

Building Inclusive Higher Education Programs in Places Where They Don't Exist: A Series of Family Perspectives

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About this Series

This profile is part of the series, *Building Inclusive Higher Education Programs in Places Where They Don't Exist: A Series of Family Perspectives*. The series introduces inclusive higher education (IHE), shares lessons learned, and presents the stories of parent leaders who helped create IHE programs in places where they didn't exist. Author **Elise McMillan, J.D.** is the retired former director of the Vanderbilt Kennedy Center University Center for Excellence in Developmental Disabilities (UCEDD) and was the founding faculty member of Next Steps at Vanderbilt University, the first IHE program in Tennessee. This spotlight highlights the work of parent leader, **Stephanie Smith Lee**.

Stephanie Smith Lee

Introduction

Stephanie Smith Lee is Co-Director of Policy and Advocacy for the National Down Syndrome Congress and chairs the new Inclusive Higher Education Accreditation Council (IHEAC).¹ The late Laura Lee graduated from the Mason LIFE Program at George Mason University and worked at the World Bank.²



Why?

As Stephanie Smith Lee's daughter, Laura, was finishing high school, she told her mother she wanted to go to college like her older brothers and her friends. "Where do I go to college?" Laura asked. This was in 2001. At that time, Lee reports that there were no databases to search for IHE programs, and there was nothing near their home in Fairfax, Virginia. So began the family's search for a program for Laura, who had Down syndrome. "We appealed to Dr. Michael Behrmann at George Mason University to create such a program. We knew that we would need to work with the college to help build the program. We also knew we would need to find a champion at the school, and that champion was Michael Behrmann." Lee said.

How?

In preparation for engaging George Mason University, Lee worked with fellow families and advocates, employing the same strategies she now recommends to groups nationwide to

¹ The IHEAC accredits college and university programs for students with intellectual disability (ID). Learn more at <https://www.iheacouncil.org/>.

² The Mason LIFE Program is a four-year postsecondary comprehensive transition program for young adults with intellectual and developmental disabilities (IDD) who desire a university experience in a supportive academic environment. More information can be found at <https://masonlife.gmu.edu/>.



successfully establish IHE programs. She met with other students, families, and disability service providers in the region to build interest in program development. She also researched funding sources to support a college program. Working with other advocates, she honed the group's mission and focus so that this could be shared with the university. She also gathered information about existing programs.

Behrmann was the leader of the special education program at George Mason. He developed a strategy to pilot an inclusive program by utilizing students from the master's program in special education. Lee and other interested students and families worked with Behrmann to develop funding sources and create a program that included student practicums, internships, and research. Key factors in the successful development of the program included demonstrating how including students with disabilities aligned with the school's mission and priorities, such as diversity, outreach, community engagement, and teacher preparation. The George Mason LIFE Program is a four-year, residential program for young adults with IDD. Students audit traditional classes, have career exploration classes, and internships on-and-off campus during the program. Lee shared that the program became a wonderful training opportunity for teacher preparation as well as a life-changing opportunity for students with IDD.³

In Closing

Laura graduated from Mason LIFE and worked at the World Bank after graduation. She volunteered at a food bank and spoke at national conventions. After Laura's passing in 2016, Lee continued her work to help make college possible for students with ID. The former congressional staffer and advocate for building inclusive opportunities in K-12 schools had already served as Director of the Office of Special Education Programs (OSEP) for the U.S. Department of Education. At OSEP, she provided funding so that databases could be developed for students and families searching for programs and funding for model programs. After leaving her position at OSEP, she became Senior Policy Advisor for the National Down Syndrome Society, where she directed a postsecondary project that developed IHE programs in various states, as well as helped lead the successful effort to amend the federal Higher Education Act (HEA) to obtain federal financial aid and model programs for students with ID.

³ The Higher Education Opportunity Act (HEOA) includes a definition of a student with an intellectual disability (ID). Provisions of the HEOA including federal financial aid, Comprehensive Transition and Postsecondary Programs (CTP), and Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) are specifically provided for students with ID. The term Intellectual and Developmental Disabilities (IDD) is often used to describe students with both ID and another developmental disability (DD) or students with ID or another DD. Some of the alliances mentioned in this series are working to build programs and services for the broader category of students with IDD who in some cases may not have an ID. Find out more information at <https://www2.ed.gov/policy/highered/leg/hea08/index.html>.



Lee is now Co-Director of Policy and Advocacy for the National Down Syndrome Congress, a founder and the president of IHEAC, and continues to be a member of the Think College Accreditation Workgroup. She presents nationally and partners with groups across the country to continue to develop programs.

Advice from Stephanie Smith Lee

Partnering with interested people and organizations is imperative. Convene a team from the community to show a potential partner institution the level of interest in IHE. Stakeholders to engage include parents, self-advocates, disability leaders, the special education director, local provider agencies, businesses, Parent Training Centers, Vocational Rehabilitation, disability agencies, the State Council on Developmental Disabilities, and the University Center for Excellence in Developmental Disabilities.

Join alliances in your state or region. Identify alliances through the Think College Inclusive Higher Education Network. Holding a roundtable or invitation only conference is another way to learn about other programs.

Align the goals of your program with the university's mission. Ensure the program aligns with the mission or missions of the institution with which you want to partner. These are easily found on college websites. Your work can be key in areas of diversity, outreach, community, and teacher preparation.

