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A Truly Inclusive Society: Encouraging the Ability in Disability

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Commission on Security and Cooperation in Europe
234 Ford House Office Building
Washington, DC 20515
202–225–1901
csce@mail.house.gov
http://www.csce.gov
@HelsinkiComm

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ABOUT THE ORGANIZATION FOR SECURITY AND COOPERATION IN EUROPE

The Helsinki process, formally titled the Conference on Security and Cooperation in Europe, traces its origin to the signing of the Helsinki Final Act in Finland on August 1, 1975, by the leaders of 33 European countries, the United States and Canada. As of January 1, 1995, the Helsinki process was renamed the Organization for Security and Cooperation in Europe (OSCE). The membership of the OSCE has expanded to 56 participating States, reflecting the breakup of the Soviet Union, Czechoslovakia, and Yugoslavia.

The OSCE Secretariat is in Vienna, Austria, where weekly meetings of the participating States' permanent representatives are held. In addition, specialized seminars and meetings are convened in various locations. Periodic consultations are held among Senior Officials, Ministers and Heads of State or Government.

Although the OSCE continues to engage in standard setting in the fields of military security, economic and environmental cooperation, and human rights and humanitarian concerns, the Organization is primarily focused on initiatives designed to prevent, manage and resolve conflict within and among the participating States. The Organization deploys numerous missions and field activities located in Southeastern and Eastern Europe, the Caucasus, and Central Asia. The website of the OSCE is: <www.osce.org>.

ABOUT THE COMMISSION ON SECURITY AND COOPERATION IN EUROPE

The Commission on Security and Cooperation in Europe, also known as the Helsinki Commission, is a U.S. Government agency created in 1976 to monitor and encourage compliance by the participating States with their OSCE commitments, with a particular emphasis on human rights.

The Commission consists of nine members from the United States Senate, nine members from the House of Representatives, and one member each from the Departments of State, Defense and Commerce. The positions of Chair and Co-Chair rotate between the Senate and House every two years, when a new Congress convenes. A professional staff assists the Commissioners in their work.

In fulfilling its mandate, the Commission gathers and disseminates relevant information to the U.S. Congress and the public by convening hearings, issuing reports that reflect the views of Members of the Commission and/or its staff, and providing details about the activities of the Helsinki process and developments in OSCE participating States.

The Commission also contributes to the formulation and execution of U.S. policy regarding the OSCE, including through Member and staff participation on U.S. Delegations to OSCE meetings. Members of the Commission have regular contact with parliamentarians, government officials, representatives of non-governmental organizations, and private individuals from participating States. The website of the Commission is: <www.csce.gov>.

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A Truly Inclusive Society: Encouraging the Ability in Disability

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September 24, 2018

Commission on Security and Cooperation in Europe
Washington, DC

The briefing was held at 3:30 p.m. in Room 2220, Rayburn House Office Building, Washington, DC, Allison Hollabaugh Parker, General Counsel, Commission for Security and Cooperation in Europe, presiding.

Panelists present: Allison Hollabaugh Parker, General Counsel, Commission for Security and Cooperation in Europe; Sara Hart Weir, President and CEO, National Down Syndrome Society; Kayla McKeon, Manager of Grassroots Advocacy, National Down Syndrome Society; Dr. Sheryl Lazarus, Director, The TIES Center; John Cronin, Entrepreneur with Down Syndrome and Co-Founder of John's Crazy Socks; and Mark Cronin, Co-Founder and President of John's Crazy Socks.

Ms. PARKER. Good afternoon. My name is Allison Hollabaugh Parker. I am general counsel at the Helsinki Commission, also known as the Commission on Security and Cooperation in Europe, and it's my pleasure to welcome you this afternoon to our briefing on creating "A Truly Inclusive Society: Encouraging the Ability in Disability."

As you may know, 57 million Americans are living with disabilities, 400,000 of them with Down syndrome. Almost three decades ago, President Bush signed into law the Americans With Disabilities Act (ADA). This provided individuals with disabilities access to the same employment opportunities and benefits available to people without disabilities, encouraged employers to make reasonable accommodations, required state and local governments to make all services and programs available to individuals with disabilities, prohibited places of public accommodation from discriminating against individuals with disabilities, and directed businesses to make reasonable modifications when serving individuals with disabilities.

In so doing, the ADA has broken down many barriers blocking the full participation of individuals with disabilities in their communities, in the economy, and across the United States, in every sphere in which they would like to participate. While the United States has an exemplary system of integration, empowerment, and protection, individuals with intellectual disabilities, like Down syndrome, have recommended numerous further

improvements to U.S. law in order to fully realize the goals of the Americans With Disabilities Act.

This briefing will explore best practices developed federally and locally in the United States to empower and integrate individuals with intellectual disabilities. We'll also discuss changes that will enable individuals with disabilities to reach their full potential. The law on this subject is a work in process and I look forward to hearing from our five panelists this afternoon, the first of whom is Sarah Hart Weir. She is the president and CEO of the National Down Syndrome Society (NDSS), which is the largest nonprofit in the United States dedicated to advocating for people with Down syndrome and their families. As president, she oversees the organization's mission, vision, and administration. Ms. Weir works each day to ensure people with Down syndrome are represented at every table where critical decisions are made, whether it's the White House, the U.S. Congress, the United Nations, or in state capitols across the country. Ms. Weir has a Bachelor of Arts in psychology and political leadership from Westminster College and a Master of Science in public policy and management from Carnegie Mellon University's Heinz College.

Ms. Weir.

Ms. WEIR. Good afternoon. My name is Sarah Hart Weir and I'm the president and CEO of the world's largest Down syndrome advocacy organization, the National Down Syndrome Society.

I have had the opportunity to work with people with Down syndrome for almost 20 years and was inspired to get involved in this amazing community from my best friend, Kasey, who happens to have Down syndrome and lives in Kansas.

On behalf of NDSS, the leading human rights organization for all individuals with Down syndrome, it's an honor to sit at this table today to present to the Helsinki Commission with Dr. Lazarus, one of our favorite NDSS #DSWORKS® employment 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 that, even in our great nation, the United States of America, and still in 2018 is far more discriminated against than any other community.

Today's topic, "A Truly Inclusive Society: Encouraging the Ability and 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 United States.

Our great nation's first motto, "E Pluribus Unum," is embedded in every fabric of our country's rich history. The phrase is used on the currency, the seal of the president, vice president, the U.S. Congress, the U.S. House, the U.S. Senate, and on the seal of our Supreme Court. It is cemented in our country's rich history, culture, and values. Life, liberty and the pursuit of happiness comes from the Latin phrase "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 your 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, a fourth 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 their input and the input of our self-advocates.

