

Testimony Brenda Dare ABLE testimony August 17, 2022

Senate Special Committee on Aging Hearing

Saving with ABLE: Financial Security for Pennsylvanians with Disabilities

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Good morning, Senator Casey. I am Brenda Dare and I have worked for my entire career. I have spent decades helping others to succeed in obtaining the supports they need to be successful. My own disabilities and life circumstances combined with the education I received from Edinboro University gave me the foundation for a career that I'm proud of. By most measures I am successful. However, I have built surprisingly little wealth throughout my professional career. Many of my friends with disabilities could say the same. Living with a disability is expensive, but that's not the reason for my lower-than-average credit score or the fact that I haven't taken a vacation in more than a decade.

I'm not good at money. As I approach my 50th birthday I am slowly beginning to remedy that. I want to tell you the story of how I got here. It is not a remarkable story, but it does illustrate some things that are common to experiences of people like me.

I am the youngest of 5 children born to factory workers in the early seventies. I started receiving Supplemental Security Income (SSI) somewhere around the time I started kindergarten. My parents had split up by then, and my benefits helped provide financial stability for my mother, myself and my siblings. I learned early on that receiving benefits meant having a healthy fear of the system and of wealth. Friends and family were cautioned not to add money to my birthday cards or Christmas stocking as it might need to be reported to the Social Security Administration and would affect my check the following month. I remember being carried on my mother's hip to attend frequent case reviews at the Social Security office. These were always a source of stress.

Before I was in 4th grade, I knew to fear the envelope the review documents came in. As I got a little bit older, I started to think about what I wanted for my future. My mother was fortunate enough to have been a homeowner for many years before I was born. While homeownership was not necessarily my goal, independence was. When I turned 16, I asked my mother about getting a job over the summer at the grocery store near our house. This question was met with "absolutely no." She knew nothing about any work incentives and explained that if I earned a paycheck,

I would compromise the benefits we relied on to keep the house in smooth working order. I might also jeopardize eligibility for college funding and other things I was going to need. It was a hard first dose of young adult reality that my disability was going to mean having to watch my income all the time.

I turned 18 mid-way through my first semester in college and along with birthday cards, I received a slew of predatory credit offers aimed at unsuspecting college students without credit histories.

In a not so atypical act of rebellion the first thing I did was overspend on one of those shiny new cards. You might ask yourself why somebody who never received much cash would make such impulsive decisions. I say that question answers itself. I was a kid who was good at restricting the use of money and had spent years wondering what it would be like to have a chance to spend some! I know that my typically developing peers had very similar experiences, but a lot of them had some savings to fall back on. Remember what I said about not getting money and birthday cards? I didn't have my first bank account until I went away to school, and now, with credit card debt, there was no hope of building any money in it.

I also had never had that summer job I wanted so badly. I was book smart but had no practical experience. When I left school at 21, a friend connected me to a job with an employer that must have held a 14 C certificate. I didn't know what that meant at the time, but I did earn less than minimum wage and was very limited in the number of hours I could work. I developed a good work ethic. However, I didn't handle my finances much better. I always made sure that rent and bills were paid, but I never had the hang of budgeting for much else. Nor was I very successful in correctly reporting my earnings to the Social Security Administration or learning about work incentives.

I did everything I could to stay away from the system I grown up fearing so much. I lived in a very small fair market apartment where I paid 75% of my total income to rent and utilities. I knew that I could qualify for public housing, but I did not want it. That would mean another periodic review and more worries over watching pennies. I didn't know it, but I was locked into a cycle that would make it extraordinarily difficult to build any resources. By this time, I was receiving Social Security Disability Insurance (SSDI) through my father's record because he had become disabled as well.

Through a technical glitch, I also lost my Medicaid during the 24 month waiting period for Medicare to kick in. I didn't know the system well enough to realize I

could have fought that. Consequently, for 2 years I often spent what little discretionary income I had on doctor visits for the frequent infections that are part of my everyday life. I knew that I wanted to get ahead, but for the life of me I couldn't see how that was going to happen.

I was 24 when I found a full-time job I thought I'd be qualified to do at a disability organization. I remember being asked in the interview about prior work experiences. I told him about volunteer things I had done and the 14 C certificate subminimum wage job. The next question was "Do you have any other experience?" I felt so small when I had to explain that I didn't have any work experiences throughout school or my younger years because it would've meant risking benefits. Luckily, after their first choice fell through, I got my shot. I kept that job for 10 years. I was able to move to a slightly larger apartment and I learned how to navigate work incentives.

I was finally free to build up a little bit of a financial cushion. I got employer-sponsored health insurance for the first time and was literally able to go to the doctor's office and not have to discuss the cost of medication before it was prescribed. Still, I didn't have the skills I really needed to be smart about money. I made some mistakes on my taxes and ended up owing the IRS. If I thought Social Security envelopes had been stressful, the IRS envelopes were a whole new ballgame. I got through it, but I will say it was a struggle.

