

Testimony of Edward Mitchell, MBA  
Before the U.S. Senate Special Committee on Aging  
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Hearing on Supporting Economic Stability and Self-Sufficiency  
As Americans with Disabilities and Their Families Age

Hello, Chairman Collins, Ranking Member Casey and members of the Committee! My name is Edward Mitchell I come today as an individual with a spinal cord disability.

Let me share a bit of background on myself. I have not always lived with a disability. My disability occurred on March 29, 2003, in Jackson Tennessee. On that ill-fated day, my life was nearly destroyed when I decided to go for a bike ride with my little brother before going to my first high school part-time job at newly opened Little Caesars pizza in Jackson by the owners, Mr. Kevin and Rachel Colbert. It was about 11 o'clock in the morning when I started biking on Ash Port Road. My little brother, Rendell, said he needed care for his tire and needed to go back to the house to get it aired up. Since my brother was much more of an athlete than me, I thought I would continue biking on and he would catch up. As I continued biking up the straightaway country road, I noticed a truck approaching very fast in my rear. I gave the proper hand signals to change lanes but had to wait for a red sports car to pass in the left lane. After giving my hand signals I switched into the left bound lane and that's when my life changed. The truck crossed over the double lines and clipped me from behind and threw me into a ditch by a cornfield. I was thrown from my bicycle. I landed on my back and neck causing an incomplete fracture to my C5- C6 vertebrae.

This is where my life took a turn, after being stabilized in Jackson General Hospital and receiving preliminary physical and occupational therapy, my family was informed of a unique place that specializes in spinal cord injuries: the Shepherd Center in Atlanta Georgia. The Shepherd Center is where I learned their version of boot camp style therapy. I worked my way through inpatient under the tutelage of therapists Cathi Dugger who can get the most out of young teens and adults. What made this experience so unique is at the Shepherd Center everyone has a different level of injury. While I was inpatient, I shared a room with three other individuals with varying levels of spinal cord injuries.

At Shepherd, I continued to work the program 'hard' and eventually made it to the day program. I was taught more life skills and therapy from, Martha McGourk. The other true anchors while working my way through the program at the Shepherd Center were Cheryl Linden, a counselor, and James Sheppard, who the Center was founded for because of his injuries.

Through my hard work and dedication, I was able to return back to high school for the start of my 11<sup>th</sup>-grade year at North Side High School as well as return to my place of employment, Little Caesars Pizza.



My boss, Kevin Colbert, said that I was his first interview and first hire as a small business owner and he saw something special in me and he wanted me to come back and work despite my disability. He said he would make any accommodations to the store in order for me to continue working.

The bittersweet of my recovery and employment is that the individual who caused my hit-and-run accident was never found. It continues, to this day, to be a cold case. In order to keep hope alive, I created a website (<https://edwardmitchellhitandrunk.weebly.com/>) as a digital archive of my hit-and-run accident in my own words, news publications, local TV interviews, as well as an about me section that lists my accomplishments, goals and aspirations, such as one day getting into TV or film acting or opening my own small business. I also try to prod the local sheriff's department into reviewing my cold case and featuring it on the local Crimestoppers of the week series. At this point in time, in my own personal opinion, I think it would take some type of national media programs such as cold case files or AnEs live PD, to help pull information from reluctant witnesses and their guilty consciences.

Till this day, whenever someone asks me about my hit-and-run accident, I tell them I'm glad it happened to me and not my little brother Rendell. I know he is strong, but I don't think he would've been able to deal with the obstacles that come along with having to live with a spinal cord injury and use a wheelchair. As it stands today, I primarily use a power chair as not to wear myself out, I do have feeling in my legs but no voluntary movement. I can feel pressure and hot and cold in my legs and trunk. If there are medical research advancements in stem cells, the connection is still being made for my brain to my legs and it is only the scar tissue that needs to be cleared up in order for me to walk again. But until then, I'm dealing with the "bad poker hand" and making the best of it.

As they say, it's hard to keep a determined individual down, after being equipped with the tools necessary to be as independent as possible and you can say that about me. But I still need nursing care assistance with my nighttime routine and with getting up and ready for the next day. I also need assistance with home modifications. I need to try to figure out what I could do and what changes are needed for my family to take care and assist me. My determination is the same but my and my family's roles have change now that there are things I can't do on my own.

One of the problems is when nursing care does not show up to assist and an agency doesn't notify me that no one is coming. Then my parents have to do my care. After all, I still have to go to work.

One of the consequences of my accident is that my father had to reduce his work and dip into savings. . He used some of his 401 savings to help with expenses. He also took a job in another state to keep me and my family in a stable environment.