At NDSS, our programs—including our National Advocacy and Policy Center here in Washington, DC, our #DSWORKS® employment program, and our health promotion and resources program—each of these programs are dedicated to advancing proactive policies and providing invaluable resources on issues across the lifespan, from birth to old age, and across five key critical pillars: health care and research, education, employment, community integration, and economic self-sufficiency.

Next year, we will celebrate NDSS's 40th anniversary. During this time, one of the most important advancements for individuals with Down syndrome has been an increased access to advancements in health care. This result has led to a dramatic increase in the life expectancy for people with Down syndrome. In 1983, it was 25. Today it's well into the 60s. And this is 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 efforts as well as judicial efforts that have helped individuals with disabilities become more included in society: The passage of IDEA that guarantees students with disabilities the right to be educated alongside their peers in their neighborhood school; the Americans With Disabilities Act, 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; of course the shutdown of Willowbrook in New York, which was brought to the forefront of the public's conscientiousness to shut down institutions across the country; and something we at NDSS are extremely proud of, the landmark passage of the Stephen Beck Jr. Achieving a Better Life Experience Act, best known as the ABLE Act, which allows individuals with disabilities to save their own money for the future.

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, 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 into place when we were still institutionalizing people with disabilities, the life expectancy was very, very low and a time when perceptions of people with Down syndrome were not even realized.

Still, today, individuals with disabilities still do not have access to marriage equality. Individuals with disabilities cannot maintain their vital benefits while working, despite—and you'll hear from Kayla and John—being ready, willing, and able to work. Though we fought for IDEA, many students do not have the access to inclusive education to which they are entitled to and is the basis of life in our schools each and every day.

Many cannot choose where they want to live and housing options are extremely low. And many are still not economically self-sufficient, despite ABLE accounts being open to qualifying individuals across the Nation.

Outrageously, many are still getting paid way below the minimum wage. We still have Section 14(c) of the Fair Labor Standards Act, a law that was put in place in 1938, where businesses can apply for wage certificates from the Department of Labor to pay individuals with disabilities way below the Federal minimum wage, sometimes as low as

30 cents an hour. Something we at NDSS are advocating very aggressively for is the passage of the TIME Act led by Congressman Greg Harper. Last year, NDSS launched our campaign to end #LawSyndrome, to draw attention to these issues and to advocate for change.

Down syndrome does not hold Kayla, John or any of our friends and loved ones with Down syndrome back. It's truly these antiquated laws that are preventing individuals with Down syndrome from reaching their full potential. And we at NDSS 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 individuals with Down syndrome are not even—not just part of our incredible team and wonderful 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 those decisions and how they are made. When it's your table, you make the decisions. This is how we end #LawSyndrome.

I'm honored to introduce—and I know Allison will as well and let Kayla follow—my colleague, who has not only earned a seat at the table, she owns the table and she owns Capitol Hill.

Thank you, Allison, and the members of the Helsinki Commission and staff for making today possible.

Ms. PARKER. And thank you, Ms. Weir, for the long and hard work of NDSS to ensure that we continue to move forward in the United States in the advancement of human and civil rights for individuals with intellectual disabilities.

I'd like to next introduce Kayla McKeon.

Am I saying that correctly?

Ms. MCKEON. Yes.

Ms. PARKER. She is the first registered lobbyist in the United States with Down syndrome and she's a member of the Down Syndrome Society's Self-Advocate Advisory Board where she serves as manager of grassroots advocacy. Prior to joining the NDSS team, she worked for Congressman John Katko from New York. Ms. McKeon is also a Special Olympics athlete and a Special Olympics congress member. In 2011, she competed in the Special Olympic World Games in Athens, Greece, winning a silver and a bronze medal.

Kayla.

Ms. MCKEON. And thank you, Allison.

And good afternoon. And to echo Sarah's words, thank you to Allison and the Helsinki Commission for letting me speak today.

My name is Kayla McKeon and I am the manager of grassroots advocacy at the National Down Syndrome Society and I am the first registered lobbyist who just happens to have Down syndrome.

Down syndrome doesn't define me and it definitely does not stop me. What limits me and my fellow advocates and friends with Down syndrome—as Sarah mentioned, #LawSyndrome is a series of very old and antiquated laws that were passed when I would not have lived past my adolescence or even my childhood, and even 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 involved me in an early education program. I progressed through school alongside my classmates and graduated at 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. And there were times when they pushed me, but it was only because they knew I could succeed.

I earned awards in 8th and 9th grades—character, commitment and courage—as well as in English and math. My final grade for algebra was in the 90s. I got a 93 in a math regent's exam. So if you are familiar, you know how tough that was. [Laughter.]

Later, an agency known as Vocational and Educational Services for Individuals with Disabilities, or VESID, and my high school had set up a program to take an office technology program. It was a 6-month certificate program for adults. They arranged it where I could do it—go through it twice. I passed the program, earned a certificate and, as a result, I am very fast on the keyboard. I was even the commencement speaker.

I also attended Onondaga Community College taking some noncredit courses. But I thought to myself, does it make sense I'm doing all the work without earning any credits? But I like the classes, so I began taking one class per semester for credit. I can happily say I am now more than halfway to earning my Associate's degree. I started back in August. I love taking classes with my peers. Many of my classmates are a little bit younger than me, but so what?

I started advocating a number of years ago. I started advocating on laws about the differently abled by going to elementary schools, going to middle schools, colleges, and the schools of nursing. I try to motivate them to do the best that they can do. My message to kids is to persevere. I am who I am today partly 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 intern for him. When he won, I became an intern in the 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 that time it was with the National Down Syndrome Society. It was there at the end of the meeting that Sarah 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 very 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, the 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 stops us. And there are some old, antiquated laws that hold us back. One example is the 80-year-old provision with the Fair Labor Standards Act, known as Section 14(c) that Sarah had mentioned. People like me are still getting paid cents an

hour while other individuals performing the same task that are paid at least minimum wage. These issues segregate us from the rest of society. We are still viewed as "less than."

Society is ready to move past these laws. When will the government keep up? [Laughter.]

We still 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 from achieving my own hopes, dreams and passions. What I want for my life and all individuals with disabilities is for us to be treated just like everyone else, an opportunity to live the American dream.

Thank you. [Applause.]

Ms. PARKER. Thank you, Kayla. I have no doubt that you will achieve all that you set your heart and your mind to do.

Ms. MCKEON. Thank you.

Ms. PARKER. Next we have Dr. Sheryl Lazarus. She is the director of the TIES Center at which she conducts research and provides technical assistance on educational change that will support the integration of all students into inclusive learning settings. She addresses barriers to inclusion and works to build consensus and capacity among practitioners and policymakers for sustainable inclusion. Dr. Lazarus has published more than 200 articles and reports, including on the instruction and assessment of students with disabilities and English learners with disabilities.

Please welcome Dr. Sheryl Lazarus.

