

Remarks by Madeleine Will

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2022 State of the Art Conference – Syracuse, New York

Good afternoon. I'm very pleased to be here. Thank you for this extraordinary honor.

I'm privileged to receive this lifetime achievement award from the State of the Art Conference -- which is chaired by distinguished director Beth Myers.

I'm grateful, I'm humbled and thrilled. It is especially gratifying to receive this award at this conference celebrating a decade of development of inclusive postsecondary education programs.

And, simultaneously, the anniversary of a decade of State of the Art Conferences. These meetings bring together parents, students, and professionals. A highly unique endeavor to collaborate on postsecondary education issues for individuals with intellectual disabilities.

It is also gratifying to have Stephanie Smith Lee, a tireless advocate, a brilliant policy expert, a distinguished colleague and mentor, and a close friend, present this award. Friends, it is said, are the family we ourselves choose. I think of Stephanie, her beautiful husband Gen, their beautiful son Andrew, their beautiful daughter Laura, who passed away, as part of my family.

I would be remiss if I did not thank Think College and the National Coordinating Center at the Institute for Community Inclusion in Boston for its extraordinary contribution to the development of postsecondary education for students with ID.

Individuals at Think College, like Bill Kiernan, Debra Hart, Meg Grigal, and Cate Weir, at the Institute for Community Inclusion in Boston, have provided an extraordinary contribution to this amazing movement that we're celebrating today.

Another person who should be mentioned is Steve Riggio, the co-founder of Barnes & Noble. Through a foundation he created, Steve and his family,

motivated by their daughter with Down Syndrome, funded two successful early initiatives in New Jersey at Mercer County Community College and the College of New Jersey.

I would also like to mention Donald Bailey, who some of you may know. He is an extraordinary and prominent South Carolinian who has a son with a disability. Donald was a successful businessman with excellent contacts, both in the legislature and at the University of South Carolina, and was determined that this young man – his son - would attend a postsecondary program. And as a result of Donald’s dedication, five programs emerged in South Carolina and more in other southern states.

I'd like to thank Captain Robert Taishoff for the fact that he is, and has been, an important advocate for such a long time, and particularly for his creation and funding of the Center for Inclusive Education here at Syracuse University.

Again, these developments were happening when most people were rolling their eyes when we talked about postsecondary education, as I'm sure he remembers.

The reality is that hundreds of professionals and parents and others have collaborated to develop this amazing movement that exists in localities across the country.

Celebrating both our achievements and our challenges is in keeping with the apt title of this conference, “A Decade of Progress at State Of The Art: Exploring the Next Frontier of Inclusive Higher Education for Students with Intellectual Disabilities”. There's much to celebrate and to absorb at the closing of this decade certainly, as these days at this conference have truly underscored. But challenges remain and new challenges will continue to emerge.

The Great Modernization

I regard this period as the period of great modernization. We explore postsecondary education, but this must be done in the larger context of the huge amount of change and reform individual advocates have been pursuing and implementing. It is sort of an explosion of emotion and energy that has led to significant progress. From my perspective, over a period of years, there was a continually evolving view and hope concerning the capabilities of persons with

intellectual disabilities and what the future might be like for them. This was thanks to special education, transition from school to work, new concepts of community living, and ongoing pressure to deinstitutionalize.

But there was also a failure – a nudging failure to achieve more and better employment and community living outcomes for students exiting K-12. This reality left parents, students, and professionals haunted by the perpetual question, “What will life in adulthood look like for students exiting K-12...for my adult child?”

In essence, there was hope because new programs such as inclusion, transition, and supported employment were being invented. You will recall that for many, many years there was not an accepted concept of people with significant disabilities being employable.

Occasionally, the US Department of Education would get visitors from abroad interested in special education. I met with a group on one occasion who presented me with pamphlets they had produced. And after they left, as I was going through the pamphlets, I noticed that one of them was entitled “How to Prepare Your Child for a Life Without Work”. It remained on the corner of my desk for very long time to motivate me while working on supported employment.

