

March 21 2016

Testimony of Marisol Ramos

I wanted to start by thanking all of you for the support that you have given to me and my family over the years.

My name is Marisol Ramos. Twenty-two years ago, I came here from Puerto Rico with my husband, Jose Ramos. I have a daughter and a son, Naomi and Justin. I work for a company called Vision For Equality. This company helps educate families of people with disabilities. It teaches them how to become advocates for their loved ones. Since, my own children have physical and intellectual impairments, I can fully appreciate the importance of the work I do. This is the reason that I chose this line of work.

I will talk to you now about my first born, my daughter, Naomi Ramos. She is now 20 years old. She was born premature at only 24 weeks old. She is medically fragile, this means that due to her physical disabilities she is dependent on medical care every day. She is also intellectually impaired. She requires a lot of care and round the clock supervision. After she was born, the doctors told me that the best place for her would be an institution. I decided against this. This was not the life I wanted for my daughter. I wanted her to have as normal a life as possible living at home with parents who love her. I believe that people with disabilities have the right to live at home with their families. Along with the normal parenting skills, I had to learn how to take care of my daughter's very specialized needs. Through the years, her needs have changed but the severity of her condition has not. I take her everywhere with me. I buy her the things she loves like CDs and magazines. We have traveled to Puerto Rico to visit with family. I worked hard so that she could have a life filled with the same opportunities that every person in this room has had. This is Naomi.

Next, I will tell you about my son, Justin. He is, now 14. When Justin was 2, I realized something was different about him. He did not act like other children his age. I took him to the doctor and he was diagnosed with autism. Already coping with a daughter suffering from severe intellectual and physical disabilities; made Justin's diagnosis simply heartbreaking. But, I accepted it and started working with him right away. And this is Justin. I am worried about his future because there is a waiting list for the autism waiver.

The reason I came to tell my story today is because I want everyone here to understand how difficult it is to deal with this from day to day, but that it is possible. For my husband and I it is truly gratifying to have our children living with us in our home. We work together for the benefit of our daughter and son. I want to maintain this life for the both of them. However, the reality is that Naomi is 20. She is on the waiting list for an intellectual disability waiver. Next year she will be 21. Instead of being a time of celebration as it should be, this is when she will lose all her services. Right now, she has a nurse, who takes care of her 10 hours per day and has worked with her and our family for the past 13 years. Naomi requires 24/7 care without the nurse services and extra supports, my husband and I will have to quit our jobs in order to care for her. However, without both of our incomes it will be hard to maintain the quality of life that our children deserves.

In the last few months I received a letter from the medical insurance company that Naomi's nursing hours are going to be cut from fifty to thirty hours week we filed an appeal and we were as denied and then we filed a second appeal. This has been every stressful since we are afraid of losing her hours and our jobs.

Thank you for listening to me. Please think of families like mine. Please think of those children that need these services to live the type of life they deserve.

Thank you,
Marisol Ramos
Philadelphia, Pennsylvania