Dr. LAZARUS. Thank you. I would like to thank the Helsinki Commission for the opportunity to talk with you today. I'm the director of TIES Center. TIES is funded by the U.S. Department of Education and is the national technical assistance center on inclusive practices and policies. Its purpose is to create sustainable changes to educational systems so that students with the most significant cognitive disabilities can fully engage in the same instructional and noninstructional activities as their general education peers, while being instructed in ways that meet their individual needs.

Expectations for students with disabilities in the United States historically have been low, but several laws have encouraged a more inclusive educational system. Beginning in 1975, Public Law 94–142 set a precedent for inclusive education with its least-restrictive environment clause. The Individuals With Disabilities Education Act of 1997, which is often referred to as IDEA, says that students with disabilities have the right to learn the general curriculum based on the same standards as their peers who do not have disabilities.

The most recent reauthorization of IDEA, as well as the 2015 reauthorization of the Elementary and Secondary Education Act, also known as the Every Student Succeeds Act, or ESSA, states that education must be designed to promote progress in the general education curriculum.

IDEA also mandates that students with disabilities be provided with a free and appropriate public education which includes both special education and related services, and that students are to be educated in the least-restrictive environment. This creates a legal presumption that the general education setting is the default unless the child cannot be educated satisfactorily there, even after the necessary support is provided.

These laws and others provide the underpinnings of inclusive education in the United States, but the real heroes are the individuals with disabilities, their families, and advocates. They have exercised their rights, and sometimes had to push, shove, and hold the educational system to what the law required, though they must consider themselves fortunate to be in a country in which individuals with disabilities and their families have the legal right to disagree with schools and the government.

Next, I'll discuss two critical components that support sustainable inclusion for all students. The first is raising expectations. It's important to note that students with the most significant cognitive disabilities are very diverse. For example, more students with significant cognitive disabilities can read than you might think. Two-thirds are readers. Unfortunately, in the past, students with the most significant cognitive disabilities often were only taught functional skills such as how to care for themselves.

The curriculum started to change in the early 2000s when accountability for academic performance for students with disabilities was strengthened. As teachers introduced content similar to what peers were learning, students with the most significant cognitive disabilities surprised us with what they could do. We heard over and over, who knew that these students could learn to read and do math and social studies and science?

A second critical component that supports inclusion is what we call communicative competence. Most students with the most significant cognitive disabilities communicate verbally just like everyone else. However, a few students communicate in other ways or show minimal response to stimuli. Students who lack a consistent mode of communication are often served in segregated educational settings because many teachers feel unprepared to support them. A key to successful inclusion and better outcomes is getting a communications system in place, ideally by kindergarten or the early primary grades.

Here is an example which illustrates how a commitment to building communicative competence helps enable students to thrive in inclusive contexts. Jaimar Fish is a middle school student in Danville, Kentucky. He has multiple disabilities. He did not have a consistent communication system. He gets along well with other students, but it was difficult for him to develop relationships with them because he could not communicate. His educational team addressed his communications needs by first figuring out what he enjoyed and might want to communicate about. Then they gave him what we refer to as an augmentative and alternative communication device. In his case, this is a simple motion-detection switch. It is activated by his smallest movements and translates these movements into verbal language. Now Jaimar can respond to questions during math, reading, and other classes, talk with his friends about his likes and dislikes, and is one of the group.

In addition to raising expectations and communicative competence, there are many other components of successful inclusion, such as high-quality, accessible instructional resources and providing training and professional development to all teachers so that they can confidently instruct students with the most significant cognitive disabilities in inclusive settings. Please see my written statement for additional details.

Research has shown us the path to successfully educating all students, including those with the most significant cognitive disabilities. And the United States has taken some steps in that direction, but we need to have the commitment to make sustainable inclusion happen for all students. To improve outcomes for kids, the behavior of adults needs to change. There needs to be shared responsibility across educators for all students with all students being held to high expectations. Together, we can create a future that

supports the learning of all students in inclusive settings, which will lead to a future with communities where all individuals are valued members.

Thank you.

Ms. PARKER. Thank you, Dr. Lazarus. Thank you for the very practical suggestions that you've both developed and shared with us today.

Next, we have John Lee Cronin. John is a 22-year-old man full of life and aspirations, who also happens to have Down syndrome. His love of colorful and fun socks and desire to perform meaningful work inspired him to found a new business, John's Crazy Socks. John is the chief happiness officer of John's Crazy Socks. John is a graduate of Huntington High School and a Special Olympics athlete.

John.

Mr. J. CRONIN. Good afternoon. My name is John Cronin and I am the co-founder and chief happiness officer of John's Crazy Socks. I come here to stand up for people with Down syndrome and all people with different abilities.

I have Down syndrome and Down syndrome never held me back. I am 22 years old and I work hard every day to show the world that people with Down syndrome are ready, willing, and able to work. Give us a chance and we can be successful.

You may have heard about John's Crazy Socks. We have a mission to spread happiness. We have a good story, but we are a good business, too. We offer 2,300 different socks. We have shipped our socks to every state and 80 different countries. This year, we will ship over 170,000 orders and earn over $6 million. I may be cute, but I run a serious business.

I started this business with my dad, Mark. It was my idea and I came up with the name. My dad—my dad—believed in me and he gave me a chance. I love my dad. I work hard every day. I love my business. And let me tell you why I started John's Crazy Socks.

In the fall of 2016, I began my last year of school and needed to decide what I would do. When school ended, I had received a good education at Huntington High School. I was healthy and ready to go. I looked around, but I saw few choices and opportunities. I knew I could do more. I wanted a good job just like my brothers, Patrick and Jamie. I decided to create my own—my own job. I told my dad that I wanted—I wanted to go into business with him. I came up with the idea to sell crazy socks because I had always worn and loved colorful and fun socks. We opened John's Crazy Socks in December 2016. We were entrepreneurs and we took a chance.

Now everyone wears my socks, even the movie stars, prime ministers and presidents. We have created 35 jobs and 18 of my colleagues have a different ability. We make films that have been seen over 4 million times. We have raised over $135,000 for our charity partners. We are making John's Crazy Socks a success, and we owe it to our colleagues. I can be in my own business because I had a great teacher. I want to do a shout-out to Dr. Erica Murphy-Jesson and Patricia Klee, my speech teacher. I can lead my own business because I played Special Olympic sports. I can lead my own business because my dad gave me a chance.

I want you to know what people like me can do. Give us a chance and watch what we can do. [Applause.]

Ms. PARKER. Thank you, John. I'm so glad that you took that business risk and had the courage to create your own opportunity because it is changing the world.

Mr. J. CRONIN. Thank you so much.

Ms. PARKER. Next we have Mark X. Cronin, who is the co-founder of John's Crazy Socks along with John. He serves as the business's president and developed the social enterprise model for the business. Mark spent much of his earlier career in the health care field leading management and technology firms seeking to improve health care to the poor and strengthen doctor-patient relations. He's also led political campaigns, published numerous short stories, and taught school.

