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# SAVING WITH ABLE: FINANCIAL SECURITY FOR PENNSYLVANIANS WITH DISABILITIES

## **HEARING**

BEFORE THE

# SPECIAL COMMITTEE ON AGING UNITED STATES SENATE

ONE HUNDRED SEVENTEENTH CONGRESS

SECOND SESSION

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### SAVING WITH ABLE: FINANCIAL SECURITY FOR PENNSYLVANIANS WITH DISABILITIES

#### WEDNESDAY, AUGUST 17, 2022

U.S. Senate SPECIAL COMMITTEE ON AGING Washington, DC.

The Committee met, pursuant to notice, at 9:30 a.m., at University of Pittsburgh Alumni Hall, 4227 Fifth Avenue, Room 121, Pittsburgh, Pennsylvania, Hon. Robert P. Casey, Jr., Chairman of the Committee, presiding.

Present: Senator Casey

#### OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR., CHAIRMAN

The CHAIRMAN. Good morning. The Senate Aging Committee will-this hearing will come to order for the Senate Aging Committee. We are grateful that everyone is here to talk about these issues. I am really grateful that our witnesses are here this morning and grateful for those who are in attendance.

Today's hearing highlights the experiences of Pennsylvanians who are ABLE account owners, and who wish to open an ABLE account but cannot do so. We are focused on both those who have ABLE accounts, as well as those who would like to open an ABLE account but are limited because of the constraints of the law.

The original legislation in 2014, the Stephen Beck, Jr., Achieving a Better Life Experience Act, we shortened that to ABLE Act, was signed into law in December 2014. I introduced the ABLE Act to provide people with disabilities the opportunity to build wealth without risking the loss of their Federal disability benefits.

This is especially important for people with disabilities who have a poverty rate more than twice that of those who don't have a disability, so the poverty rate is twice that for people with disabilities of those who do not have a disability. That means that one in four of the 61 million people with a disability in the United States live

in poverty—one in four.
One of the reasons for this is that Federal programs limit the amount of money that people with disabilities can save. This means a person cannot save for a home. They cannot purchase a needed assistive technology or even save for a car that would be accessible to them. That is why we created ABLE back in 2014, to knock down a barrier that people with disabilities face every day as they work to improve their lives, so far, 46 states and the District of Columbia have used the ABLE Act to create special savings

accounts that enable people with disabilities receiving federal benefits to save like every other American was able to save.

Here in Pennsylvania, as of August the 5th, there are more than 6,750 ABLE account owners who have saved nearly \$74 million. Those nearly 7,000 Pennsylvanians have been able to, on average, save nearly \$11,000 per account, because of ABLE, people with disability can save for education, they can save to start a business, they can save to buy a home, or even save for retirement, but there are limits on who can open an ABLE account. A person with a disability must have acquired their disability prior to their 26th birthday in order to open an ABLE account. That is a limitation that we have to change. There are millions of Americans who acquire their disability later in life. They may acquire the disability after the age of 26. It might be when they are age 30 or 35 or 40, and we want to make sure that we are providing this opportunity for as many Americans as possible, so I introduced a bill, the ABLE Age Adjustment Act. It is Senate Bill 331, and this bill would increase the age of eligibility to own an ABLE account to age 46 instead of 26. This would make 6.2 million more Americans eligible to open an ABLE account, including one million veterans.

This bill was recently voted out of the Senate Finance Committee, and I am fighting every day to make sure it is the law. I hope we can pass this, and we are going to try as best we can to get it passed by the end of this calendar year, so today we are gathered to hear more about why Pennsylvania families need ABLE and why we have to expand it. Let me turn to our witnesses.

I will just provide ever so brief introductions of our witnesses, but we are so grateful they are here, willing to testify, share their experience, and to enlighten us and educate us about what we have got to do next. Our first witness is Ms. Brenda Dare.

Ms. Dare has experience as a community advocate and artist. She opened her ABLE account in March 2021 and is a supporter of the program for sure. I want to thank Ms. Dare for being here and look forward to your testimony. Our second witness is Colton Vazquez. Colton is a senior at Duquesne University, where he studies performing arts.

He is the mascot for the Pittsburgh Thunderbirds, a welcome director at an Open Up yoga studio, and one of Kenny's kangaroos at Kennywood Amusement Park. I want to thank Mr. Vazquez for sharing his story with us today. Our third witness is Ms. Carrie Bach, who is currently the Chief Operations Officer at Voices for Independence in Erie, Pennsylvania. In addition to her work at Voices for Independence, she also spent 15 years working for the Pennsylvania General Assembly, the Pennsylvania Legislature.

Ms. Bach, I look forward to hearing your testimony as well. Our fourth and final witness is Andrew Duch. Mr. Duch has worked at Giant Eagle for nine years. He will tell us about a major purchase he made with ABLE account funds that he helped—that has helped increase his personal independence.

Mr. Duch, thank you for sharing your story with us today and being with us, so we will start with our first witness. Ms. Dare, you may begin your testimony.

#### STATEMENT OF BRENDA DARE, COMMUNITY ADVOCATE AND ARTIST, PITTSBURGH, PENNSYLVANIA

Ms. DARE. Thank you, Senator. Good morning to everyone that is here with me today. I would like to tell you a little bit about my historical perspective. I am nearly 50 years old. I grew up with my disability. I have had it since birth, and being a person who grew up with a disability, I was taught to have a very different attitude

about finances and money than most of you in this room.

While wealth is something that you aspire to—it is something that I was taught to fear. Most kids welcome birthday cards and eagerly take the money out of them to put into their piggy bank. Friends and family were cautioned not to put money in my birthday cards and Christmas stockings, as it would have to be reported and might affect the next month's SSI check.

When I turned 16, I was thrilled at the possibility of gaining a little more independence from my mother and my family. I said, it is time to get a job. There was a grocery store within walking distance of my house and the manager, Henry, had agreed he would teach me how to use a pricing gun so that I could work in stock. My mother's response was absolutely not. She knew nothing of work incentives or Social Security programs that might have en-

abled me to get a job.

She was deathly afraid that if I earned a paycheck, it would negatively impact the small benefit that we needed to keep the house in running order. It was seen as my responsibility to forgo that little bit of independence and wealth to help the family. This had a major impact on how I felt about wealth. I developed the attitude that I just wasn't going to own anything. That meant that when I did leave college at the age of 21, I didn't have any practical work experience, and so when I went for my first job, I ended up getting a part time job at a disability organization that held a 14C certificate. For those of you that don't know what that is, it enables employers to pay less than minimum wage to people with disabilities simply because they have a disability.

I was grateful for that money, but I sure didn't know what to do with it. I had gone through a cycle in college where I had gotten the predatory credit offers that come to all new 18 year olds who are away at college, and I had overspent on that shiny new credit card just as soon as I got it, so I was already digging myself out of a hole, and that \$5 an hour job helped a little, but not much.

I really didn't see how I was going to get ahead in the world. Well, then I began to know that there were ways around those things. By that time, I was receiving SSDI on my father's record because he had become disabled as well, so I had a little bit more money coming in, and when I say a little, I think the difference between my SSI benefit and my SSDI benefit was \$17, but that \$17 meant that I had lost my Medicaid while I was in the waiting period, so what discretionary income I did have from that little job and the one that followed, I spent on medical expenses to deal with the minor infections that are part of my everyday life. I sure didn't see a way to financial success. The only savings I had existed in a water cooler bottle because as a person with a disability, getting to the bank was difficult.

Using bank machines was even more difficult because we hadn't reached the point where—although the ADA was passed, access was minimal, so I really didn't know what my financial future was going to be. Well, I made a mistake on my taxes one year and got a little further behind that financial eight ball, and I just accepted the fact that I was going to live in lower middle class for all of my life and I wasn't going to own anything. I was going to be an apartment renter and I was going to live moment to moment. I remember a very telling argument with my mother. There was a Starbucks across the street from where I lived, and any of you who know me well know that I don't go anywhere without a coffee cup. Well, I was a regular customer, sometimes three or four times a day.

My mother and I were arguing one day. She said, you spend hundreds of dollars a month on coffee, imagine what you could do with that money, and I looked at her and I said, not much, if I don't want to lose my Federal home and community based services benefit. That has an income cap too.

I lived my whole adult life in a fair market apartment where I spent 75 percent of my income some years on rent utilities because I didn't want to live in public housing, not because of any shame or stigma attached to it, but because I didn't want yet another financial review.

I had spent my entire childhood deathly afraid of the Social Security envelope that came every year to trigger our annual service review where my mother would, when I was a child, carry me on her hip, to prove I was still disabled and prove we needed the money. Wealth was certainly not in my future, though I did dream of hitting the lottery and buy tickets once in a while.

When I heard about—the full time job I eventually got with a center for independent living, I started to learn a little bit more about what I could have. I started to learn there were people that knew how to use work incentives and other things that the Social Security Administration offered, and I learned about something called the PASS program, which, if you haven't heard of that, it is exactly what you should do with that opportunity. It is a tremendous amount of work for a terribly constrained program that never did function efficiently and forced people with disabilities to come up with a goal before they knew, before they saved the money, they didn't know what they were saving it for.

ABLE gives us a way around that. ABLE gives us a way to be fully functioning citizens who are able to save and prepare for futures. I am now raising my eight year old niece, living in a home full of love and security, and when I had to quit my job six months ago, ABLE gave me the cushion to be able to do that.

I want other people to realize how powerful this program is, and I want more people to be able to take advantage of it, through the Age Adjustment Act and through what I hope we can establish, a program where account holders serve as mentors to people who want to become involved in the process.

I want to help Senator Casey make these changes, and I know that all my other fellow witnesses do, too. Thank you.

The CHAIRMAN. Ms. Dare, thanks so much for your testimony and the comprehensive story you told about your own life and how it has been improved through the ABLE Act-

Ms. DARE. You are welcome.