The emotion and energy that I mentioned earlier was partly hope and partly anxiety. My belief is that these emotions collided one day and created an explosion that led to advocacy on the part of parents, students and educational professionals which resulted in the beginning of small postsecondary programs at the local level and, ultimately in 2008, to the passage of the Higher Education Act.

This law was very far-sighted because it authorized financial aid for students with intellectual disabilities. It established a program of model demonstrations, the TIPSIDs, which were not funded immediately but were authorized. It created the National Coordinating Center, which is Think College, to foster coordination amongst the models and an evaluation of these programs. Congress also created an Accreditation Workgroup specifically to develop accreditation standards.

Led for ten years by Stephanie Smith Lee, the Accreditation Workgroup was placed under the auspices of the National Center and is now chaired by the distinguished Martha Mock, who is the director of the Center for Disability and Education at the University of Rochester. Both leaders and members of the

Workgroup together have developed accreditation standards and provided them to the field.

A final footnote regarding the advocacy ferment. It has not been written about much. Although we do not fully understand it, there is a recognition that it was certainly groundbreaking.

Within a period of ten years, the post-secondary education movement for persons with intellectual disability had grown considerably. Amazingly, there are now over 6,500 students who attend programs at over 300 programs in the states of our country. In terms of the TPSIDS, the model demonstrations that Congress began to fund in 2010, there are programs at 121 colleges in 34 states.

And the progress continues. A few short years after the Higher Education Act reauthorization, the Achieving a Better Life Experience Act (ABLE) was passed by Congress in 2014. Prior to the enactment of this law, there was no tax-exempt vehicle that permitted saving for expenses like for post-secondary education.

In that same year Congress passed the Workforce Investment Opportunities Act (WIOA) of 2014, which created the concept of competitive integrated employment (CIE) and placed limitations on the use of subminimum wage in sheltered workshops and established a path for workshops to move in the direction of paid employment.

Besides the legislation already discussed above, there is currently the Transformation to Competitive Integrated Employment legislation which would provide grants to states and providers to aid in the transition to CIE and additional legislation that would increase supplemental security income and eliminate the marriage penalty

Another important proposal is the RISE Act. This bill would generally make it easier for college students with disabilities to receive accommodations and for their families not to have to pay for an expensive evaluation to demonstrate their eligibility.

There is also a developing movement to eliminate the waiting lists for services, which are very long in many states of the country.

Challenges Abound

Success produces challenges. Martin Luther King, Jr. said, “Human progress does not roll in on the wheels of inevitability.” Some challenges are a natural result of success, like the necessity to grow exponentially, which is evident in postsecondary education, and something we particularly need to attend to geographically.

There is a need for more programs within states and across states as well as a diversification of the population of students admitted. There should also be more careful adherence to the statutory language of the HEA which carefully defines post-secondary education programs as statutorily intended for students with intellectual disabilities.

It is also very clear that more trained personnel are required to work in these programs. This task is extremely difficult to achieve, given the national shortage of labor we face in the world of care giving. But this challenge can be addressed over time. After IDEA passed, some 30,000 special educators were trained because there were a million students who had not attended public school before the passage of P.L. 94-142.

Students, parents, and teachers must receive more information about postsecondary education. The Think College Inclusive Higher Education Network that was recently created is an excellent entity to convey information to students and their families and educators about this exciting opportunity for students after they exit high school.

Some challenges, mentioned above, are an outgrowth of the successes achieved. But some challenges are existential, meaning they are often unanticipated and are more serious and dangerous than others in that, if done badly, permanent damage can be done to the movement.

I see several existential challenges ahead.

For example, we are striving to become a more integral part of higher education, with very large, bureaucratic and politically powerful institutions in our country that were never designed for people with intellectual disabilities.

Please recall that higher education is fragmented. Like most federal agencies, institutions of higher education exist in a silo and are often isolated from other educational systems and agencies.

Professionals working in post-secondary education are retrofitting an institution that has existed for hundreds of years. And they are retrofitting step by step, one issue at a time, one program at a time. This is not only a slow process; it is not a comprehensive and integrated enough strategy to achieve the desired holistic change.