Mark.

Mr. M. CRONIN. Good afternoon. My name is Mark X. Cronin. As you've heard, I'm John's father and partner in our business, John's Crazy Socks.

We are here today to share some best practices, or at least our practices, of working with people with differing abilities. And what we do in our business is simple: We want to show what's possible, we want to show what people with differing abilities can do if given a chance.

In John's Crazy Socks, we have built a social enterprise, so we have a social mission and a business mission and they're indivisible. Our social mission shows the world what people with differing abilities can do and we give back by supporting and raising money for our charity partners, like the National Down Syndrome Society. But we can only succeed if we run a rigorous business. We compete with some of the world's largest and best companies—Amazon, Walmart, Target—and we must match or beat what they do. For us to do good, we have to do well.

And that's why we hire people with differing abilities. Doing so serves our social mission, but it also serves our business mission. To succeed, we have to provide great service. We do same-day shipping. We make sure our customers are happy. And we hire people with differing abilities because they help us run that great business. We do not hire out of charity or altruism; we hire because it is good business.

John told you that we have been fortunate enough to create 35 jobs with 18 held by people with differing abilities. Our starting pay is $12 an hour, $1 more than the New York State minimum wage. Our colleagues do not do minimum work, so we do not offer minimum pay.

Too often, people with differing abilities are not offered jobs or they can only find work in sheltered workshops. They might be offered positions out of pity or charity. Our business demonstrates that people with differing abilities are just like the rest of us. They want meaningful work where they can make a contribution and receive fair pay. After all, that's how we got started.

When John was finishing school, healthy and ready to go, he did not see many choices and the entrepreneur in him said great, I'll create my own job. What does it take to hire people with differing abilities? We simply need to focus on what people can do, not what they cannot do. Match the skills of the worker to the job.

We operate a pick-and-pack warehouse. Our warehouse workers—we call them sock wranglers—those with differing abilities and neurotypicals all pass a test to prove they can do the job. No charity, just real work.

We have no government support. We have no special programs. Yes, we make accommodations for our differently abled, but we also make accommodations for our neurotypical employees. We have created a unified workplace where people of differing abilities work side-by-side neurotypical employees. And everyone benefits. We have better productivity, better morale, better retention.

And yet, we're talking about best practices. Small accommodations can make a difference. We make sure everyone has an email address and knows how to use email, even if they're not working with a computer. We give everyone a business card as a symbol of their professionalism and we watch as they give that out proudly to family and friends. We schedule regular social events outside of the office for all of our staff, like attending a chamber of commerce dinner. Having a job gives our employees standing in the community. And these are small initiatives, but they have a big impact on our differently abled population.

We have learned that hiring the differently abled gives us a competitive advantage. The United States and other industrialized nations are now facing shortages of workers, and yet we have this great, untapped, natural resource in the differently abled. Employers will learn that those with differing abilities are an asset, not a liability, and the employers who learn this lesson the fastest will be at an advantage and have greater success.

Our governments need to change, too. We need to see the differently abled as full-fledged citizens, people able to contribute, not helpless beings who need pity. We need laws that guarantee the same rights, including the same wages, as the neurotypical population. Here in the United States, the Fair Labor Standards Act of 1938—which is anything but fair—allows employers to pay people with disabilities less than a minimum wage. Just because you can pay people less does not make it right. And it may make you some extra money, but it will leave you morally bankrupt. We are working with the National Down Syndrome Society to support passage of the TIME Act to afford all people a fair and minimum wage in the U.S. and elsewhere.

We have benefit programs that limit the ability of the disabled to work. Many of our colleagues who are differently abled can only work part time. Why? Because if they work too many hours they will lose their Medicaid and they cannot afford to do so. Take Aliya, one of our colleagues who has a form of autism and works as a sock wrangler. Aliya does a great job and would love to work 40 hours a week, but cannot because she cannot afford to lose her Medicaid. Don't we all want Aliya to work full time? Then why have laws that limit how much she can work?

And my son, John—he does not receive benefits yet; however, when he needs those benefits in the future, he will need to choose between his benefits and the equity in the company he created. Do we want to prevent people from engaging in entrepreneurship?

It is time to decouple the poor from the disabled in our means-tested programs so that people with differing abilities can work full time and maximize their contributions to society. We want to encourage people to work and to pay taxes, so let's remove the disincentives.

In the end, our message is simple: It is good business to hire people with differing abilities. John created his own future when he created John's Crazy Socks. We need more businesses that offer a future of meaningful work to all people. Employers here in the U.S. and around the world will come to learn that people with differing abilities make great employees.

John and I, we're a couple of simple guys from Long Island. We're a couple of knuckleheads selling socks. [Laughter.] We have no special training. We have no special talents. If we can do this, anyone can. No more excuses. Let's show the world what's possible.

Mr. J. CRONIN. I love you, dad.

Ms. PARKER. Thank you, Mark. Thank you for your vision and creating a very successful business and social enterprise model for the rest of us to take note of and follow.

You mentioned in your statement that the minimum wage floor does not apply to individuals with intellectual disabilities at this point. And there is a bill that's been introduced called the TIME Act that will address that issue. Will that bill also address the issue of part-time work, which you also mentioned, meaning individuals with intellectual disabilities who do not have the option to work full time and keep their benefits? Or will that be addressed by different legislation?

And, Sarah, please feel free to jump in.

Mr. M. CRONIN. Well, I mean, Sarah's more of the expert than me. The TIME Act will only prevent employers from paying people less than minimum wage. To change that issue about the limits on what people can work, the ABLE Act changes some of that on the margin, but that's a fundamental change that would have to—we would have to change the way we provide health insurance to working people who are disabled.

And the reason it's critical, Medicaid covers more than what traditional health insurance pays. So even if you have traditional health insurance, there are some benefits that are crucial to many people with disabilities that they can only get through Medicaid.

But, Sarah, you know, you're the expert on this.

Ms. WEIR. Sure. It's actually one of the main reasons we launched our Law Syndrome campaign last October. And Mark pointed this out in his testimony and it's exactly what we're trying to achieve with the work we do at the National Down Syndrome Society, and that's, essentially, we need to decouple the poor from the disabled in these means-tested programs.

We still have very obsolete income and asset limitations that exist as far back as the 1960s and 1970s that prevent individuals with Down syndrome and other disabilities from keeping what they can earn and what they can save. ABLE was a huge step forward and it doesn't solve all of our issues, but it created a financial tool, a 529A or a 529 ABLE account to allow individuals with disabilities to save their money in an ABLE account without putting benefits in jeopardy.