The CHAIRMAN [continuing]. we are grateful, and that is about as good a summation of why we need to not only keep what is in place growing and moving in the right direction, but also to make the changes we have to make to improve it, so thank you.

Ms. DARE. You are welcome.

The CHAIRMAN. Next, we will hear from Mr. Vazquez. You may begin your testimony.

#### STATEMENT OF COLTON VAZQUEZ, WELCOME DIRECTOR, OPEN UP PITTSBURGH, PITTSBURGH, PENNSYLVANIA

Mr. VAZQUEZ. Good morning, Senator Casey. My name is Colton Vazquez. I am 23 year old. I live in Pittsburgh. I vote-

Voice of CANDY VAZQUEZ. You vote in every election.

Mr. VAZQUEZ. I vote in every election.

Voice of CANDY VAZQUEZ. You are senior at Duquesne University.

Mr. VAZQUEZ. Yes. Thank you. Voice of CANDY VAZQUEZ. What are you here to talk about?

Mr. VAZQUEZ. My account. My credit card.

Voice of CANDY VAZQUEZ. So you are here to talk about your ABLE account and how you use it.

Mr. VAZQUEZ. ABLE account.

Voice of CANDY VAZQUEZ. Okay, and why it is important to you, right?

Mr. VAZQUEZ. Yes. I work at Open Up and at Kennywood and at Castle Camp.

Voice of CANDY VAZQUEZ. You had four jobs this summer.

Mr. VAZQUEZ. Four jobs this summer.

Voice of CANDY VAZQUEZ. Do you love to work?

Mr. VAZQUEZ. Yes.

Voice of CANDY VAZQUEZ. Say that.

Mr. VAZQUEZ. Yes.

Voice of CANDY VAZQUEZ. Colton loves to work and make money. What are you studying at Duquesne?

Mr. VAZQUEZ. I study history of theater and acting.

Voice of CANDY VAZQUEZ. History of theater and acting. Would you like some help with that one? I travel to different cities to audition for theater jobs. I have to save money to pay for it. Where did you go this summer to audition?

Mr. VAZQUEZ. Florida. Sesame Street live.

Voice of CANDY VAZQUEZ. You went to Florida to audition for Sesame Street live?

Mr. VAZQUEZ. Yes. Harry Potter-

Voice of CANDY VAZQUEZ. Yes, you did get to go to Harry Potter also. What is your dream job?

Mr. VAZQUEZ. Dream job, wiggles—become wiggles—Voice of CANDY VAZQUEZ. Colton's dream job is to become a wiggle and perform for kids. What are you saving your money for now? Mr. VAZQUEZ. Saving money—Australia.

Voice of CANDY VAZQUEZ. He is saving his money to go to Australia.

The CHAIRMAN. Wow. Voice of CANDY VAZQUEZ. Colton had the opportunity to perform with The Wiggles when they were in Pittsburgh.

Mr. VAZQUEZ. Saving money-

Voice of CANDY VAZQUEZ. He must have a way to save money. You also want to save for what?

Mr. VAZQUEZ. My own apartment and my own wedding, and my

own dog.

Voice of CANDY VAZQUEZ. You want some help with this one? Okay. All of these things cost money. I have to be able to save money to do this. Without an ABLE account, I am only allowed to save \$2,000. That is not enough to buy a house or a condo.

Mr. VAZQUEZ. And this.

Voice of CANDY VAZQUEZ. You want that one too? Okay. If you allow me to save money, I can provide many of my own supports. I will always need some help and I must have health insurance, but I am capable and need the chance to save money without being afraid of losing many of my other benefits. Thank you.

The CHAIRMAN. Well, Colton, thanks so much for your testimony

and for sharing part of your life story with us. Mr. VAZQUEZ. Thank you.

The CHAIRMAN. We are grateful.

Mr. VAZQUEZ. Thank you.

The CHAIRMAN. You even have a game plan for your career, so that is I think, more than I did at your age, so you are ahead of where I was at your age, so thanks for sharing that, and your mom Candy is here. I should have introduced you earlier. Mrs. Candy Vazquez is here to be with Colton as his communication supporter.

Next, our third witness is Ms. Bach, thank you for being with us

today and look forward to your testimony.

#### STATEMENT OF CARRIE BACH, DIRECTOR OF MCO OPERATIONS AND BUSINESS INTELLIGENCE VOICES FOR INDEPENDENCE, ERIE, PENNSYLVANIA

Ms. Bach. Thank you for having me today.

The CHAIRMAN. Sure.

Ms. BACH. My name is Carrie Bach, and I am living with quadriplegia as a result of a spinal cord injury from an accident that occurred on November 3d, 2019. I was 41 years old. This accident happened in my own living room when I slipped, broke my neck at the C5, C6 level, which is about in this area, and my life changed forever in the blink of an eye.

Prior to my fall, I worked as a professional in an office just like all of you, but I also had a second career and identity as a professional performer. I am a classically trained ballerina. However, I realized pretty early on that I was not physically built for a career in ballet. I am 5.2" and I had a compact, muscular build, which was not exactly where ballet companies were hiring at the time, so instead I took my training, and I focused it on swing dancing, partnered acrobatics, aerial performance, and stilt walking. This allowed me the opportunity to travel around the United States as well as 33 different countries. I also spent a little time as a competitive bodybuilder. My husband here is also a professional performer, too, with talents that far exceed my own.

We had both decided that we were going to retire as performers that year. In fact, I finished my final gigs three weeks before I fell. However, those are all stories for another day. I am here to talk about November 3rd, 2019, the day both of our lives changed forever and in an instant. We all know that accidents happen every day and it could be any one of us. I even worked for an organization, Voices for Independence, that assist people with disabilities, but I still never thought it would be me.

We planned and saved money for vacations, for buying a new car. We planned for our kid's college educations and our retirement, but no one ever makes plans to have a disability. We just don't. Even though we know it could happen to any one of us or our loved one

at any moment.

When I had my accident, we were both gainfully employed and had retirement accounts set up. I have a State pension plan which I invested in, my husband has a 401k plan, and we both have IRAs. Our income and assets put us above the limit to qualify for

most programs assisting people with disabilities.

When I was in rehabilitation for my injury at UPMC Mercy Hospital, I remember being told that people with ACIs rarely ever return to work, and if they do, it usually takes two to three years. I returned to work three weeks after I left rehab. I also was told by the social workers that my options for going home were for my husband to quit his job to care for me at home, or I would have to go to a nursing facility.

Luckily, I knew from my years of working with the legislature and BFI that I had other options and I discharged to my own home, because of our financial situation and not qualifying for most programs, we immediately amassed a bill over \$70,000 to get our home ready for me. This included new flooring that could withstand the wear and tear of my wheelchair, a ramp, accessible bath-

room, and a van.

We had to wait to install door opener at the cost of over \$6,000. That is all right, I cannot safely exit my home if I was by myself, and a fire broke out. Luckily, we were able to make that investment this year so I can get out of my house. However, the \$6,000 investment does not include the daily medical supplies that are not covered by my insurance.

The past two years, my company has offered a health insurance option for a high deductible health plan with an HSA account. We changed our insurance company this year and there is no longer

the option for an HSA.

Like most people, I read to the policy, but only yet fully understand how much my medical expenses will cost me this year between different deductibles, co-pays, co-insurance, or items that are not covered at all. I also no longer have the benefit of a plan that offers me a program with tax benefits for saving money for my medical expenses.

I do not have the option of an ABLE savings account with similar tax benefits since I acquired my injury and disability after the age of 26. I would absolutely open an ABLE account for my medical expenses right now if the law allowed for it. I was lucky that I did

not sustain a traumatic brain injury when I hit my head.

My brain still works even if my body doesn't. I chose to continue working because I can. My husband and I chose not to spend down our resources so that the Government would be responsible for paying my care. It would be nice to have the opportunity to open an ABLE account where we would have the same tax benefits as other people with disabilities.

Therefore, I urge Congress to pass the ABLE Age Adjustment Act that would change the age requirement to 46 instead of 26 years old for onset of a disability. Thank you for the opportunity

to submit my testimony for this hearing today.

I hope that you will remember and consider my story if this legislation ever does come before you for a vote, and so I do have to leave you with one last question. Have you made your plans for having a disability? Yes, today this is my story, but tomorrow it could just as easily be yours. Thank you very much.

The CHAIRMAN. Carrie, thanks so much for sharing that, and I am going to have to call you by your first name, and your husband Jeff is helping you provide your testimony. We are grateful you are

both here.

Ms. Bach. Yes. He took off work today to be here with me.

The CHAIRMAN. Thanks, Jeff, for doing that and helping our hearing, but Carrie, you made the case for why a ABLE age adjustment has to get passed——

Ms. Bach. Correct.

The CHAIRMAN. Simple as that. Now that I know your story and now that I have been made aware of your legislative experience—

Ms. BACH. Ah, use me up. I am ready. I think that goes for everybody at this table.

The CHAIRMAN. Yes. Visit some offices, and we can give you the address of where those offices are.

Ms. Bach. No problem.

The CHAIRMAN. It is easier to do it in Washington because you can go up and down hallways instead of having to fly from one State to another.

Ms. BACH. Right. Yes. Yes. Absolutely.

The CHAIRMAN. I think I can get the office numbers for you.

Ms. Bach. No problem. It is very interesting to be on this side of the table instead of the other side of the table, but you know, it is also really helpful to me to be on this side of the table and I am happy to do it.

The CHAIRMAN. Well, with your Harrisburg experience, I am

sure, it will help us in Washington.

Ms. BACH. Oh yes, I am sure they still hear my high heels clicking around those halls.

The CHAIRMAN. Well, we are grateful. Thank you.

Ms. BACH. You are welcome.

The CHAIRMAN. Our fourth and final witness, Mr. Duch, you may begin.