When I first got home from the Shepherd Center and returned to school, I had to be ready for the bus every morning, which came by at 6:30 am. My mother, having two children in school and the closest relatives being 7 hours away in Cincinnati, Ohio, had to do everything herself. Other complications included my mothers' aging parents aging and my fathers' aging parents and my mother's only sister getting breast cancer. Despite these challenges, my family supported me and I flourished and finished high school, magna cum laude. I graduated with a regular high school diploma, like everyone else,

although I did have accommodations for testing, such as more time and note taking due to me having paralysis in my hands.

Before making my college matriculation. I experienced a once-in-a-lifetime opportunity in writing an essay for a competitive cross-cultural study abroad program. Mobility International USA (MIUSA) is a disability-led non-profit organization headquartered in Eugene, Oregon. MIUSA's mission is to advance disability rights and leadership globally. By implementing innovative programs to empower people with disabilities to achieve their human rights through international exchange programs and international development (<http://www.miusa.org/>). My essay won me a spot in the MIUSA 2005 Tokyo Japan cross-cultural exchange with 14 other individuals.

After that great international experience, I was ready to begin my college quest, but how? I was totally lost as to where I would end up going to college because before my hit-and-run accident I told everyone that I either want to attend Arizona State or UC Berkeley in California. But after my accident, those options seemed so far out of reach and unreal. Being paralyzed for two years, I didn't know how I would make it. And how much more could I put on my family? But I was determined to go to college. My parents said what ever it takes, so my mother started researching options while I was still in high school. She started by contacting the Tennessee vocational Rehabilitation program.

The strange part is that ever since we moved to Jackson, TN from California, the president of Lane College, Dr. Wesley Cornelius McClure, had taken a keen interest in me. Lane College is a Historically Black College/University. President McClure said to me the Sunday after my high school graduation that I would be attending Lane College and that I could put those other institutions out of my mind. He said Lane College is where I needed to be and Lane was where I was going. My parents thought, and I thought, that President McClure's invitation was a very good gesture, but no one at Lane had a disability like me. How would I get around? The campus and the buildings didn't seem accessible. I have enough issues with accessibility. I didn't need to go to a college where I couldn't get into the classrooms or offices. As the time approached to attend school, we explained to Dr. McClure that the offer was great but I would have to go somewhere I could get around. He said "No," that Lane would be accessible when I came to school and that I would live on campus just like other freshmen. He was going to make it happen and that my attending Lane would also make it possible for others to attend. With that being said, it was done.

I was offered a full scholarship to Lane, not because of my disability, but due to the fact I had the grades and ACT scores to back it up. I accepted the scholarship and then would give it back to the school because I qualified for vocational rehabilitation benefits, which would pay for my schooling I figured my scholarship could be used for another deserving student. President McClure made arrangements with the Shepherd Center to make sure that the dormitory I was to live in was fully accessible so I could live have the full college experience, just like any other student.

My college life was like any other hard-working student. No slack was given to me because of my disability I was taking 21 to 23 credit hours per semester because I wanted to graduate on time, I was

also working on the weekends. Before graduating college I had the honor and privilege of joining the Beta Pi chapter of Alpha Phi Alpha Fraternity Inc. Alpha Phi Alpha fraternity is the oldest Black Greek-letter organization in the United States. I graduated Lane College, magna cum laude.

One of my best experiences was learning to drive and finally being able to be independent. Unless you've been in my position you don't know how it feels not to be able to drive yourself to your high school prom or do the things typical teenagers do between the ages of 16 and 23. I had great fraternity brothers, as well as a high school friend, who had the skills necessary to drive one of the big conversion vans to different events, such as movies, concerts and anything in between. I had worked on driver training since my senior year of high school and then was working with my local vocational rehabilitation office to get a modified vehicle. After much back and forth during my years in college, they finally approved me to be able to drive a 2008 Chevy UPLANDER. I had to pay for the cost of the minivan, approximately \$35,000, and VR covered the modification of the vehicle, as well as the hand controls. The modification cost in excess of \$100,000.

Driving, especially in a rural area, is freedom when you have a disability, but it is quite costly. Without the continued help of vocational rehabilitation I would not have the freedom I have today. Hopefully vehicle manufacturers will be able to cut the cost of vehicle modifications by doing them in-house instead of letting third-party companies do the modifications. With factory-installed modifications, more individuals with disabilities would be able to drive. Vocational rehabilitation supports obtaining adapted vehicles to keep individuals with disabilities employed and to have their independence..

While continuing to be infatuated with the independence I had by being able to drive, as college graduation approached I had to buckle down hard and prep for my GMAT test in order to get into the Union University MBA McAfee School of Business program. Union University is a four-year, liberal arts, top-ranked, private Christian university located in Jackson, Tennessee. I made the scores I needed on my GMATs and I was accepted into the MBA program. Thus began my two years at Union in a cohort that met every Tuesday from 6 to 10 p.m., as well as unofficially during the week so our cohort could help each other study. While I was obtaining my MBA, I secured my first professional job after graduating with my undergraduate degree as academic mentor/Dean of students at Lane College. Dr. Wesley Cornelius McClure wanted to hire someone the students could relate to as well as someone who was in their age range who could be there for activities on campus and knew the campus Greek life.