One urgent challenge is that we must define person-centered planning. Period. But to accomplish this in a system that is a self-contained bureaucracy is no easy task. What does “person-centered planning” mean in terms of a bureaucracy that has its own statutory authorization, its own mission, its own budget, its own processes, its own regulations, and its own evaluation?

We need to begin by communicating to those working in higher education and, equally importantly, those civil servants working in state government and the approximately 190 programs across 23 departments of the federal government, that individuals with disabilities “move across the lifespan”. How many of them understand this concept? Many do not.

One person, who had the experience of bringing a multiplicity of programs together to ensure that there would be a strongly evaluated requirement for communication and collaboration, is Governor Tom Ridge, the first head of Homeland Security after 9/11.

The disability community requires something similar, but we must first answer, “What is collaboration and what constitutes meaningful systemic collaboration, including the blending and braiding of resources across funding streams to support individuals with disabilities.” The words collaboration and coordination are omnipresent in policy documents, in proposed laws, and in laws that are enacted. But what do these words mean with respect to bringing coherence “across the lifespan” to our system of disability policy and disability laws.

Another great existential concern is the importance of attracting behavioral expertise to our work in order to help us to understand the difficulties that students encounter. There have been some studies about the transition to college and the first year, but really very little has been written overall and very little

attention paid to the other three years. My conclusion is that we need research help from these experts. We need studies. We need data.

One of the advantages of the Higher Education Act is that it requires us to prioritize inclusive academics, employment training, social integration, and community and independent living. In truth, this represents a big piece of the lifespan. It gives us an advantage when disability policy experts attempt to update transition from school to work when IDEA is reauthorized in the next few years. Or when disability policy experts approach vocational rehabilitation civil servants to try to create the partnerships that the HEOA already states should be created.

Recently, Congress has been engaged in developing legislation to modernize and expand the national apprenticeship programs that have existed for decades. Ultimately, the new National Apprenticeship Act will include apprenticeships for people with disabilities, but there is not yet clarity as to how the apprenticeship process for persons with disability will be defined and implemented, especially for persons with intellectual disabilities. The disability community will have to fill in the blanks and help determine what that process looks like as part of the ongoing modernization of the adult service system.

This will include working with people in businesses and human resources offices, helping them to understand how to identify required skills and how to develop an appropriate credential, or mini credentials, for persons with disability, including those with intellectual disabilities. This also means preparing the unit of employees into which the person with a disability will be placed. Pretty much we place a person with a disability in a job and in a unit of co-workers that have a range of attitudes about people with disabilities, from not knowing very much about disability realities or knowing things that are incorrect to having accurate knowledge and welcoming attitudes.

Another existential challenge is re-consideration of the parent/institution relationship. There is nothing that exists like the relationship between parents of adult children with intellectual disabilities and an institutional behemoth like higher education. The relationship requires redefinition. And we need our best minds to focus on the how and the what -- how to define the new definition and what that definition will look like in its final form.

We need to focus on the area of complaints, when the institution of higher education has a complaint regarding a student, or when the student has a

complaint regarding the institution. Again, the drafters of Title IX did not anticipate what we have created in terms of postsecondary education but applying Title IX must be based on justice and equity.

I know these are many challenges, and I do not raise them to make your heart sink. I raise them because I believe firmly that we can address them successfully. When we continue to talk about a problem like fragmentation for decades and decades and never do anything about it, we create a sense that the problem is impossible to solve.

Of course, retrofitting, whether it is higher education, or a broader set of agencies, is long and complicated. However, the process can be accelerated when the participants in the Think College Alliances examine what is going on at their state level and identify fragmentation, disconnects and contradictions, and help with strategizing solutions. We simply cannot not address every single piece of fragmentation separately. It's too simplistic, too cumbersome, and wasteful of time and money. The work must be done comprehensively and holistically.

This may take time, but it is doable. We have proved during this current phase of modernization that we can achieve what were viewed as unimaginably difficult accomplishments. Martin Luther King, Jr. defined believing in possibilities when he said, "Faith is taking the first step at the head of the staircase when you can't see the whole staircase below."

That is very important advice that bears remembering -- because it is something that we have done successfully throughout the history of the disability community.

Let me end by repeating how grateful I am for this award. Thank you.