# STATEMENT OF ANDREW DUCH, ADVOCATE, GIBSONIA, PENNSYLVANIA

Mr. DUCH. Thank you for this opportunity to testify before the Senate Special Committee on Aging. My name is Andrew Duch. I live in Gibsonia, Pennsylvania, 15 miles North of Pittsburgh.

I am 27 years old and work in stock for Giant Eagle. I have been working for Giant Eagle for nine years. I have a great interest in amusement parks, especially rollercoasters. I am a coin collector and I enjoy the outdoors. I have lived in the Pittsburgh area for my entire life. Also, I was diagnosed with Autism Spectrum Disorder at the age of three.

I received special education services in school and participated in the marching band in high school—go Talbots. In 2013, I graduated from Hampton Township School District. I went on to attend Project Search at UPMC Passavant Hospital, where I trained in

the linen, pharmacy, and emergency room departments.

While I was still in high school, my family and I attended the PA Department of Education's Transition Conference in Hershey, where I learned about PA ABLE. Since I receive benefits like a PFDS waiver and medical assistance, I couldn't have a lot of money in a savings account, or I could lose those benefits, so my family and I found out more about PA ABLE and opened an account.

At the same time I was working part time at Gian Eagle. I am working a lot more hours now than when I started at Giant Eagle. Some weeks I work 40 or a few more hours. Recently, I also became eligible for health insurance. I was glad that Giant Eagle offered me health insurance because I could not be on my parent's insurance anymore.

There are other things that I didn't want to rely on my parents for as an adult, like transportation. I always knew I wanted to learn to drive, but I would need a car. I decided that I would put money—put away money to help buy a car for myself. I used my PA ABLE account to save money.

It is pretty easy to use. When I was still in school in Project Search, I would use paratransit. It was okay, but there are some challenges to using paratransit. I had to call ahead. Sometimes they were late or too early.

Sometimes I had to wait a long time for a ride. When I was 24, I decided it was time to learn to drive. I used the Penn DOT app to practice the written test. It took a few tries, but I passed. Then I took driving lessons. In July 2020, I took my road test and passed on the first try. The next day, my family and I went to look at cars.

We knew I might not find something right away. They showed us some and they were okay, but then they showed me a black cherry Honda Civic. I loved the color, and I liked how the car looked. It was perfect. Thankfully, I had saved quite a bit of money with my PA ABLE account, and I was able to put down a good amount for a down payment.

By putting down more money, my monthly payment and my insurance payments are very manageable. Since I have gotten my license and my car, I am able to drive to and from work. I am able to meet friends at the driving range for my church group and I don't have to rely on my family to drive me around.

If I want to drive to Sheetz for a coffee, I just do it. Using PA ABLE, I was able to save enough money to buy a car. I am much more independent than I was when I had to use paratransit or rely on my family to drive me somewhere.

My car has allowed me to do things I wouldn't have done if I didn't have it, and it gives me independence to do what I want. Now, I am saving so that I can live on my own. I am saving for the first and last month's rent for an apartment.

PA ABLE has helped me learn to save money and taught me that by saving I can get the things I want to live a good life. Thank

The Chairman. Well, Andrew, thanks so much for sharing that, and it is just such a specific example of what ABLE can mean for someone's life. Just the ability to save for, in your case, a car among other savings that you can achieve, so thanks for sharing that. I will start our questions and I will start with, I will come back to Andrew in terms of the order, but I wanted to direct this first question to three of our four witnesses, to Brenda, Colton, and Andrew, because you have ABLE accounts.

When we envisioned these accounts back in 2009, we started working on the legislation and then it passed it in 2014, other Senators and I knew that people and House members as well, we obviously passed it in both places, we knew that people with disabilities were being denied a chance to save, just as several of our witnesses talked about.

We knew that the asset limits for supplemental security income, SSI, and for Medicaid and other Federal assistance programs put arbitrary limits on a person's ability to save and therefore limited their future.

The asset limits for these Federal disability programs were essentially keeping people either close to or in, living within the poverty rate. Since ABLE accounts have been available, these Americans have been able to save, and each of you have highlighted some of those examples today.

I guess I am going to start with Brenda, and maybe Colton, and then Andrew. What is the best thing about having an ABLE account?

Ms. DARE. The best thing for me about having an ABLE account is that now that I am not working, it gives me a little bit of financial security and a place to fall back on. One of the things people don't think about—you mentioned assistive technology.

I have a lifting system in my home that helps me get out of bed every morning. It costs me about \$3,000 a year to maintain that. I can apply to the Office of Vocational Rehab to manage those expenses and pay for them, but that takes months and sometimes I don't have months if the battery decides to die and I all of a sudden need \$1,000 for battery and maintenance.

ABLE gives me that cushion, so it is one less thing I have to worry about, because when those emergencies come up or when the breaks went out on my van, I could just write the check, just like everybody else does. It is not scrambling around to see what support source can I get to the fastest, so it is a real stress relief.

The CHAIRMAN. Brenda, thanks. Colton, how about you, if you could point to one thing, what is the best thing about an ABLE account?

Voice of CANDY VAZQUEZ. What is the best thing about having your own account?

Mr. VAZQUEZ. Account-

Voice of CANDY VAZQUEZ. What do you like the most about it?

Mr. VAZQUEZ. Save money-

Voice of CANDY VAZQUEZ. You like to save money, but you also like to whip out your debit card. Mr. VAZQUEZ. Yes.

Voice of CANDY VAZQUEZ. You like the access.

Mr. VAZQUEZ. Debit card, yes.

Voice of CANDY VAZQUEZ. For dating, right?

Mr. VAZQUEZ. Yes.

The CHAIRMAN. Debit card for dating. That is good.

Voice of CANDY VAZQUEZ. That was awesome. That is exactly what you use it the most for.

The CHAIRMAN. Thanks, Colton. Mr. VAZQUEZ. You are welcome.

The CHAIRMAN. Andrew, how about you? I think we—I might

know your answer. It might rhyme with car.

Mr. Duch. Well, I like to save from my ABLE account because, what if I need tires changed on my car? What if my engine needs to be replaced? I could use some of that money for it, I have some money in my drawer, actually, where I live.

I can probably use some of that to use for if I want to change my tires, if my engine needs to be replaced, or if something where to happen on my car. I could definitely use it for things like that.

The CHAIRMAN. Yes, and Carrie for you, if you had an ABLE account, what would be the best use of it for you the best?

Ms. BACH. Well, for me, I would most likely use mine kind of as an in and out to pay my bills, but yet still get the tax benefit of placing the money in the account. As a full time employee, those are the types of things that help us plan for our future, but you know, as I said in my testimony, \$76,000 right out the door just to come home.

You know, those are the types of things that people can't afford to do. That was really a struggle for us. That was part of my motivation for getting back to work after just three weeks, is that I had

a bill to pay off, so we had to get going.

That and of course, you know, I was just sitting around, so I felt idle. Work is very important to me, but that is probably how I would use mine, as more of an in and out for medical expenses as

they come up.

The CHAIRMAN. Well, and I wanted to stay with you for a question. As I menioned earlier, we believe that if we can pass the ABLE age adjustment, as you have been advocating for, that about 6.2 million Americans would become eligible, and after you had shared your story about your injury, I guess at that time you were how old?

Ms. Bach. I was 41. The CHAIRMAN. 41.

Ms. Bach. I will never forget.

The CHAIRMAN. Well, and we know that there are a lot of Americans in that category—

Ms. Bach. Absolutely.

The CHAIRMAN [continuing]. who have those injuries. I am told that it is 18,000 spinal cord injuries each year, and most of those 18,000 are older than the age of 26. I guess you may have already answered this question by way of your testimony, but when you consider just those Americans, what is the best case for the ABLE Act for those Americans?

Ms. BACH. How do we get them to sign up? Well, you know, Brenda actually tested, or touched on this in her testimony, the fear. There is a general fear of losing other benefits that you just, you can't take that chance, because for me, if I didn't have personal assistance services, I would not be able to get out of my bed. I can't do that on my own. I have to have somebody else there with me, so to lose a service like that—now again, my—I am able to have that through a different program in Pennsylvania called the Act 150 Program, and that is unique to Pennsylvania and allows people with—who are working or have a slightly higher income to have PAF benefits where you pay on a sliding scale based on your income, but to lose those benefits, at the risk of this new account, where I am told that I can save something but what if in the end it doesn't work and I lose everything, that is the reality, I think, of what we are going to be dealing with, and so I think that one of the best ways to do that is word of mouth of people who are actively using this account, doing something at-for example, I work for a Center for Independent Living. If I was able to open one, I am going and I am talking to my coworkers about how to do it.

Getting them to open up an account because they are the ones that are working with other people with disabilities every day and can encourage them and let them know that it is exactly as it seems. You are not going to lose your benefits over making this investment. As big or as small as it may be, get it started, but I think we need to do it by example.

The CHAIRMAN. Yes. Well, thanks. I know when you are advocating for this bill, you are speaking for not just folks who might be beyond the age limit, but individuals who have suffered the same injury you have, so.

Ms. BACH. Absolutely.

The CHAIRMAN. You are being a voice for them. I want to turn back to Brenda. One of the greatest challenges for some people with disabilities is finding home. Affordable housing is challenging for everyone and that goes beyond the disability community, but ever more so if you are in the disability community.

We are told that a 2020 study found that only six percent of apartments or homes in the United States are accessible. Six percent of homes and apartments accessible in the United States of America.

I say that again with emphasis. Brenda, can you tell us how you are planning to use your ABLE account to help improve your housing situation if you have used funds to make your home more accessible?

Ms. DARE. Well, I have used ABLE to help maintain the equipment that makes my home accessible to me, but I just want to reit-

erate, when you are talking about one in five Americans that have a disability of some sort. That six percent of homes and housing stock is woefully insufficient. When we bought our home, we looked at 32 houses in 16 months.