Now, really, our focus on the employment side is to address the archaic, outdated income limitations. And we really feel at the National Down Syndrome Society and with the partnership of businesses, like John's Crazy Socks, $800 billion corporations like Voya Financial, from Main Street to Wall Street, the way to do that is to essentially eliminate the ability to pay people with disabilities far below minimum wage. The TIME Act is one example. We know that there are other efforts here on the Senate side to introduce new legislation to address this. And then we're exploring opportunities to address this administratively with the administration and look at ways to make sure that no new 14(c) certificate holders are created in a time when the supply and demand for sheltered workshops are the lowest it's been in, you know, recent decades.

So there's multiple ways to do this. But from an equality and a human rights perspective, I think there's nothing more discriminatory than a 1938 provision that tells somebody who was born with Down syndrome that you're far less valued in an employment setting than anybody else.

Ms. PARKER. Thank you. We'll have to probably take the additional bills up in the next Congress because we're coming to the end of this Congress. But it sounds like there's some great work still to be done.

I wanted to ask John, what is a typical day like for you at John's Crazy Socks?

Mr. J. CRONIN. When I get at work, I do—I handle all the—I do videos. I do a bunch of videos, like I tell you new ones and call it John's networking. We're doing—we're doing "Mad Science," a "Mad Science" show. [Inaudible.] And we're doing "Cooking Up Happiness." I'm doing it with a guest with differing abilities on "Cooking Up Happiness."

Mr. M. CRONIN. So it's videos that you do.

Mr. J. CRONIN. I do a—there's a video. I do a—I'm pulling—I'm pulling sock records. I help pick out socks, every order. And after that, I'm doing a video order or a video of that, and I write personal notes, personal videos, all that. I'm doing a big engagement right now. I'm just having fun.

And my—and mostly I like making home deliveries. If fun things are going on—and I—[inaudible]—candy, and thinking of it is something sweet.

Ms. PARKER. Thank you, John. It sounds like you have a very busy day doing public relations, merchandising and shipping for the socks.

And do you typically work part time, full time, does it vary from week to week depending on how busy things are?

Mr. J. CRONIN. Actually, I'm going to tell you I have work when I—when I—I'm an entrepreneur, me and my dad. When we get up, we get in the office around 9. And some nights—some nights, around 6, 7 at night. We work—me and my dad work long hours. And I tell you that because we're going two more years. We're going on vacation in two more years. We're entrepreneurs. [Laughter.]

Mr. M. CRONIN. So we work hard, huh?

Mr. J. CRONIN. We work very hard and so it's very appreciated.

Mr. M. CRONIN. But you like it?

Mr. J. CRONIN. But, yes, I like it. [Laughter.] Yes.

Ms. PARKER. Thank you, John.

Kayla, I had a question for you. You mentioned in your testimony that "I am who I am today in large part because I was included with my peers throughout my childhood."

Ms. MCKEON. Correct.

Ms. PARKER. And I'm wondering, what are your best memories of inclusion during your childhood? And what are also your memories of times when you wish you had been included more in your childhood?

Ms. MCKEON. You're making me think . . . It's been a while. I remember being in a classroom with a special education teacher and I didn't have a one-on-one yet. But I will probably get a one-on-one after I—sorry to say this—but I went into the woods. I was—I behaved like I shouldn't when I was little. And so I have this bad memory, but it was part to get a one-on-one that helped me gain independence, it helped me build the skills I needed to get up to where everybody else was.

And back then, I was in high school and I still had this one-on-one who had to hold my hand in the hallways. I said, um, no, thank you, we're going backward, I don't want to backpedal, I'm independent and I can cross a hallway on my own. Well, they thought I needed that extra help where I did not need it, but I needed the help in the classroom

where they were able to break down the instructions, make it easier for me to learn. And doing things more hands-on helped me greatly. So I'm not saying it was a bad memory, but it helped get that one-on-one that I needed to propel me to work harder.

And one of my one-on-ones was Ms. Powers who helped me to be more independent and got me into a club in school that I really enjoyed. And again, it helped with the independence.

Ms. PARKER. Sounds like you had the extra support when you needed it, but also the freedom to say I can stand on my own two feet now, thank you, when you didn't need it. So I'm glad to hear that.

Dr. Lazarus, I wanted to dig deeper into how teachers can be better prepared to instruct students with the most significant cognitive disabilities when they're trying to create an inclusive setting and the student may need quite a bit of extra support.

Dr. LAZARUS. What we've found is that the students, they understand each other. They want to work together, they want to be friends, they want to be colleagues. But it's often the adults who can get in the way. And teachers all, I truly believe, every single teacher out there wants what is best for students. And they also want what they—they want to feel like they are successful as teachers. And when they lack the skills to instruct some of their students, then they start thinking, well, maybe this isn't a good fit for this child.

So what we really need is to create schools where all teachers have the confidence that they can successfully instruct all students. And so to get this, it involves teacher prep programs where all educators have the opportunity to instruct, learn how to instruct the widest range of students, the development of instructional materials and resources that are easy to use and can be used with students across the range of students.

We also need to think about administrators and how they might support inclusion and the importance of all people in the school taking responsibility for the learning of all students. Too often we have silos that the special educator does this and the general educator does that, and if we can combine where everyone in the school cares about all students, then we will have much better places.

Ms. PARKER. Thank you, Dr. Lazarus.

Before we run out of time, I want to make sure that we leave some time for any questions from the audience or online as the case may be.

I'll give you a moment to think while I follow up with Dr. Lazarus.

How does being included in regular classrooms with peers without disabilities help prepare students for better quality outcomes for adult life? Why is this a key goal?

Dr. LAZARUS. The early inclusion supports later inclusion. Early segregation almost ensures that there will be segregation later in life. That's so important to think about, what do we want in our communities, in our country? And when we think about our schools are preparing our future corporate leaders, our future civic leaders, our faith leaders, and if those individuals are comfortable with—familiar with—individuals who have a wide variety of characteristics, whether it be ethnic diversity, English learners or individuals with significant cognitive disabilities, we are creating communities that value all individuals. And I just see inclusion right from the get-go as being a really important part of that.

Mr. M. CRONIN. If I could add to that—you know, at a personal level and in our business. So John is the youngest of three sons. John benefited from his older brothers leading

him and taking care of him. But his older brothers benefited from John and they are better people because of it. And in our workplace—so we have this unified workplace. We see minor miracles every day with our differently abled. But our neurotypical staff, they're better off, they're happier. And that diversity that we bring benefits the business. So everyone—it's not that inclusion doesn't just benefit the differently abled, it benefits everybody.

Dr. LAZARUS. And I totally agree with Mark. That is just so, so true.

Ms. WEIR. Well, and I echo both what Dr. Lazarus and Mark said. But I think it comes down to the treatment of people with disabilities. It should be no different than anyone else. The way and the reason we fight for inclusion for students with Down syndrome is so they have access to the general curriculum, they have access to a great education. And the expectation when they graduate from high school or college needs to be employment, just like everyone else.

