Remarks by Stephanie Smith Lee on

Receiving the State of the Art Conference

Lifetime Achievement Award

Sacramento, California October 29, 2026

Thank you. I'm honored to receive this lifetime achievement award from the State of the Art Conference chaired by the distinguished Taishoff Center director Beth Myers.

It is also an honor to have Martha Mock present the award. She is an outstanding leader making a real difference in inclusive higher education.

It has been said that it takes a village to raise a child. It also takes a village to build and sustain a movement. I want to recognize and thank so many individuals for their invaluable contributions to this movement, more than I can name today. The reality is that hundreds of students, parents and professionals have collaborated to develop this amazing movement that has created inclusive higher education opportunities across the country.

Most importantly, I want to recognize the students and alumni here today and across the country. You are the pioneers whose courage and potential are the reason we are here. Yours is the voice that matters the most.

I would like to give special recognition to Think College and the National Coordinating Center at the Institute for Community Inclusion in Boston for advancing college education for students with intellectual disabilities. Key colleagues like Meg Grigal, the late Debra Hart, the recently retired Cate Weir, and others at Think College have made extraordinary contributions to this movement.

I couldn't have done my part without my husband, Gen, who is here with us. When our late daughter, Laura, was born in 1982, Gen and I were urged to "put her away". We were fortunate that our 3 year old son happened to attend one of the first inclusive preschools in the nation. Preschool parents came to visit us in the hospital and urged us to have Laura's heart checked since she had Down syndrome. The doctors either didn't notice or didn't tell us that Laura was missing the middle of her heart. After testing she was rushed immediately to Children's Hospital where she stayed for most of her first 2 years and had her first two open heart operations. Expectations for children and adults with intellectual disability (ID) were very low at that time. We were told that Laura would never advance beyond an 8 year old level, work outside a sheltered workshop or live anywhere except at home with us or in a group home. Laura exceeded every expectation. She attended an inclusive postsecondary program, lived with support in a townhouse with friends, took public transportation to her job at the World Bank, testified before state legislative committees and Congress, and lived a full life. While everything is not perfect, the educational advancements and higher expectations for individuals with intellectual disability since Laura was born have been astounding. In just over four decades we have gone from institutionalization to Institutes of higher education.

I first became involved in inclusive postsecondary education twenty-five years ago when Laura asked me where she would go to college. Laura was a senior at an inclusive high school and Gen and I wanted her to have the choice and opportunity to go to college. At that time there were no postsecondary education options anywhere near us and very few anywhere for students with ID.

I started visiting colleges in Virginia to determine if one might be a good fit for a pilot program and if it was possible to make Laura's dream of going to college a reality. I heard about Dr. Michael Behrmann at George Mason University and his reputation as a visionary who could get things done. I visited with him with a couple

of friends, had follow up conversation. I committed to finding funding and students to enroll and Dr. Behrmann committed to establishing a pilot program. Laura and her two friends were the first students at the first inclusive university program.

Shortly after Laura started at Mason, I entered the US Department of Education as the Director of the Office of Special Education. My role as OSEP Director gave me the opportunity to fund model inclusive programs and the first program database, and to use my position to promote inclusive higher education.

While I was at the department, my friend and colleague Madeleine Will, who has a son with Down syndrome, approached Steve Riggio, the co-founder of Barnes & Noble. Steve and his family, motivated by their late daughter with Down Syndrome, donated over $600,000 for successful early initiatives in New Jersey at Mercer County Community College and the College of New Jersey. This endeavor was a model of systems change – the focus of this conference – with a steering committee including family members, higher education professionals, disability organizations and state agency representatives.

When I left the department in 2005, I joined Madeleine and the Riggio project and we arranged for folks from a number of states, including South Carolina, Tennessee, Virginia, Florida, Indiana and others, to visit these model programs in New Jersey. With additional funding support from Rob Taishoff, we also traveled to quite a few states and assisted in the development of new programs and state coalitions. The systems change approach of developing state coalitions that included families, students, disability organizations, higher education, state agencies, University Centers on Developmental Disabilities, Developmental Disability Councils, and others was key to success.

Some of you know Donald Bailey. He is an extraordinary and prominent South Carolinian who has a son with an intellectual

disability. Donald was a successful businessman with excellent contacts in the legislature and at the University of South Carolina, and he was determined that his son would attend college. Donald raised substantial private donations and over $1 million from the state. We worked together, along with an effective steering committee, to develop five programs in South Carolina that are still going strong, and he generously volunteered his time to assist others start coalitions and programs in other states.

Around this time advocates in Massachusetts, with strong support from former State Representative Tom Sannicandro, who has a son with Down syndrome, convinced the Massachusetts legislature to start funding inclusive programs in that state.

A key part of the Riggio Project was developing and implementing a successful strategic plan that led to statewide inclusive higher education coalitions, new inclusive programs, Department of Education research funding, and a large Department of Health and Human Services technical assistance grant. To achieve the goal of inclusive postsecondary options for students no matter where they live or their families' financial situation, we knew we needed federal financial aid for students, funding for model programs, and a national technical assistance center.

