



**Statement Submitted by the National Down Syndrome Society  
Commission on Security and Cooperation in Europe: Helsinki Commission**

**Briefing on "A TRULY INCLUSIVE SOCIETY: ENCOURAGING THE ABILITY IN DISABILITY"  
September 24, 2018**

**Kayla McKeon  
Manager of Grassroots Advocacy  
National Down Syndrome Society**

Good afternoon, everyone. To echo Sara's words, thank you to Allison and the Helsinki Commission for inviting me to speak.

My name is Kayla McKeon and I am the Manager of Grassroots Advocacy at the National Down Syndrome Society. I am the first registered lobbyist who just happens to have Down syndrome. Down syndrome doesn't define me, Kayla, and it definitely does not stop me. What limits me and my fellow advocates and friends with Down syndrome and other disabilities across our great country is Law Syndrome.

As Sara mentioned, Law Syndrome is a series of VERY old laws that were passed when I wouldn't have lived past my adolescence or even my childhood, and if I did, I would not have left the hospital with my parents because people with Down syndrome were still being institutionalized. These laws were put in place when the social acceptance of individuals with disabilities was at an all-time low.

I was lucky in my upbringing in Syracuse, New York. When I was 18 months old, my parents enrolled me in an early education program. I progressed through school alongside my classmates and graduated at age 18. As soon as inclusive education became possible, I was always in an inclusive setting. I won't deny there were bumps and stumbling blocks along the way, but my parents always thought it was best for me to be included with my classmates and placed in settings that challenged me to reach my highest potential. There were times when they pushed me, but it was always because they knew I could succeed.

I earned awards in eighth and ninth grade for character, commitment, courage, English and math. My final grade for algebra was in the 90's and I got a 93 on my math regents' exam. If you are from New York, you know how tough that was.

Later, an agency known as Vocational & Educational Services for Individuals with Disabilities, or VESID, and my high school set up a program for me to take an office technology program. It was a six-month certification program for adults. They arranged the program for me to go through it twice. I passed the program, earned the certificate and, as a result, I am pretty fast on a keyboard. I was even the commencement speaker.

I also attended Onondaga Community College taking some non-credit courses, but I thought to myself, it doesn't make sense that I'm doing all the work without earning any credits! But I liked the classes, so I began taking one course per semester for credit. I can happily say I am now more than halfway to earning my associate's degree. I start back up later this month. I love taking classes with my peers. Many of my classmates are a little bit younger than me now, but so what! I started advocating a number of years ago. I started educating others who are differently abled by going to elementary schools, then moved on to middle schools, colleges and the school of nursing. I try to motivate them to do the best that they can do. My message to kids in school is to persevere. I am who I am today in large part because I was included with my peers throughout my childhood.

One day in Syracuse, I met John Katko at a baseball game. He was running for the U.S. House of Representatives. He handed me his business card so I handed him mine. He called me later and said if he was elected he wanted me to come and work for him. When he won, I became an intern in his Syracuse office. I represented him at different events and did office work. In June of last year, he asked me to go with him to a disability conference in Washington. We didn't realize at the time it was with the National Down Syndrome Society. It was there at the end of the meeting that Sara Hart Weir, our President and CEO of NDSS, offered me the job of Manager of Grassroots Advocacy. I started last October.

With my position as the first registered lobbyist with Down syndrome, I go to Capitol Hill and speak to many Members of Congress and their staff on issues that are important to me. I helped lobby to pass the original ABLE Act as a volunteer for NDSS and now the ABLE to Work Act and the ABLE Financial Planning Act as a lobbyist. These laws allow me and my friends who are differently-abled to have savings accounts and meaningful employment without giving up our benefits.

We are now tirelessly working on ending #LawSyndrome. Down syndrome doesn't stop us. It never stopped us. It is just some old, antiquated laws that hold us back. One example is the 80-year-old provision within the Fair Labor Standards Act known as Section 14 (c) that Sara mentioned. People like me are still getting paid cents an hour, while other individuals performing the same tasks are paid at least minimum wage. These issues segregate us from the rest of society. They show we are still viewed as "less than". Society is ready to move past these laws. When will the government catch up?

We have a long way to go for individuals with Down syndrome to be fully included in society. To me, having Down syndrome is who I am but it has never stopped me for achieving my own hopes, dreams and passions. What I want for my life and all individuals with disabilities is for us all to be treated just like everyone else. I want to live the American Dream.