



**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”
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Good afternoon. My name is Sara Hart Weir, and I am the President and CEO of the world’s largest Down syndrome advocacy organization – the National Down Syndrome Society (NDSS),

On behalf of NDSS, the leading human rights organization for all individuals with Down syndrome, it is an honor to sit at this table (today) to present to the Helsinki Commission with Dr. Lazarus, one of our favorite NDSS #DSWORKS® partners, Mark and John Cronin, from John’s Crazy Socks and of course, my esteemed colleague, Kayla McKeon.

At NDSS, we believe if you’re not at the table, you’re on the menu. I, personally, want to thank the Helsinki Commission, for today’s imperative discussion and lending a critical voice to a population, even in our great nation, the United States of America, and still in 2018, that is far more discriminated against more than any other community.

Today’s topic - “A TRULY INCLUSIVE SOCIETY: ENCOURAGING THE ABILITY IN DISABILITY” is something we live and breathe at the National Down Syndrome Society – as we strive to achieve equality for all Americans with Down syndrome in the U.S.

Our great nation’s first motto- “E Pluribus Unum”- is embedded in almost every fabric of our country’s rich history. The phrase is used on our currency, the seal of the President, Vice President, United States Congress, of the United States House of Representatives, of the United States Senate and on the seal of the United States Supreme Court. It is cemented in our country’s rich history, culture and values—life, liberty and the pursuit of happiness— e pluribus unum comes from the Latin phrase meaning “OUT of many, ONE”.

From this belief, springs a unifying purpose for our nation. Equality. Unfortunately, in the United States, and around the world people with Down syndrome and other disabilities are not treated as one.

At NDSS, we believe no matter your differences or abilities you should have a fair shot at the American Dream – and we work hard each and every day to ensure America’s motto is upheld for people with Down syndrome and that ONE truly means ONE.

At NDSS, ¼ of our staff have Down syndrome and work across all of our programs and departments. Not a single decision within our organization is made without the input of our self-advocates. At NDSS, our programs, including:

- our National Advocacy and Public Policy Center
- our #DSWORKS® Employment Program
- our Health Promotion and Resources Program

These programs are dedicated to advancing proactive policies and providing invaluable resources on issues across the lifespan, from birth to old age, across five critical pillars: healthcare and research, education, employment, community integration and economic self-sufficiency.

Next year, we will celebrate NDSS' 40th anniversary. During this time, one of the most important advancements for individuals with Down syndrome has been an increased access to and advancements in healthcare. The result is a dramatic increase in life expectancy of individuals with Down syndrome from 25 years old in 1983¹, to about 60 years old today² - all a result of early detection of co-occurring conditions like congenital heart defects, quality dental care and of course, inclusion.

From its origins in 1979, NDSS has been involved in so many federal and state advocacy as well as judicial efforts that have helped individuals with all disabilities become more included in society:

- The Individuals with Disabilities Education Act (Public Law 101-476), or "IDEA" that guarantees students with disabilities their right to be educated alongside their peers in their neighborhood school;
- The Americans with Disabilities Act (Public Law 101-336), or "ADA", that prohibits discrimination against individuals with disabilities in all areas of public life and the subsequent Olmstead Supreme Court decision that requires public agencies to provide services in the most integrated settings possible;
- The shutdown of the Willowbrook Institution in New York that was brought to the forefront of the public's conscious; and
- The landmark passage of the Stephen Beck Jr., Achieving a Better Life Experience Act (Public Law 113-295), best known as the "ABLE Act", that allows individuals with disabilities to save money without it affecting their benefits.

These accomplishments and milestones were vital to ensure individuals with disabilities have access and adequate supports to the basic liberties those without disabilities enjoy – education, community integration, a housing, employment and savings.

Despite these significant advancements, we have a long way to go. People with Down syndrome are still held back and confined to laws that were put in place as long ago as the 1930's – a time where the life expectancy rate was very, very low, a time when we were still institutionalizing people with Down syndrome and perceptions of the people with Down syndrome were not even realized.

Today:

- Individuals with disabilities still do not have access to marriage equality

¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4445685/>

² <https://academic.oup.com/eurpub/article/17/2/221/435114>

- Individuals with disabilities cannot maintain their vital benefits while working, despite being ready, willing and able to work
- Though we fought for IDEA, many students still do not have access to the inclusive education to which they are entitled and is the basis of a life of inclusion
- Many cannot choose where they want to live as housing options for individuals with Intellectual and Developmental Disabilities especially are extremely limited
- Many are still not economically self-sufficient despite ABLE accounts being open to qualifying individuals across the nation

Outrageously, many are still not getting paid the minimum wage that all other Americans are entitled to. Under Section 14c of the Fair Labor Standards Act (of 1938), businesses can obtain a special wage certificate from the Department of Labor to pay individuals with disabilities below minimum wage, sometimes as little as thirty cents an hour – the only group of people it is still legal to pay below minimum wage. For purposes of conscious, inclusion and equality, this is unacceptable.

Last year, NDSS launched our campaign to end #LawSyndrome to draw attention to these issues and advocate for change. Down syndrome doesn't hold anyone back but rather these antiquated laws prevent individuals from fulfilling their potential. We will not stop until every single American with Down syndrome has the same rights as every other American.

One of my proudest accomplishments at NDSS is ensuring that individuals with Down syndrome are not only part of our incredible team and organization, but they are at every table where key decisions about their future are made. When you have a seat at the table, you have a say in the decisions that are made and when it's your table, you make the decisions – this is how we end Law Syndrome. I am honored to introduce my colleague who has not only earned a seat at the table – she owns the table and Capitol Hill.