Madeleine and I started knocking on doors in the US Capitol in 2006 and 2007 and were initially met with "You want to do what for whom?" We worked with a small group, the Inclusive Higher Education Committee, to draft an amendment to the Higher Education Opportunity Act of 2008 and organized advocacy efforts in support of the amendment, in collaboration with other organizations.

A pivotal development was when Madeleine brought Eunice Kennedy Shriver to visit the programs in New Jersey and at George Mason in 2007. One of my favorite quotes is when Mrs. Shriver told

Madeleine, “This is wonderful! I must tell Teddy!” She did tell her brother, Senator Kennedy, and Senator Hatch, and the Secretary of Education, and made a real difference in the bipartisan support for successfully including this amendment in the reauthorization of the Higher Education Act in 2008 so that students with ID may receive certain financial aid and funding was authorized for model programs called TPSIDs and the National Coordinating Center, which is at Think College. The amendment would not have passed without advocacy from students and families across the country, motivated by a desire for something better for their sons and daughters.

Now that Congress had authorized these provisions, we needed appropriations, which can be hard to come by. The Inclusive Higher Education Committee continued to work with Congress, and advocates across the country met with their Members of Congress and staff. In 2009, Madeleine and I met with former Congressman Gregg Harper, whose son has an intellectual disability and was interested in going to college. Mr. Harper then played a key role in obtaining appropriations for the new model programs and national coordinating center. He also visited Mason LIFE and was so impressed that he created a Congressional internship program for Mason LIFE students that continues today. These internships are a great opportunity for the students AND they provide an opportunity for Members of Congress and their staff to get to know and appreciate the abilities of our students.

We also needed regulations for the revised HEA. I served on the federal Negotiated Rulemaking Committee that developed those regulations and met Department of Education research staff who became very interested and hosted the State of the Science conference at George Mason University in 2009. Mason then sponsored the first State of the Art Conference in 2010. These

conferences continue under the outstanding leadership of the Taishoff Center at Syracuse.

As we reflect on the successes of the past twenty-five years and the challenges and opportunities in the next twenty-five, accreditation will play an increasingly important role in program development, continuous improvement, acceptance in higher education, and accountability. Think College played an important role in supporting the development and use of model accreditation program standards. Under the leadership of Martha Mock and Mary Judge the new Inclusive Higher Education Accreditation Council is accrediting programs and assisting programs in becoming accreditation ready.

As we consider the theme of this conference, "Changing Systems, Changing Lives" we need to address federal, state, and higher education systems change, particularly at a time of increased financial pressures on institutions of higher education and on families. A movement takes sustained persistence. After over 20 years of advocacy, starting when I was at the US Department of Education, the department finally issued guidance making it very clear that vocational rehabilitation funds may be used to support postsecondary students with ID. Now the field is working to ensure that all students have that opportunity in every state.

There is an ongoing need to make inclusive postsecondary education financially accessible. In addition to expanding vocational rehabilitation funding, Medicaid funding needs to be available as well as IDEA funding for 18 to 21 year old students. Systems change within institutions needs to include increasing partnerships on campus with mental health, career, disability services and other departments and expanding apprenticeships and industry recognized credentials.

In addition to continuing to address affordability, there is a need for more programs and opportunities within states and across the country. There are far more students who want to attend college than

there are spots available for them. We also need to carefully adhere to the Higher Education Act. This law clearly defines that these programs are for students with intellectual disability. Expanding the ability of higher education to educate and provide individualized supports for students with more significant support needs is essential.

Finally, we need to recognize and support the pivotal role parents have in this movement. Parents have been a driving force who should be recognized and welcomed as collaborative partners. Parents have successfully advocated for legislation, and funding, and are often key to colleges and universities starting programs.

We also need our best minds to focus on how and what the relationship between the college program and parents should look like. Under IDEA, the special education law, parents are legally required members of the IEP team that determines the educational services the student receives and often have to work very hard to ensure their student receives those services. The role of parents changes, and should change, as their adult sons and daughters turn 18 and attend college. The parent role becomes one of supporting independence and self-advocacy, rather than being the only advocate for their student. At the same time, parents and families are the constant in a student's life supporting their pursuit of postsecondary education, and encouraging persistence to complete a college credential and launch into life after college. While the students are in college, families remain involved behind the scenes managing transportation, Medicaid and other bureaucratic paperwork, medical complications, financial benefits and paying for college. Parents often have a deep understanding of how the student learns and what supports are needed. Students are most successful when programs develop an appropriate partnership with parents, with the student's permission. And frankly, parents will very likely remain a part of a student's life long after the student graduates.

You may recall Abagail Adams appeal in a letter to her husband, President John Adams, to “remember the ladies”. As our field continues to grow and expand, I appeal to you to “remember the families” – not just in advocating for new programs and funding – but as real partners and leaders in advocacy, policy, program development, evaluation and research.

Thank you again for this recognition! As Justin Dart would say, “Lead on”!