than any other child.

I like to hope that someday the kind of care children with special needs require will never have to be fought over, or bargained for.

On that day, they listened – not as politicians, not as committee members with a budget to balance – but as parents - just like me – because I stood up and told my story. It's time that you did too.