We bought the one that I could get inside of. It still required two years? worth of modifications. If I had had an ABLE account at that time, the timeframe for those modifications would have been greatly reduced, but because I had to depend on the Office of Vocational Rehabilitation, it took two years for a concrete pad in our driveway and a lifting system to be installed.

That was all that needed done. For people that are aware of what those things are, that should have been six months at the most rather than almost two years, so I think having my ABLE account and being able to tell people, if you really want to help us out as a family, if you really want to help me out, if you know that I have gone—I am going through some tough health stuff right now, if you want to help out, I tell people, use the you gift code for some money in my ABLE account.

I don't need flowers. I don't need cards, but what we need as a family is to increase that financial buffer we have, and it has really been, I think, a powerful thing to be able to say to people, this is how you can really make a difference.

The CHAIRMAN. Brenda, you said for those home improvements,

you needed a concrete pad and what was the other thing?

Ms. DARE. I needed a lifting system put in. It is called a surehands lift. It attaches to the ceiling and picks me up and can even pick me up off the floor, but it gets me out of bed and into my chair. Out of my chair and onto the toilet and into the shower. Greatest piece of equipment I have ever owned.

I would like to see them become more common, but they are very expensive, and I think that ABLE gives people some ability to have those things, but also some very simple things. There is an 8-year old over there in the chair who really wants to go to Disney World.

It is going to cost me some extra money to take a personal care assistant with us to make sure that the car rental we have is accessible, to make sure that everything we need is on that trip. ABLE will be part of that, and no, Kaitlyn, I am not saying it is coming next week.

The CHAIRMAN. Well, you are very focused on that future.

Ms. DARE. Yes, and to speak to what you were saying about how to reach people, I think people really do not only have to see it from us, they have to start hearing it from financial services professionals that they encounter on an everyday basis.

The CHAIRMAN. Right.

Ms. DARE. You know, back when we had a retirement account where I worked, I went to our planner when I was thinking about opening ABLE account. I would have opened it sooner except that he said, I don't know anything about that, and your employer is not going to match, so, you know, you are better off just using our account. It shouldn't be that way.

We should have the ability to do a one-time rollover of a larger amount every once in a while if, say, an inheritance comes, and financial planners need to know how ABLE works and how it interacts with other programs so that they can offer, you know, really

good advice.

The CHAIRMAN. Well, Brenda, thanks for that. I wanted to turn to Colton for a question about education and employment. We know that, as I made reference to earlier, the unemployment rate for people with disabilities is less than half for that of people without disabilities.

We are grateful today that our witnesses here today are working and that some of you hold multiple jobs. That is not easy. Colton, I know you have been using some of your ABLE funds to be able to prepare for and interview for jobs.

Can you tell us how you have used ABLE savings to prepare for a job interviews, and tell us about some of those interviews, if you

don't mind.

Mr. VAZQUEZ. I—audition in Florida——

Voice of CANDY VAZQUEZ. What did you audition for in Florida? Mr. VAZQUEZ. Sesame Street.

Voice of CANDY VAZQUEZ. Sesame Street, and then where else?

Mr. VAZQUEZ. At New York.

Voice of CANDY VAZQUEZ. New York City?

Mr. VAZQUEZ. Yes.

Voice of CANDY VAZQUEZ. What did you audition for there?

Mr. VAZQUEZ. A movie.

Voice of CANDY VAZQUEZ. For the Netflix show Orange is the New Black?

Mr. VAZQUEZ. Yes.

Voice of CANDY VAZQUEZ. Pittsburgh has some performance, but you have to go to other cities all the time, right?

Mr. VAZQUEZ. Yes.

Voice of CANDY VAZQUEZ. It is expensive. Where else are you headed to, for the movies?

Mr. VAZQUEZ. Yes.

Voice of CANDY VAZQUEZ. To California. Colton is exhausted because of work

The CHAIRMAN. Oh, yes. I was going to say, sorry for that delay. I wanted to make sure that—but, so you are planning to go to California.

Mr. VAZQUEZ. Yes.

The CHAIRMAN. You have been to New York and Florida. You have got a busy schedule for a college senior. That is the reality for folks who are pursuing their career goals or dreams.

Mr. VAZQUEZ. Yes.

The CHAIRMAN. Sometimes you have to travel and traveling costs money, and Colton is able to use those funds to prepare for and take advantage of those opportunities to audition, and that is—in essence, we all, at some point in our lives, are auditioning. A job interview is an audition of any kind, so we are grateful that he is willing to share that story with us, and Colton all I can say is, I don't think you are going to need luck, but I wish you luck when you go to California, too. I just hope you come back to Pittsburgh. We don't mind you leaving Pennsylvania for a while. We hope you come back, but I wanted to turn next to a question for a number of our witnesses, for Brenda and Andrew and Colton again. Then I think we will at that point probably wrap up.

I mentioned in my opening statement, there are about 120,000 ABLE account owners across the country that have now saved \$1 billion. I am not sure I said that, but I know I set it out in an interview walking in the door, but to have \$1 billion in assets saved across the country is a significant advancement for the Nation, but we want to get that number up and we want to get the account holder number way up, so we know that those who have those accounts have a measure of financial security they wouldn't have otherwise, and we know that for some, they might be aware of ABLE, they might be aware of the opportunity, but we still hear stories about people being hesitant, reluctant, whatever the word is, to open an ABLE account.

Some say that opening an account is difficult and some are scared that their benefits will be affected. That fear that Brenda and others have spoken to still persists, even though we have an avenue or a pathway that wasn't available before under the tax

I wanted to ask Brenda, then Colton and Andrew, can you talk about the experience of actually opening the account, opening an ABLE account, and if it has had any effect on your Federal disability benefits? Maybe Brenda, we will start with you.

Ms. DARE. Well, for me, it was very easy. Now, I had the advantage of, I helped consumers open their accounts from the time the program launched, but I opened my account at 3:00 a.m. I wascouldn't sleep. I took out my iPad. I knew that a bit of a windfall was coming my way thanks to a very generous bonus from my employer, and I just went ahead and opened the account online.

One of the things I think would have been less intimidating to me would have been if I could have opened an account with a bank that I was already familiar with. The limited number of providers,

I think, will be a barrier for some folks.

The fact that I deal with one bank for my everyday spending and another bank for my ABLE is something I am able to manage, but a lot of people see that as a hassle. They don't want-

The CHAIRMAN. Having to go to another bank for another part

Ms. DARE. Right, because in Pennsylvania, only Fifth Third offers ABLE accounts, and as a lifelong PNC customer, I had the same bank account since I was 16, you know, it is a lot to have to manage that second relationship, and for some folks, that is a barrier. They just, they are very resistant to that change.

The CHAIRMAN. Brenda, I want to be clear, you recommending

that everyone open their ABLE account at 3:00 a.m.?

Ms. DARE. I recommend that everybody open their ABLE account as soon as they are eligible. I think it should be something that when younger folks come out of rehab, they should be given that pamphlet. They should sit down with somebody who understands it and just get it open, even if it is just \$5 or \$10.

You know, I waited until I had a fair amount of resources, and that was not very smart of me, I will freely admit. For all the things I am good at in this life, I am not good with money. I am

working to change that, thanks to ABLE.

The CHAIRMAN. That recommendation about getting that information just as you are finishing a rehabilitation is important.

Ms. DARE. Yes, and also high school seniors. Kids who grow up grow up with disabilities, it should be part of their transition planning.

The CHAIRMAN. Colton, how about you?

Voice of CANDY VAZQUEZ. Do you remember when we opened your account? We did it together.

Mr. VAZQUEZ. Oh, yes.

Voice of CANDY VAZQUEZ. How did we do it?

Mr. VAZQUEZ. Do it——

Voice of CANDY VAZQUEZ. On a computer. I support Colton with this financial, and I know everything that Brenda said on the transition, schools should be told about this. Colton had his first job in eighth grade at 14 and paid taxes and earned money. He should have known then, and the, you know, putting it in those hands and also a bank that was—actually had a branch in Pennsylvania would be a huge benefit. He currently has three checks that need to be deposited, and sometimes there is a delay because of just getting organized, huh?

Mr. VAZQUEZ. Yes.

The CHAIRMAN. A Pennsylvania branch would be-

Voice of CANDY VAZQUEZ. Would be really nice. That was easy, huh? We didn't have to do anything other than a computer.

The CHAIRMAN. Yes. Andrew, how about you?

Mr. Duch. Well, for me—

The CHAIRMAN. Was it 3:00 a.m.?

Mr. Duch. No, it was not. For me, I get up to PFDS waiver services, and that has not impacted my benefits at all. I actually had enough—I had enough money in my ABLE account to put a down payment on my Honda Civic that I mentioned, and I plan to save even more of that money probably for an apartment down the road when I move out of my parents' house.

The CHAIRMAN. That is great. You have had the car how long?

Mr. Duch. About two years.

The CHAIRMAN. Two years. Does it run pretty well?

Mr. Duch. Yes.

The CHAIRMAN. That is great. We just need to get gas prices even lower, right?

Mr. DUCH. Yes.

The CHAIRMAN. Well, that will be the subject of another hearing. I guess the last thing I wanted to ask about was some suggestions for others who may hear about the work we are all trying to do together. One of the great promoters and really the offices around the country that are implementing the ABLE Act are State Treasury offices around the Commonwealth and—or I should say around the Commonwealth, around the country and including here in Pennsylvania.

Our State Treasurer, Stacey Garrity and her team have work to promote ABLE accounts all over the State and are also advocating for the passage of the ABLE Age Adjustment Act. Our office in Pennsylvania has done a lot of outreach to inform people about these accounts, and as I said earlier, we have got almost 7,000 accounts in Pennsylvania, and we have accounts in 64 out of 67 counties, which is significant. There is three we don't and working on all three, but there are thousands more people that are eligible for

ABLE accounts both in our State and around the country, if we can

get this legislation passed to raise that age.

