Thank you for giving me the opportunity to read my testimony here today.

My name is Holly Bortfeld. I am the mother of 2 children with Autism Spectrum Disorder. My son Max, who is here today, is 18 and my daughter is 20. Neither were born with autism but both regressed into it, at age 2 for my son and age 5 for my daughter.

It's taken a lot of time, effort, money, services, pain and supposedly 'alternative' treatment from some of the most prestigious hospitals in the country and also some nondescript medical offices to get my kids healthy. The medical establishment has fought us the entire way, never a partner in our health care needs. I would not have healthy children if I didn't fight the medical system and their status quo.

It took more than 2 years to find medical practitioners who tested and treated my son's many co-occurring issues, and he can now do all the things the "best specialists" promised me he'd never do. And I have no doubt that had I listened to them and medically drugged him into submission rather than treat the underlying cause of his autism they would have been right. He would have rotted and like many of his peers, died from wandering or seizures, or spent the last 16 years in unnecessary pain.

Parents should not have to fight their doctors for medical care or travel all over the country to get help like we did, and still do.

I have calculated that it's cost me, insurance and the state $1.6 Million dollars to get my son to this point. He is not recovered from autism and will still need lifelong care, but he's not in pain anymore and that's priceless.

Our kids have treatable medical conditions that can turn them from sick children to healthy taxpayers when we can get proper medical care. All you need to do is look at the body and what's wrong with it, then fix those things, and you'll be amazed. Autism is treatable. Autism is recoverable. It really is.

Now, let's have a reality check about what autism does to our country. With the recent CDC announcement of the rising numbers of ASD, now 1 in every 68 children in the US, what did we get from our government? Not much, as usual, "just better diagnosing, nothing to see here". Well, guess what America?, this is a NATIONAL EMERGENCY. Even if it doesn't affect one of your family members, YET, it DOES affect your pocketbook. Who do you think is going to foot the bill for my son's care? Or the other 1.2 million children, much less the uncounted adults? The taxpayers.

Between educational, medical and therapy costs, my son costs the state $100K a year for appropriate treatment. And he still lives at home. The residential placement costs are over $100K per year per person. Do the math: $200K per year for 1.2 million kids for the next 70 years. That's 16.8 TRILLION DOLLARS just for these kids much less all the adults and all the children not yet included in the “prevalence estimates”.

Autism is recoverable. It really is.
Plus add in their loss of income and tax base since they won't have jobs as 90+% of people with ASD are unemployed or underemployed. When they turn 22, and the school bus stops coming, our kids have nothing but wait lists. Nothing to do, nowhere to go. That means that we have to quit our jobs to be able to care for them all day. So now you get two people on public assistance. Who will pay for your Social Security? No one. Scared yet?

180 children in America will be diagnosed today. 180 more will be diagnosed tomorrow. And EVERY SINGLE DAY. Where is the urgency? It certainly isn’t coming from the federal government. What number will it take until the federal government gets it? What number will it take before members of this committee get it?

And we’re NOT buying that there is no real increase anymore. If there is no real increase, where are the 1:68 adults with autism, more than 50% of whom should be nonverbal? They’re not misdiagnosed, they’re not wandering the streets. They don’t exist. And neither do any adult services programs that WOULD exist if they did.

Almost 15 years ago, the CDC introduced the “Learn the Signs. Act Early.” campaign which costs about $3 Million annually, but according to their own data, the median age for diagnosis is still 4.5 years old so the campaign has done absolutely nothing to reduce the age of diagnosis despite spouting the efficacy of early intervention on long term outlook. Being diagnosed at 4.5 years old is 1.5 years too late to get any Early Intervention at all! STOP WASTING OUR TIME AND MONEY.

So what does my family want?

We want the government to declare autism a crisis, the national emergency that it is. We want the CDC to actually count, and do it properly. New Jersey does it properly, follow their lead, and do it in a timely manner. With proper counts, we can accurately judge changes in autism over time and plan for the needs of individuals with autism throughout their lifespan.

Stop the duplicative research in areas that have been researched unendingly but produce no treatments and focus on the environmental impacts on our children's health. The federal government has spent $1.6 billion on autism since 2006, but the money is not helping those affected in meaningful ways. We need to improve medical treatment for the many co-occurring health concerns of individuals with autism and address the wave of students who are aging out and entering an adult world with no plan for them. Study our sick kids, find out why they are sick and what they have in common. Listen to parents and community stakeholders. Stop blowing us off. We were there, you weren’t. We'll be here when you're gone.

NOTHING SHOULD BE OFF THE TABLE. NOTHING. Until you can definitively prove what does cause autism, or autisms, EVERYTHING, including vaccines, should be researched. Every time you cut that discussion off, you cut off your usefulness to our community. Make yourself irrelevant, and we will make sure you are replaced.
The government hasn’t prevented one case of autism, hasn’t produced one treatment. Since the CDC started “watching autism”, autism has increased 14,700%. In the public sector, this type of performance gets you fired.

Get on the right side of this issue and do it now. The clock is ticking and we don’t have any more time to waste.

Holly Bortfeld
Mom to 2 amazing kids