

Diverse Voices, Common Cause

**VT LEND Trains
Health Professionals to
Advocate for Change**

BY ERIN POST

For 26 years, the Vermont Leadership Education on Neurodevelopmental Disabilities program (VT LEND) has been focused on preparing health professionals with the skills—and the drive—they need to improve the healthcare system's service to children with developmental and intellectual disabilities and their families. →



UNDER THE LEADERSHIP OF VT LEND
Program Director Maria Mercedes Avila, Ph.D., associate professor of pediatrics, the program has also built a national reputation for its comprehensive approach to diversity, equity and inclusion. Not only does the program emphasize culturally responsive care, Avila has set goals for diversity in each cohort to increase the number of people trained from diverse communities. In doing this work, she emphasizes that the importance of crafting a program that speaks to a range of experiences and backgrounds.

"The content we teach is essential to recruiting and retaining trainees," says Avila. "Our content reflects the populations we serve."

VT LEND accepts 12 to 14 individuals annually for the nine month, 300-hour program, a group that includes health care and education professionals, individuals with developmental and intellectual disabilities, graduate students, and family members of persons with disabilities. Trainees take two graduate level courses and participate in legislative, policy and advocacy training, leadership discussions, and internships.

As one of a network of 52 LEND programs funded through the U.S. Maternal Child Health Bureau, VT LEND has become a sought-after resource for other programs looking to diversify their ranks. Recognition for VT LEND's work has been coming at a fast pace: Recent awards include the *Profiles in Diversity Journal* 2020 Diversity Team Award, 2018 AUCD National Multicultural Council Leadership in Diversity Award, and Green Mountain Self-Advocates 2018 Ally of the Year Award. In 2020, Avila received the Vermont Public Health Association 2020 Public Health Champion Award.

In this year's cohort, 10 of the 13 trainees—77 percent—are from under-represented groups, making it the most diverse cohort in the program's history.

Learning Through Robotics

Danielle Boyer wants every kid to have a robot. She also wants all children—especially those with neurodevelopmental challenges—to experience the joy of learning through science, technology, engineering, art and math (STEAM).

As a college junior double-majoring in electrical engineering and mechanical engineering, she's well on her way to achieving both goals. In the VT LEND program, her mentor is Joshua Allison-Burbank, Ph.D., who is Diné and Acoma Pueblo and a speech-language pathologist at Northern Navajo Medical Center in Shiprock,

N.M. Boyer, who is Ojibwe, seeks to combine Indigenous teachings with STEAM learning through her internship project.

"We're focusing on building a STEAM project for parents to help prevent learning development delays and to boost STEAM learning," she says. "We're also partnering it with different tribal teachings, like traditional farming and physics."

In 2019, she launched a non-profit called The STEAM Connection. With guidance from her mother (an artist) and father (an electrical engineer), Boyer designed and developed a robot, named EKGAR (for Every Kid Gets a Robot), that costs less than \$20 and is sent to children—primarily girls and students who are Black, Indigenous or People of Color (BIPOC)—for free. Manufactured with a 3D printer, The STEAM Connection has distributed more than 4,500 kits. In November of 2020, she created Twenty, a new robotics kit to celebrate her 20th birthday. Boyer's work has gained wide recognition: She was named one of PEOPLE Magazine's "Girls Changing the World" and was featured on the NBC special *L'Oréal Paris Women of Worth*, available on Hulu.

VT LEND is helping her develop skills to connect with a diversity of students in new ways.

"I have a learning disability and I work with a lot of kids who have different learning challenges," she says. "I come from a lot of the communities that I'm serving, and my board as well. My board is half Indigenous, half women, and we're all undergraduate students. We want to focus on the kids who are getting left out of what I think are key opportunities."

The Power of Advocacy

Through the VT LEND program, Eva Wilson witnessed the power of advocacy first-hand. During the Association of University Centers on Disability (AUCD) Conference in Washington D.C., which many VT LEND participants attended, she was part of a group who spoke with a staff representative from the Congressional Office of Stacey Plaskett, congresswoman for her home territory of the U.S. Virgin Islands.

"At the Hill visit, we talked about the impact of COVID-19 on education and health disparities funding and resources for individuals with disabilities, especially during COVID," she says. "The platform allowed us to show how residents of the U.S. Virgin Islands are affected in these areas."

In VT LEND, Wilson has found a strong community: Participants and mentors bring a wealth of knowledge from their professional experiences.

