

My name is Alison Jacobson. I am a nationally recognized family safety expert known as [The Safety Mom](#), wife and, most importantly mom of four children. My first child, Connor, died of Sudden Infant Death Syndrome in 1997. My second child Spencer, is 16 now and is severely intellectually disabled. I also have two beautiful girls. As I said, I'm also a wife. I was married to my second husband in 2011 and three weeks after we were married he was diagnosed with Primary Progressive Multiple Sclerosis. I have watched him go from walking at our wedding to, today, being completely confined to a wheelchair.

I am the sole provider for the five of us and I will be the caregiver for both my husband and son for the rest of my life. The therapy and medical bills for both men in my life are incredible and I feel blessed that I am able to work consistently to cover our household expenses. Undoubtedly I will need to be doing this for the rest of my life.

But, underneath it all I have a fear that is always at the back of my mind. What happens if I can't? What happens if I die? WHAT THEN HAPPENS TO SPENCER?

Because he's only 16, I've been too busy dealing with his day to day schooling, therapy and being a mom to look into the supports he will be entitled to when he gets out of school. It would be an understatement to say I was shocked and, quite frankly terrified, to learn that there is no money available to my son when he leaves school for residential support. How could that be when there's a BILLION DOLLAR budget in this state? And then I learned the answer. The answer that so many of my friends with special needs children don't know yet. The money has been allocated so disproportionately that only the smallest percentage of individuals who need it, are getting astronomical amounts while the greatest percentage of those families who do, are being turned away.

And so, I'm here today, wishing that someone in the government could explain to me, in very plain language, how it makes any sense or is in any way equitable that some individuals are actually getting close to \$ 350,000 per year and others are being told THERE'S NO MONEY FOR YOUR CHILD? Here are some facts that I know. I live in Fairfield County, the most affluent area of this state, and my family of 5 with TWO disabled family members gets by on \$110,000 per year. Someone who is in a nursing home, needing round the clock care can expect to pay about \$180,000. It simply makes no sense that one person receive \$350,00 per year.

My eyes were truly opened to this horrific situation when I went to a family meeting and met parents whose intellectual disabled children are in their 30's. I wept listening to how these loving, kind parents who are in their late 60's and have worked their fingers to the bone, struggle to carry their fully grown adult children up and down stairs. How they've sacrificed their other children's education because they could not afford college for them. I heard their utter fear contemplating what would happen to their child should they have a stroke or a heart attack or break their hip falling down the stairs.

And so I ask you WHAT IS GOING TO HAPPEN TO SPENCER? What is going to happen to all of these intellectual disabled citizens of this state who have the right to have support? Are they less important than any other citizen in this state? It would appear that people who are incarcerated in this state have more financial support than my son.

Spencer loves cooking and he gives great back rubs. He says he has "magic knuckles." He loves meeting his friends for pizza, watching movies and he loves swimming at the Y. In other words, he's like so many

other teens out there with interests and hobbies. All I want for him is what every mom wants for their child – to be happy. I want to be at peace knowing that when I'm gone he will have a wonderful life where he's safe and cared for. While Spencer will never be able to live alone or drive a car, he could certainly be a productive member of his community.

How do I look my son in the eye, as he hears his sisters talk about their future and tell him I have no idea what his future looks like?

Logic needs to prevail and the system **MUST** be fixed! I'm not asking for more money to be put in the budget, I'm simply asking for the budget to be allocated in a fair and equitable way. That's not politics, it's common sense.