Senator Klobuchar and Distinguished members of the Subcommittee:

My name is Mary Moen. My husband Steve and my 10 year-old son, Max, are here with me today from our home in Minneapolis, MN. When Max was three years-old he was diagnosed with an Autism Spectrum Disorder called Pervasive Developmental Disorder-Not Otherwise Specified. The diagnosis came after a year of fear and frustration as our bright and active baby had become increasingly agitated and aggressive as a toddler.

As a preschooler, any social situation was very challenging for Max. He became difficult to manage outside the home safely and was increasingly bothered by loud and high-pitched noises, smells and touch. His reactions to things he didn't like were explosive and often dangerous. His brother, Theo, was born during this time and the stress of a new baby and an uncontrollable 3 year-old was more than we could bear.

We took him for lengthy evaluations through Minneapolis Public Schools and medical assessments at two different autism specialty centers. The school district gave him an educational label of autism spectrum disorder. The doctors' and psychologists' reports gave similar findings.

At the time he was diagnosed, many around me were asking how Max got autism. We suspected a genetic link and I wondered about the effects of the infertility medications I had taken for the two years previous to his birth, but at the time it didn't matter. I was focused on moving forward to help my son who was, by now, so obviously different from his peers.
Everything we read about treating autism told us that early intervention was key so we could not wait for services to come to us. We bought books, went to conferences and begged for consultations with over-scheduled experts in the field. We learned what methods would be most effective for Max, but were frustrated to find waiting lists as long as 6 to 12 months at facilities that offered these treatments. We sought out private therapies until we could get into an autism program. These therapies often were not covered by insurance. Thankfully we live near Fraser Child and Family Center, the largest provider of Autism Services in the Midwest. At Fraser I was assigned a case manager and Max was admitted into a day treatment program for children with autism. The words of one psychologist haunted me. "You're going to have to teach your son many of the developmental things that other kids learn naturally." I wondered, "What were those things?" and "What if I missed something?". I quit my teaching job and threw myself into this full-time. My husband also cut back on his orthopaedic surgery practice to be home more. It became our mission to put together an appropriate treatment plan that would address Max's unique needs and we worked and tweaked this plan for the next few years of Max's life.

When he began kindergarten at age 6, we learned that our local community school did not have an autism program and although Max's reading and math skills were

far above grade level, his poor social skills and lack of self-control meant he needed more support. We had to send him to a school outside of our community that had an Autism Program. We always thought it was strange to take kids with a social disorder and send them to a school outside of their community, where there are even more impediments to making friends.

Our goal was to bring his skills to a point where he could be fully mainstreamed and moved to our community school with no autism support by first grade. It took a lot of hard work to make this happen-including doubling-up on therapy and intensive summer programming.

Moving to our community school was an extremely difficult transition despite some very well-meaning teachers. The staff was not experienced in working with kids on the autism spectrum. Despite these challenges, we felt it was important for Max to experience a mainstream school setting instead of being accommodated in a special education program. My husband calls it the "school of hard knocks", and there have been plenty of hard knocks. Max works so hard each day that it is not uncommon for him to fall asleep in exhaustion before dinner.

Life is somewhat easier now, but not without struggles. We made the difficult decision start medication to help control his impulses and stay calm. Meltdowns come weekly rather than daily. Max's interests are not like his peers and making friends is very difficult. Teaching him tools to resolve conflict is an ongoing lesson. He is often inflexible and resistant to change. Things like playing on a sports team, making friends and going to summer camp, that are just natural steps in a neuro-typical child's life come carefully planned and prepared for Max. Setting him up for success takes understanding his challenges as well as a tremendous amount of time and forethought.

Max turned 10 last Sunday and will be starting 4th grade in a few weeks. He is a bright, outgoing star at school. He is known and loved by his teachers and staff. He is beginning to have success in age appropriate experiences after 6 years of Special Education, therapies, medication and social skills training. He plays on basketball, baseball and soccer teams and joined the chess club. He would tell you that he has a few friends. He is going to sleep away camp for the first time next week , which is a milestone for any child, but particularly for a child with autism that has difficulty making friends and adapting to change.

So while things look pretty good right now, we never really know what will set Max back or how long he will need our help. We hope he will continue to excel academically and go on to college and be a productive and happy adult. In contrast, Max's 48 year-old aunt who we suspect is also on the autism spectrum, is unemployed, socially isolated and entirely dependent on her aging parents. People like her, with undiagnosed or untreated autism, are an example of autism's cost to our economy and society.

Our family is at a point now where I feel like I can look beyond our situation and address some of those questions others were asking me when Max was first diagnosed. How did Max get autism? Why is autism increasing? And what can I do to help so other parents and children can be spared this difficult path? There are many unanswered questions that can only be answered with more research. As families of children with autism we each struggle with the "why". The manifestations of autism are as diverse as the families and communities from which children with autism come. I do not believe we can come to simple conclusions when it comes to the cause and effects of such a complex disorder as autism. While there is an urgent and growing need for resources for early identification and intervention, on-going treatment, medical care and social services for children and adults with autism, it is also imperative that we focus resources on continued research so that we can one day identify its cause. Until we have done the extensive research necessary to understand autism, we cannot leave any stone unturned or rule out any possible factors as a cause of this disorder.

Thank you for the opportunity to share my story with you today.