

The focus of this blog is an interview with Charlotte Woodward, a friend of mine and a shining advocate. She is an individual with Down syndrome who shows us all the myth of limitations. She had a challenging beginning and an on going path of amazing accomplishments.

Can you tell us what the Charlotte Woodward Organ Transplantation Discrimination Prevention Act means to you?

The Charlotte Woodward Organ Transplantation Discrimination Prevention Act is near and dear to my transplanted heart! If I had not received my heart transplant, I would not be here today – I had had four previous open-heart surgeries and there were no other surgical options available to help me other than a heart transplant. Fortunately, my transplant team considered me a good candidate for transplantation and did not deny me the opportunity due to me having been born with Down syndrome; they looked beyond my diagnosis and acknowledged my inherent worth. That is why it is so important that this bill – my bill – gets signed into law. I want people with disabilities to have the same opportunity that I was given, one that others who are nondisabled are given without having to have legislation passed in order to do so. People with Down syndrome and other disabilities shouldn't have to fight for the right to what is a basic human right. We should already have the right to access organ transplants! However, since people with Down syndrome and other disabilities continue to be denied the right to lifesaving organ transplants, I will continue to advocate for their right to obtain them. I am proud that my organ transplant bill was re-introduced in the U.S. Congress in the Senate on April 18th and in the House of Representatives on April 19th.

Can you tell us what you do and why it is important for you to have a competitive job?

I am the Education Program Associate at the National Down Syndrome Society. I love my job! I have my hands in all of NDSS's programmatic areas. I give speeches, presentations, and interviews, create resources such as videos and one-pagers, and advocate for the passage of legislation that will benefit people with Down syndrome and those with other disabilities. I am the third registered lobbyist who has Down syndrome.

People with disabilities, including those with Down syndrome, have the right to be included and treated with dignity and respect in the workplace, and to be paid a living wage. The world is a better place when everyone is able to participate and contribute to the best of their abilities. When I was born, doctors told my parents that I would never read or write and that when I grew up, I would work in a sheltered workshop where I would receive subminimum wage. I am proud to say that I have proved them wrong in so many ways.



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May 2023

You also serve on A Life Like Yours Steering Committee with the Arc of Virginia. Can you tell us about your role and what is important to you?

Mary Ford, the former Executive Director of the Down Syndrome Association of Northern Virginia, helped me get involved with the A Life Like Yours Self-Advocacy Alliance as a liaison between DSANV and the Arc of Virginia in 2020. I am currently a co-chair of the ALLY Arc Alliance. I really enjoy working with the ALLY Arc Alliance, especially on fun inclusive projects. The ALLY Arc Alliance not only values belonging, inclusion, community, and friendship but also influences the Virginia General Assembly. We have an advocacy agenda that includes topics on Home and Community Based services, the Developmental Disability Workforce crisis of direct support professionals, access to technology, access to education, and how to navigate the Virginia criminal justice system because people with I/DD too often end up in the criminal justice system. Some of the projects we have worked on were the A Declaration of A Life Like Yours video, we formed our leadership structure, we have provided advocacy skills training, provided training on inclusive services to 141 people with I/DD, and provided training on inclusive services to 166 people with providers. We have hosted mobilization events, rallies, and retreats. We partner with programs like Patient-Centered Outcomes Research Institute, VCU's Partnership for People with Disabilities, and VCU's Building a United I/DD Front through which we educate doctors and researchers and give people with disabilities access to research opportunities like research trials. If this is something that you are interested in, please let me or the Arc of Virginia know.

I am honored to serve with you as a board member of DSANV. What does that role mean to you?

I too am so very honored to work alongside you as well, David. Being a DSANV board member puts me in the driver's seat to continue to push for progress and change. As the DSANV Advocacy Program director, it is my vision that DSANV expands into being a Center for Independent Living/YMCA-YWCA type of organization where it is run by people with Down syndrome for people with Down syndrome.



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I graduated from George Mason University in May 2022 with a Bachelor of Arts degree in Sociology, with a concentration in Inequality and Social Change. I loved every minute of being a college student! With the help of the disability services department, I felt like a butterfly exploring a world of endless opportunities. I made great friends in college but some of my biggest achievements were making the Dean's List, being inducted into several honor societies (Delta Alpha Pi, which recognizes high-achieving college and university students with disabilities, Phi Gamma Mu, for students in the social sciences, and Alpha Kappa Delta, for students of sociology). I am proud to have also received the 2021 George Mason Outstanding Sociology Undergraduate Student Award and the 2022 George Mason University Trailblazer Award. I was also asked to contribute some of my writing on the intersection of race and disability for a book written by two of my favorite GMU professors. All in all, I had a wonderful time in college.



Where do you see yourself advocating in the upcoming years and what our priorities should be as individuals with Down syndrome and advocates?

Your story of advocacy has inspired me to think about all that is possible. Our priorities must be solidarity, and not giving up or backing down as there are so many social injustices in the disability community that need to be addressed. These issues are not just going to go away on their own. If we don't continue to fight for our human and civil rights, who will? Advocacy against systemic and structural inequalities must be done. If we don't do it now, then when? The upcoming younger advocates are looking up to us to continue the legacy of disability civil rights movement leaders from the 1960s-70s. We need to be role models for them, and to inspire and encourage them.

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