"I appreciate the emphasis on diversity and engaging in a learning community with fellow professionals from different cultural backgrounds," she says.



Danielle Boyer



Whitney Terrill



Pierrette Lumumba

"My training during VT LEND prepared me to think holistically about disability communities and cultural and linguistic competence."

— WHITNEY TERRILL



Eva Wilson

"I have gained a better understanding of advocacy work. It can be both rewarding and uncomfortable. Advocacy entails good planning," she says. "It's about taking time to understand the system issue and the change you want to make. Advocacy takes courageous effort and the support of community stakeholders."

VT LEND has also connected her with like-minded professionals. Through her internship, she's working with a Vermont-based intervention team. Participating virtually in meetings and workflow is helping her to see similarities and differences with the special education department in the U.S. Virgin Islands.

"I've learned about processes to incorporate into the work we're doing now, including new ideas that can help strengthen our program and the delivery of services to families even more," she says.

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Documenting the Immigrant Experience

With African Americans experiencing a disproportionately high rate of COVID-19 infection, Pierrette Lumumba has been focused on giving voice to those impacted. Her own life story—and her career as a registered nurse—has informed this work, which she is doing through her VT LEND internship.

"As a daughter of an immigrant family, it was very personal," she says. "In my current profession, I do have a voice in integrating more Africans into the healthcare system and trying to figure out ways to gain trust and educate not only my family, but others in the community."

Through her internship, a PhotoVoice project with the PCORI-funded Patient-Led African Immigrant Health Research Consortium, she has been working with recent immigrants to help them document their own life stories through photography.

A method often used in the fields of public and mental health, PhotoVoice builds the skills and capacity of individuals, often from marginalized communities, to help them advocate for social change. Lumumba says certain themes emerged through the project, titled "Impact of COVID-19 on African Immigrants Living in New England."

"We talked a lot about mental health,

especially in the younger group, and how some of these individuals struggled having hope and maintaining hope throughout the pandemic," she says. "Being in homes with their families, it was really hard to address those feelings of fear and sadness because mental health isn't necessarily acknowledged as much in their parents or grandparents."

Lumumba came to the U.S. from the Democratic Republic of Congo with her family at the age of five. Her mother and her older sister, both of whom work in healthcare, inspired her own career path. Although she now works as a transplant nurse, she's planning to earn her master's degree in forensic nursing, a field that requires advanced technical training and deep empathy.

"Individuals with disabilities have a higher rate of being impacted by domestic violence and sexual assault," she says. "So VT LEND, as well as my goal to go back for my master's, go hand in hand."

Health Equity in Minnesota

As the COVID-19 pandemic barreled down on Minnesota in the spring of 2020, Whitney Terrill found herself at the epicenter of the state's response. A disability fiscal policy

analyst with the Minnesota Department of Human Services, she was eventually redeployed to the Minnesota Department of Health (MDH) to develop and launch the COVID Community Coordinators initiative (CCC), a program offering an additional layer of systems navigation for cultural, disability, and faith communities.

"My redeployment was like a dream come true for me because I wanted to be a part of responding to COVID, such an important global issue with ongoing disparities," she says. "I got to work with colleagues I deeply admire at the MDH Center for Health Equity to solve emergent community issues related to COVID-19. The intensity and sense of urgency was very challenging, and we all had to bring our full knowledge and skills to the response."

Her time in the VT LEND program has already strengthened her skill set and her resolve.

"My training during VT LEND prepared me to think holistically about disability communities and cultural and linguistic competence," she says. "It gave me self-advocacy stories, frameworks, and evidence to address barriers facing people with disabilities and other key populations in our community response model during COVID."

Terrill's path to disability rights and advocacy has been circuitous: After graduating from Hampton University, she spent time working for Goldman Sachs before changing course. When she experienced a stillbirth while working for the U.S. Green Building Council in Washington D.C., she decided to become a doula part-time to support expectant mothers and families.

"That was a really challenging period of my life. When I lost my son at that time, I found myself confronted with grief, statistics, and a need to seek out more education and resources," she says. "But it also was the spark for me to try to understand more about primary care. I was consumed, and kept asking myself: How do I stop this from happening to another family? How can I help other mothers?"

Although she considered medical school, she saw the promise of creating change through public policy and moved back to her home state of Minnesota to work in the field. VT LEND has been a source of great knowledge and support.

"Building relationships through such a transformational learning and advocacy community is something that I know has already transformed me personally," she says. "I will carry it with me for the rest of my life." **VM**