

Sean Tyree, KU Center on Disabilities (KUCD)

“Untapped Talent in America: Removing Barriers to Work and Supporting Opportunity for Individuals with Disabilities.”

Dear Chairman Smith and members of the Social Security Subcommittee:

My name is Sean Tyree, and I am a research aide and self-advocate at the University of Kansas Center on Disabilities (KUCD). Authorized under the Developmental Disabilities Act, KUCD is the University Center for Excellence in Developmental Disabilities, also known as a UCEDD, in the state of Kansas.

I am testifying today regarding my journey through several government programs and service systems, including Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), that have supported me to become competitively employed in the state of Kansas. I am a person with a disability. I have a neuromuscular condition called Charcot-Marie-Tooth or CMT type 1A that was inherited at birth through my father. CMT is a degenerative disease, meaning it does NOT ever get better; it only gets worse.

As someone who has had a disability their whole life, when I turned 18, my mom helped me get on the Medicaid Home and Community Based Services waitlist for people with physical disabilities. In the state of Kansas, this waitlist is around 2 years. After high school, I was able to get services I needed after being on the waitlist. High school was a challenging time for me with my disabilities, as I was recovering from multiple leg surgeries and rehabilitation, and I faced near-constant bullying.

As an adolescent, I also received Vocational Rehabilitation or VR services from ages 14 to 21. In school, I took the initiative to invite a VR counselor to my annual Section 504 meetings at school. Section 504 is part of the federal Rehabilitation Act, and my 504 Plan ensured that I got the accommodations I needed to be successful in school. My school did not always invite VR, but I knew they could help me reach my employment goals. VR services supported me with person-centered, strengths-based job search. With these services, I received tuition and assistance from a tech specialist to attend community college online. This allowed me to continue working toward my employment goals while also remaining close to home as my dad at the time became a double amputee due to CMT type 1A.

I graduated with an Associates of Arts degree in August of 2023; supporting my goal to become an elementary school teacher. I worked from October 2021 to September 2024, as a substitute teacher. With the support of VR, I received supports to be successful in my position, including purchasing work clothes, required technology, and completing background checks. These VR funds come from the Federal US Department of Education, specifically through the Rehabilitation Services Administration, and they have been critical to me gaining the skills I needed to be successful in employment.

After years in the classroom, I decided to make a career change and find a new way to make important connections to new jobs. This led me to volunteering for the My Transition My Career Topeka community team, an initiative led by KUCD. These community teams bring together students, families, schools, VR professionals, and community members to support youth with disabilities to get jobs in the community through education and monthly resource meetings.

At these meetings, I learned about the research aide job at KUCD and thought my strong voice as a self-advocate and my lived experience with a disability could be useful to the work that KU was doing to enhance employment for people with disabilities.

When I got the job offer, it made me realize how beneficial these systems of supports are for the success of people with disabilities, like myself. Which unfortunately due to the lack of federally funded job supports and accurate benefits planning, many people with disabilities do not get. As a research aide, I work to advance employment and transition supports for other people with disabilities while also allowing me to earn competitive wages and benefits through the State of Kansas employee healthcare system.

While I am in competitive, integrated employment, I also receive Medicaid and Medicare benefits and personal care services – all essential to my health and success. While these systems are typically difficult to navigate, the people at Working Healthy, a program in Kansas that supports people to work while keeping their essential Medicaid benefits, supported me to learn how my benefits would be impacted if I worked beyond the trial work period limits. As I made this transition and began my new career at KUCD, I had additional barriers to navigate, as my dad passed away after his battle with CMT type 1A. I became eligible for some of his benefits in addition to my own SSDI monthly payment. With Working Healthy's support I learned that I could keep my essential benefits while working as long as I didn't have assets over \$2,000 – which allows me to continue to qualify for the Home and Community Based Service Waiver.

The \$2,000 asset limit is a huge barrier to people with disabilities like me in seeking employment. However, I was recommended to open an ABLE savings account, which allows me to save up to \$19,000 per year for "Qualified Disability Expenses." This lets me save for things like a car to get to work and other supportive technology that costs over \$2,000 and is not typically covered by Medicaid or Medicare. ABLE accounts come from the federal "Achieving a Better Life Experience Act" and allows individuals with disabilities to save money in a tax-advantaged account without losing essential benefits. Because of my ABLENow savings, I can safely feel like I have a little nest egg for emergencies. People with disabilities deserve to be able to maintain benefits that support their health and independence and have a job.

Largely because of federal and state programs and supports from the disability field like the Kansas Department on Aging and Disability, KUCD, and the School of Martial and Meditative Arts in Topeka specifically my mentor and friend Hanshi Steve Twemlow "My Hero," I have learned that my long-term potential for job growth and benefits are far better with a meaningful job in the community.

I love my job at KUCD and believe that as people with disabilities go after employment, they should have the benefits and supports to empower them. I have shared today about my experience and journey into competitive integrated employment. Since being employed, I have had fewer hospital visits, and now have a real purpose in my life to help others with disabilities reach their goals.

I have developed as a professional and have become a true, independent adult in society. An adult who is brave enough to testify in front of Congress about his personal lived experiences. I would not be sitting before you today without the federal and state level supports and services I have received such as Medicaid, Medicare, SSDI, ABLE, Section 504, and VR. I also want to thank my family, friends, mentors and supporters who have guided me through these systems. I have a higher quality of life because of my work and these services.

People with disabilities can achieve far more than society often expects; like everyone else, they simply need the right supports to learn, grow, and pursue their purpose in life. Thanks to the opportunities provided by KUCD, I was able to discover a career I love. Without federal programs that promote competitive, integrated employment while ensuring access to essential Medicaid benefits, many people like me might face institutionalization or lose the support needed to thrive and grow professionally in a career they are passionate about.

Thank you for your time and attention today. I appreciate the opportunity to share my story with you all.