I guess for all of our witnesses, maybe I will start with Carrie, what are your suggestions for reassuring people the ABLE will not affect eligibility for Federal disability benefits? And how do we encourage—how should we encourage people to become ABLE account owners?

Ms. Bach. Sure. First of all, I have to share two secrets.

The CHAIRMAN. Sure.

Ms. Bach. This one is for Colton. My husband and I used to be mascots. My name was Whiplash, and he was Clutch.

The CHAIRMAN. Wow.

Ms. BACH. We have—yes, we have that in common. That is hard work. Really hard work, and good for you, and the other secret is, that my husband works in that field. He whispered in my ear. He said, I should be telling people about this.

Ms. Dare. Do you feel like you are sufficiently informed enough

to do that, Jeff?

Mr. Bach. I absolutely do. I am a branch manager and a mortgage lender, and I often run into people that say, I want to buy a house, but I am not allowed to have money, and an obstacle to buy a house is you have to have a down payment and pay closing costs, so either a program that allows for no down payment, which is not likely, but something that will allow people to grow an asset to be able to spend for that, because otherwise they are victims of whatever the landlord decides to raise the rent to.

Ms. DARE. Right, right.

Ms. BACH. They are also stashing money. You know, it is not safe to do that, but they are stashing money, some in safes and some they are taking it old school and boxes and burying it.

Ms. DARE. You heard about my water cooler bottle during my testimony, and that is where my savings was for a very long time.

Ms. Bach. I heard nothing about that water bottle. I heard absolutely nothing, but yes, this program would help, as Jeff said, for those individuals to not be collecting it in a box buried in the ground, which doesn't help them in securing a mortgage. You have to have that money in the bank, and as soon as they put it in the bank, it triggers that review that is going to knock them off of their benefits.

The CHAIRMAN. Yes.

Ms. DARE. I just have to add one comment to your testimony, Carrie, and that is that even Act 150 has an asset limit, so I know that you play a shell game in making sure things get moved around properly but having an ABLE account would remove that stress from you as well.

Ms. Bach. Absolutely, and I have a good SC, service coordinator that, you know, helps me navigate that program.

The CHAIRMAN. Well, anybody else? Colton, did you want to add anything or not?

Voice of CANDY VAZQUEZ. What would you tell them?

Mr. VAZQUEZ. Just do it.

Voice of CANDY VAZQUEZ. Just do it.

The CHAIRMAN. Just do it.

Voice of CANDY VAZQUEZ. Never looked back, and it has not affected any benefits ever.

Mr. VAZQUEZ. Yes.

The CHAIRMAN. Maybe we could add just to it at any time of the day, right?

Ms. Dare. Yes.

The CHAIRMAN. Well, let me—unless Andrew, you have anything

you want to say?

Mr. Duch. What you mentioned about the Senate—I think the passage of this Act will expand eligibility for Pennsylvanians because there is a lot of them that are like in their 30's and 40's that don't have ABLE at all. The passage of this Act will expand that, and expand the three counties that we don't have.

The Chairman. We may have to put you on the road. You have

got a car.

Ms. Dare. Yes.

The CHAIRMAN. Those three counties from here are a pretty good ride but I think he could make it. Well, thank you very much. I just want to read for the record a closing statement, but I want to start with gratitude. I can't thank our witnesses enough, and those who are working with our witnesses, for today and getting here and taking the time to do this, because I could give 150,000 speeches, but that won't have the same impact as your testimony.

I am not saying that to convey some kind of humility, it is actually the truth. The best way for us to tell the story of why it is important to pass the bill is to have you tell your stories, right, and nothing is more compelling to a fellow human being than hearing

another human being tell their story.

All the charts and data are not nearly as persuasive and as important and meaningful as the testimony that you are providing today, so I know that you are doing this because you care about these issues, but I want you to know that you are helping your country by making the case for ABLE age adjustment, so we are grateful for that, and speaking of our country, in a country as prosperous as the United States of America, no one with a disability should be forced to live in poverty to provide essential benefits. No one should be forced to live in poverty.

As our witnesses told us, people with disabilities are often, as Brenda said, taught to fear, building wealth. No American should be taught to fear building wealth and providing savings for themselves and for their families, and thanks to ABLE accounts, that no longer is the case for millions of Americans, but we have more work to do to improve the ABLE program, so I want to thank, I want to thank Brenda and Carrie and Colton and Andrew for sharing their stories about what an ABLE account can help them accomplish in their lives, whether it is saving for a rainy day, paying for health care expenses, buying a house, buying a car, even traveling halfway across the country to go audition for the job of your dreams.

These goals can all be supported by ABLE savings accounts. In addition to the testimony of our witnesses today, we had a number of Pennsylvanians write to us about their ABLE accounts, their own personal experience, their own testimony.

I want to submit for the record nine additional, I am holding them up now, nine additional statements from Pennsylvanians highlighting how they are using their ABLE accounts for everyday needs to meet their long term goals, so we will make these a part of the record. As we say, without objection.

People with disabilities have goals, they have dreams, they have ambitions, just like every other American, and we want to make sure that we provide every tool necessary, every tool, every support that we can to allow them to fulfill those dreams and to achieve

those ambitions.

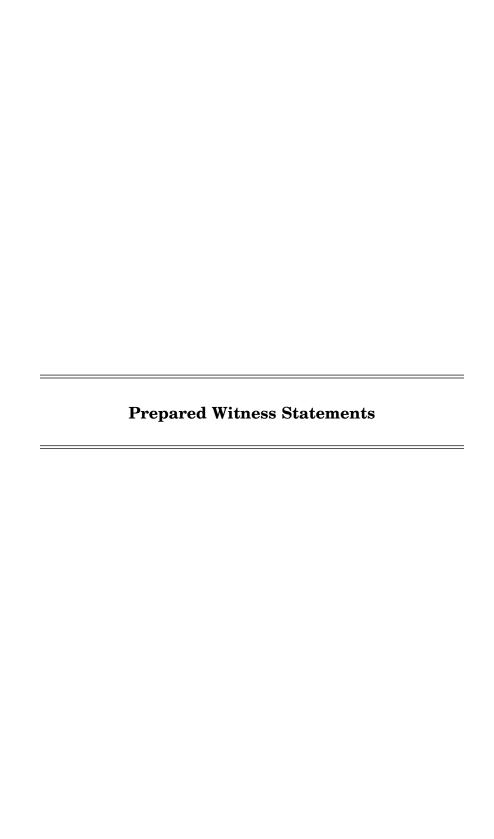
Everyone deserves the opportunity to work and to be able to save for emergencies and future goals. ABLE gives that opportunity to eight million people with disabilities. The ABLE Age Adjustment Act, the Senate bill I mentioned, Senate Bill 331, will expand that opportunity to another 6.2 million Americans, including, as I have said, more than one million veterans.

I want to thank all the witnesses for contributing their time, and as I mentioned earlier, sharing their experiences and telling us their stories to help us pass the bill. The hearing record will remain open until Thursday, August 24th for additional statements for the record.

I want to thank you all for participating, and that will conclude today's hearing.

[Whereupon, at 10:39 a.m., the hearing was adjourned.]





#### Testimony of Brenda Dare

#### Senate Special Committee on Aging Hearing

Saving with ABLE: Financial Security for Pennsylvanians with Disabilities

August 17, 2022

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 to 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.

#### Testimony of Colton Vazquez

#### Senate Special Committee on Aging Hearing

Saving with ABLE: Financial Security for Pennsylvanians with Disabilities

#### August 17, 2022

Good morning, Senator Casey. My name is Colton Vazquez, and I am 23 years old. I was born with multiple disabilities, and I live in Pittsburgh. And I have voted in every election since I turned 18 years old. I am a senior at Duquesne University. Thank you for inviting me to speak. I am here to talk to you about why my ABLE bank account is so important to me.

I started working and paying taxes when I was 14 years old. This summer I have 4 jobs. I love to work and I'm proud to earn my own money. I'm studying Theater and Acting at Duquesne University and want to work in the theater.

I travel to different cities to audition for theater jobs. I have to save money so I can pay for it. In June I flew to Orlando, Florida to audition for Sesame Street Live. I made it to the finals and have a real shot at working for Sesame Street. My dream is to become a member of the Wiggles and perform for kids. I am now saving my money to go to Australia and audition for the Wiggles. It will cost several thousands of dollars to do that. I met the Wiggles in Pittsburgh and performed on stage with them four years ago. I know I can do it. But I must have a way to save my money.

It has always been my dream to get my own place and get married. I also want to have a dog. All of these things cost lots of money. I have to be able to save money to do this. Without an ABLE account, I am only allowed to save \$2000. That is not enough money to buy a house or condo. If you allow me to save money, I can provide many of my own supports. I will always need some help, and I must have health insurance. But I am capable and need the chance to save money without being afraid of losing my other benefits.

#### Witness Testimony for United States Senate Special Committee on Aging

ABLE Account Hearing
Pittsburgh, PA
August 17,2022
Submitted by Carrie L. Bach

Director of MCO Operations & Business Intelligence, Voices for Independence

My name is Carrie Bach, and I am living with Quadriplegia as a result of a Spinal Cord Injury (SCI) from an accident that occurred on November 3, 2019. I was 41 years old. This accident happened in my own living room when I slipped, broke my neck at the C5-C6 level, and my life changed forever in the blink of an eye.

Prior to my fall, I worked as a professional in an office just like all of you, but I also had a second career and identity as a professional performer. I am a classically trained ballerina; however, I realized early on that I was not physically built for a career in ballet. I am 5'2", and I had a compact, muscular build, not exactly what ballet companies hire. I took my training and focused it on swing dancing, partnered acrobatics, aerial performance, and stilt walking. This allowed me the opportunity to travel and perform around the United States and 33 countries. I also spent time as a competitive bodybuilder.

