

Senator Wieland and members of the committee:

Ladies and gentlemen, thank you for the opportunity to speak to you and for your interest in “our kids”. My name is JoAnne Vieweg. I am the grandparent of a 12 year old boy with Asperger’s Syndrome. You have already had the opportunity to meet him, Colin Vieweg.

As a grandparent, I share the same hopes and dreams for the future of my grandchild as my daughter does and as I did for my own children. So I grieved with her the day we received the diagnosis of Asperger’s Syndrome. At first I felt it would be something to limit his life prospects, but later came to believe it would provide him some safety and a level of understanding, particularly within the public school setting. Some of the time that was true, but not always. We’ve had to fight hard to get him the level of understanding and services he needs to be successful in school.

Grief over the loss of what might have been for your child is a hard thing to carry. So eventually I let it go and began to rediscover the wonderfully talented, funny and endearing person he has always been. He wasn’t diagnosed until 3rd grade because the differences in his functioning weren’t so apparent until then. Ironically, as a preschooler he was enrolled in a special education preschool as a “typically developing peer” to provide good models for disabled children. When I get too sad about his “disability”, I go back to remembering him as a young child with the whole world open to him. I like to think that prospect is still true, but there are a lot of roadblocks for him.

It breaks my heart when he isn’t invited to birthday parties or when the kids don’t come to his party. It is difficult to explain to him why that might be. I am one step removed from the situation, so I can only imagine how hard that is for my daughter to bear.

There is a lot of worry that accompanies even the smallest details of his life. He can’t just go outside to play. Playing in the back yard requires someone nearby to help monitor how he is handling the pick-up ball games that don’t follow the rules, or handle the kids who are loud and unpredictable. It brings tears to my eyes to realize he will never have the fun of a sleep over (too different and unpredictable), that he consistently needs someone to cue him on how to respond to another person’s question or interaction. We are always on the alert to his level of anxiety. He is one of the children with Asperger’s who has outbursts when he can’t cope. This puts him at great risk for being misunderstood and subject to “punishment” instead of understanding. This heightened level of alertness takes its toll on Colin’s mother, grandfather and me.

There has been strain between my daughter and me as we've navigated how to redefine our relationship as co-supporters of Colin as well as mother and daughter. With counseling and personal insight, we've managed to find the way. Actually we are living the extended family lifestyle that used to be more common in our society.

In addition to the watchfulness and supervision he requires, we are always coaching him as to the appropriate way to enter a situation, handle a frustration, answer a person's question, respond to a particular look from someone. This is like a preschooler—teaching him to maneuver in the world and understand it. But he is 12!! Shouldn't he be able to do this? No, he can't very well, but is learning. Funny how he is so smart and remembers every detail of our vacation trip three years ago, can name every Pokemon, their various evolutions and which region they live in, and yet needs me to help him figure out how to get ready to stop one activity so he can move on to the next one, like leaving the McDonald's playground.

On the other hand, Colin is a delightful, smart, charming, caring boy. He is the light of our lives and constantly intrigues us with his knowledge and his interest in the world. I do believe he will one day be a great contributor to our society. He will probably invent the next form of robotic machinery or prosthetic limb. At the very least, he will make the world a more interesting place. I melt every time he takes my hand and comforts me when I am not feeling well or wishes me a good day. I have every hope that he will find a wonderful life partner and build a happy life.

And then again I worry about what the future holds for him. It is always a roller coaster ride of small successes and fears for what's around the corner. While we celebrate each of his accomplishments, we are then terrified of the roadblocks that will face him next, such as how to learn to drive with a high level of anxiety and with people on the road who don't follow the rules, how to navigate school hallways and classrooms when there is no longer an Asperger Coach on staff to help him and his teachers, how to talk to a girl, how to react when a girl flirts with him, what to do on a date, and then how to have a good job interview without talking on end about his favorite topics, how to work with other people, how to take direction from his boss without thinking he did something wrong. The list is endless, and we are constantly on the watch for where the next stumbling block will be. I pray for him to have, when the time comes, vocational guidance, help transitioning to high school, then to college and living independently, and then guidance from his employer. We can't do it alone, as much as we want to. We, the family, don't have the resources or expertise.

Having a child with Asperger's reminds me of my friend with a child with diabetes. Their bodies are different from other people—one's pancreas does not

produce enough insulin, the other's brain processes information from his senses differently. These conditions will never go away but can be treated. They both need on-going help learning to manage their condition, counseling to help them cope with their differences, maybe case management to help coordinate all the services they need, and help teaching the family how best to support them.

I am lucky to be able to help my daughter by picking Colin up from school each day because he can't manage the noise and unexpected activity on the school bus. He needs a place to "decompress" at the end of the day because it has taken all his energy to cope through the school day. I also help out by supervising him when Mom needs to or wants to do something. While I love doing this, it does shorten my days and limit my ability to visit my two other grandchildren who live out of state. Finding a "kid sitter" who understands him is a challenge.

He has a lot of medical needs and his mother is able to pay for many of them, but that leaves little extra money for the month. Grandpa and I are able to pay for his school lunches, summer care tuition, clothing and orthodontia work. As a result of these practical and money needs, my husband and I have altered our final retirement plans. We will continue to live nearby until Colin finishes high school, and we will have a smaller retirement fund to live on.

Yet I wouldn't trade him for the world. Colin once told me he is glad he has Asperger's because it makes him smart, gives him Super Powers and makes him unique. But he hurts when others don't accept him. I bless the mother of the triplets who are his friends, because their mother taught them to understand and accept differences. I cherish the boy with Asperger's who coaches Colin to "go to your happy place when you are upset". And I'm heartened when the classmates who think he is weird, are happy to have him on their science team because he always has the right answer.

I wouldn't have him be any different. I love him exactly as he is, quirks and all.

What I long for is for the world to be an easier place for him to maneuver in. I would just ask for all of us to accept differences, be more understanding, and accept him for the terrific boy he is with all the potential one could wish for.

Thank you and I will answer any questions that you may have.