Ms. PARKER. We have run out of time, unless there's a burning question from the audience.

And if not, I will thank the panelists for bringing us both tangible examples as well as the challenges of creating a truly inclusive society. I am so encouraged by the success that you are, Kayla, the success that you are, John, and the success that you are encouraging amongst your peers and urging others in your life to achieve by changing laws that are holding you back. And so I thank you for being here today. Thank you for your insights.

And I hope that everyone in the audience will join me in thanking them. [Applause.]

Ms. MCKEON. And thank you for having all of us. We very much appreciate it.

Ms. PARKER. Our pleasure.

[Whereupon, at 4:36 p.m., the briefing ended.]

A P P E N D I X

Prepared Statement of Sara Hart Weir

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 mottos—"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 1983,[1] to about 60 years old today[2]—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, 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
- 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

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4445685/
[2] https://academic.oup.com/eurpub/article/17/2/221/435114

- 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 14(c) 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 #LawSyndrome. I am honored to introduce my colleague who has not only earned a seat the table—she owns the table and Capitol Hill.

Prepared Statement of Kayla McKeon

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.

PREPARED STATEMENT OF DR. SHERYL LAZARUS

Written Opening Statement of Sheryl Lazarus, Ph.D.
Director, TIES Center

Congressional Briefing on "A Truly Inclusive Society: Encouraging the Ability in Disability"

Hosted by the Helsinki Commission

Monday, September 24, 2018, 3:30 p.m.

Dirksen Senate Office Building, Room 562

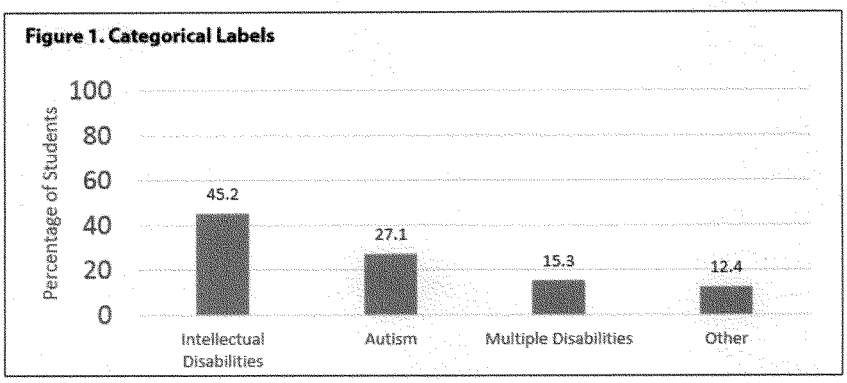
I. Introduction.

I would like to thank the Helsinki Commission for the opportunity to talk with you today. I am the Director of TIES Center.[1,2,3] TIES is funded by the U.S. Department of Education[4], and is the National Technical Assistance Center on Inclusive Practices and Policies. Its purpose is to create sustainable changes to educational systems so that students with the most significant cognitive disabilities can fully engage in the same instructional and non-instructional activities as their general education peers while being instructed in a way that meets individual learning needs. This is based on the belief that inclusion is a human rights issue, and that inclusion leads to better outcomes.

In the United States, there are 13 federally defined disability categories. Many students with the most significant cognitive disabilities take alternate assessments for accountability purposes. As shown in Figure 1, the three most common disability categories for these students are intellectual disabilities, autism, and multiple disabilities.

[1] TIES Center website: https://tiescenter.org/
[2] The word "TIES" stands for increased **Time, Instructional** effectiveness, **Engagement**, and **State Support** for inclusive practices. These four pillars support sustainable inclusive education.
[3] I am also the Associate Director of the National Center on Educational Outcomes (NCEO).
[4] TIES Center and NCEO are funded by U.S. Department of Education's Office of Special Education Programs or OSEP. Both are part of the Institute on Community Integration (ICI) in the College of Education and Human Resources at the University of Minnesota.

Figure 1. Teacher Reported Federal Disability Categories for Students with the Most Significant Cognitive Disabilities Who Take Alternate Assessments[5]



II. Laws and Regulations

Expectations for students with disabilities in the United States have historically been low, but several laws have encouraged a more inclusive educational system. Beginning in 1975, Public Law 94-142 set a precedent for inclusive education with its least restrictive environment clause. The Americans with Disabilities Act of 1990 focuses on the rights of individuals with disabilities in all spheres of public life – including education, access to employment, transportation, and accommodations.

The Individuals with Disabilities Education Act of 1997, which is often referred to as IDEA, says that students with disabilities have the right to learn the general curriculum based on the same standards as their peers who do not have disabilities. The most recent reauthorization of IDEA, as well as the 2015 reauthorization of the Elementary and Secondary Education Act (ESEA), also known as the Every Student Succeeds Act (ESSA), reaffirmed the right of students with disabilities to have access to the grade-level curriculum provided to all students. These laws state that instruction must be designed to promote progress in the general education curriculum. IDEA also mandates that students with disabilities be provided with a free and appropriate public education, which includes both special education and related services, and that students are to be educated in the least restrictive environment. This creates a legal presumption that the general education setting is the default UNLESS the child cannot be educated satisfactorily there even after all the necessary support is provided.

[5] This figure is based upon the findings of a study conducted in 15 states. Figure source: Thurlow, Wu, Quenemoen, & Towles (2016).

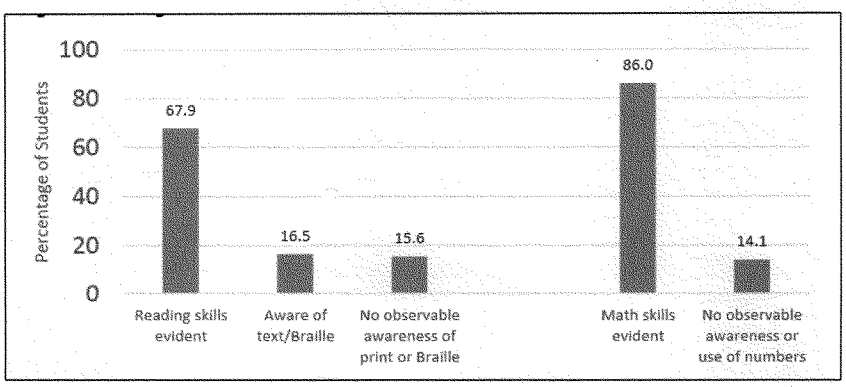
These, and other laws and regulations, provide the underpinnings of inclusive education in the United States, but the real heroes are the individuals with disabilities, their families, and advocates. They have exercised their rights, and sometimes had to push, shove, and hold the educational system to what the law required; though they must consider themselves fortunate to be in a country in which individuals with disabilities and their families have the legal right to disagree with schools and the government.