My husband is a professional performer, too, with talents that far exceed my own. We had both decided that we were going to retire as performers that year – in fact, I finished my final gig three weeks before I fell. However, those are all stories for another day. I am here to talk about November 3, 2019 – the day both of our lives changed in an instant.

We all know that accidents happen every day, and it could be any one of us. I even worked for an organization, Voices for Independence (VFI), that assists people with disabilities, but I still never thought it would be me. We plan and save money for vacations, buying a new car; we plan for our kids college educations and our retirement, but no one ever makes plans to have a disability. We just don't - even though we know it could happen to us or one of our loved ones at any moment. That is exactly what happened to my husband and me.

When I had my accident, we were both gainfully employed and had retirement accounts set up. I have a state pension in which I am vested, my husband has a 401(k) plan, and we both have IRAs. Our income and assets put us above the limit to qualify for most programs assisting people with disabilities. When I was in rehabilitation for my injury at UPMC Mercy Hospital, I remember being told that people with SCIs *rarely* return to work, and if they do, it usually takes 2-3 years. I returned to work 3 weeks after I left rehab.

I was also told by the social workers, whose job is to prepare people for a safe discharge, that my options were for my husband to quit his job to care for me at home or go to a nursing facility. Luckily, I knew from my years of working with the legislature and VFI that I had other options, and I discharged to my own home...well, a hotel to start while our home modifications were being completed, but then my own home.

Because of our financial situation and not qualifying for most programs, we immediately amassed a bill over \$70,000 to get our home ready for me. This included new flooring that could withstand the wear and tear of my wheelchair, a ramp, accessible bathroom, and a van. We had to wait to install a door opener at a cost of over \$6000. That's right, I could not safely exit my home if I was by myself if a fire broke out. We finally were able to make that investment this past year. That \$76,000 investment does not include the daily medical supplies that are not covered by insurance.

Speaking of insurance, my company's plan included 20 physical therapy sessions per year. I ran through those 20 sessions in two and a half months. That is certainly not enough therapy for a SCI; I was doing 6 hours each day at UPMC Mercy. What do you do the rest of the year to continue progressing when it takes three people to help you get in your braces to do therapy? I pay out-of-pocket because while I have finally, after almost 3 years, accepted that this is my "today," I simply CANNOT bring myself to accept that this is my "tomorrow."

The past two years, my company offered a health insurance option for a High Deductible Health Plan with a healthcare savings account (HAS) account. We changed insurance companies this year, and there is no longer the option for an HSA. Like most people, I read through the policy, but I do not yet fully understand how much my medical expenses will cost me this year between different deductibles, copays, co-insurance, or items that are not covered at all. I also no longer have the benefit of a plan that offers me a program with tax benefits for saving money for my medical expenses. I do not have the option of an ABLE Savings Account with similar tax benefits since I acquired my injury and disability after the age of 26. I would absolutely open an ABLE account for my medical expenses right now if the law allowed for it.

I was lucky in that I did not sustain a traumatic brain injury when I hit my head. My brain still works even if my body does not work. I chose to continue working because I can. I find my work fulfilling and necessary for so many reasons, personal and professional. My husband and I chose to not spend down our resources so the government would be responsible for paying for my care. When I say that, I am not being critical of those who may not have the option to work and do need government programs. What I am saying is that it would be nice to have the opportunity to open an ABLE account where we would have the same tax benefits. Therefore, I urge Congress to pass the ABLE Age Adjustment Act that would change the age requirement to 46 instead of 26 years old for onset of a disability.

Thank you for the opportunity to submit my testimony for this hearing on behalf of myself and others with situations similar to mine. I hope that you will remember and consider my story if this legislation comes before you for a vote. And so, I leave you with this last question...have you made plans for having a disability? Today, this is my story, but tomorrow it could just as easily be yours.

If you have any questions or would like additional information, I will make my self available to you and your colleagues. I can be reached by phone at 814.806.5449 or by email at cbach@vficil.org.

#### Testimony of Andrew Duch

#### Senate Special Committee on Aging Hearing

Saving with ABLE: Financial Security for Pennsylvanians with Disabilities

## August 17, 2022

Good morning, Chairman Casey. Thank you for this opportunity to testify before, the Senate Special Committee on Aging.

My name is Andrew Duch. I live in Gibsonia Pennsylvania, 15 miles north of Pittsburgh. I'm 27 years old and work in stock for Giant Eagle. I have been working for Giant Eagle for 9 years. I have a great interest in amusement parks, especially roller coasters. I am a coin collector and I enjoy the outdoors. I have lived in the Pittsburgh area for my entire life.

Also, I was diagnosed with Autism Spectrum Disorder at the age of 3. I received special education services in school and participated in the Marching Band in High School—GO TALBOTS.

In 2013, I graduated from Hampton Township School District. I went on to attend Project SEARCH at UPMC Passavant Hospital where I trained in the linen, pharmacy and Emergency Room departments.

While I was still in high school, my family and I attended the PA Department of Education's Transition Conference in Hershey where I learned about PA ABLE. Since I receive benefits like a PFDS waiver and Medical Assistance, I couldn't have a lot of money in a savings account or I could lose those benefits. So my family and I found out more about PA ABLE and opened an account.

At the same time, I was working part time at Giant Eagle. I am working a lot more hours now than when I started at Giant Eagle. Some weeks I work 40 or a few more hours. Recently I also became eligible for health insurance. I was glad that Giant Eagle offered me health insurance because I could not be on my parent's insurance anymore.

There are other things that I didn't want to rely on my parents for as an adult---like transportation.

I always knew I wanted to learn to drive, but I'd need a car. So I decided that I would put away money to help buy a car for myself. I used my PA ABLE account to save money. It's pretty easy to use.

When I was still in school and at Project SEARCH, I would use para-transit. It was ok, but there are some challenges to using para-transit. I had to call ahead. Sometimes they were late, or too early. Sometimes I had to wait a long time for a ride.

When I was 24, I decided it was time to learn to drive. I used the Penn DOT app to practice the written test. It took a few tries, but I PASSED!

Then I took driving lessons. In July of 2020, I took my road test and PASSED on the first try!

The next day my family and I went to look at cars. We knew I might not find something right away. They showed us some and they were ok. But then they showed me a black cherry Honda Civic. I loved the color and I liked how the car looked. It was perfect.

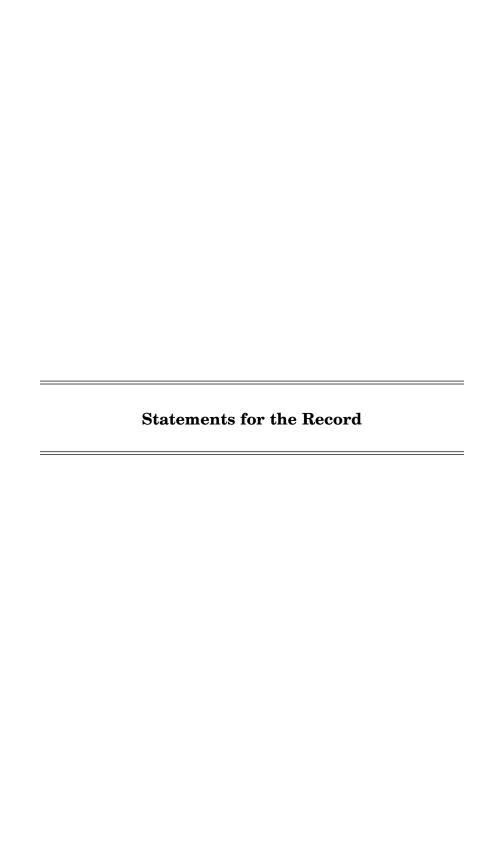
Thankfully, I had saved quite a bit of money with my PA ABLE account and I was able to put down a good amount for a down payment. By putting down more money, my monthly payments (and my insurance payments!) are very manageable.

Since I've gotten my license and my car, I am able to drive to and from work. I am able to meet friends at the driving range or my church group and I don't have to rely on my family to drive me around. If I want to drive to Sheetz for a coffee, I just do it.

Using PA ABLE, I was able to save enough money to buy a car. I am much more independent than I was when I had to use para-transit or rely on my family to drive me somewhere. My car has allowed me to do things I wouldn't have done if I didn't have it and it gives me independence to do what I want.

Now I am saving so that I can live on my own. I am saving for the first and last months rent for an apartment.

PA ABLE has helped me learn to save money and taught me that by saving, I can get the things I want to live a good life.



Lucinda Schaeffer Statement for the Record on behalf of Adam Schaeffer for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities"

August 17, 2022

This is my witness statement regarding PA ABLE.

My name is Lucinda Schaeffer, and I have a 20-year-old son, Adam. Adam has autism and intellectual disability. He is ready to begin his final year of school. We started an ABLE account for Adam a few years ago when we learned about the program from community members, heard about it at conferences, and saw that some of our friends opened accounts for their disabled children.

At that time, I understood the ABLE account would provide a shelter for savings that would not count against Adam when he began to receive SSI, but I did not know much else about the benefits. Now I have come to understand the ABLE accounts can be used for necessities such as housing, medical events, and other important expenses a person may face in their lifetime.

What I find as the beauty of Adam's ABLE account is that he can now be a saver. With the government's rule that disabled individuals receiving benefits may only have \$2,000 in their name at one time, I encouraged Adam to "spend, spend, spend." My daughter, Abigail, who is 15 years old, only hears me say, "save, save, save." How terrible is it to have a child encouraged to use all his money each month, not save for something special, and have nothing set aside for emergencies?

Now that we have an ABLE account, Adam can learn the importance of saving and being prepared. Instead of receiving money for special events like birthdays and holidays, family and friends can make deposits to Adam's account. I am thankful for this opportunity for my son and now find myself encouraging other parents of children with disabilities to consider opening an account.