It was during this time I met the person who would become the love of my life. He lived more than a thousand miles away in Colorado. I had a goal to save up for now. I needed to travel to see him. I understood that I was allowed to save more money on SSDI than I had been on SSI, but the SSI threshold was so ingrained in me that my savings existed in an empty water cooler bottle rather than an interest-bearing bank account.

Only looking back do I see the ripples of financial illiteracy as a theme throughout these years. I helped others to learn to budget every day and I could manage the day-to-day stuff very well, but I wasn't smart about financial planning and most financial planners I asked at community events weren't familiar enough with home and community-based services supports or things like work incentives to be able to offer anything constructive. I could have looked around harder for disabilities focused financial service providers to help me on that path, but I saw those folks as my colleagues and didn't want to admit what I didn't know.

So, I lived by a simple rule. I planned to never own anything of value that could be considered an asset and I enjoyed things in the moment. There was a Starbucks across the street from where I lived. I was a daily customer because I've always had a real fondness for caffeine. I remember getting into an argument with my mother one day when she told me "You spend hundreds of dollars a month on coffee, think of all the other things you could do with that money!" I told her simply that there wasn't much else I could do with that money. I was never going to own a house or a car. If I saved up too much money, I risked the supports I needed to live in the community. She didn't like my point, but she couldn't argue it much.

I started to change my mind about money after my first trip to Colorado. It was clear that this young man would be someone special in my life and I wanted to move to be with him. Because of some unforeseen complications, that took longer than expected. Finally, at the age of 35, I made the leap. I left the job I loved in the city I loved for the man I loved more. Still, my savings for the trip were in that empty water cooler bottle. I had amassed a very small retirement benefit package from working. I did know enough that I didn't want to touch that. We settled in Illinois so that he could be close to his family, and I wouldn't be quite as far from mine.

After I had a serious health setback, we decided to move back to Pennsylvania. It was 2012 and we were ready to buy a home. After much discussion, we decided that we would not apply jointly for the loan. My credit needed too much repair. A lifetime of disability coupled with a weak foundation of financial literacy meant this was our only real option. We spent 16 months looking for the right home. We viewed 32 houses and bought the only one that I could get inside of. Significant modifications were needed. Pennsylvania Office of Vocational Rehabilitation funds made it possible for me to enter the home safely and have full use of the bathroom.

Also during this time, we purchased a new accessible van. Money was tight and I was very thankful for a new full time job at Transitional Paths to Independent Living, a disability advocacy organization that empowered me to learn about many things, including the ABLE Act savings program. This job was a much needed boost to my career, but my earned income meant an end to my SSDI.

I immediately recognized the power the ABLE program could have. Imagine living your whole life fretting over income caps to maintain eligibility for every day

support needs. Most people have never thought about needing to choose between a good investment opportunity and the right to take a shower, but people with disabilities make these decisions all the time. Or, worse yet, take the opportunity and then lose eligibility for services that keep them out of institutional settings. ABLE offered a way to build a little bit of wealth without facing such horrible choices.

Within three months of PA ABLE launching, I began helping people learn about the program and get their accounts started. I saw people saving for vehicles and moving to more accessible housing. When they would ask if I had my own account, I always said I was “getting around to it.” I was a busy, exhausted working woman with a car payment and a mortgage. There just weren’t the resources to save any significant amounts of money.

That changed in the summer of 2020 when I was fortunate enough to receive a bonus from work. The amount of the bonus plus my small retirement savings would have rendered me ineligible for my home personal care assistance through Pennsylvania Act 150. The asset limit there is less than 20,000 and I would’ve gone over by a few hundred dollars. Without my newly opened ABLE account, I might have been forced to spend down that bonus. I feel very fortunate that I was able to put that money aside because there were and still are many unforeseen expenses ahead.

My ABLE account has meant having the ability to maintain my accessible vehicle and cover maintenance costs for the lift system I have in my home. Without these things, my ability to live in my own home and in my own community and be productive would be seriously jeopardized. This would end my ability to do the things that give my life its meaning. I would no longer be able to raise my niece or be surrounded by the well-loved rescued pets we have in our home. I would not have enjoyed the pandemic hobby of painting I picked up that just might be my next earning opportunity.

Health changes and challenges forced me to leave my job six months ago. My ABLE account means I have a little bit of breathing room while I figure out my next steps. This program is vital. Some changes would strengthen it even more and I’m excited to help you Casey make some of them happen.

We need passage of the ABLE Age Adjustment Act so that more people who acquire disabilities in the workforce can save to protect themselves from ending up in costly institutions. We also need the ability to make periodic one time

investments above the established limits so that parents and spouses don't fear leaving an inheritance to disabled loved ones. This would also be helpful for people who have retirement savings before they acquire disability. We need to educate mainstream financial planners on the value of this program so that it becomes a routine part of the advice they offer. We need employers to be able to match ABLE contributions. Lastly, I think we need volunteer ambassadors who are actual account beneficiaries to get the word out to our peers.

We need to end the fear of acquiring wealth that is so often a part of the disability experience. I am finally able to plan for a future and I want to help others do the same.