III. Critical Components

Several critical components that support sustainable inclusion for students with the most significant disabilities include: raising expectations, increasing educator capacity, access to the content, and systems change.

Raising Expectations: It is vital to raise expectations for students with the most significant cognitive disabilities. When given the opportunity to learn they often surprise us. It is important to note that students with the most significant cognitive disabilities are very diverse. For example, as shown in Figure 2, more than two-thirds are readers.

Figure 2. Reading and Math Skills of Students with the Most Significant Cognitive Disabilities (Based on Teacher Perceptions) [6]



Content expectations have changed over time. Historically, students with the most significant cognitive disabilities often were only taught functional skills; that is, how to do self-care, tell time and use money, or routine daily tasks. The curriculum started to change in the early 2000's when accountability for academic performance for students with disabilities was strengthened. Currently, there are requirements that content must be aligned to grade-level standards. For example, federally funded projects worked with educators to develop high-quality standards-

[6] This figure is based upon the findings of a study conducted in 15 states. Figure source: Thurlow, et al. (2016).

based materials and training on how to implement them successfully.[7] However, in practice this shift to more rigorous and grade-level content-based curricula does not always occur, and there are concerns about whether access to general education have been actualized (Ryndak, Moore, Orlando & Delano, 2008; Soukup, Wehmeyer, Bashinski, & Bovairdet, 2007).

As teachers began introducing new content for students with the most significant cognitive disabilities similar to what their same-age peers were learning, we heard over and over, across the entire country, "Who knew that these students could learn to read, and do math, and social studies, and science?" The reality is that most of us do not learn things that we have never been exposed to. It is no different for students with disabilities.

As students with the most significant cognitive disabilities taught us what they could do when taught well, we realized we had to continue raising our expectations for them. We must presume competence of students because the most dangerous assumption we can have as educators is that students CANNOT learn and therefore we do not teach them. If that is our mindset, then students with significant cognitive disabilities most certainly will not learn because they have not been afforded the opportunity. But if we do teach them, using practices that have been shown to be effective, then students can learn. And, if this learning can occur alongside their same-age peers in a general education classroom, then ALL students can benefit. This goes back to the point about this being a human right. Presuming competence is a human right, and inclusion is a human right.

Increasing Educator Capacity. Although the learning curve for the adults is sometimes steep, students – both the included student and their student peers - often make the shifts well when all are supported. Improving the quality of instruction is critical to successfully increase the amount of time in inclusive settings and the amount of educational engagement. Teachers need to feel confident that they have the knowledge and skills needed to successfully instruct all students in their class. Successful inclusion in the academic content as well as in the physical space creates a shared bond of common experiences and learning that results in natural peer acceptance in activities outside the classroom. For this to occur, special education and general education teachers – and the school administrators who support them – must have the knowledge and skills to confidently instruct all students, including students with the most significant cognitive disabilities.

Access to the Content. Meaningful access to content continues to be one of the biggest challenges for students with the most significant cognitive disabilities. The diversity of this population creates challenges for educators as they work to create inclusive learning environments and design accessible academic instruction. For example, Jamie uses oral speech, is mobile, has adequate hearing and vision, but requires academic accommodations and adaptations that are significantly different than typical peers to meaningfully participate in academic instruction. Shelby has limited mobility, no oral speech, uncertain use of vision. When engaged by peers, she alerts to others and smiles. She learned to use a single switch to indicate "more" of the activity in which her peers were participating in a short five-minute teaching

[7] For example, the National Center and State Collaborative's online Wiki at https://wiki.ncscpartners.org/index.php/Main_Page or the Dynamic Learning Maps professional development site at https://www.dlmpd.com/

session. Then there is Stevie. Like Shelby, Stevie does not have oral speech but does use some signs, pictures, facial expressions, and vocalizations to communicate a variety of messages. He can follow 1 -2 step directions when motivated to do so, and answer questions about literature by pointing to the picture. He is beginning to use a picture-based voice output augmentative and alternative communication device which will enable him to communicate a wider array of messages and participate actively in lessons.

The use of the principals of Universal Design for Learning can be used to create instruction that is accessible to a wide range of students (e.g., Coyne, Pisha, Dalton, Zeph & Smith, 2012; Spooner, Baker, Harris, Ahlgrim-Delzell, & Browder, 2007). In Universal Design for Learning, lessons can be designed by the general educator and special educator collaboratively with ALL students in mind. For example, if you think back to when you were in school, you likely used a graphic organizer such as a Venn Diagram or a T-chart. This support benefits students with disabilities directly because it provides an organizing schema, but it also may benefit other learners in the classroom who need help with organization.

Systems Change. Creating systems that facilitate the successful implementation of inclusive education is key. For example, districts that have found improved outcomes for students with disabilities demonstrated that a shared commitment to educating all learners was requisite to breaking down traditional programmatic silos (e.g., general education, special education, gifted education, etc.). It is essential to create collaborative structures that allow personnel at all levels of the educational system to learn together, and that bring the collective expertise of all educators to bear in improving instructional practice and addressing student instructional needs.[8] This shift away from longstanding isolated practice to collaborative practice cannot be achieved without focused and intentional action of the adults.

Communicative Competence. Most students with the most significant cognitive disabilities communicate verbally just like everyone else. However, a few students communicate in other ways or show minimal response to stimuli. Students who lack a consistent mode of communication are often served in segregated educational settings because many teachers feel unprepared to support them. A key to successful inclusion, and better outcomes, is getting a communications system (e.g., augmentative and alternative communication) in place in a timely manner – ideally by kindergarten or the early primary grades. According to Kleinert, Holman, McSheehan, and Kearns (2010), "Augmentative and alternative communication (AAC) includes all forms of communication (other than oral speech) used to express thoughts, needs, wants, and ideas" (p. 1).

Here is an example, from the next issue of *Impact*[9] magazine, which illustrates how a commitment to building communicative competence helps enable students to thrive in inclusive contexts. Jaimar Fish is a middle school student in Danville, Kentucky. He has multiple disabilities. He did not have a consistent communication system. He gets along well with the other students, but it was difficult for him to develop relationships with them because he could

[8] For example, see *Moving Your Numbers*.
[9] *Impact* is published by the Institute on Community Integration at the University of Minnesota. Available in November at https://ici.umn.edu/index.php?products/view_all/14 . See article by Kleinert, Land, Newton, & Logsdon.

not communicate. His educational team addressed his communication needs by first figuring out what he enjoyed – and might want to communicate about. They soon realized that he could follow simple directions. Next they gave him an augmentative and alternative communication device. In his case, this is a simple motion detection switch. It is activated by his smallest movements and translates these movements into verbal language. Now Jaimar can respond to questions during his classes; talk with his friends about his likes and dislikes; and is one of the group.