Astrid Arroyo and Michael Uzyak's Statement for the Record for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities" August 17, 2022

We are Astrid Arroyo and Michael Uzyak, parents and legal guardians of Kai Arroyo, a 21-year-old with intellectual and physical disabilities. In March of 2022, we opened an ABLE account on Kai's behalf with the primary purpose of ensuring that he could save money from his SSI income for things not paid for through Medical Assistance/Waiver without jeopardizing those benefits due to the \$2000 asset cap.

While we are very thankful that the ABLE program exists (and firmly believe it should be expanded to include Pennsylvanians of all ages), the fact that it was necessary for the state to establish an investment/savings vehicle to avoid the asset cap is clear evidence that the rules governing income and assets for individuals with disabilities need to be changed. It is unfair and that these people are forced to walk a tightrope along the poverty line in order to receive the full benefits they are due.

We are both college educated individuals who have familiarity with savings accounts, 401(k) plans, etc. Even with that experience and the great support from the staff at ABLE, setting up and managing an account is not easy. Make no mistake: this is a burdensome process, and families already dealing with the difficulties of living with a disability do not need any additional handicaps placed on them.

Thank you very much for the opportunity to provide this testimony, and for your continued support of Pennsylvanians with disabilities and their families.

Astrid Arroyo Michael Uzyak

## Jacey Surbrook's Statement for the Record for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities" August 17, 2022

I was born with my disability which is Cerebral Palsy. It affects just the right side of my body and by looking at me, however, it would not appear that I have it. This at times can make it difficult for me to get services because I do not look like I have a disability. During my childhood I always had services. However, once I turned 17 years old the services stopped. I was discharged from the services and myself and my parents were not given enough information and guidance on agencies that could continue to help me. The individuals that worked with me for years never said anything about agencies that I know about today. As an adult I tried to get SSDI benefits but was denied because I made too much money. I was working two jobs with no health insurance and still was denied. I could have been on SSDI benefits as a child but because my dad has a good job that paid well things were assumed to be fine and there was no need for it. The only service I did receive for a little while was through The Office of Vocational Rehabilitation or OVR. I have struggled and still struggle. I try to persevere as best as possible.

Because of what I have experienced, the PAABLE account has already helped my tremendously. I have not used the money that I have in it yet, but I am saving up to get a service dog to help me with my mobility issues with falling and some daily life activities like helping with carrying groceries. It will also help me in the future for when I plan on buying a home and need accommodations/modifications in it as well as adaptive equipment in my car in order for me to drive. I would like to get another set of this equipment for a second car. This account will also help with anything that may come about in the future. My only vise with the account is the

minimum amount we need to put into it. \$25.00 for some people is a lot and it would be nice to decide for yourself how much you can put into it. I really like that there is no hoops and waiting periods to have this. PAABLE accounts are a godsend for the disability community and will make such a difference for life today and in the future!

Sincerely,

Jacey Surbrook

Kelly Barrett Statement for the Record for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities"

August 17, 2022

My name is Kelly Barrett, I reside at 211 Preston Avenue, Apt. 1D, Erie Pennsylvania 16511. I am a 33-year-old woman born with Cerebral Palsy. I utilize a power wheelchair for mobility and home and community-based services to live and work in my community.

In recent years, safety has been a topic on the forefront. As a young woman with a disability, I have had to re-examine my perspective on safety and guard it even more closely, as I have a plethora of unique needs to meet in order to live and thrive every day. My ABLE account, which has grown to save approximately \$50,000 over the last five years is an irreplaceable tool that I utilize to ensure my safety

The primary mode of transportation I use is an accessible van driven by any of the many members of my support network. My current vehicle has required several major repairs in the last few years. When these repairs are needed, I have to seek out specialized mechanics to work on my vehicle, which can take weeks or months to schedule. As a result, due to my demanding work schedule, I find myself putting off repairs because the necessity for personal accessible transportation is essential; however at the same time, I am risking my safety. My ABLE account allows me to save for a new accessible vehicle. With the ability to save for a vehicle, I have the opportunity to create a source of financing for an accessible vehicle that is available when I need it. Many of the processes to obtain funding may take several months and would not be immediately helpful in an emergency.

Shelter is often a great source of safety for many. People with disabilities, including myself, have faced a crisis in available accessible housing stock for decades. It is so important to me to be able to care for my family in a safe and healthy environment. Currently I am renting an apartment that mostly fits my needs with my partner Armando and our daughter Elizabeth. I am using my ABLE account to save for the purchase of an accessible home. In my experience however, I have come to learn that home modifications to existing homes are limited by the structure itself; as such, I would like to purchase land and build a customized completely accessible home for myself and my family. I envision open spaces for all of my durable medical equipment, access to a bathtub for the simple luxury of a bath, and home automations so that I have access to doors, lights, and thermostats.

Finally, it can sometimes be a hard concept to grasp, but I have to think about how I would survive if my life took a turn for the worst. What if I lose my job? What if I become seriously Ill and that compounds with my disability? In that worst case scenario, there is money in my ABLE account to maintain my current rent payment and buy food. I would be able to continue to pay out of pocket for medications and supplies I use every day that Medicaid and Medicare do not cover. There is a sense of relief and security knowing that the money in my ABLE account belongs to me and cannot be taken away, in a world where so much in my life hangs in the balance.

Kathy A. Hertzog's Statement for the Record for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities" August 17, 2022

Kathy A. Hertzog 1018 West 20th Street Erie PA 16502-2403 Mobile: 814-397-2863

Email: kathyzog28@gmail.com Date Prepared: 07/21/2022



#### 1. Tell us about yourself, your background, etc.

- I'm the oldest of two children. I'm currently 58 years old. I either have Cerebral Palsy and/or a high Incomplete C3/C4 Spinal Cord Injury caused at or during birth. In my teens, I acquired scoliosis, and began wearing a plastic molded back brace during the day to support my trunk. I use a powered wheelchair for mobility. And, I rely on attendants for almost all my needs. I type on my computer using a mouth-stick on a specially designed Maltron keyboard which I originally obtained from England.
- During my youth into my early teens, I attended the Easter Seals Camp Lily summer program
  which was great fun for me and gave my parents some well deserved respite during the
  weekdays.
- In 1978, I was mainstreamed into 6th grade from special education (half-day mornings) into
  the public school system (half-day afternoons). By 7th grade, I attended public school full-time
  and graduated from Exeter Township Senior High School with honors in 1984.
- When it came to college choice, the Office of Vocational Rehabilitation gave me the option to
  choose Edinboro or Edinboro, so naturally, I chose Edinboro, a mere 7 to 8 hour drive away
  from home, but where 24-hour attendant care, meal aides, academic aides to assist with
  writing and research, and other disability supports were available. I went on to graduate Cum
  Laud with a Bachelor of Arts degree in Speech Communications from Edinboro University of
  Pennsylvania in December 1988.
- From there, I went home for about two months until attendant care and housing became available in Edinboro. Because my parents were unable to take me back to Edinboro at the time I needed to be there to secure my attendant care, a friend drove down and took me back to a friend's apartment where I slept on his sofa bed for a month and a half until my apartment next door was ready for move-in. On April 1, 1989, my Dad hauled all my treasured belongings back to Edinboro and helped me move into the apartment where I would reside for the next 9+ years with various roommates who came and went, some of whom assisted with my care, and for some, whom I also assisted due to visual impairments. (I actually created my own "shared living" experience way before it became "a thing." Although we all had various disabilities, we roommates all did things to help each other out, which was great because we didn't have many services back then to assist us!)

#### Meeting with Senator Casey About ABLE Account July 21, 2022 – 4:00 to 4:30 p

Kathy A. Hertzog 1018 West 20th Street Erie PA 16502-2403 Mobile: 814-397-2863 Email: kathyzog28@gmail.com

Email: kathyzog28@gmail.com Date Prepared: 07/21/2022



- In August 1989, I began working at a Center for Independent Living where I remained for a few
  years providing Information & Referral for 13 counties in Northwestern Pennsylvania, including
  Intake, completing applications for Act 150 attendant care services and ADA Paratranist
  Services, Individual & Systems Advocacy, Housing Counseling for Mortgage Foreclosures, Case
  Management and serving on advocacy committees and work groups before I retired for heath
  reasons.
- During this time of employment, I was honored to be one of approximately 3,000 persons who
  were invited to sit on the white house lawn on July 26, 1990, for the Presidential signing of the
  Americans with Disabilities Act (ADA) by President George H. W. Bush.
- Once I regained my health again, I became extremely involved in the Independent Living Movement and advocacy for the rights of individuals with disabilities.
  - Due to philosophical differences about consumer control and independent living, I helped form Voices For Independence in Western Pennsylvania. I have been Board President since its formation in the early 1990's.
  - I have served on several Governor appointed councils and advisory boards including the PA Statewide Independent Living Council (PA SILC), Pennsylvania Developmental Disabilities Council, Governor's Advisory Committee for People with Disabilities, just to name a few. (A complete list of my advocacy activity is attached).
  - Over the last 30 years or so, I have been actively involved in wide variety of advisory committees, work groups, and transitions of services in an effort to enhance and improve services provided to individuals with disabilities in Pennsylvania.
- My family, friends and attendants have never let my disability stop me from participating fully in life.
  - My Mom, a registered nurse, gave up her work to care for me full-time, including keeping
    me alive through countless health battles during my younger years, spending hours and
    hours of time with me at school carrying me up and down the stairs in Junior High, and
    more ceaseless hours writing out my homework assignments and book reports.
  - My Dad and I used to ride his Yamaha 120 dirt bike through the woods in back of our house. (Amazing what a little duct tape can do to help keep me on a motorcycle!)
  - I'm thankful that I have fulfilled one of my life-long dreams by snorkeling along the coral reefs of Hanauma Bay, Oahu, Hawaii!