After completing my MBA in 2011, I continued to work for Lane College up until October 2014 when the new president, Dr. Logan Hampton, took over and had to make hard decisions to reduce staff because of the pressures historically black colleges endure. I was downsized, along with others in key departments, in order for the betterment of the school.

At that point, I went through a period of unemployment. I went to numerous career fairs, such as attending National Black MBA conferences and interviewed for local jobs, but it always seemed that I was perfect on paper but once I enter the interview room, they saw more of the wheelchair than the individual. Living in rural West Tennessee, the biggest town in between two major cities, options are

limited. The commutes to Memphis, an hour and a half away, or Nashville, which is two hours away, weren't feasible. And I could look outside of the state for a full relocation. It seemed like a daunting task that I was not up for due to so many factors such as ensuring I had healthcare and accessible living arrangements.

That's when I noticed an internship available at the Jackson Generals minor league baseball team here in Jackson Tennessee. The Generals are the AA affiliate of the Seattle Mariners, I applied for that internship on LinkedIn but never got a email back. When I called to inquire after two weeks of no response, I was informed that the person responsible for posting that internship was no longer employed at the Generals. The individual I talked to was Blake Leonard, the ticket operations coordinator for the Generals, who told me to send him my resume and he would review it. Mr. Leonard replied with a sense of urgency saying they had a job fair that was coming up and he had a position that he thought I might be interested in. After going to this job fair I met with the assistant general manager, Nick Hall, and Mr. Leonard. They were blown away by my resume and interviewing skills and said they had a part-time position available in a new department called Fan Relations. They wanted to know if I would be interested in the position and that it could potentially lead to a full-time position with Generals. I took the position because I liked what the Nashville Predators were doing with their new Department of Fan Relations and want to be a part of this growing field.

At the same time I accepted another part-time position with the Jackson Center for Independent Living ([www.j-cil.org/](http://www.j-cil.org/)). The director, Beth James, had gotten word of my downsizing from Lane College and stated that I could come work for the independent living center because I could be a real asset. I had a lot of background in the independent living philosophy because I had been on the board since I had returned from the Shepherd Center back in 2003.

To this day, I work with the Jackson Generals minor league baseball team AA affiliate of the Arizona Diamondbacks (going on 4 years) and continue to be a independent living specialists at the Jackson Area Center for Independent Living.

Now I know you're probably wondering why do I keep taking part-time jobs? Even at Lane College I had taken a reduced salary, compared to others who were at my same job level. Working part-time and taking reduced salaries hurts my income. I have been gaining experience and have completed my Masters, but I can't accept a full salary because it would impact my nursing benefits. If I accepted a full salary, I would make too much and lose my disability benefits but I would not make enough to directly pay for nursing care, even if I gave the home care agency my entire check. Of course, if I did that, then how would I pay for medical expenses, car insurance, car repairs and gas. I need money to have my vehicle maintained at a dealer who is 85 miles away, the only authorized mobility dealer in the area. And, I pay a portion of my income for rent to live at home. I don't want to put more of a burden on my family.

When it comes to my support services, my father still works out of state, so he can't help. I have limited nursing hours through my Medicaid waiver, so my mother stills perform at least 35 hours of my support

a week. From the state, I only receive 27 hours of support, which I appreciate, but many times those hours are not used because the agency can't find a nurse.

We are sometimes told by my agencies that because I don't have an 8 to 5 job that they can't find staff to support me. It is not easy to find a job if you're disability, but I have been able to get and maintain jobs, not because I ask for my bosses to make exceptions, but because I have the ability to learn the job, to learn new skills at the job and to be the best person for the job, with or without a disability. Everyone wants the best person for the job, I train and perform the job with or without a disability. I do what is required of the job to maintain, it no exceptions.

My mother, Ms. Simone Hayes Mitchell, who is here at this hearing with me, was up late one night due to us not having a nurse and my needing support to get to bed. My work hours are unique because I have the nurses come in at 11 pm and they don't leave until 3 AM. To some, this might sound strange but I have been doing this routine since 2003 because it allows me to do everything I need to do such as work and social life with friends, and family. Any individual with a disability that is also working can attest that no one wants to have their day stop at 6 pm or 9 pm to receive any care that they might need. I implore all of you within the sound of my voice to look at your own schedule and visualize stopping your day at 6 pm or 9 pm. I push my day as late as reasonably possible so I can accomplish everything I need to. So 11 PM works and the rare times where I need to be out past 11 I try to make compromises with those who provide my nursing services. I do start my day early, 6 or 7 am in order to get to work on time. When I do have a late night out, it is usually for a comedy show or a basketball game. The only thing that has suffered because of my hours is my sleep. Four or five hours of sleep is not recommended, but if that's what it takes for me to succeed in life and be productive, that's what I'll do and I've been doing it since 2003.