IV. Summary

Research has shown us the path to successfully educating all students, including those with the most significant cognitive disabilities; and, the United States has taken some steps in that direction, but we need to have the commitment to make sustainable inclusion happen for all students. To improve outcomes for kids, the behavior of adults needs to change. There needs to be a shared responsibility across educators for the success of all students with all students being held to high expectations. Together, we can create a future that supports the learning of all students in inclusive settings, which will lead to a future with communities where all individuals are valued members.

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Prepared Statement of John Cronin

Good afternoon. My name is John Cronin, and I am the co-founder and Chief Happiness Officer of John's Crazy Socks. I come here to stand up for people with Down syndrome and all people with differing abilities.

I have Down syndrome and Down syndrome never holds me back. I am 22-years old and work hard every day to show the world that people with Down syndrome are ready, willing and able to work. Give us a chance and we can be successful.

You may have heard about John's Crazy Socks. We have a mission to spread happiness. We have a good story, but we are a good business too. We offer 2,300 different socks. We have shipped our socks to every state and 80 different countries. This year we will ship over 170,000 orders and earn over $6 million. I may be cute, but I run a serious business.

I started this business with my dad, Mark. It was my idea and I came up with the name. My Dad believed in me and gave me a chance. I love my Dad. I work hard every day. I love my business.

Let me tell you why I started John's Crazy Socks. In the fall of 2016, I began my last year of school. I needed to decide what I would do when school ended. I had received a good education at Huntington High School. I was healthy and ready to go. I looked around but saw few choices and opportunities. I knew I could do more. I wanted a good job just like my brothers Patrick and Jamie.

I decided to create my own job. I told my dad that I wanted to go into business with him. I came up with the idea to sell crazy socks because I had always worn and loved colorful and fun socks. We opened John's Crazy Socks in December 2016. We were entrepreneurs and we took a chance. Now, everyone wears my socks, even movie stars, Prime Ministers and Presidents.

We have created 35 jobs and 18 of my colleagues have a differing ability. We make videos that have been seen over 4 million times. We have raised over $150,000 for our charity partners. We are making John's Crazy Socks a success and we owe it to our colleagues.

I can lead my own business because I had great teachers. I want to shout out to Dr. Erica Murphy-Jessen and Patricia Klee, my speech teacher. I can lead my own business because I played Special Olympics sports. I can lead my own business because my Dad gave me a chance.

I want you to know what people like me can do. Give us a chance and watch what we can do.

PREPARED STATEMENT OF MARK CRONIN

Good afternoon. My name is Mark X. Cronin and I am John's father and partner in John's Crazy Socks. We work to show what is possible, we work to show what people with a differing ability can do if given a chance.

In John's Crazy Socks, we have built a social enterprise; we have a social and a business mission and they are indivisible. Our social mission shows the world what people with a differing ability can do and we give back by supporting and raising money for our charity partners. But we can only succeed if we run a rigorous business. We compete with some of the largest and best companies in the world—Amazon, Wal-mart and Target—and we must match or beat what they offer. To do good, we have to do well.

Hiring people with differing abilities serves our social mission, but it also serves our business mission. To succeed, we must provide great service, so we do same day shipping and that makes our customers happy. We hire people with differing abilities because they help us fulfill our mission. We do not hire people out of charity or altruism. We hire because it is good for business.

John told you that we have been fortunate enough to create 35 jobs with 18 held by people with differing abilities. Our starting pay is $12 per hour, $1 more than the New York State minimum wage. Our colleagues do not do minimum work, so we do not offer minimum pay. The sad reality is that we could pay less, much less, and many of our workers and their families would still welcome the job because meaningful work is so scarce. But that would be wrong. Taking advantage of vulnerable workers may put money in the bank, but it would be morally bankrupt.

Too often, people with differing abilities are not offered jobs or they can only find work in sheltered workshops. They might be offered positions out of pity or charity. Our business demonstrates that people with differing abilities are just like the rest of us: they want meaningful work where they can make a contribution and receive fair pay.

What does it take to hire people with differing abilities? We simply need to focus on what people can do, not what they cannot do. Match the skills of the worker to the job. We operate a pick and pack warehouse. Our warehouse workers—those with differing abilities and neuro-typical—all pass a test to prove they can do the job. No charity, just real work.

We have no government support and no special programs. Yes, we make accommodations for our differing abled, but we also make accommodations for our neuro-typical employees. We have created a unified workplace where people of differing abilities work side-by-side with neuro-typical employees. And everyone benefits. We have better productivity, better morale and better retention.

And yet small accommodations can make a big difference. We make sure everyone has an email address and knows how to use email. We give everyone a business card as a symbol of their professionalism and watch as they proudly give them out to family and friends. And we schedule regular social events outside the office for all of our staff like attending a Chamber of Commerce dinner. Having a job gives our employees standing it the community. These are small initiatives, but they have a big impact on our differing abled population.

We have learned that hiring the differently abled gives us a competitive advantage. The United States and other nations are now facing shortages of workers, and yet we

have a great untapped natural resource in the differently abled. Employers will learn that those with differing abilities are an asset, not a liability. And the employers who learn this lesson the fastest, will be at an advantage and find greater success.

Our governments need to make changes too. We need to see the differently abled as full-fledged citizens, people able to contribute, not helpless beings who need pity. We need laws that guarantee the same rights—including the same wages—as the neuro-typical population. Here in the U.S., the Fair Labor Standards Act of 1938 allows employers to pay the people with disabilities less than a minimum wage. We are working with the National Down Syndrome Society to support passage of the TIME Act to afford all people a fair, minimum wage.

In the U.S. and elsewhere, we have benefits programs that limit the ability of the disabled to work. Our colleagues with disabilities work part-time. Why? Because if they work too many hours, they will lose their Medicaid and they cannot afford to do so. Take Aliya, who has a form of autism and works as a Sock Wrangler. Aliya does a great job and would love to work 40 hours per week but cannot because she cannot afford to lose her Medicaid. Don't we all want Aliya to work full-time? Then why have laws that limit how much she can work?

And my son John, he does not receive benefits yet. However, when he needs those benefits in the future, he will need to choose between his benefits and equity in the company that he has created. Do we want to prevent people from engaging in entrepreneurship?

It is time to decouple the poor from the disabled in our means-tested programs so that people with differing abilities can work full-time and maximize their contributions to society. We want to encourage people to work and to pay taxes, so let's remove the disincentives to work.

In the end, our message is simple. It is good business to hire people with differing abilities. John created his own future when he created John's Crazy Socks. We need more businesses that offer a future of meaningful work to all people. Employers here in the U.S. and around the world will come to learn that people with differing abilities make great employees.

John and I are a couple of simple guys from Long Island, a couple of knuckleheads selling socks. We have no special training and no special talents. If we can do this, anyone can. No more excuses. Let's show the world what is possible.

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