#### Meeting with Senator Casey About ABLE Account July 21, 2022 – 4:00 to 4:30 p

Kathy A. Hertzog 1018 West 20th Street Erie PA 16502-2403 Mobile: 814-397-2863

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- I have seen / attended several musicals and other shows including but not limited to:
   "Cats" (at least 3 times), "Evita," and "Jesus Christ Superstar," plus two David Copperfield
   magic shows, two Air Supply concerts, one Hall & Oates concert, two Jan & Dean Concerts,
   a Barry Manilow concert, a hockey game (which I did not like) and the Ringling Brother's
   Circus. to name a few.
- Over 14 years ago, I joined Second Life (SL), a virtual community, (and other virtual worlds since that time), where I get to meet people from all over the world and exchange knowledge, ideas, and advice about any number of things, as well as learn new skills.
  - In the various virtual worlds, I have provided a large number of people in the US with information on how and where to receive home and community based services in their areas, how to obtain equipment or assistive technology, ABLE Accounts, and I've even aided in suicide prevention.
  - Further, I provide weekly non-denominational Christian church services for individuals with disabilities in Second Life.
  - Through the help of friends in SL, I have learned skills such as DJing, video recording and editing, sound recording and editing, and photo and image creation and editing, and other in-world designs and creation.
  - I have discovered that nearly 70% of the people in SL have some form of health issue or disability.
  - I have found this is a great way to remain connected, involved and socially active, even if unable to get out and about, especially during the start of Covid-19.

## 2. Why did you decide to get an ABLE account?

- I decided to get an ABLE account so I could save money without it counting as a resource
  against my disability benefits and other services I was either receiving or thinking of applying
  for in the future such as my Medicaid, my CHC waiver program, Section 8 Housing, and SNAP
  (food stamps).
- I also like the fact that my ABLE Account automatically deducts a pre-set amount from my normal checking account on a monthly basis, thus making it easier to save money since it's saved in a different location from my day to day expenses account.
- Another feature I like is the fact that my ABLE Account offers a VISA Debit/Credit Card so I can shop online and track my purchases.

#### Meeting with Senator Casey About ABLE Account July 21, 2022 – 4:00 to 4:30 p

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Date Prepared: 07/21/2022



#### 3. Are there particular goals you are saving for?

- I'm saving up to pay for:
  - A new powerful gaming computer capable of handing high intensity graphics for photo and video creation and editing, extensive use of the Internet for emails and video conferencing, music streaming, and managing and advocating for independent living services, disability benefits, for myself and others, etc.
  - New headphones with built-in microphone (possibly wireless)
  - o Video cameras to be placed around the house for increased safety and security
  - A two-way communication camera (video doorbell with two-way audio) for our front door for security and to assist me in explaining to new attendant care workers how to get into our home.
  - Home Maintenance & Repairs: sewer, plumbing and clogged drain repairs, and possibly a new hot water tank at some future time.
  - A new Tempur-Pedic mattress and the expensive required water proof cover to replace my current one that's over 10 years old (or something similar) for my hospital bed for pressure relief
  - A trip home to see my parents
  - o Trips to meet friends I haven't seen in a long time or one's I have not yet met face-to-face
  - o A few meals at my favorite restaurants with loved ones

## 4. Have you used your funds for anything in particular? Why?

- Yes, I have made purchases with my ABLE Account:
  - Specialized Adaptive Clothing
    - Silverts (https://www.silverts.com)
    - Buck and Buck (https://www.buckandbuck.com/)
- Orthopedic Shoes to fit over my AFO ankle braces (not covered by insurance) (https://markellshoe.com/)
- Groceries & Household Supplies (because I didn't have food stamps and needed to eat)
- Wheelchair Accessible Van Maintenance & Repair, Gasoline (when I had one)
- Travel & Meal Expenses for myself and my driver/attendant (when we traveled to Ohio and New York for van repairs)

### Pat Grandy's Statement for the Record on behalf of Chris Grandy for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities" August 17, 2022

I am the eldest sister of Chris Grandy. He is a person with Down Syndrome. Our parents are deceased. He lives in a supported living situation with one roommate. The residence is in the same community he has lived his entire life. His roommate is a person who has been his friend since middle school.

Chris was born in a local community hospital. Our parents were not informed of his disability at the time if his birth in 1967. When he was two months old he developed jaundice and had to be treated at Children's Hospital of Pittsburgh. When my parents were ready to take him home, one of the doctors said "since your child has Down Syndrome you should place him in an institution". My parents were stunned but my mother told the doctor they were taking him home to be raised with our family.

This was the beginning of their life long advocacy for people with disabilities. My parents formed the local ARC chapter. Chris attended the first pre-school program for children with disabilities in our community. My father eventually became the president of the national ARC and later chairman of the Pennsylvania Developmental Disabilities Council. My mother was the membership chair for Pennsylvania ARC.

Chris has had opportunities to travel with our parents across the United States. They worked closely with the school district to provide the most inclusive educational opportunities. He was the band manager for the high school band, one of his favorite things. He is an Eagle Scout, a member of the Lions Club, and an acolyte in our church. He worked at Pizza Hut for 30 years until the pandemic ended his position. He is now retired.

Years later my mother and brother were at an event attended by the doctor who recommended institutional living. My mother had Chris introduce himself to the doctor. The doctor asked if he should know him. My mother's response was "this is the young man you told me to put in an institution when he was an infant. I hope you don't say that to anyone anymore." The doctor and no response. It was my mother's favorite story to share.

Our parents are now deceased but their legacy of advocacy lives on in Chris. He too is a member of Pennsylvania Developmental Disabilities Council. He is a past co-chairman, the only individual with an intellectual disability to serve in this capacity in the United States. He has also served on Pennsylvania Special Education Advisory Panel. The issue of Transition has been his primary focus. He has attended state and national conferences addressing the topic.

The creation of ABLE accounts has been important for us. This account allows us to provide security and opportunities for Chris. We have a sibling who lives in Texas. These funds can be used for him to have family visits which would not be possible otherwise. We opened the account in 2019. We are grateful to Senator Casey for all his efforts to support people with disabilities. Going forward, I know there will be more needs for Chris as he ages. Having this fund will support him. There is a difference between us, so this account can provide security and support when I am no longer here. Thank you for your consideration of this testimony.

Patricia Grandy Berquist 899 Patton Street Monroeville, PA 15146

# Rachel Shandler's Statement for the Record for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities" August 17, 2022

My name is Rachel Shandler, I live in Bucks County Pennsylvania. I have Cerebral Palsy and use a motorized wheelchair. I have worked with people with disabilities for several years now and I am also an advocate. As someone who has experienced the difficulties of being on Social Security and navigating the confusing disability system, having and ABLE account is a breath of fresh air. An ABLE account gives people with disabilities financial freedom Money saved in an ABLE account cannot be taken away. Having an ABLE account makes me feel like I have control and allows me to be financially empowered!!! I never thought I would be able to save for an apartment, but having an ABLE account allows that thought to hopefully become a reality.

Rachel Shandler

Jennifer Rivera Statement for the Record for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities"

August 17, 2022

## **Statement from Jennifer Rivera:**

My husband and I are trying to use an ABLE account as a cushion for our son Jose. We worry about his future when we are no longer here to care for him. This is something that haunts most people I know that have special needs or differently abled children. Our adult son is intellectually disabled and will never be able to live on his own, and we do not fully understand yet what his employment income earning potential is. What we do know is that if his only income is social security disability he will be living at poverty level with an income of less than \$16,000 a year. We want to make sure that our son has a cushion for life's needs, but also for some of his wants. We are typical parents and just want him to live a happy, healthy, full life but we are also realistic and know that money is a part of that.

Ronna Riffle's Statement for the Record for the Special Committee on Aging's hearing entitled, "Saving with ABLE: Financial Security for Pennsylvanians with Disabilities"

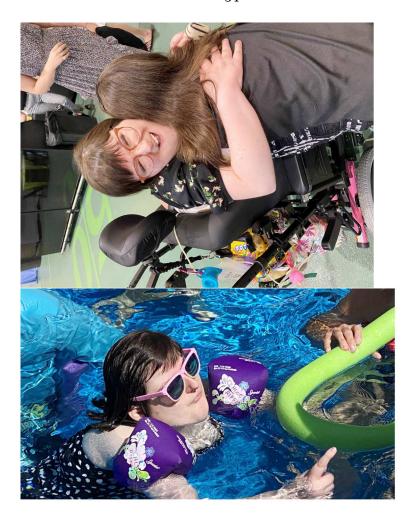
August 17, 2022

#### **Statement from Ronna Riffle:**

#### Good afternoon

I am writing this to be Chloe's voice about how important it is to have an ABLE account. Here's a quick picture of who Chloe is... Chloe is my awesome, social, nonverbal, medically complicated daughter who turned 21 years of age in May. She is well covered by our (and her) insurances and she was granted CONSOLIDATED WAIVER, also in May. We learned over the past few months that she is not being accepted to day programs due to the need to be urinary catheterized ONCE during the hours of attendance taking only 5-10 minutes. We will be sending her back to school this fall due to Governor Wolfe's Act 55. If laws do not change over the upcoming school year we will become Chloe's hab aide, nurse, job coach, aide, transporter and entertainer all the while being the best parents we can be.

We learned of ABLE accounts a few years ago. We opened hers in May 2019. Although, since birth we have had a third party special needs trust for her upon our deaths, she cannot deposit in to it. With SSI having a cap on her money at \$2,000 this will not help her with big purchases outside of waiver/insurance. We plan to save her money for an adult stroller to take her out to parks and anywhere a wheelchair cannot go. We think about a swimming pool/hot tub for therapy. We will eventually need a new accessible minivan. We purchased our current one at a cost of \$72,000 (-)\$10,000 grant. Then struck COVID, and Chloe was given the stimulus money which immediately was over \$2,000. All these reasons are very important for her to be able to save her money.



I do not have a crystal ball to see what the future holds for Chloe, but I will do everything in my power to provide as much as I can to make her complicated life as comfortable and fun as possible.

Regards,

Ronna Riffle