On this one evening, as my mother was trying to wind herself down for the night after helping me, she stumbled onto the Tennessee ABLE program. Tennessee's ABLE program is called [ABLE TN](#). ABLE accounts are bank accounts that allow people with special needs to save money without jeopardizing their disability benefits. ABLE accounts come from the *federal* [ABLE \(Achieving a Better Life Experience\) Act](#), but they are established and managed on a *state* level. Not all states have ABLE accounts (yet), and each state has slightly different rules and procedures for opening and using an ABLE account

Once we stumbled upon ABLE, we thought it was a lifeline. It would allow me to start saving without penalizing or jeopardizing my benefits. You see, my parents worry what will happen to me when they are no longer able to help or they have died. They keep this thought in their heads every day.

You see, when people with special needs apply for disability benefits, they must show that they do not have enough money to support themselves independently. Money saved in a traditional bank account counts against the ability to qualify for disability benefits or Medicaid waiver programs.

As a result, individuals with special needs are not able to build savings with the money they earn or that they receive through inheritance, gifts or a life insurance policy. On a day-to-day basis, this means that individuals must live with very little money if they want to receive government aid. Or, as in my case,

qualify for a Medicaid waiver program that pays for nursing care. As I've said, I get 27 hours a week of nursing support, which breaks down to four hours a night and three hours on Fridays. The reason I only qualify for 27 hours is due to the fact I have a spinal cord injury but because of the things I am able to do it doesn't allow me to have the full benefits that I once had which allowed me to have someone there at night to help me get down but also to get up in the morning.

One way in the past to save money and avoid losing benefits is to use a special needs trust, which provides a place to save money that can be used for the benefit of the person with a disability, without affecting his or her eligibility for benefits. But special needs trusts must be controlled by a trustee or trustees, not by the person with special needs who benefits from the trust. Not only does this leave the individual with the disability with little control over his or her finances, it also limits the person's independence.

ABLE accounts give individuals with disabilities the opportunity to manage a modest bank account without penalty against their eligibility for SSI, Medicaid, or other government benefits. Contributions are capped at \$15,000 per year and the account cannot exceed \$100,000 or else you can begin to lose your disability benefits. Funds must be used for qualified disability expenses such as housing, education, transportation, employment training, health and wellness, financial management, legal fees, and more.

Since I found out about ABLE I've tried sharing it with all the consumers that come through the Jackson Center for Independent Living. I shared with my former friends at different therapy centers I've attended such as the Shepherd Center in Atlanta Georgia, the Fraser center in Louisville Kentucky, the Shriners Hospital in Oak Park Chicago and the Tennessee Rehabilitation Center in Symera. ABLE is a great starting point for any family that has a child or young adult with a disability that qualifies for the program because it allows them to save money. Or, if someone should happen to leave an inheritance to an ABLE account owner, the money can be funneled away into the ABLE account without fear of losing benefits. The only drawbacks that I have heard some people voice about ABLE accounts in some states is that unused funds must be used to pay back Medicaid after the account owner dies.

I have tried to put away a little bit from each check since opening my ABLE account but it is hard to contribute much when you can only earn \$2000 a month. But the ABLE program has given my parents peace of mind because they are aging. My father, Sandy Mitchell, has just turned 60, and my mother is 57. They have started looking to the future. Almost all of my grandparents have passed away and the only one left alive, my 87-year-old grandmother is currently living in a nursing home. My parents want to make sure that I am self-sufficient and able to provide for myself, because the three biggest expenditures of my life - nursing care, housing and transportation. The ABLE programs helps with becoming self-sufficient.

I want to make two recommendations about making it possible for people with disabilities to be economically self-sufficient. It is my wish that states would make it easier to transfer waiver programs. If you receive waiver services in one state, you can't take those services with you to another state. That means you are locked into staying in your state and can't go to another state to get a better job. The

second recommendation is that it would be better if individuals like myself could continue to advance in our careers without losing our benefits. I would be willing to pay according to a sliding scale for my nursing care. Basically as people like me advance in our careers we could pay a percentage back into the waiver program as we obtain higher rates of pay. We shouldn't be scared of losing our benefits and we shouldn't be held back from advancing our careers. We need to be able to build a future for ourselves and also have a family and do the things other hard-working Americans do.

In closing, I want to be self-sufficient and continue climbing the career ladder. I never wanted to be receiving SSI benefit, but my life changed in 2003. As my path is leading me, maybe into a career in politics, I might, with the help of the disability benefits I receive and my ABLE account, be able to help make changes and improve the lives of others.